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Ways public health users interact with online health information: a qualitative study

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Abstract

Purpose The use of internet for health-related purposes has increased in the past years; however, the overabundance of information led the world to a health "infodemic". Little is known about the ways public health users seek health information online and how it influences the relationship between patients and healthcare practitioners. We aimed to investigate how public health users seek health information online and how this practice affects health encounters.

Methods We conducted a qualitative study in a public secondary level healthcare facility. Thirty participants were interviewed using a semi-structured grid designed upon the definition of digital health literacy. Participants were mostly women with an average age of 50 years old and educational level equal to or lower than high school degree. Traditionally and digitally illiterate participants participated in the study. Data analysis was performed using a reflexive thematic analysis underpinned by critical theory.

Results We identified three interrelated themes: (1) failing to be a digitally engaged patient, (2) health information on the internet resonates better with individuals' literacy, and (3) vulnerability is welcomed on the internet. Themes explored power dynamics that appeared to be mediated by formal knowledge, sociocultural contexts, use of technical language, and the presence of emotional and affective domains.

Conclusion Our findings suggest that health information online might facilitate the understanding of technical terms and fill an emotional gap often overlooked by healthcare practitioners. Findings may assist health professionals in developing ways of considering health information online as part of the health encounter.

Keywords Critical theory · Internet · Health information · Power · Middle-income country

1 Introduction

Over the past 30 years, the development of information and telecommunication means favored the internet to permeate most domains of human life, including health [1–3]. Health information of all types has never been as available and accessible as it is in the 21st century. Although they can contribute to patients' knowledge and informed health decision-making [4, 5] they also challenge health systems and health dynamics. These challenges are evidenced by the large amount of information, poor quality control, and high risks of spreading untrustworthy information within digitized environments [6–8].

Since the COVID-19 pandemic, the world has been hit by a global epidemic of misinformation that rapidly spreads through social media platforms, the so-called "infodemic" [9]. In Brazil, for example, 81% of the population older than ten years has access to the internet, and 72% went online to

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seek health information in 2020 [10]. Similar percentages of internet users sought health information online in the United States [11] and across Europe [12]. Internet's pervasiveness and easy and rapid transmission of information add pressure on patients [13] who are expected to know how to find appropriate health information among all available online information [14, 15].

The internet appears to contribute to how everyday health is understood and experienced [4], so being a digitally engaged patient (i.e., a patient who uses digital technologies routinely for engaging in health practices, such as self-monitoring and self-care) [16] seems to be an important feature. Presumably, being a digitally engaged patient includes competencies to seek, understand, and appraise health information consumed online [16, 17], engage with self-management strategies, and participate in online support groups. Therefore, this description assumes that digitally engaged patients are empowered individuals and use online health information and resources to take action and engage with healthcare practices [13, 16]. However, digital engagement relies on aspects beyond access to technology (i.e., device and internet connection) [18]. The description of a digitally engaged patient appears to overlook aspects related to digital and health literacy levels and previous experiences with technology [13, 19, 20]. Critical approaches to digital health technologies offer an alternative lens to consider social and cultural aspects in discussing access to and use of online health information [21].

Digital and health literacy levels are associated with health determinants such as education and income [14, 22]. Lower digital and health literacy levels may lead to a biased selection and evaluation of online health information (i.e., confirmation bias), which strengthens beliefs and assumptions [6, 7]. In Brazil, substantial socioeconomic inequities contribute to the low or very low health literacy levels presented by a considerable proportion of older adults [19, 23]. The relationship between patients and health professionals might be affected by literacy levels and also by this biased behavior of consuming online health information [15, 17, 24]. Previous studies evidenced that an unintended consequence of individuals seeking and using online health information may be the increase of medicalization [13, 16]. Health professionals may feel threatened, challenged, or confronted when patients make treatment requirements based on online health information [17]. The ways patients, online health information, and health professionals relate is a topic that has not been thoroughly investigated in low- and middle-income countries. In those settings, adopting a critical lens to consider context, assumptions, and social determinants of health may be crucial.

We aim to elucidate how health information online figures in the landscape of a health encounter from the perspective of public health system users. We adopted a branch of the critical theory called critical digital health technology to foster an analysis considering power dynamics, socioeconomic and cultural contexts, and access to technology.

