ARTICLE

Barriers to health information on social media

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ABSTRACT

Introduction: The use of social media for self-management of health information is a recurrent practice for lay users who experience different health contexts. Although social media facilitate information access and sharing, they can contribute to the emergence of possible risks to health and well-being, as they increase emotional vulnerability and misinformation experiences. **Objective**: To discover current evidence impacting the beneficial use of social media for health information purposes; the investigation sought to examine how barriers to health information on social media perceived by lay users are presented in recent empirical research. **Method**: A qualitative exploratory research was carried out through a literature review on the SCOPUS database. **Results**: Although the barriers are multiple and vary according to health contexts and situational motivations, they can be articulated in a mesh composed of the following meta-barriers: diasporic, misinformation, literacy, interaction, and emotional. **Conclusion**: The study concluded that the presented mesh of barriers, associated with other structural barriers, can contribute to the construction of research instruments and digital interventions involving the use of social media for health information purposes.

KEYWORDS

Health information. Social media. Information practices. Information barriers. Users.

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Barreiras à informação em saúde nas mídias sociais

RESUMO

Introdução: A utilização das mídias sociais para a autogestão de informações sobre saúde constitui uma prática recorrente dos usuários leigos que vivenciam diferentes contextos de saúde. Embora facilitem o acesso e o compartilhamento de informações, as mídias sociais podem contribuir para a criação de possíveis riscos à saúde e ao bem-estar, uma vez que ampliam as experiências de vulnerabilidade emocional e desinformação. **Objetivo**: Para descobrir as evidências atuais que impactam o uso benéfico das mídias sociais para fins de informação sobre saúde, buscou-se examinar como as barreiras à informação em saúde nas mídias sociais, percebidas pelos usuários leigos, são apresentadas em pesquisas empíricas recentes. **Método**: Realizou-se uma pesquisa qualitativa de caráter exploratório por meio de uma revisão da literatura na base de dados SCOPUS. **Resultados:** Observou-se que, embora sejam múltiplas e variem conforme os contextos de saúde e as motivações situacionais, as barreiras podem ser articuladas em uma malha composta pelas seguintes meta-barreiras: diaspóricas, desinformação, letramento, interação e emocionais. **Conclusão:** Conclui-se que a malha de barreiras apresentada, associada a outras barreiras estruturais, pode contribuir para a construção de instrumentos de pesquisa e intervenções digitais envolvendo o uso das mídias sociais para fins de informação sobre saúde.

PALAVRAS-CHAVE

Informação sobre saúde. Mídias sociais. Práticas informacionais. Barreiras de informação. Usuários.

JITA: CB. User studies.

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1 INTRODUCTION

The use of social media as a source of health information is growing in the contemporary scenario. The literature has widely discussed that social media platforms have both benefits and drawbacks for lay users' self-care (DE MARTINO *et al.*, 2017; WANG *et al.*, 2019). The benefits are related to the convenience to find, access, compare and share information. The disadvantages are related to issues of credibility, quality, veracity and information overload. Whether to reflect on the benefits or the disadvantages, studies on communication/information/health on social media tend to focus on a perspective related to the usual and material aspects of platforms, involving, for example, public availability, ease of use, and immediacy of information (AGARWAL; YILIYASI, 2010).

However, fully understanding the use of social media as a space for health information requires going beyond the materiality of platforms. It requires unveiling the complexities involving the challenges and dilemmas of self-management of information (BRASHERS *et al.*, 2002) on social media; therefore, it requires integrating materiality to contexts and situations (SCHATZKI, 2005). In this sense, the information practices approach (LLOYD, 2010), from a perspective of transition of health contexts (LLOYD, 2014), significant and personal (CLEMENS; CUSHING, 2010), is relevant as it allows thinking about the health context as an experience detached from stable routines (CLEMENS; CUSHING, 2010) – of rupture of information bases and, at the same time, of (re) construction of new information bases (LLOYD, 2014). In this transitory perspective, the tensions related to the use of social media overlap with the tensions that emerge from the experienced context, producing ambivalent and unknown information experiences.

