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Sharing and Informing: Scientific Communications on the Therapeutic Use of Cannabis on Digital Platforms

Compartilhar e Informar: Comunicação Científica sobre o Uso Terapêutico de *Cannabis* em Plataformas Digitais

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Abstract

In this article, I analyse how digital platforms have enabled people to share their experiences of illness, substance use and alternative therapies more widely, as well as disseminate scientific information obtained through the development of lay expertise. To show how, I explore the content produced by patient associations in scientific communications about the therapeutic use of cannabis. The associations have been sharing research on these substances in different areas of knowledge, especially the biomedical area. Focusing on the connections between the different actors involved, I examine the content generated by three of these associations on the Instagram platform between 2020 and 2021. Based on data coding, the analysis shows that the work of these associations has improved the availability of information that can help ensure access to health.

Keywords: Cannabis; social studies of science and technology; lay expertise.

Resumo

Neste artigo, analisamos como plataformas digitais têm contribuído para o compartilhamento de experiências de adoecimentos, usos de substâncias e terapias alternativas, além de informações científicas a partir do desenvolvimento de uma *expertise* leiga. Para isso, foram considerados conteúdos de comunicação científica produzidos por associações de pacientes em torno do uso terapêutico de *Cannabis*. As associações têm compartilhado o que vem sendo produzido em diferentes áreas de conhecimento com essas substâncias, sobretudo biomédica. Ao focar nas conexões entre os diferentes atores, examinamos o conteúdo produzido por três associações entre 2020 e 2021 disponibilizado na plataforma Instagram. A partir da codagem de dados, a análise evidenciou que o trabalho das associações tem colaborado para o acesso a informações que contribuem para a garantia do acesso à saúde.

Palavras-chave: *Cannabis*; estudos sociais da ciência e tecnologia; *expertise* leiga.

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Introduction[2]

In 2013 and 2014, discussion of a derivative of cannabis called cannabidiol spread widely on digital platforms, principally among groups of people sharing their experiences of illness on Facebook.[3] The life stories concerning the use of this marijuana derivative were mainly shared in relation to rare diseases and difficult-to-control epilepsy in children. One such story, the case of Charlotte Figi, was shared on a Facebook group: she was a girl who lived in the United States and suffered from seizures caused by Dravet syndrome.[4] The girl's father claimed that Charlotte's condition had improved significantly when she started using the substance, something that had not previously occurred with any conventional medication. After her story was published, other families and patients started to seek more information on the potential therapeutic applications of cannabis derivatives. Digital platforms have this search a huge boost.

Digital, in the sense explored here, refers to "a heterogeneous and very broad set of objects, actions and sociotechnical relations that have become part of our everyday experience" (Lins, Parreiras & Freitas, 2020, p. 2). Recognizing the advance of digital networks and platforms over recent years, this article sets out to analyse the contents of scientific communications produced by patient associations concerning the therapeutic use of cannabis and its derivatives, based on the development of lay expertise (Epstein, 1995; Oliveira, 2017). Cannabis associations, as they are called by the activist movement itself, have undertaken this information work on digital platforms, like Instagram,[5] by sharing what is produced in scientific studies in relation to these substances. These associations have shared this kind of information – which generally uses a more technical language – in a more simplified form to their followers.

I analysed the content produced by three associations: the Associação Brasileira de Apoio Cannabis Esperança (Abrace), Apoio à Pesquisa e Pacientes de Cannabis Medicinal (Apepi) and the Associação de Cannabis e Saúde (Cultive), published on Instagram in 2020 and 2021. Drawing from the concept of lay expertise, formulated in the works of Steven Epstein (1995) and Monique Oliveira (2017), the aim of this article is to demonstrate how the internet and digital platforms have emerged as allies in the work of sharing experiences and information that contribute significantly to the lives of people seeking access to the right to health, whether through conventional or alternative treatments. To do so, in the first section I describe the how the research was undertaken. In the second, I discuss the biosocial trajectories that are undertaken via the internet, focusing on Facebook and Instagram. Next, I turn to discuss the associations themselves and the circulation of scientific products

[2] A first version of this text was presented at the 33rd Brazilian Anthropology Meeting (RBA) on the workgroup 'Digital Anthropology: processes, dynamics, counteruses and disputes on sociotechnical networks.' I thank Patrícia Pavesi and Carolina Parreiras for their comments on the paper, I also thank the valuable comments made by the reviewers for *Mediações*.

[3] The Facebook social media network was created by Mark Zuckerberg in 2004. Users can create profiles, pages and groups and can interact through posts or by using the online chat function.

[4] Dravet's syndrome is a disease characterised by a progressive encephalopathy, accompanied by a difficult-to-control epilepsy that tends not to respond to the kinds of medication usually prescribed.

[5] Like Facebook, the Instagram social network is now owned by the company Meta. Launched in 2010, it allows the publication and sharing of images and videos, as well as allowing uses to interact through posts, chat conversations and 'stories,' which disappear after 24 hours.

through social media posts. I seek, then, to understand how scientific production circulates on digital platforms, emphasizing the work undertaken by cannabis associations in the construction of lay scientific communication (Epstein, 1995; Oliveira, 2017).

Methodology

The results presented here are part of a broader study undertaken as part of my doctoral research at the Postgraduate Program in Social Anthropology (PPGAS) of the Federal University of Rio Grande do Norte (UFRN). This research, still being developed, sets out to understand how cannabis has become configured as a therapeutic technology, considering a wide range of actors and practices. When I began my initial analyses, I created an Instagram account as a researcher to be able to accompany the flow of information on the accounts of central actors in the current debate on the therapeutic use of the substance and its derivatives, including the cannabis associations. Having worked more specifically on the scientific production on the topic during earlier research (Caetano, 2023a), one of the first things to call my attention were the association posts related to the scientific production and knowledge.

Analysing the Brazilian biomedical studies of cannabis and its products published between 2014 and 2019 (Caetano, 2023a), I saw that authors that spoke about their therapeutic use emphasized the applications and diseases, stressing the importance and necessity of conducting more research on the topic. The language was strictly technical with terms and sayings specific to the health area. However, what I encountered on the social media posts was something different but at the same time familiar: they passed on information similar to what I saw during my master's research, but in a different form, with simpler terminology and associations that allowed followers to understand the content better. Instagram was chosen because of the platform's dynamic, which offers users forms of capturing and sharing life moments through images, texts and videos[6] (Zandavalle, 2018). As well as providing medical and legal support, the associations also offer themselves as spaces for constructing and sharing experiences and information. This becomes even clearer when we analyse the content of the posts.