2 Methods

We conducted a qualitative study based on semi-structured interviews with online surveys that served exclusively to retrieve information on the characterization of the participants. This study was approved by the Research Ethics Committee of the Research Ethics Committee of the Universidade Cidade de São Paulo (UNICID), Brazil (CAAE: 20309919.5.0000.0064) and the Municipal Health Secretary of Campinas (authorization 053/2019 - CETS).

2.1 Theoretical framework

We used critical theory [25, 26], and the critical digital health literature more specifically, to inform our research questions and analysis of the data. Critical theory is a philosophical school of thought from the 20th and 21st centuries that aims to articulate a debate about science underpinned on social and political contexts. Critical theory refers to various approaches with the overarching interest in aspects such as power dynamics, autonomy, culture, beliefs and assumptions [26]. As a branch of critical theory, critical digital health studies focus on the implications of digital health technologies to the social, political, cultural, and ethical domains [21]. Critical digital health challenges the assumption that digital health technologies are a "solution" to overcome geographical and socioeconomic barriers and a pathway to broad, universal, and democratic access to health services [4, 21].

We use the work of Lupton [16, 21, 24] to unpack how power dynamics influence encounters between patients and healthcare professionals in the context of seeking online health information. The emphasis on power dynamics provides insights on how patients relate to health professionals, how health knowledge is constructed and is present in a health encounter, and to what extent this knowledge is valued or marginalized within the health domain [24] .

2.2 Setting

We conducted the interviews at a public secondary level healthcare center (i.e., specialized care) situated in Campinas, São Paulo, Brazil. The center provides multidisciplinary care focusing on rehabilitation, including physical therapists, medical doctors (orthopedics, acupuncturist, and physiatrist), occupational therapists, speech therapists, psychologists, and social workers. The population attending the center is heterogeneous and must be referred from primary tertiary care levels. Due to the pandemic context, the center focused on care of acute and most severe cases.

2.3 Data collection

Data collection occurred from November 2020 to February 2021. We interviewed individuals who attended the center for the first/initial assessment or were undergoing any treatment or follow-up, and companions (i.e., family or friends) or caregivers. To be eligible to participate in this study, participants had to provide verbal and written consent, speak Portuguese, and actively engage with the interview flow. The interviewer (LF) approached the participants in the waiting room, invited them to participate in the study, and used a computer to complete the consent form and online survey. The interviewer assisted in reading the survey questions aloud and in clarification in case of misunderstanding, allowing the inclusion of traditional and/or digital illiterate patients. Twenty-eight interviews were recorded and transcribed verbatim. Two interviews were not recorded due to participants' preference; however, the interviewer took notes and self-recorded the main bullet points.

2.4 Interview guide and pilot testing

Two authors (LF, BS) developed the interview guide using as a framework the definition of health literacy and digital health literacy: "[set of] skills that enable individuals to obtain, understand, appraise, and use [online] information to make decisions and take actions that will have an impact on health status" [27, 28]. The research group revised the interview guide, and the final version is available in Supporting Information. Modifications regarding readability and wording were performed according to feedbacks. We conducted a pilot interview to check for flow and duration and this interview was not included in data analysis. A major modification that was performed in the interview guide concerned the opening question: from "where do you usually search for health-related information?" to "what comes to your mind when I say 'health information'?". The choice of beginning the interview in such a manner promoted an environment of alliance between participant and interviewer.

2.5 Data analysis

We analyzed the interviews using a reflexive thematic analysis adapted from previous studies [29, 30]. Data analysis was performed by LF (a healthcare professional and researcher experienced with different research designs within the qualitative paradigm) and KM (a healthcare professional and experienced qualitative researcher). We started our analysis inductively and transitioned to a theory-driven approach underpinned by critical digital health studies at the final rounds of coding. We adopted a six-step analysis comprising in-depth familiarization with data, rounds of coding and interpretation concerning our theoretical framework, and development of themes. Final themes are reported according to the 15-point checklist for a rigorous thematic analysis suggested a priori [30, 31].