Considering that these tensions involve multiple objectives, resources, and impositions/standards, an alternative strategy to reveal the challenges and dilemmas regarding the use of social media for health information purposes can be the analysis of information barriers. Information barriers, according to Araújo (2021), are inherent to the informational phenomenon, as they are related to the informational subject and their abilities to determine their informational needs, as well as to develop searches and effective uses of information in a context of precarious informational skills and complex and adverse environments. In this sense, in the experience dimension, information barriers can be configured as an objective analytical element that allows revealing complex issues involving different contexts and health situations, such as, for example, the multiple conflicting objectives a situation can present (GOLDSMITH, 2001). Although barriers are indicated as an element of analysis for studies on health care involving social media (ANTHEUNIS *et al.*, 2013), a need to deepen the relational understanding of these barriers is verified, which is capable of covering the articulation between the uses of social media and the tensions inherent in the transition of contexts.

Both the identification and the articulation of information barriers related to social media, perceived by users who experience or face transitory tensions in their health contexts, are believed to contribute to the development of studies and/or interventions related to the promotion of information resilience (LLOYD, 2014; LLOYD, 2015; BRASILEIRO, 2020) and the regulation of self-management of health information practices (BRASHERS *et al.*, 2002). In this direction, therefore, the approach to information practices (LLOYD, 2014; LLOYD, 2010) in a situational perspective can favor the development of an original framework about information barriers linked to social media, in articulation with the perspective of contextual transition.

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From these initial reflections, aiming to examine how barriers to health information on social media can be configured, which impact the self-management practices of health information, a review of contemporary empirical research was carried out, indexed on an international database, which explore the use of social media for information purposes from the perspective of lay users who experience different health contexts. This review allows the development of an analytical framework for future studies. Thus, the following specific dimensions were taken as the scope of the review: the barriers or difficulties perceived by the researched subjects; these subjects' motivations regarding the use of social media for health information purposes; related social media; and the experienced health contexts.

2 METHODS

The research strategy of this literature review follows the guidelines of the PRISMA model (MOHER *et al.*, 2009). The research took place on the SCOPUS database, a comprehensive international database, which involves abstracts and citations of works in different areas of knowledge. The time frame included the records published between 2015 and 2020. The research protocol involved the following terms: barriers OR restrictions OR difficulties OR impediments AND health information OR health misinformation AND social media OR digital media OR social network OR online network.

The record identification phase considered the following selection criteria, available on the SCOPUS system: (a) scientific articles or conference proceedings published in the last five years; (b) texts published in English or Portuguese. The screening and eligibility phases involved reading of the titles and abstracts based on the following inclusion criteria: (a) studies on social media; (b) studies on health information; (c) studies involving barriers to health information on social media; (d) studies that address the perspective of lay users of health information; (e) studies on the real use of social media, resulting from empirical and original research.

The following exclusion criteria were considered when reading the eligible texts: (a) studies that do not explore social media; (b) studies that do not explore health information; (c) studies that do not explore barriers or difficulties to health information on social media; (d) studies related to the perspective of health professionals; (e) studies of expert opinions or interviews lacking methods; (f) studies that do not deal with empirical and original research, such as literature reviews.

The assessment phase of the included studies involved a detailed reading of the full texts and considered the following elements for data extraction: (a) barriers or difficulties to health information on social media; (b) social media used by users for health information purposes; (c) users' motivations or intentions related to the use of social media; (d) users' health contexts. The steps in the research flow are represented in Figure 1, available in the following section.

3 RESULTS

A total of 4,268 studies were identified on the SCOPUS database (Figure 1). After removing 25 duplicate studies, 4,243 studies remained for review. Of these, 1,882 were excluded after applying the selection criteria – year (2015 to 2020), language (Portuguese or English), type of study (Articles and Conference Proceedings). After screening the titles and abstracts based on the adopted inclusion and exclusion criteria, 38 studies were eligible for full-text reading. Of these, 27 were discarded for being beyond the scope of the research. A total of 11 complete studies were included for the qualitative review.

