

Evidence-Based Activism and Knowledge Co-Production: A Case Study of Online Communities on Therapeutic Cannabis

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Abstract. This study examines the role of online health communities in Brazil dedicated to cannabis treatments for chronic diseases as platforms for evidence-based activism. Using a mixed-methods approach, the research combines qualitative analysis with computational techniques, including Latent Dirichlet Allocation (LDA) topic modeling, to analyze six online groups from WhatsApp and Facebook. Key themes emerging from the analysis include treatment per pathology, treatment effects, access barriers, peer support, and advocacy efforts. The findings reveal how these communities act as epistemic networks, where patients and caregivers co-produce knowledge by sharing personal experiences and engaging in dialogue with healthcare professionals. This study highlights how online health communities transform experience sharing into structured evidence, enabling collective action to address barriers such as limited access to cannabis-based treatments. It underscores the potential of digital platforms to empower patients, foster collaboration with healthcare professionals, and influence health governance.

Keywords: Online Health Communities, Evidence-based Activism, Health Information needs.

1 Introduction

Online communities play a crucial role in providing emotional and informational support to patients facing health issues, particularly in the context of chronic diseases where traditional research is lacking. This study examines how these communities operate as epistemic networks, driving the production of new knowledge and promoting evidence-based activism.

1.1 Healthcare in the digital patient era

Digital health, or eHealth, encompasses health services delivered through information and communication technologies [1]. Its adoption has significantly transformed healthcare by enhancing chronic disease management, patient satisfaction, and self-management [2]. Digital health is not only a technical innovation but also a shift in

mindset, fostering global collaboration to improve health systems locally and globally [3]. This transformation impacts not only health outcomes but also the relationships and dynamics between patients and healthcare providers.

Health information technologies, such as portals, mobile applications, and online social networks, have empowered patients to take an active role in medical decision-making [4], [5], [6], [7]. Among these, online communities have become spaces where patients can access information [7], [8], [9], [10] and receive peer support [6], [11], [12]. These platforms enable collective learning and foster new interactions between patients and healthcare providers [9], [13], [14].

For communities centered on rare diseases, the dissemination of knowledge and the collaboration among patients and professionals are essential components of a hybrid collective model. This model differs from experiential knowledge by emphasizing collaboration among patients, families, and researchers, uniting them in around a “war on disease” [15], [16].

1.2 Online health epistemic communities and evidence-based activism

Epistemic communities are networks of professionals or experts who share expertise and values, collaborating to address policy-relevant issues by articulating scientific and technical knowledge [17]. These communities play a crucial role in bridging knowledge and policy, enabling informed decision-making even in uncertain contexts. Extending this concept to online health communities, Akrich [18] argues that these groups can evolve into epistemic communities through collective learning and the co-production of knowledge. These groups not only challenge established medical and scientific practices but also facilitate collaboration between patients, caregivers, and with healthcare professionals, democratizing the creation and dissemination of knowledge [19].

Building on this framework, evidence-based activism extends the dynamics of epistemic communities within online health communities. It highlights how patients, caregivers, and health activists collaborate to produce and mobilize knowledge, influencing health policies and practices. Patient groups, particularly those focused on rare diseases or specific treatments, as well as broader health communities, influence research agendas, advocate for public health issues, and democratize expertise [20].

This activism stems from empirical knowledge produced within health communities, particularly those mediated by digital technology. Online platforms enable patients to share experiences, validate them through collective discussions, and refine them with input from healthcare professionals. These interactions transform personal anecdotes into structured and actionable evidence [18], [19]. By leveraging the accessibility and collaborative potential of digital environments, evidence-based activism provides a framework for integrating patient-driven priorities into healthcare governance, promoting inclusivity and shared expertise in knowledge societies [20], [21].

1.3 Social Media Analysis

The use of social media by patients introduces a new source of analysis [22] and an unprecedented opportunity to advance health sciences [23]. Methods such as topic modeling, particularly Latent Dirichlet Allocation (LDA), and classification techniques have proven valuable for analyzing textual data, uncovering trends, patient sentiment, and behavioral patterns [24], [25], [26]. These methods enable the rapid analysis of large amounts of content [24], [26], [27], [28], facilitating a deeper understanding of the dynamics within health communities.