Our choice to use a reflexive thematic analysis as described by Braun & Clarke for data analysis reflects an attempt to fully embrace the values of the qualitative paradigm, namely subjectivity, interpretation, and active role of researchers during data analysis [32].

3 Results

The description of the 30 included participants is presented in Table 1, and their digital health literacy levels are available as a Supporting Information. Interviews lasted from 12 to 45 min. We collated our findings in three main themes: (1) failing to be a digitally engaged patient, (2) health information on the internet resonates better with individuals' literacy, and (3) vulnerability is welcomed on the internet. Within the first theme, we explore "lack of interactional power" and "lack of structural power" as restricting the "digitally engaged patient" to thrive. We changed participants' names to guarantee anonymity.

3.1 Theme 1: failing to be a digitally engaged patient

Our data indicated that participants' behavior in seeking and discussing health information online, and therefore the attempt to become a digitally engaged patient, was systematically discouraged either by lack of relational power or lack of structural power. Power here refers to patients' position in relation to health professional in two distinct situations: in the first, less power means that participants had lower medical/technical knowledge; in the second situation, less power means that participants came from disadvantaged and marginalized groups.

3.2 Lack of interactional power

Our analysis suggested that health professionals discouraged participants' attempts to be an active, independent, informed, and, therefore, digitally engaged patients (by seeking and using health information online). Participants highlighted that health professionals seemed angry and uncomfortable with the information found online. Some

Table 1 Characteristics of the subjects

Characteristics	N = 30
Gender, n (%)	
Men	13 (43%)
Women	17 (57%)
Age in years, mean (SD)	50 (14)
Marital status, n (%)	
Single	8 (27%)
Married	16 (53%)
Divorced	6 (20%)
Level of education, n (%)	
Unfinished primary school	8 (27%)
Primary school certificate	3 (10%)
Unfinished high school	5 (17%)
High school certificate	8 (27%)
Unfinished Bachelor degree	2 (8%)
Bachelor degree	1 (3%)
Postgraduate degree	3 (10%)
Family income*, n (%)	
Up to 2 minimal wages	13 (43%)
2–3 minimal wages	5 (17%)
3–6 minimal wages	5 (17%)
More than 6 minimal wages	2 (7%)
Prefer not to answer	5 (17%)
Number of people living in the house, median (IIQ)	3 (1.75)
Main health comorbidities, n (%)**	
Hypertension	5 (17%)
Diabetes	3 (10%)
Chronic musculoskeletal pain (cLBP, OA)	10 (33%)
Post/long COVID-19	3 (10%)
Upper/lower limb fracture	2 (7%)
None	11 (37%)
Used any emergency service in the previous year, n (%)	11 (37%)
Was admitted at the hospital in the previous year, n (%)	5 (17%)
Used the internet to seek for health-related information in the previous 3 months, n (%)	16 (53%)

cLBP: chronic low back pain; OA: osteoarthritis

*Minimal Brazilian wage is approximately U$209

** Subjects could present more than one comorbidity

health professionals even explicitly argued, "*who is the doctor/health professional here?*" in an attempt to demonstrate their power over the information shared by the participant. Participants often felt uncomfortable with these demonstrations of interactional power, as illustrated in the following quote:

> *"It was really uncomfortable. She [the doctor] didn't like it. Because she felt, from what I noticed, she did not feel comfortable with being questioned. The way she responded and the way she looked at me implied that "I'm the doctor, I'm the one who know what you need, end of the story" [Junior].*

Although some participants felt in a position to question their health professionals, when they did the situation commonly evolved to health professionals reclaiming back and reassuring their power as experts. Therefore, the attempt of participants to access knowledge and information online seemed to be discouraged by health professionals.