Figure 1. Research flow on SCOPUS database.
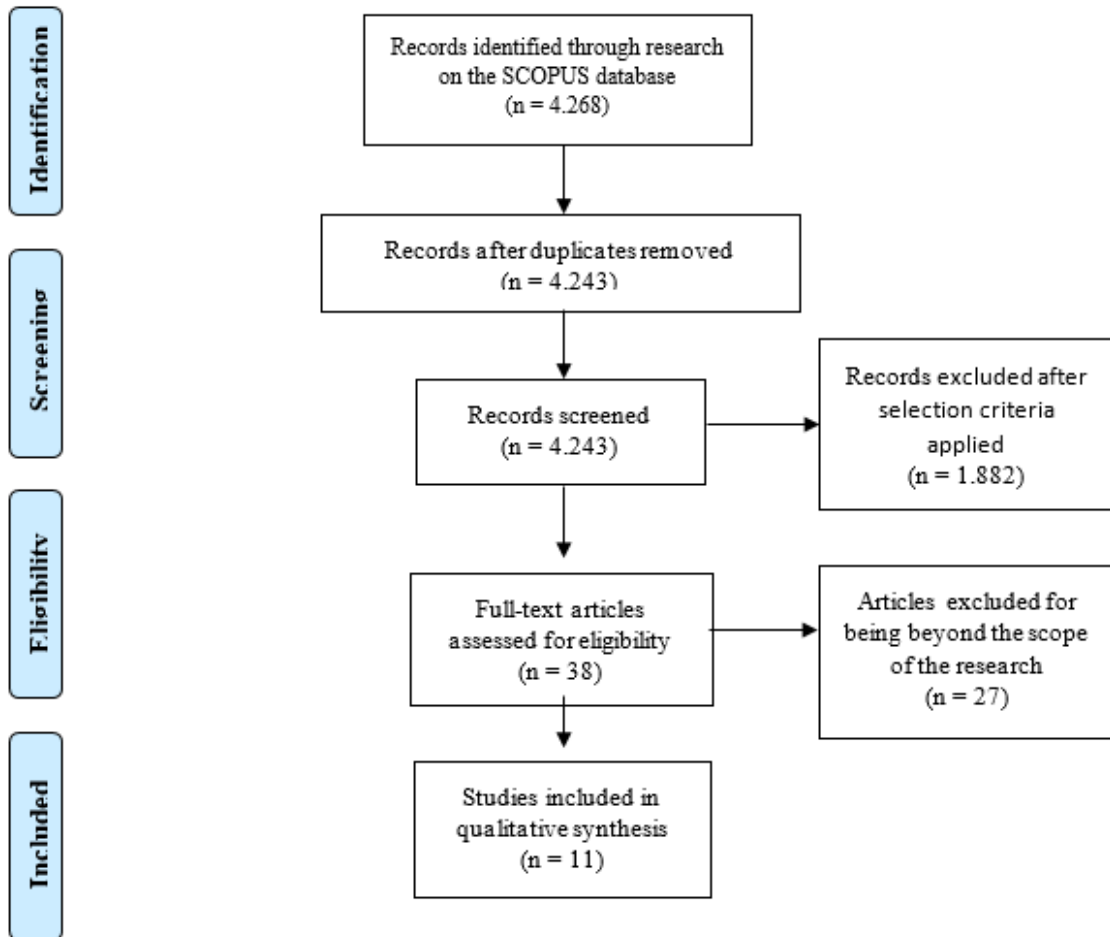
Source: Research data, 2020.