2 Methodology

This research employs a mixed-method approach to analyze the dynamics of online health communities, combining qualitative methods with computational techniques to enhance data analysis. The research is guided by the following research questions:

1. What are the dynamics of information sharing in online health communities in Brazil discussing the therapeutic use of cannabis for chronic diseases, and how do these discussions reflect patient priorities and concerns?
2. How does the sharing of personal experiences within these groups contribute to the production of empirical knowledge, and what processes facilitate this transformation?
3. To what extent do online communities discussing therapeutic cannabis exhibit evidence-based activism by influencing research agendas, healthcare practices, or public policies?

2.1 Group analysis

We selected six groups for the case study, five from WhatsApp and one from Facebook, from various regions of Brazil. We used five methods for collecting data: direct observation, a questionnaire, interviews, chat history analysis, and metadata analysis from the selected groups. We employed an integrated analysis of qualitative and quantitative data, following a “parallel mixed analysis” approach [29], which enabled cross-validation of findings. Unless indicated otherwise, all results are a product of cross-validating sources.

A questionnaire was distributed across all groups, receiving 158 responses. We interviewed six members: one physician, three caregivers, one cannabis grower, and the president of a non-governmental patient support association. Initial interviews were conducted with the physician who created the patient communities to facilitate mutual support. All groups are, thus, linked to that doctor, primarily as patients. Subsequent interviews were conducted in a semi-structured format after analyzing group history. To ensure privacy, all interview excerpts were anonymized.

We collected group history from WhatsApp using a web crawler script and from Facebook through a third-party application, Grytics. The chat history and other types of data were processed separately. We imported the entire history into R and preprocessed data before analysis. Demographic data from Facebook and WhatsApp groups

were analyzed through descriptive statistics, while the text content was examined using LDA Topic Modeling. Figure 1 illustrates the text analysis process with LDA Topic Modeling, highlighting the stages and the R packages used in the analysis.

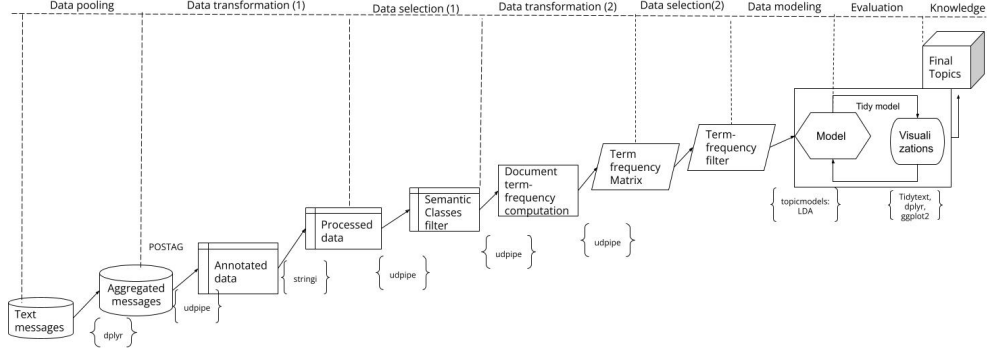


Fig. 1. Flowchart for Topic Modeling. Each task is labeled at the top, with the corresponding data at the bottom. R packages used in tasks are in braces. Recurring tasks are numbered.

During the data pooling phase, text messages were aggregated to improve the performance of the LDA model, as suggested by Alvarez-Melis and Saveski [28]. For Facebook, messages were aggregated into threads using the parent comment ID. Since WhatsApp does not have such a structure, multiple tests were conducted to determine the optimal aggregation form. These included creating one document per group content, one document per month, one document per week, and one document per group per week. Ultimately, aggregation by one document per week was chosen, based on a manual evaluation of topic coherence.