To construct the analysis presented here, I examined the Instagram profiles of three cannabis associations (Abrace, Apepi and Cultive) using the Atlas.ti qualitative data analysis program. This program allows the researcher to organise the collected material, whether image, text or video. These three associations were selected because they cultivate and produce cannabis derivatives and also already have a lengthy history of working in cannabis activism. A total of 97 posts were collected between 2020 and 2021. The analysis was based on data coding, which is a technique allowing the creation of categories and subcategories that assist the researcher in the investigative process. In terms of the partial results presented here, one of the main categories was Disease. In analysing the content, different subcategories related to disease became perceptible, such as cancer, depression and epilepsy. Utilizing these categories and subcategories enabled me to trace similarities

[6] As Ana Claudia Zandavalle (2018) points out, it also allows the insertion of hashtags and tagging of other users.

between the posts, as well as identify the nuances and approximations between them. In this way, it became perceptible that these associations have constituted themselves as legitimate actors by being seen as capable of talking about health science and technologies to their followers.

Digital Platforms and Biosocial Trajectories

Discussing mediatisation as an interactional process, José Luiz Braga (2006) argues that social processes of mediatised interaction include and encompass others, which end up adapting to them. The author describes this situation as a transition from writing as the default interactional process to a growing technology-based mediatisation. Technologies develop, expand and can also fill lacunas. In this way, shifts in technological processes, Braga suggests (2006, p. 15), may go be beyond the originally designed action, "based on other social expectations and motivations, foreign to the moment of invention."[7] Carlos d'Andréa (2020) registers how studies of social media and other digital platforms have grown over recent years, as well as diversifying with an intensity similar to their popularisation and to the controversies unleashed by and through technological artifacts. The so-called Big Five – Google, Amazon, Apple, Meta and Microsoft – d'Andréa argues have consolidated and centralized everyday and strategic activities. Consequently, mediatisation (Braga, 2006) and technological artifacts, including digital platforms (d'Andréa, 2020), have modified over time, assuming new functions and guises.

As Carlos d'Andréa (2020) points out, online platforms have adopted a computational architecture based on connectivity and the exchange of data, while simultaneously becoming consolidated through a model based on the flow of information and finance. The academic field of platform studies, the author shows, call for us to focus attention on the ways in which, amid complex and asymmetric power dynamics, users and materialities mutually constitute each other, whether through the perceptions of users or through the appropriations that they create and recreate on an everyday basis. For d'Andréa, it is not about attributing technological artifacts with a certain power to control or steer practices, but of recognising that platforms can have a decisive influence on how we understand and manage our day-to-day relations. Along these lines, d'Andréa argues that online platforms both generate and participate in controversies – that is, situations marked by disputes and uncertainties – and, in this way, the contemporary 'platformisation of the social' ends up complexifying the relations between the actors in action. Following Ítalo Vinicius Gonçalves (2020), looking at digital platforms allows us to see spaces of communication or sociabilities, as well as perceive infrastructures that configure ways of life and social organisation.

Paul Rabinow (1991) saw life practices as central to understanding new forms of knowledge that awaited discovery. Through the 'new genetics,' the author asserted that networks of circulating identities would be formed, individual and group practices that can be called biosociality. An example of biosociality, for the author, would be the carriers of a genetic disease like Dravet's syndrome, who meet to share

[7] José Luiz Braga (2006) argues that the process of mediatisation of society is now so advanced that it is already assumed to be dominant, yet it is in fact still accelerating, meaning that the process is not yet completed.

their experiences of sickness. Inspired by the concept of biosociality defined by Rabinow, here I seek to show that what I call biosocial trajectories are traced through digital platforms. But rather than being centred on a disease or symptom, it is cannabis and its derivatives that cause these paths to be taken. In this sense, as d'Andréa explains (2020, p. 18), 'platforms are not mere intermediaries on which society becomes visible and through which social interactions may be studied, but rather environments that condition the emergence of the social.'

In 2007, the social network Facebook arrived in Brazil, bringing new modes of interaction between users who joined the platform. As well as the profiles of each user and the pages created by musical bands or organisations, groups emerged where shared interests helped created a kind of community, an online space where information, experiences and opinions could be exchanged on specific topics. One type of group created involved people with similar diseases or symptoms, who came to see the platform as a place to share their experiences of sickness and their journeys in search of a better quality of life. These groups were essential to the circulation of information on the therapeutic use of cannabinoids.[8] There were exchanges of support and knowledge on therapies and the use of substances that could help improve the quality of life of each of the users. Fabiana Oliveira (2016), in her ethnography on *maconheirinhos* (marijuana users), described some events that were important to amplifying the discussion on the therapeutic use of a marijuana derivate,[9] cannabidiol. In describing the journeys made by families and patients to obtain the substances, the author shows that some cases ended up becoming more emblematic than others. This was the case of Charlotte Figi, for example. As well as circulating on digital platforms, her story became international news after a report made by the US Cable News Network (CNN) in 2013. For many people actively involved in the debate, this was one of the initial events[10] that boosted the flow of information on the use of such substances in health treatments.

The Facebook groups contributed to Brazilian families acquiring knowledge of the therapeutic use of cannabis-derived substances. People from various parts of the country and the world were able to share experiences of sickness, whether by talking about similar symptoms or discussing forms of care and therapies. Digital platforms thus allowed sick people, their friends and family members to share experiences and enabled the creation of expertise and the sharing of problems (Frossard & Dias, 2016). These groups also actively shared scientific data and products on both conventional and alternative substances and therapies. One of the families who had access to this information on Facebook were the parents of Anny Fischer. Anny, five years old at the time, had suffered from strong seizures from her first months of life. None of the conventional medications used was able to have a prolonged effect on alleviating her symptoms. Through the Facebook groups, Anny's parents sought information on how to get access to the oil. They spoke with other

[8] Cannabinoids are chemical compounds found in plants of the *Cannabis* genus, such as cannabigerol, cannabidiol and tetrahydrocannabinol (THC).

[9] Cannabis and *maconha* are terms used to refer sometimes to the same thing, sometimes to different things. The former is generally associated with scientific and therapeutic procedures, while the latter is linked to adult use as a narcotic. Here use of the terms blurs, which reveals the complex relationship between the different statuses assumed by the substance (Caetano, 2023a).

[10] This is not to say that there was no kind of therapeutic use before the events described here. What I am trying to show is a certain chronology of events that helped consolidate the discussion in Brazil.

members of the group who had acquired and used the substance and obtained positive results. They needed to understand not only how to obtain the oil, but also its use since there was no official dosage instructions to be followed. More than sharing information, the story of the Fischer family shows a biosocial trajectory that was pursued until arriving at the cannabidiol oil.