Chart 1, shown below, presents the summary of the characteristics of the 11 studies included in this review. The number of empirical studies related to barriers to health information on social media is increasing between the years 2015 (01/11) and 2019 (05/11). This trend indicates that researchers have increasingly recognized the need to understand the use of social media for health information purposes (BIXTER *et al.*, 2019), considering the current scenario of proliferation of social media platforms. It is noteworthy that, although no studies within the scope were included in the period from January to March 2020 (0/11) (which marks the time frame of data collection), there may be publications in the year 2020 with other/new terminologies and perspectives.

Chart 1. Summary of the general characteristics of the included studies.

Item	Ocorrência
Year of Publication	2020 (0/11); 2019 (5/11); 2018 (2/11); 2017 (1/11); 2016 (2/11); e 2015 (1/11).

Country of the first author	USA (3/11); United Kingdom (3/11); Canada (1/11); Germany (1/11); Iran (1/11); Pakistan (1/11); Saudi Arabia (1/11).
Area of knowledge	Medicine (7/11); Social Sciences (2/11); Computer Science (1/11); e Multidisciplinary (1/11).
Type of studies	Artigos (10/11) and Conference Proceedings (1/11).
Methodological Approach	Qualitative (5/11); quantitative (3/11); quali-quantitative (3/11).
Topic of the study objective	Accessing and using health information on the Internet (2/11); sharing health information online (2/11); role of the internet in self-management of health (1/11); online involvement of the health service audience (1/11); use of social media for health purposes (3/11); information literacy on health related to the media (1/11); and information seeking behavior on health (1/11).

Source: Research data, 2020.

The 11 included studies are from seven countries, distributed in three continents: America – United States of America (3/11) and Canada (1/11); Europe – United Kingdom (3/11) and Germany (1/11); Asia – Iran (1/11), Pakistan (1/11) and Saudi Arabia (1/11). Such distribution demonstrates a common reality in global societies: the presence of social media in the daily practices of subjects searching for health information. Furthermore, it suggests that problems related to health information on social media affect both developed and developing countries. The growing trend in recent years of studies in developing countries in Asia stands out: 2019 (Pakistan; Saudi Arabia) and 2018 (Iran).

The area of health has the largest number of studies – Medicine (7/11). However, the cluster of studies from other areas of knowledge – Social Sciences (2/11), Computer Science (1/11), Multidisciplinary (1/11) – constitutes a significant percentage (36%), which indicates the interdisciplinary character of this review object; which implies that the investigated object integrates different interests and theoretical-methodological perspectives related to the axis of communication, information, health, and computing.

The included studies are in the English language, typified as articles (10/11) and conference proceedings (1/11). All of them are the result of empirical research – with lay users of health information – consisting of qualitative (5/11), quantitative (3/11), and quali-quantitative (3/11) methodological approaches. The empirical methods were: online survey (3); survey (2); semi-structured interviews (2); focus groups (2); content analysis (1); interviews paired with online activities (1); and in-depth interviews (1).

The objectives of these studies address the use of health information from four perspectives: the first perspective around the general internet environment (6/11); the second one directly linked to social media (3/11); the third one covering online and offline media (1/11); and the fourth one without mentioning any type of media (1/11). It is noteworthy that some objectives do not address the term social media in their statements. However, all studies address or approach social media platforms in their methodology and/or results. In addition, they present results about barriers – difficulties, risks, challenges – related to health information on social media, considering the perspectives of lay users.

The health contexts investigated are diverse: sexual health of adolescents or young adults (2/11); general health patients (2/11); diabetic patients (1/11); people diagnosed with depression and anxiety (1/11); adolescents susceptible to high-risk behavior (1/11); elderly people who express feelings of depression (1/11); Lesbian, Bisexual and Queer (LBQ) women trying to get pregnant (1/11); participants in sexual health interventions (1/11); and women in

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search of healthy foods (1/11). Some contexts do not present motivations regarding the use for health information purposes (Chart 2).

Chart 2. Contexts, motivations, and social media.