3.3 Lack of structural power

In addition to interactional power, our analysis indicated that participants from a disadvantaged or marginalized context also failed to be digitally engaged patients. The social and cultural structures were determinant factors for participants' access to the internet and health services. Although power is not located in a specific point of the social structure, unfavorable social and cultural structures, as observed below, appear as mediators that shift power away from patients, thus eliciting feelings of resignation, lack of support, and poor assistance:

> *"LF: What do you think about seeking health information online?*
> *M: Oh, dear, no way I'm doing that. First, I don't know how to use the internet, and I don't have these devices, these modern devices to research these medical topics. [.] we used to live in the countryside of Ceará [a state in Brazil], and over there, we had no way of attending*

> *to health appointments; you live in a rural area where there is nothing around. You have a health center that is really far, it's not in the neighborhood, you have to go to a different city, so you have to leave your land to go to this center. […] It's somewhere completely forgotten by the government." [Marina].*
>
> *"I'm a layperson on the internet; I have to be honest with you; I'm not able to use the internet. We use the cell phone because we have to, but the internet…it is difficult to use the internet." [Luri].*

Social and cultural structures, illustrated by poor access to technologies or the low digital literacy to deal with them, seemed to be a premise to leave participants with less power and possibly reinforce the dominance of health professionals in patient-health professional relationships.

3.4 Theme 2: Health information on the internet resonates better with individuals' literacy

According to our analysis, the health information on the internet is more accessible and resonates better with individuals' literacy. This versatility of materials and the possibility of finding a source that better matched individuals' literacy seemed to offer a space for equal power relations. Participants found the online information more accessible to understand than the ones provided by health professionals.

Participants consulted the internet both before the encounter with the health professional and afterward. Before the encounter, the internet was used to provide a general overview of the health situation: it guided participants' understanding of the health situation in terms of its severity, potentially avoiding unnecessary consultations. However, the internet was also used after a health encounter to help participants understand and interpret the information they did not completely understand or memorize at the time of the consultation. Both quotes below demonstrate the power relation created when patients did not comprehend what health professionals said due to the presence of too many technical terms:

> *"In some cases, I've found the internet easier to understand than health professionals. Because health professionals use those technical terms, and even when you ask for, or demonstrate you don't understand something, even if you do it, they continue to adopt a technical approach. There is an obstacle there."[Lisandra].*
>
> *"That's it, people! Translate those terms! Because a layperson will be like: 'what is that?!' It is not everybody that has access [to information]. I know I'm a layperson but there are people much less informed than me. Just like us that come from a very modest background, and then [health professionals] share technical information that is really difficult to understand." [Maria Fernanda].*

Participants in this study reported that poor understanding or memorization could result from the overuse of technical language or medical jargon by health professionals. Our analysis suggested that the use of jargon appeared to distance patients and health professionals, endorsing power dynamics mediated by technical knowledge and formal education. The internet, on the contrary, was seen as accessible, easier to understand, since it had a variety of material (in different formats such as videos, texts, images) that could be consulted, solely or combined, to fill the gap left by the interaction with the health professional.

3.5 Theme 3: vulnerability is welcomed on the internet

The emotional and affective burden commonly associated with the presence of a condition (e.g., disease diagnosis, physical and psychological trauma, or pain experience) appeared to be greater valued (and welcomed) on the internet than on the health encounter. Participants reported that health professionals might undervalue their perspectives and knowledge about health. They suggested the internet is used to find support groups, real (coping) stories, and comments/testimonials about lived experiences. The first quote demonstrates how a gradient of power is endorsed by lack of interest from health professionals in listening to participants. The second quote exemplifies a participant calling the emotional comfort provided by the internet.

> *"When you have a complaint, you know at least a little bit about what is happening because you've searched for information [online]. But it's not always that health professionals want to listen to what you think about. They have their opinion, their health knowledge, so it's not easy.[.] The understanding between patient and health professionals is difficult; patients understand one thing and health professionals another." [Pamela].*
>
> *"I believe that when you read a real story about a personal experience, I believe it gives you some emotional safety, I guess.[…] Because you face a situation that you don't know which will be the exact outcome, so everything that gives you hope may be the support you need to overcome this situation. Because if you think nothing will help, you end up not trying. Although it is not a guarantee that your effort will*

> *result in something, it is a hope. I believe that being hopeful makes a difference." [Juliana].*

We identified that by connecting and welcoming participants' emotional states, the internet seemed to provide an unexpected source of empowerment in the face of health uncertainty. In both quotes, health information found online appears to participate on how individuals make sense of what they are feeling or experiencing. The internet seemed to fill part of the emotional gap often present in situations encompassing health issues (vulnerability, anxiety, sadness, hopelessness) and when participants did not feel they were listened to by health professionals.