D'Andréa (2020) argues that social media and digital platforms constitute spaces for debates and actions that question governance policies. Today, the content posted on digital platforms is essential to understanding exchanges of experiences among users and to how these spaces become important in the sickness process of different people. For Daniel Miller et al. (2019), it is important that we, as researchers, pay attention to the content circulated on digital platforms, especially when we consider that these networks have changed our ways of being in and inhabiting the world – that is, they have modified the forms in which we communicate and express ourselves. Fabiana Oliveira (2016) discusses how, in 2013, the father of a Brazilian girl saw a post on Facebook showing a child in the United States who had been given cannabidiol oil, reducing the monthly number of seizures. The girl's parents contacted the American family in question via the group to learn how to get access to the substance, given that, in Brazil, the oil was banned at the time as a cannabis derivate (Oliveira, M., 2016).

Following a conversation with the American father via Facebook, the Brazilian parents were able to contact the company Hempmeds.[11] A medic from the company replied in an e-mail to them and offered to send a sample of the product free of charge for the family to test. Although the treatment proved successful, the parents were subsequently faced with the problem of how to obtain the product in Brazil since none of the cannabis compounds was legally authorized for circulation. This is where the process of making the cause visible began, taking the form of a public denunciation in the sense formulated by Luc Boltanski (2000). For Boltanski, public denunciation is a collective act. The denouncer must, therefore, convince other people to join the protests and mobilize. In the case of the therapeutic use of cannabis, the injustice resided in the difficulty of accessing a product that, though considered a 'drug' by the Brazilian state, had helped improve the quality of life of Anny and others. The story of the Fischer family[12] became well-known in Brazil at the time through publicizing of the case on digital platforms and in newspaper reports.

Over recent years, different works have been published on the therapeutic use of cannabis in Brazil in the social sciences and humanities. Among them are the works of Monique Oliveira (2016) and Fabiana Oliveira (2016), which focus on the early years of the campaigns when the issue was more closely linked to the specific use of cannabidiol and not cannabis itself. The study by Policarpo, Veríssimo and Figueiredo

[11] Currently with offices in the United States, Mexico and Brazil, Hempmeds is a company specialising in cannabidiol products. In 2014, Real Scientific Hemp Oil, produced by the company, was the first such product to be approved for import by Brazil's National Health Surveillance Agency (ANVISA). See https://bvsms.saude.gov.br/bvs/saudelegis/anvisa/2015/rdc0017_06_05_2015.html. Consulted 24 January 2024.

[12] Journalist Tarso Araújo sought people to take part in a news report on the use of a cannabis derivative, cannabidiol, for the magazine *Superinteressante*. His idea was to enable cannabis to be seen outside 'the ghetto,' thus disconnecting the substance from the figure of the *maconheiro* or 'pothead.' He saw the Fischer family as potentially emblematic. For Tarso, the Fischer family was ideal for the role since they looked like a family from a 'margarine commercial': white, blonde and middle class (Oliveira, M., 2016).

(2017), based on cases in Rio de Janeiro, problematized the articulations between the biomedical and juridical discourses in defining what could be considered a 'drug' (*droga*) and what could be seen as 'medication' (*medicamento*). Discussing the costs and problems involved on obtaining cannabis-derived products, Motta (2019) showed that patients provided mutual assistance –– that is, they helped each other and learnt together about the process of growing the plant and extracting the oil, which effectively assured them access to the substances. Other works, like those of Natália de Campos (2019), Luciana Barbosa (2021) and Romário Nelvo (2020), show how activism around the therapeutic use has grown since 2014, attracting more adepts and broadening the discussions.

The internet and digital platforms have been important allies since the earliest phase of this activism, when discussions on therapeutic uses or regulation were still relatively undeveloped (Reed, 2014). Manuel Castells (2003) shows that the utilisation of digital networks and platforms tends to be linked to the context of our everyday routines, with a focus on work, family and personal interests. The notion of network appears here in relation to the choices and interests of the actors who, in the case analysed by Castells, focused on the right to health and access to therapeutic technologies. Madeleine Akrich (2010), writing about the French context, shows that patient associations emerged from internet discussion forums. In these spaces, people exchanged experiences and information on symptoms and diseases, while also offering each other support and assistance. Additionally, there was a circulation of publications, references and articles. When it comes to Facebook groups, the context and dynamics are similar. These groups helped create bonds and foster exchanges on sickness experiences of different people in diverse places and contexts, whether based on patient knowledge or something more technical. These exchanges helped each patient to find their own way to access cannabis-derivatives for therapeutic use, including the utilisation of the digital platform to achieve their objective. People created ways of experiencing and dialoguing with and on the basis of similar diagnoses and symptoms (Rabinow, 1991), in this case in search of access to cannabis-derivatives.

The use of smartphones and digital platforms has modified the environments and contexts of which they are part. Mobile applications have enabled new forms of communicating with the world, while internet access via mobile has helped us access these apps and networks at any moment. Discussing the therapeutic use of cannabis, Silva (2021) analysed the WhatsApp platform, more specifically a group from the Cannabis League of Rio Grande do Norte.[13] The author's objective was to accompany the movements of social mobilisation surrounding the legalisation of marijuana through the group. Monitoring the dynamics and conversations present on the WhatsApp groups helped Silva comprehend the networks of articulation that were formed to increase the visibility of the benefits of marijuana for medicinal use. Marins (2020) argues that the digital universe is an integral part of our everyday life and it is up to anthropologists to focus attention on the implications of this phenomenon in our lives. To this end, in the next section I shall analyse the profiles of the associations and the scientific communication work performed by them on the Instagram platform.

[13] In Portuguese: *Liga Canábica do Rio Grande do Norte*.

Cannabis Derivatives and Lay Expertise

In terms of the development of therapeutic technologies, one of the most notable events in the history of world health was the HIV/AIDS epidemic. Steven Epstein (1995), discussing the epidemic in the United States, shows how activism emerged as a form of demanding effective measures for prevention and treatment. The participants in this type of activism began to organise and participate actively in public discussions on the epidemic. In this sense, the author shows that the work of these activists mostly involved white middle-class men, many from the gay movement, for whom raising funds and also exerting political influence was relatively easy. According to Epstein, the actions were based around each individual's 'cultural capital,' which ensured that the activists not only participated in the discussions but were also able to challenge experts from different areas of knowledge, principally biomedicine. In the process, these activists became people with the credibility and legitimacy to speak in the language of science – in other words, they developed what the author calls 'lay expertise.'

Based on Epstein's writings (1995) on the AIDS epidemic, Monique Oliveira (2017) shows that the activists involved in the discussion of cannabis's therapeutic use did not bend to the time of science and institutions. Despite differences in terms of identity and representation, the author argues that the activists successfully mobilised agendas and groups against policies that interfered with access to cannabis derivatives. In Oliveira's view, these activists – who were above all mothers and family members – refused the role of passive victims, seeking active positions in the process and demanding a say in the decisions taken by official bodies and institutions, at the same time as they challenged the hierarchies imposed between experts and lay people. According to the author, it was the development of lay expertise that enabled the changes that benefitted the families to occur, whether in terms of regulations or daily routine, in terms of making access to the substance easier. In this sense, rather than being activists, the individuals close to the cause acquired the skills needed to speak in the language of science. For Akrich (2010), there is no clear separation between lay knowledge and lay experience. It is in this entanglement of types of knowledge that people manage to become informed and make their health demands legitimate.