Next, we applied Part of Speech Tags (POSTAG), as proposed by Jacobi et al. [24]. Text preprocessing involved converting text to lowercase and removing punctuation. We filtered relevant semantic classes (adjectives, verbs, and nouns) during data selection and computed document term frequency to create a term frequency matrix. Finally, the data was modeled several times with variations in the K, alpha, and beta (number of topics) hyperparameters (number of topics). After each run, the topics were manually inspected and converted into a tidy model until we found the best results.

3 Group dynamic analysis

This section outlines the data collected and presents the findings of the study.

3.1 Participants in groups

We gathered demographic data from Facebook and WhatsApp metadata. As the available metadata differed between platforms, the results are presented separately for each platform. On Facebook, demographic data included age, gender distribution, and city distribution of group participants. The majority of Facebook participants were women (63.2%), and most participants were between 35-44 years old (34.6%). Figure 2 illustrates the age and gender distributions, categorizing between women, men, and those who did not disclose their gender.

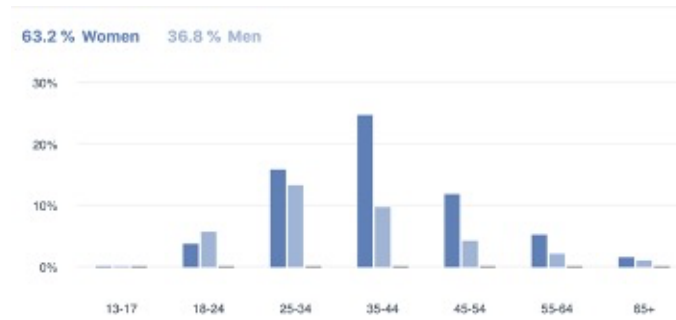


Fig. 2. Facebook demographic distribution.

On Facebook, participants are primarily concentrated in the southwestern states, although all regions of Brazil are represented to varying degrees. Figure 3 presents the geographical distribution. WhatsApp, on the other hand, provides only city-level data. As shown in Figure 4, the geographical distribution on WhatsApp closely mirrors the pattern observed on Facebook.

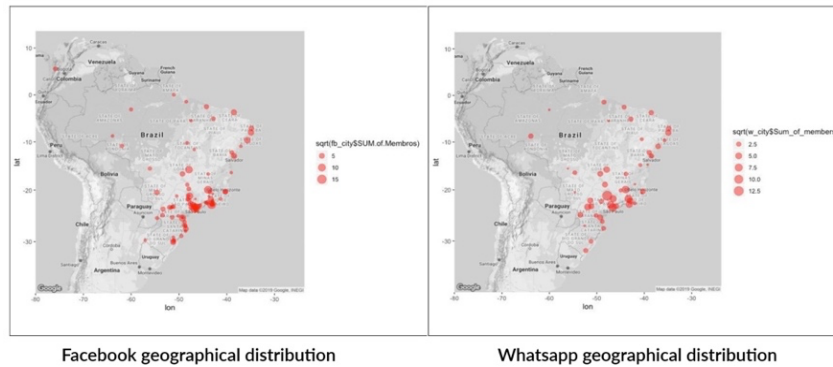


Fig. 3. Geographical distribution per platform.

Observations, surveys, and demographic data reveal that the groups primarily consist of caregivers and patients. Caregivers are predominantly mothers with children, from young to adult people, while men are mostly patients themselves. There is a small percentage of health professionals, mainly observers, mostly sharing information about upcoming consultations, lectures, and consolidated results. Information shared by health professionals is generally regarded as trustworthy, even when it contradicts previously expressed opinions within the group.

3.2 Topics of discussion

Given the high volume of daily messages, manually analyzing the complete corpus was unfeasible. Therefore, we first concentrated on understanding the main themes of discussion across groups and the specificities of each set. We used topic modeling with LDA to extract topics, given the context of short messages.

Facebook messages were aggregated by threads. Five different configurations of LDA hyper-parameters were tested with topic coherence used as a key evaluation metric, and substantially evaluated, with topic coherence as a parameter. After selecting the final model configuration, topics were manually labeled, resulting in 40 initial topic clusters. During labeling, some topics were merged, and non-informative topics were discarded, leaving 22 final topics.