Study	Context	Motivations	Social media
Patterson *et al.* (2019)	Young people accessing sexual health information online	Although skeptical of the use of social media in the context of sexual health, they are interested in one-on-one online support for providing advice in a confidential setting.	Not specified
Liao (2019)	US General Health Patients	Facilitating social support, combating stigma, establishing self-responsibility, and managing impressions are all motivations for sharing personal health information online.	Not specified
Nisar e Shafiq (2019)	Pakistani General Health Patients	Learn skills that help manage health; observe what other patients say; provide feedback on health services; obtain information about specialists/doctors; have access to specialists and informational websites; share experiences; find recommendations and opinions about health; obtain moral support from patients and physicians.	Facebook; Youtube; Google Plus.
Alzahrani e Alanzi (2019)	People Diagnosed with Diabetes from Saudi Arabia	Search for information about diabetes; communicate with others with diabetes for help, advice, and exchange experiences; find specific information about diabetes treatment and care.	Whatsapp; Instagram; Twitter; Snapchat; Facebook; Skype; Tango.
Bernard *et al.* (2019)	People diagnosed with depression and anxiety in Germany	No specific motivations for using the Web in general for informational purposes.	Not specified
Moult *et al.* (2018)	Elderly people who express feelings of depression in the UK	No motivations for using social media. Participants associate negative online content with social media from hearing negative reports from friends about social media	Not specified
Esmaeilzadeh *et al.* (2018)	Adolescents susceptible to high-risk behavior from Iran	Seek preliminary information to address needs regarding inactivity, high-risk sexual behavior, and incidents or injuries.	Not specified
Ruppel *et al.* (2017)	Lesbian, Bisexual and Queer (LBQ) women trying to get pregnant in the US	Seek or provide medical advice related to the artificial insemination process, pregnancy, and childbirth.	Facebook
Glik *et al.* (2016)	Adolescents and young adults seeking information about sexual health in Senegal	The media can be a means by which information about sexual health is sought, avoiding embarrassment and shame when doing it with the family. Furthermore, there is the motivation to be in contact with other Senegalese.	Facebook

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Witzel *et al.* (2016)	Gay or Bisexual Men Participating in Sexual Health Interventions in the UK	Sharing information about HIV prevention to raise awareness of others; Access information about medication.	Facebook
Bissonnette-Maheux *et al.* (2015)	Women seeking information about healthy foods in Canada	Means of information about new foods, trends, healthy recipes and knowledge about nutrition in general.	Blogs

Source: Research data, 2020.

The studies have 21 barriers (Chart 3). In this review, these barriers are grouped into a mesh of meta-barriers composed of five categories – diasporic (9), misinformation (2), interaction (5), literacy (3), and emotional (2). Considering that the approach of this review is that of information practices (LLOYD, 2010) in transition (LLOYD, 2014), the investigation sought to present the mesh of barriers - to interconnect the barriers - in an articulated way with the subjects' health contexts, the motivations that lead them to consider social media as a source of health information, and the used social media.

Chart 3. Barriers linked to social media.

Meta-barriers	Barriers	Studies
1. Diasporic	1) Cultural tensions between liberal social media practices and tradition;	Glik *et al.* (2016)
	2) Distrust in information and sources;	Nisar e Shafiq (2019); Moult *et al.* (2018); Glik *et al.* (2016)
	3) Conflicts of interest regarding advertising and provision of information.	Bissonnette-Maheux *et al.* (2015)
	4) Excess of available information and notifications;	Patterson *et al.* (2019); Bissonnette-Maheux *et al.* (2015)
	5) Unknown information and sources;	Ruppel *et al.* (2017)
	6) Discrepancy between available and necessary information;	Ruppel *et al.* (2017)
	7) Inaccurate information;	Alzahrani e Alanzi (2019); Ruppel *et al.* (2017)
	8) Insufficient or limited information;	Nisar e Shafiq (2019); Ruppel *et al.* (2017)
	9) Absence of new information;	Bissonnette-Maheux *et al.* (2015)
2. Misinformation	10) Incorrect or misleading information;	Nisar e Shafiq, (2019); Alzahrani e Alanzi (2019); Ruppel *et al.* (2017)
	11) Be aware of the spread of misinformation;	Nisar e Shafiq (2019)
3. Literacy	12) Limited knowledge of online sources;	Patterson *et al.* (2019)
	13) Difficulty finding locally relevant or appropriate information;	Patterson *et al.* (2019); Esmaeilzadeh *et al.* (2018)
	14) Determine the quality of the retrieved information;	Esmaeilzadeh *et al.* (2018)