Science, technology and society are domains co-produced by human and non-human actors (Latour, 2012; Jasanoff, 2004). It is important to understand how groups of people and digital platforms construct relations (Hine, 2020). Exploring this theme, Hine (2020) argues that it is essential to examine and comprehend the processes that are produced and incorporated into other everyday activities. For Beatriz Accioly Lins (2020), the term 'internet' conveys diverse technologies, devices, circumstances, discourses and practices that build new forms of being in and inhabiting the world. According to Carneiro and Dwyer (2012), the complexity of life can also be apprehended through the relations between our lived experience on digital platforms and what we experience in our day-to-day lives away from our screens. The authors suggest that the interaction we construct on social networks is linked to our expression in everyday life. Hence it is important to consider the contexts to which we are connected, their political and also social constructions. This

becomes clearly visible when we turn to consider the activism surrounding the therapeutic use of cannabis. Patients and their families have developed expertise in diverse areas of knowledge to deal with all the phenomena that have emerged and intensified through the discussion on the different uses of cannabis and its derivatives. Sharing information, experiences and knowledge help people to live with sickness and deal with the problems arising from it. The cannabis associations, the focus of discussion in this article, have developed informative works on science, especially biomedicine, available on digital platforms, which can be understood as part of the formation of a lay expertise.

Instagram was designed and publicised as a platform on which users could publish photos and videos to their network of contacts in real time. Camila Marins Silvestre (2017) observes how, over the years, the platform began to be appropriated for commercial purposes with personal profiles but also business profiles. The author explains how the app functions as a mural for the display of photos and videos for other users to look at. As well as allowing comments and direct messaging between users, the platform currently enables posts of interest to be saved and forwarded. It is worth emphasizing, as Silvestre (2017) points out, that the latest updates of the platform cater for business interests with the supply of metrics that enable companies to survey user preferences, meaning that content that generates more impact with specific consumers is boosted. By appropriating these aspects, patient groups and associations have also take advantage of the platform to increase the visibility of their causes, as well as attract new supporters.

The Brazilian Association of Cannabis Hope Support (Abrace)[14] is a nonprofit organisation with the objective of providing support to patients and their families in all the processes relating to the therapeutic use of cannabis. Abrace is also responsible for cultivating, producing and making available cannabis-derived products at an industrial scale.[15] All these stages are undertaken at the organisation's headquarters in João Pessoa and Campina Grande in Paraíba state, Brazil.[16] On the association's Instagram page in 2020 and 2021, 40 posts were collected that relayed some type of information on science and technology to its followers. Analysing the content of the posts, it became clear that they transmitted information relating to national and global disease awareness dates. At the same time that they talk about disease, they also link to information on cannabinoids as a potential treatment. The use of hashtags[17] was fairly infrequent. Those that most often appeared included #abraceesperanca (#abracehope), #abracenaopodeparar (#abracecannotstop), #avidanaoespera (#lifedoesnotwait) and #cannabismedicinal. The term 'marijuana' was used few times with 'cannabis' almost always preferred. This is a relevant point given that, though referring to the same plant, these words do not always mean the same thing. Caetano (2023a) and Motta (2019) have already shown that these terms

[14] In Portuguese: *Associação Brasileira de Apoio Cannabis Esperança*. See Abrace, 2023. Consulted 24 July 2023.

[15] The association follows a production model compliant with ANVISA resolution 327/2019. This model is primarily intended for pharmaceutical companies and industries.

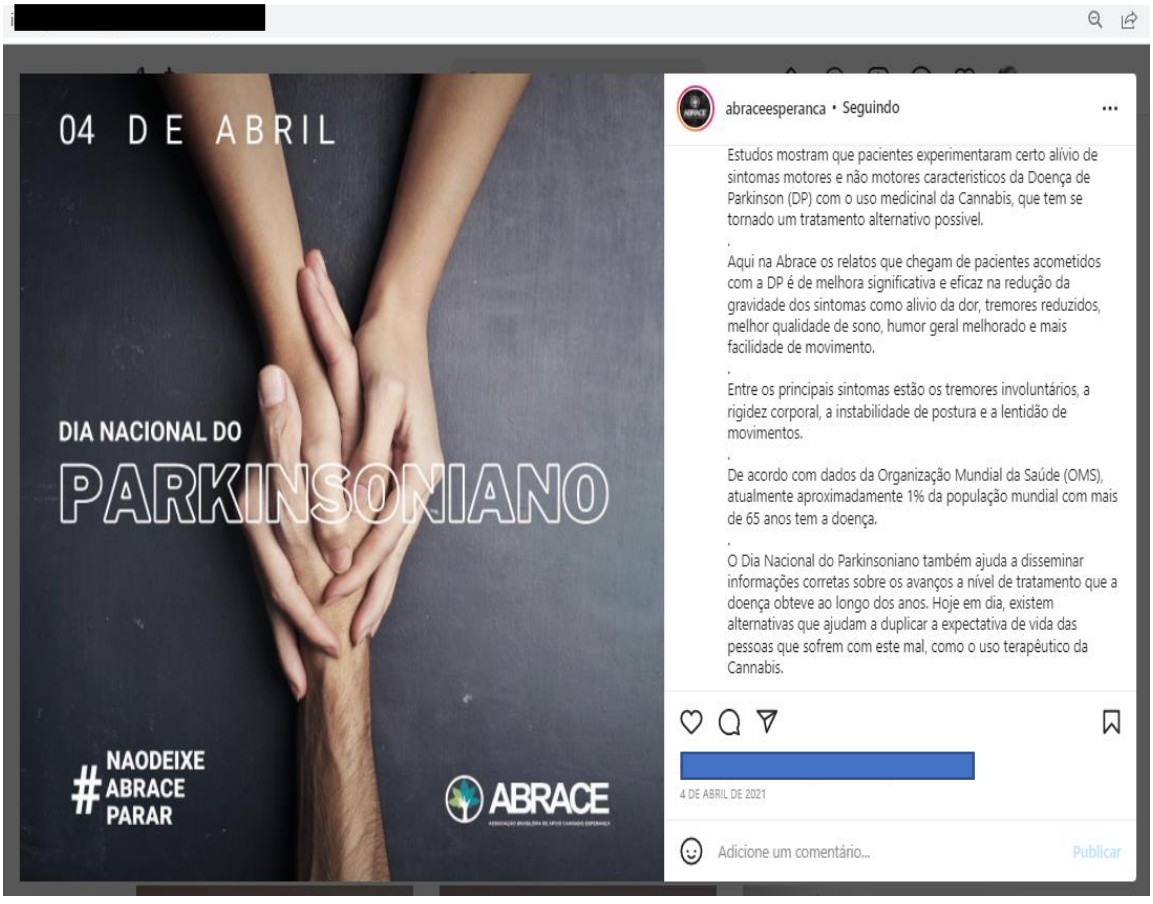
[16] To learn more about the production process at Abrace, see Jonathan Souza (2021).