For WhatsApp, weekly message aggregation produced more coherent topics. We manually analyzed documents to evaluate document-topic probability coherence. The best LDA configuration was manually labeled, yielding 28 preserved topics out of 80 initially extracted.

We interviewed administrators from each group to assess the relevance of the extracted topics. Additionally, the physician provided a list of key topics discussed, which was compared against the automatically extracted topics to identify divergences. Figure 4 presents a comparison of treatment-related topics identified by the specialist and those extracted through topic modeling.

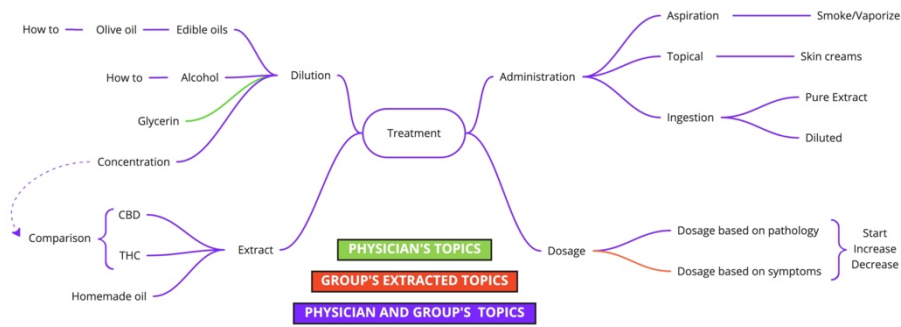


Fig. 4. Comparison of treatment information.

As shown in Figure 4, there is a substantial overlap between the topics identified by the physician and those extracted through topic modeling regarding treatment discussions. However, the comparison of pathologies, presented in Figure 5, reveals greater divergences.



Fig. 1. Comparison of identified pathologies.

As observed in Figure 5, the specialist presented a comprehensive macro vision of the discussed topics. However, LDA modeling provided more in-depth topics that complemented the specialist's understanding of those central themes. Other identified topics included in the analysis were related to treatment access, treatment effects including side effects, and topics related to peer support.

3.3 Evidence-Based Activism

Evidence-based activism plays a pivotal role within these groups. Members actively mobilize and synthesize experiential and credentialed knowledge to advocate for better access to cannabis treatments and policy reforms.

This activism is reflected in several key activities:

Knowledge Co-Production: Personal stories shared by members are often transformed into empirical data points that highlight the benefits and challenges of cannabis use. Through discussion and validation by health professionals, these narratives are transformed into actionable evidence.

Advocacy Efforts: Members collaborate to address systemic barriers, such as limited access to cannabis-based treatments and lack of standardized guidelines. They use the group to organize petitions, campaigns, and outreach initiatives targeting policymakers.

Democratizing Expertise: The groups are spaces where participants bridge experiential knowledge with scientific data. The inclusion of health professionals, who validate or challenge shared information, strengthens the credibility of the knowledge produced. This aligns with the principles of evidence-based activism, where lay expertise is legitimized and integrated into the broader healthcare discourse.

Resource Mobilization: Members actively develop resources like FAQ booklets, newsletters, and centralized drives, to structure and disseminate credible information. These tools empower patients and caregivers to engage with healthcare systems effectively and advocate for their rights.

3.4 Information credibility and technical limitations

There is a pronounced concern about the credibility of information shared within these groups, regardless of its source. An essential step in consolidating credible knowledge is the involvement of technical and scientific actors who actively deconstruct incorrect opinions and strive to organize information scientifically. This dynamic is illustrated in the physician's interview:

"[The group] shares information, and by sharing, information is produced, new information emerges which has not yet been codified in any article, publication, or understanding ... [The group is] a source of shared information and also of production of information or new knowledge, provided that we can appropriate or appropriate ourselves in an intelligent way to organize it and produce meaning." (Physician)

A common concern regarding technical support is the overwhelming volume of daily messages. This information overload, combined with the unstructured nature of platforms like WhatsApp, often leads to the loss of relevant information. To address these issues, users suggested or implemented different solutions, such as a website, a FAQ booklet, a newsletter. However, attempts to structure knowledge are often much more straightforward, such as using online drives and documents to centralize information, for example, a list of medical professionals prescribing cannabis in Brazil.