4 Discussion

Our study aimed to investigate how health information online figures in the landscape of health encounters conducted with public health users. Our findings suggest that health professionals hinder some patients' initiatives of becoming digitally engaged patients by reclaiming back their power as experts or overusing medical jargon. Cultural and social structures and the emotional and affective domains (i.e., being listened to and comforted) also appear to be part of the architecture that reinforces the patient as powerless in health encounters.

According to our first theme, health professionals often prevented participants from becoming digitally engaged patients. Health professionals explicitly and implicitly disapproved the patients for having sought for health information online. Due to its easy access and enormous availability of information, the internet has become not only a source of but sometimes the primary source of health information [17]. However, information quality is often doubtful and can misguide patients' understanding and interpretation [33, 34]. Lack of information quality is particularly problematic in the face of insufficient digital and health literacy levels [18, 22]. Previous studies discuss that hesitancy to share search results with health professionals may rely on fear of embarrassment or awareness that online health information may be misleading. [7, 35, 36] Patients may adopt a silent approach, checking and completing the understanding gained online without revealing they navigated on the internet [5, 20, 37]. On the other hand, online health information may motivate the requirement for specific medicines or treatment actions from health professionals [38, 39]. Both approaches endorse tension and power dynamics along with the health encounter.

We further observed that participants felt powerless when health professionals used technical language and medical jargon. For example, participants did not always understand what health professionals said during their encounters. From a patient-centered approach, communication is central within a health encounter and should encompass characteristics such as attention, inclusion, and empathy [40, 41]. Effective communication between patients and health professionals includes information sharing to comprehend patients' complaints and healthcare experiences. [41] The use of technical language and medical jargons reflects a hierarchical relationship mediated by formal knowledge [24], and may inadvertently drive patients to search for health information online. From the end of health professionals, enhancing communication skills by employing plain language may optimize patient understanding [42, 43]. Specific communication techniques, such as teach-back and targeted messaging, may be an alternative to build health knowledge considering digital and health literacy levels [43–45]. Therefore, our findings suggest that individuals may seek health information online as an additional source of explanation and clarification to a health encounter. Openness and receptivity to health information online and the normalization of discussing it along health encounters may also nurture environments in which patients feel welcomed to share their doubts, thus enhancing therapeutic alliance.

Health information online cannot be implemented in the health encounter without carefully examining the digital environment as a place used both for the exchange of information *and* affections [46]. Whereas the digital environment might have a global outreach, it encompasses normative behaviors linked to cultural- and context-specificities [47]. As such, power relations become evident when the digital environment, or specific social networking platforms, value certain emotional actions [46, 47]. Our analysis suggests that support groups and real coping stories may be an unexpected source of empowerment and comfort, especially in situations in which patients do not feel listened to or when prognosis and pathways to recovery seem uncertain. Doeveling and Sommer (48) expose the "emotional power" of digital environments, highlighting its ability to strengthen connections by eliciting feelings of empathy and belonging. However, digital environments can also undermine connections by nurturing resentment and hate speech [48]. For example, social media's dynamic and interactive features contribute to fake news spreading faster than reliable information [7, 8] and general anti-science discourses have gained enormous space in the digital environment [49], facilitated by platforms algorithms, confirmation bias, and politics of disinformation [7, 8, 50]. Together these studies emphasize how emotions matter to the digital environment. Our findings help comprehend the nuances of the interaction with online health information: rather than solely a technical source of information, the internet appears to provide emotional and affective support [46, 48]. Public strategies to fight disinformation could consider how individuals represent and make sense of online health information.