[17] 'Hashtag' is a term associated with topics and discussions indexed on specific social networks, including Instagram. The addition of the "#" symbol transforms the term into a hyperlink. When clicking on a hashtag, the user is directed to another webpage on which other posts on the same theme appear. According to Zandavalle (2018), the dynamic of using hashtags is itself based on the idea of identifying with a community or discussion or associating with specific topics.

refer to distinct things. The word 'marijuana' tends to be used when speaking of 'recreational' uses while 'cannabis' seems to be more readily associated with therapeutic uses. This derives from the ambiguous and complex place that the substance appears to occupy today, seen sometimes as a 'drug,' sometimes as a 'medication' (Caetano, 2023b).

According to Zandavalle (2018), Instagram possesses a flow of visual information that transmits meanings through images, texts and hashtags, which are used according to the context and the information that the poster wishes to pass on. In a post dated 4 April 2021, the Abrace profile commemorated National Parkinson's Day. In the image (Figure 1) we see intertwined hands, Abrace's logo and the hashtag "#Naodeixeabraceparar" (#DontletAbracestop). In the text accompanying the image we read that studies already exist showing how patients using cannabis feel relief from motor and non-motor symptoms resulting from Parkinson's Disease. Every day, the text adds, Abrace received testimonies from people who use the products made at the association and experience significant improvements in terms of pain, tremors, sleep and mood. It also mentions studied produced by the World Health Organisation (WHO) claiming that 1% of the population over the age of 65 has developed the disease. The text ends with the statement that the day is important for correct information to be disseminated on treatments of the disease and for showing that today there exist ways of increasing the life expectancy of these people with the therapeutic use of cannabis. Despite mentioning studies in the plural, no specific reference is listed for followers to be able to check out.

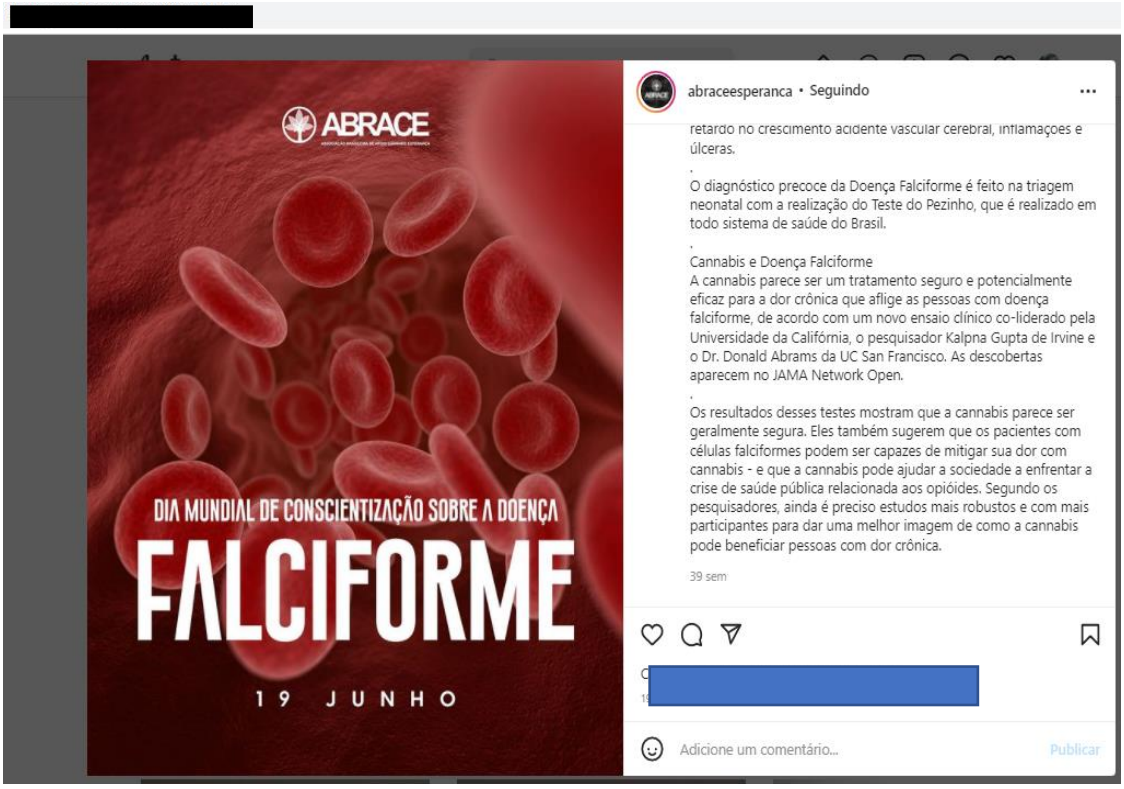
Figure 1 – Post for National Parkinson's Day



Source: Abrace Esperança (2021b).

On 19 June 2021, the Abrace profile published a post (Figure 2) for World Sickle Cell Awareness Day. This disease (called *anemia falciforme* in Portuguese) is genetic, hereditary and characterized by an alteration to the person's red blood cells that can cause chronic pain and infections and is more prevalent in darker-skinned people.[18] The accompanying text describes the relationship between cannabis and the disease, claiming that treatment is safe and effective in patients with chronic symptoms. It cites a clinical trial undertaken by the researchers Kalpna Gupta and Donald Abrams at the University of California, but does not provide any easier access to the full content of the text. The trial's results showed that cannabis appears to be safe in the treatment of chronic pain resulting from sickle cell disease and adds that the authors of the trial claim that the substance can help combat the public health crisis related to the opioid abuse.

Figure 2 – Post for World Sickle Cell Awareness Day



Source: Abrace Esperança (2021c).

In another post published on 14 December 2021, Abrace discusses the benefits of cannabis in the treatment of HIV/AIDS. Along with the benefits and collateral effects of antiretroviral therapy, the post also suggests forms of controlling these symptoms. The image (Figure 3) shows a vial containing the oil produced by the association and a prominent cannabis leaf. In the post, the association mentions a study conducted at Imperial College London in partnership with the Chelsea and Westminster Hospital confirming the benefits of cannabis in the treatment of HIV. According to the text produced by the association, the study was based on an

[18] Sickle cell disease is neglected by Brazilian health services. For a critique of health policies for the disease, see Silva 2013.

anonymous questionnaire filled by HIV-positive patients treated at the hospital. The text states that the substance was shown to be effective in combating a series of symptoms and complications caused by HIV infections, such as loss of appetite and neuropathy. According to the post, improvements were also reported in relation to muscular pain (94%) and symptoms of depression (86%). Finally, the text also states that it is important to recognise the role that cannabis performs in the prolonged treatment of HIV-positive people. There is no more precise information on the study itself, references or indications on where it can be read.