4 Discussion

As social media increasingly integrates into patients' lives, studies examining its impact on health dynamics have proliferated [2], [10], often focusing on platforms like X (formerly Twitter) and online forums. However, research on Facebook and WhatsApp, despite their broad use in countries like Brazil, remains limited—partly due to data collection challenges—though their extensive use offers valuable insights into online health communities.

Peer-to-peer online communities are viewed as mutual support networks, offering information sharing and resource access [13], [26], [30]. This study supports these observations but goes further, showing that these groups function as epistemic communities, where co-produced knowledge plays a transformative role [18], [19]. This aligns with evidence-based activism, as these communities focus on addressing chronic diseases collectively rather than solely aiding individual coping.

Building on Rabeharisoa et al. [20] who focus on patient organizations centered on specific diseases, this study examines communities united by a shared treatment—cannabis therapy—gathering participants from diverse chronic disease backgrounds. The analysis demonstrates that these communities embody evidence-based activism through their collaborative and knowledge-producing practices. Members actively share, validate, and synthesize experiential and scientific knowledge, effectively contributing to the "co-production of knowledge" [20] in health governance. While participants do not explicitly join for this purpose, as Akrich [18] notes, the production of knowledge emerges organically from the dynamic interactions. The diversity of shared experiences creates a cross-learning environment that consolidates both collective and empirical knowledge.

The evidence-based activism observed in these groups goes beyond traditional patient support. Members engage in activities such as raising public awareness and advocating for policy changes regarding cannabis treatments. The establishment of non-governmental organizations (NGOs) and structured advocacy initiatives exemplifies how participants transition from learners to experts and advocates [41]. Additionally, the involvement of healthcare professionals, industry actors, lawyers, and scientists highlights the collaborative dimension of these groups, aligning with evidence-based activism's goal of democratizing expertise and influencing health governance.

However, disparities in group dynamics are apparent. Female participants primarily act as caregivers, sharing experiences related to their children or dependents, whereas male participants are more often patients. This gendered division may shape the types of knowledge shared and influence advocacy within these communities. Further research could examine how these roles impact collective knowledge production and activism.

While digital platforms like WhatsApp and Facebook facilitate knowledge sharing, their limitations—such as group size restrictions, unstructured content, and information overload—pose challenges for both participants and researchers. Despite these constraints, text mining techniques like topic modeling proved effective in analyzing group dynamics and key discussion themes, complementing qualitative methods to provide a more comprehensive understanding of these communities. Future research

could explore digital tools, such as chatbots, to further enhance the structuring and dissemination of knowledge. In this regard, we developed a chatbot prototype to improve knowledge access within these communities [31], demonstrating the potential of such tools to support online health communities' knowledge systems.

5 Conclusions

This study explored the dynamics of online health communities, moving beyond traditional analysis of peer support and information sharing. While previous research has largely focused on these aspects, this study demonstrates how online health communities serve as significant sources of empirical knowledge, fostering evidence-based activism. By examining the dynamics of experience and information sharing within Facebook and WhatsApp groups, it highlights how participants transform personal experiences into collective knowledge. The findings underscore the role of these communities in promoting evidence-based activism, particularly in the context of cannabis treatments for chronic diseases. Members engage in knowledge co-production, advocacy, and collaboration with healthcare professionals, advancing collective goals.

The relevance of this work lies in its exploration of social media platforms widely used in Brazil, providing insights into how these groups function as epistemic and advocacy networks. However, limitations such as platform-specific constraints, unstructured data, and the lack of comparative analysis across diverse platforms suggest directions for future research. Despite these challenges, the study reinforces the transformative potential of online health communities to shape health knowledge and influence policy.

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