The expanded access and omnipresence of technology within the health domain may warrant different concepts and theoretical considerations to debate health and how people interact with the digital world [46, 51–53]. Previous authors [52, 54] have discussed about the concept of connectivity, for example, in which interactions between humans and non-humans (e.g., devices and the digital environment) are further explored. This concept defends that people develop their understanding of themselves and the world from interactions with other people, objects, technologies, environments, ideas, and places [54]. Considering our findings, embracing health information online as part of the individual construction of health may favor communication (technical and emotional) and enable the development of new and varied connections between patients-technology-data-senses-space-health professionals [5, 20, 55]. Connectivity also accounts for non-humans as active agents rather than inert objects, thus capable of mediating power relations and shape humans' experiences and understandings [52]. Implementing the concept of connectivity into health encounters invites health providers to behave differently: instead of adopting discourses reinforcing power dynamics, health providers would rather investigate ways patients' interact and connect with information, people, treatment programs, environment, and objects, to optimize outcomes [56]. Therefore, the concept of connectivity and theoretical considerations of how human and non-human actors interact in the construction of health information may allow the health encounter (and patient-health professional relationship) to be more collaborative.

4.1 Methodological considerations

Our study had the aim to contribute with the poor body of evidence on technology and health from the perspective of a middle-income country with substantial socioeconomic and health inequities and considered subjectivities linked to participants' context, previous experiences, assumptions, power relations, and cultural and social backgrounds. However, because our sample was mostly women, it could explain why emotion and affective domains were among the main findings. Furthermore, we did not distinguish between participants undergoing treatment or follow-up and those who were companions or caregivers. Although the profile of health information seekers is diverse, digital practices may be different if you search for information for yourself or on behalf of someone [20, 57, 58].

A limitation of our study includes the absence of data on participants' characteristics such as race, ethnicity, and employment status. Together with digital and health literacy and socioeconomic status, these social determinants of health are known to affect the relationship between patients and health professionals [22, 43, 59], providing a more in-depth intersectional analysis of power dynamics.

Most literature about health technology often focus on whether the internet is used or not and how does this usage pattern is operationalized, implemented, and how could it be optimized [16]. Based on these premises, the literature may regularly contribute to patients' and health professionals' blaming because it highlights the individual responsibility for developing skills that enable navigation and participation in a digitized world [60]. Here, we drew from a branch of critical theory to discuss online health information from the perspective of public health users. Our aim was not to explore which health information was discussed in the health encounter or what information was brought by the patients. However, how online health information affects the health encounter from the perspective of health professionals or how patients and health professionals discuss online health information in real-life encounters are similarly pertinent. Further studies underpinned on the qualitative paradigm may investigate these aspects to understand digital health practices further.

5 Conclusion

Health information on the internet can be easily consulted and hold the potential of contributing to the development of digitally engaged patients, i.e., individuals that are greatly aware of their health and play an active role in managing their health conditions. Our findings suggest that the apparent hierarchical relationship between health professionals and patients may limit patients' attempts to become digitally engaged. Formal medical knowledge and the common adoption of a technical language during communication (i.e., use of medical jargon) seem to contribute to consolidating this hierarchy. Barriers involving access to technology, education, digital and health literacy levels, and socioeconomic status might also strengthen the unbalanced power relationship between health professionals and patients. Moreover, the internet appears to support the emotional and affective domains that are not always cultivated in a health encounter. The continuous expansion of the internet within health and the challenges it unfolds to patient-health professional relationships may call for new concepts and theoretical approaches to understand how people interact with the digital world.

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Author contribution Dr Saragiotto and Miss Fernandes designed the study and wrote the protocol. Miss Fernandes was responsible for the main writing, data collection, analysis, and interpretation. Dr Saragiotto supervised the work performed by Miss Fernandes, help with interpretation of findings, and provided extensive revisions in the manuscript. Dr Mescouto provided feedback and contributed to the data analysis and interpretation of findings. Dr Costa critically reviewed the manuscript for intellectual content and provided feedback on the analyses. All authors revised and approved the final submission.

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Declarations

Ethics approval This study was approved by the Research Ethics Committee of the Universidade Cidade de São Paulo (UNICID), Brazil (CAAE: 20309919.5.0000.0064) and the Municipal Health Secretary of Campinas (authorization 053/2019 - CETS).

Consent to participate All participants were informed of the purpose of the study and provided written consent before their inclusion in the research. Participants were free to withdraw from the study at any time.

Consent for publication All authors revised the manuscript and agreed with its submission, and written informed consent was obtained from all participants for the publication of their anonymized data.

Competing interests The authors declare no conflicts of interest related to this study.

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