Figure 3 – Post on the benefits of cannabis in the treatment of HIV/AIDS

Source: Abrace Esperança (2021a).

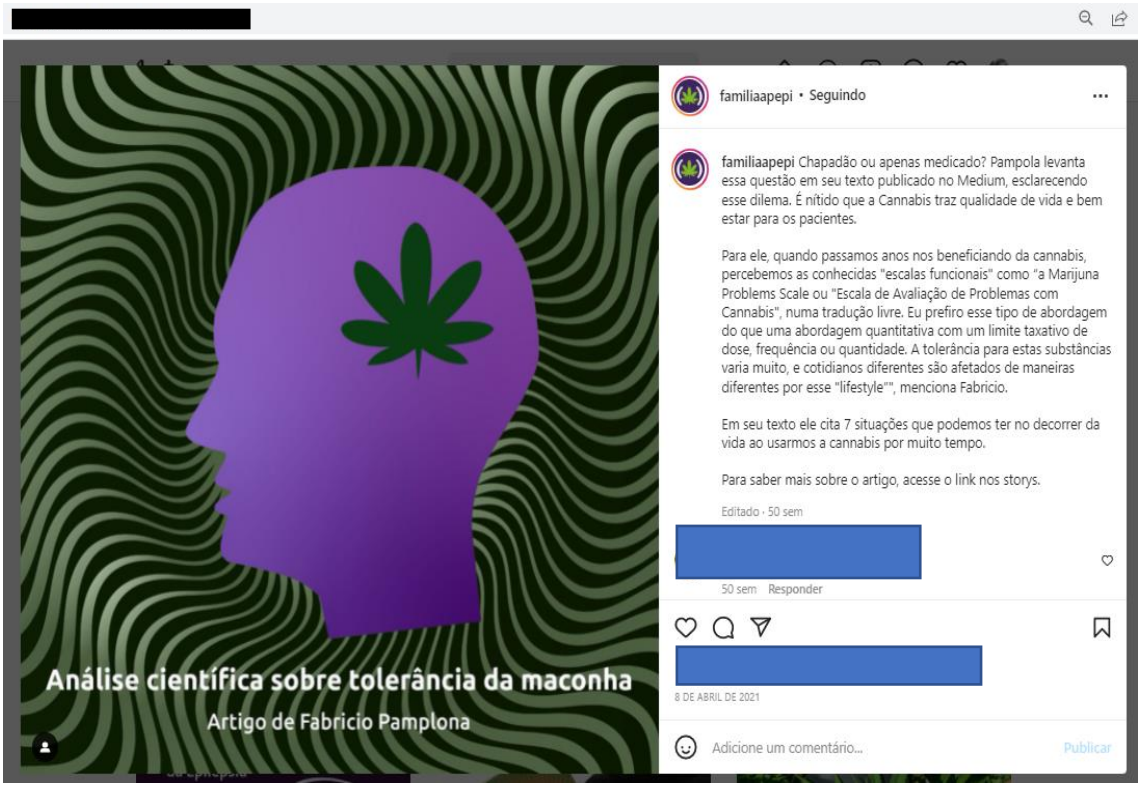
Created in 2014, the Association for the Support of Medicinal Cannabis Research and Patients (Apepi)[19] has the mission of promoting access to the medicinal use of cannabis and stimulating research and informative channels on the benefits of cannabis derivatives. The association was created by the parents of a girl who used cannabidiol to control refractory epilepsy. Today the association has a type of associative cultivation and is working towards the implementation of a Green Living Pharmacy[20] model under the guidance of the Oswaldo Cruz Foundation (Fiocruz). In the analysis of the posts published y the association on Instagram between 2020 and 2021, 26 posts were collected with lay scientific communication content. Apepi extensively uses hashtags with a variety of terms: #apepisaude (#apepihealth), #apepiinforma (#apepiinforms), #avidanaoespera (#lifedoesntwait), #cannabisbrasil, #maconhamedicinal (#medicinalmarijuana) and #maconhaterapeutica (#therapeuticmarijuana). Also, unlike Abrace, it is more common to see the use of other terms besides cannabis, whether to

[19] In Portuguese: *Associação de Apoio à Pesquisa e Pacientes de Cannabis Medicinal*. See Apepi, 2023.
[20] The Green Living Pharmacy (Farmácia Viva Verde) model aims to provide pharmaceutical assistance through the use of plants that have a scientifically proven therapeutic efficacy.

designate the plant in general with use of the term 'marijuana' (*maconha* in Portuguese), or to speak of its derivatives more specifically, like cannabidiol, CBG or THC.

On 8 April 2021, Apepi published a post about a text written by the researcher Fabrício Pamplona.[21] The image (Figure 4) shows the title of the article, a picture of a human head in purple tones and a green marijuana leaf inside the head. The posted text begins with the question: "high or just medicated?" The association has selected a specific excerpt from the text in which Pamplona states that there exist 'functional scales,' such as the Cannabis Problem Evaluation Scale, that show how tolerance of the substance varies between individuals. It can also change depending on different everyday contexts and lifestyles. The association included the link for followers to be able to access the text and learn about the seven situations discussed by Pamplona in relation to prolonged use of cannabis. Between 2020 and 2021, while analysing the content of the association's posts, I perceived that the researcher's name was repeated in a number of them. Perhaps the researcher's proximity to the agenda relating to the therapeutic use of cannabis means that Apepi uses his texts and articles to inform its followers about diseases and other issues related to marijuana.

Figure 4 – Post on the scientific analysis of marijuana tolerance



Source: Apepi (2021a).

In another post, published on 24 August 2021, Apepi's profile discusses the benefits of cannabis in the treatment of endometriosis. This is a disease that affects women of reproductive age that causes cells from the endometrium to migrate to the ovaries and the abdominal cavity rather than being expelled. This in turn causes

[21] According to Pamplona's profile on the Escavador website, the author holds a doctorate in psychopharmacology and has produced diverse publications on cannabis, cannabinoids and the endocannabinoid system (Fabricio, 2023).

some women to experience intense cramps during the menstrual period and pain during sexual intercourse, as well as develop chronic pelvic pain. In the post (Figure 5), which contains a cannabis leaf at its centre, Apepi talks more specifically about an article produced by the Neuropharmacology Laboratory at Pompeu Fabra University in Spain, which shows that THC reduced pain and limited the development of cysts in the endometrium in mice. The post contains no other references or ways to access the full article. It also states that cannabidiol, another substance present in cannabis, works well as an anti-inflammatory, helping the patient feel less pain. At the end of the post, it is reiterated that a doctor should always be consulted before using health treatments.

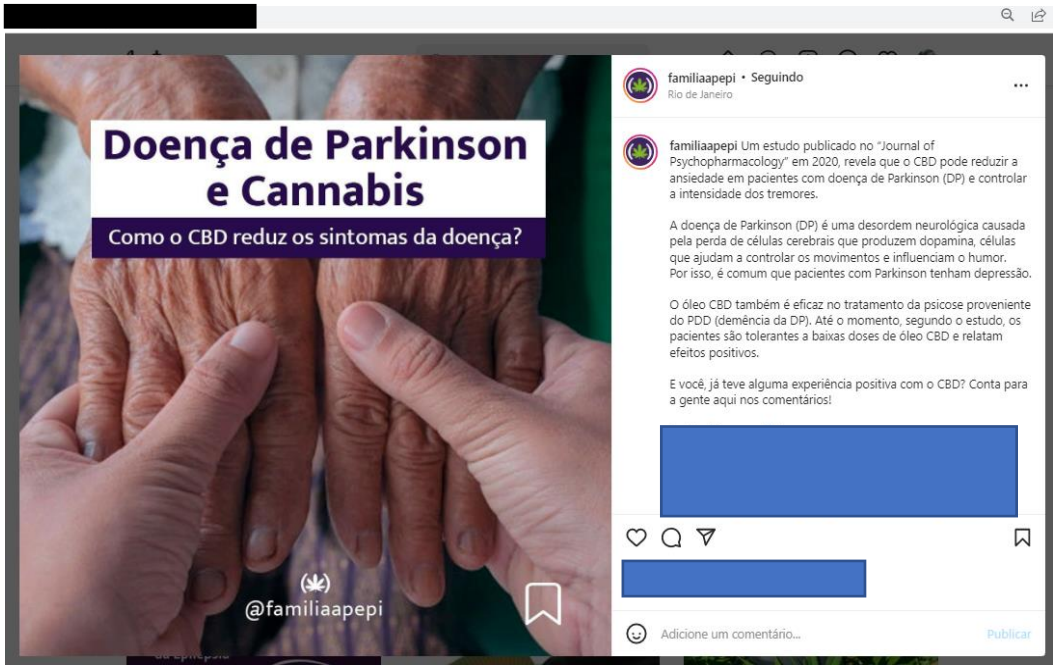
Figure 5 – Post on cannabis and endometriosis

Source: Apepi (2021b).

On 22 November 2021, the Apepi profile published a post (Figure 6) on Parkinson's disease and cannabis, asking how cannabidiol can reduce the disease's symptoms. In the image posted we can see two more wrinkled hands being held by a pair of younger hands. After explaining the disease, the text talks more specifically about a study published in the *Journal of Psychopharmacology* in 2021 showing that cannabidiol can reduce anxiety symptoms in patients with Parkinson's and also help control the tremors characteristic of the disease. It also adds that, according to the study, patients tolerate low doses of cannabidiol in oil form and that it has had positive effects. Finally, followers are asked to leave comments describing their positive experiences using the compound. The authors of the study are not identified and no link to the article is made available. Despite these absences, it not only appears that the association wishes to inform its followers but also wants to interact with them and their experiences of sickness and treatment. This point shows how

digital platforms can help share experiences of the disease and promote health therapies.

Figure 6 – Post on Parkinson's disease and cannabis



Source: Apepi (2021c).

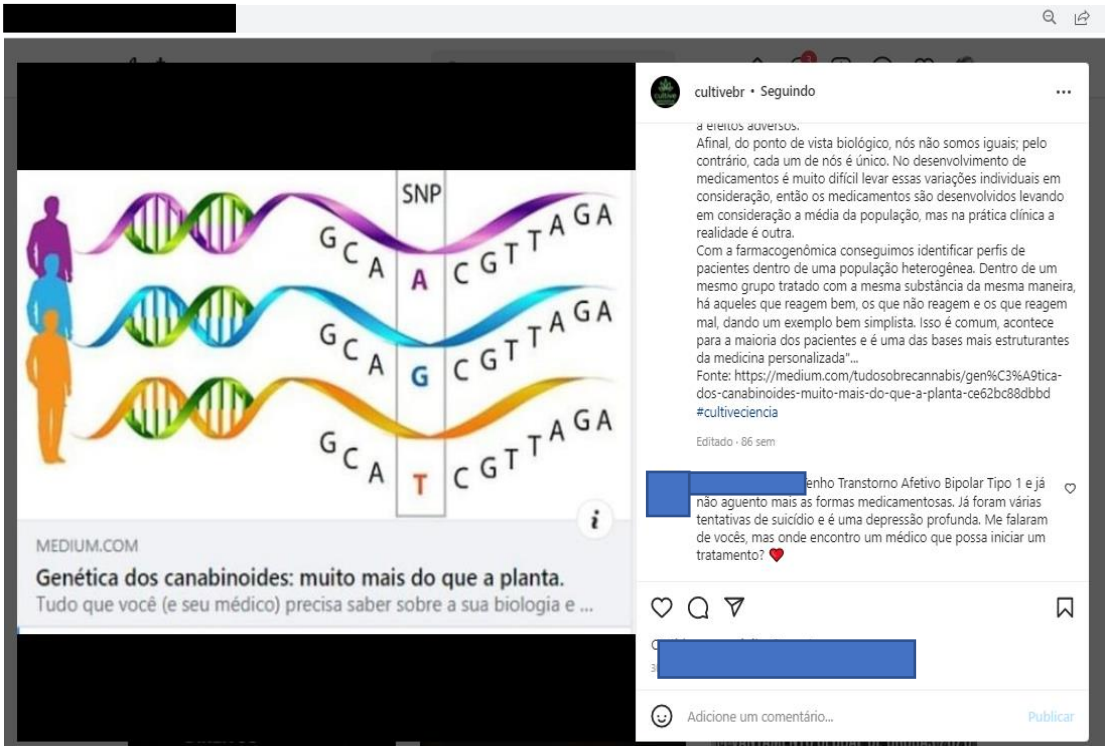
Finally, I turn to posts published by the Cannabis and Health Association[22] (Cultive). This association is formed by patients and family members with the aim of guaranteeing and expanding access for other patients. According to the association's website, its mission is to facilitate the production of cannabis derivatives and ensure the right to health through self-cultivation. During my analysis of the content published by Cultive between 2020 and 2021, 14 posts were collected relating to scientific communication, fewer than on the Abrace and Apepi profiles discussed previously. Generally speaking, the posts produced by this association talk more about the practices and techniques of associative cultivation or regulation than about scientific and health technology procedures. The use of hashtags was more frequent than on the other profiles and they tended to be associated with the association's own name: #cultivebrasil, #cultiveciencia (#cultivescience), #cultivesaude (#cultivehealth) and #cultiveseusdireitos (#cultiveyourrights).

Once again, the name of the researcher Fabrício Pamplona appears, this time in a post (Figure 7) published on the Cultive profile on 30 July 2020. The text begins with the headline: 'the genetics of cannabinoids.' It discusses the trend towards personalized medicine and the importance of knowing each person's genetic profile through testing. According to the text, the objective is to understand this profile better so that the best possible composition of cannabinoids can be prescribed for each person. The post is long and contains a variety of information, including an explanation of pharmacogenomics. This is described as the science studying how our organism reacts to the active principles of pharmaceutical drugs, emphasizing the importance of knowing not just the biology of the plant but also that of the patient. At the end is a link to the site where the text is available in full and the post ends with the

[22] In Portuguese: *Associação de Cannabis e Saúde*. See Cultive, 2023.

use of the hashtag #cultiveciencia. On this point, the first user comment is also interesting. The person states that they have Bipolar 1 Disorder and that they can no longer bear taking their prescribed medications. They had already attempted suicide and entered into a deep depression. The user asks where they can find a doctor to being treatment. The comment encapsulates the association's work of divulgation: Cultive provides information, the follower reads it, becomes interested, comments and also feels free to describe their experience of illness. There is not just the dissemination of information but also an experience of sharing.

Figure 7 – Post on the genetics of cannabinoids



Source: Cultive (2020).

In March, Cultive published various posts announcing an event, the First International Symposium on Cannabis, Science and Health, which took place in June 2021. The event's motto was "only knowledge can overturn social stigmas" and was held online (Cannabis, Science and Health Symposium, 2021). On 18 March 2021, Cultive made a public complaint against the Instagram platform in another post. The posted image (Figure 8) showed a screen capture of a promotion rejected by the platform. In the image Cultive claims that Instagram rejected boosting the post with the justification that posts cannot advertise illegal products, services or activities. The association asks for help from its followers to publicize the event and emphasizes that it will continue to 'cultivate rights.' Interestingly, in the text the association states that the event's objective is to fill gaps left by a scientific and bioethical perspective based on a simplistic and prohibitionist conception of cannabis use. Although the organisation used the platform to publicize an event on science and health, simply the use of the word cannabis was enough for it to be accused of promoting illegal activities. Even more interesting is that it continues to post ads for the event on different dates, utilizing the same term, but the problem does not appear to be the post itself but rather boosting divulgation of the event.

Figure 8 – Post on the event promotion rejected by Instagram

Source: Cultive (2021b).

Still on the subject of the symposium, on 29 March 2021, Cultive published an image similar to the one posted previously but now replacing the word cannabis (also called *machonha* in Portuguese) for *pamonha*, 'sweetcorn paste' (Cannabis, Science and Health Symposium, 2021). In the text, the association explains that the terms were changed because of the platforms privacy policies, since, in seeking to boost the divulgation of the posts, Instagram ended up associating the words cannabis and *maconha* with illegal activities. It once again asked for help divulging the event, emphasizing that dissemination of information and promotion of health should not be seen as illicit activities. In this case, Cultive not only informed its followers about an event that would discuss important topics such as the therapeutic use of cannabis, science and health, but it also made a play on words so that the platform would not be able to identify what the post was advertising. It also comprised a type of denunciation, which is further strengthened when the association points out that speaking about science and health is not an illegal activity.

Figure 9 – Post on the First International Symposium on Pamonha, Science and Health

Source: Cultive (2021a).

For Danah Boyd (2014), technologies are constructed, manipulated and modified, at the same time as new uses, senses and meanings emerge. The uses of the Instagram platform discussed in this article demonstrate how associations have promoted the debate on the therapeutic use of cannabis while also boosting the sharing of information on the subject. In this way, science and scientific products become essential to giving credibility to what is posted. The uses of these artifices are varied: sometimes a personified science is evoked that will contribute through advances and access to treatment, other times specific works and articles are mentioned with the aim of deepening and increasing the visibility of the issues. Although I did not see any mention of the rules enforced by the platform on the Apepi and Abrace profiles, it is not far-fetched to imagine that this might occur. In the case of Cultive, promotion of an event that was due to discuss science and health ended up being rejected because of the word cannabis, given that, after swapping the word for *pamonha*, the association was able to promote the event normally. In general, the association's posts mention the importance of more researchers becoming interested in the topic. Moreover, the association insists that legalization of cannabis derivatives will only be achieved with the contribution of science and scientists, thereby ensuring effective access to these remedies for more people. Towards this end, Cultive and other organisations promote a form of lay scientific communication to disseminate information on the uses and ways to access cannabis derivatives. This point, more than anything else, shows how scientific products and their technologies are central to the debate on the right to health in Brazil and worldwide, which, in the case of marijuana and its derivatives, have been strengthened by the lay expertise (Epstein, 1995; Oliveira, 2017) developed by activists.

Final Considerations

In this article, I argued that cannabis associations have extensively used the Instagram digital platform to promote lay scientific communication. To show how, I analysed the content produced by three cannabis associations between 2020 and 2021 on the platform. According to Zandavalle (2018), Instagram has considerable potential as an area of study since the very dynamic of the platform encourages daily sharing among users. Along these lines, we can take into consideration what Lins (2020) says about the new sociotechnological context in which it is possible to gain access to information and communicational possibilities that transcend physical and material barriers. In their feeds, the profiles of the associations raise important questions and information on the therapeutic use of cannabis, which can help more people to know about the benefits of the substances. Furthermore, this work contributes to the expertise of people who use them, whether these are patients or their family members and/or carers. The internet and social networks have transformed into key locations for the formation of different biosocial connections (Rabinow, 1991), essential for the biosocial trajectories of these individuals to be undertaken, considering the sharing of experience of illness and therapies.

Inspired by the studies of Epstein (1995) on the activism surrounding the HIV/Aids epidemic and the work of Oliveira (2017) concerning the lay expertise developed by activists for the therapeutic use of cannabis, I showed how the cannabis associations, formed by family members, patients and activists, have developed a work of lay scientific communication. The idea is, amid the daily posts of the associations, to

pass on scientific information in a way that is easier to read, assimilate and comprehend. A language that is scientific but above all accessible. This sharing of information also has to cope with impositions from society and the platforms themselves. In this sense, the activists sometimes need to focus on the post contents and sometimes need to find mechanisms to circumvent the policies of the digital platforms.

Cannabis associations have thus become privileged locations where the experiences of everyday life intersect with those accessed through digital platforms. These experiences cannot be dissociated from each other given that the political and social contexts in which patients live form part of their experience with the disease (Carneiro & Dwyer, 2012). By analysing the work of these associations, we can perceive how science and scientific products permeate the everyday world of people seeking access to therapies based on cannabis and its derivatives. The work of lay scientific communication undertaken by the associations is essential not only for the sharing of information and expertise concerning the access to new therapies and health technologies, but also for the democratisation of access to scientific products in general.

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