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4. Interaction	15) Overexposure – target of compliments or complaints, argumentative communication;	Glik *et al.* (2016); Nisar e Shafiq (2019); Moult *et al.* (2018); Witzel *et al.* (2016)
	16) Privacy Concerns	Patterson *et al.* (2019); Liao (2019); Nisar e Shafiq (2019); Alzahrani e Alanzi (2019); Bernard *et al.* (2019); Esmaeilzadeh *et al.* (2018); Glik *et al.* (2016); Witzel *et al.* (2016)
	17) Social comparison that generates negative affections;	Bernard *et al.* (2019)
	18) Ambivalent contacts;	Bernard *et al.* (2019)
	19) Unexpected content and unsolicited replies or comments;	Bernard *et al.* (2019); Ruppel *et al.* (2017)
5. Emocionais	20) Lack of support for error recovery and overcoming emotional difficulties;	Bernard *et al.* (2019)
	21) Contents that recall disturbing experiences or negative affections;	Bernard *et al.* (2019)

Source: Research data, 2020.

3.1 Diasporic barriers

Diasporic barriers correspond to the unstable experiences of subjects with unknown and scattered information sources in context transition (BRASILEIRO, 2019). In the digital environment, the user's diasporic experience involves the challenge of reconciling their usual practices and the unstable exercises of ambiguity and cooperation required by the translation of the information on the internet (GONZÁLEZ DE GÓMEZ, 2004). In this literature review, this challenge is addressed as a tension between liberal practices linked to social media and traditional cultural values (GLIK *et al.*, 2016). This barrier emerges from the adoption of Facebook by Senegalese adolescents as an information strategy regarding local cultural values of information about the context of sexual health (GLIK *et al.*, 2016).

Another barrier related to this sexual health context is the distrust in information (GLIK *et al.*, 2016), which also emerges in the health contexts of elderly people who suffer from distress (MOULT *et al.*, 2018), and patients, in general, using social media – Facebook, Youtube, Wikipedia, Google Plus – as a tool to search and share information about health (NISAR; SHAFIQ, 2019). In the context of the elderly, however, distrust is previously associated with negative perceptions about social media, which, added to the experienced emotional vulnerability, discourage the use of these media as social/informational support related to self-management of distress (MOULT *et al.*, 2018).

Conflicts of interest regarding access to product promotion and advertising while using nutrition information blogs are considered barriers by women (BISSONNETTE-MAHEUX *et al.*, 2015) who do not have a chronic disease but seek knowledge about healthy foods and nutrition trends for dietary care purposes. In this context, the excess of notifications about new posts and the absence of new information (BISSONNETTE-MAHEUX *et al.*, 2015) are also considered difficulties for the use of information in blogs. Excessive content is also perceived as a barrier by young adults in the UK who seek information about sexual health (PATTERSON *et al.*, 2019). The difference is that, in the context of sexual health, excess discourages active

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information-seeking practices (MCKENZIE, 2003), whereas, in the nutritional context, it generates discomfort during the practice of avoiding information (BRASHERS *et al.*, 2002).

In the context of US Lesbian, Bisexual and Queer (LBQ) women trying to get pregnant and seeking information on Facebook groups about artificial insemination and conception, diasporic barriers include: unknown and not provided information and sources; the discrepancy between necessary and available information; inaccurate information; limited information (RUPPEL *et al.*, 2017). Inaccurate information is also perceived as a barrier by diabetics who use social media in Saudi Arabia – WhatsApp, Instagram, Twitter, Facebook, Tango – to seek and share information about diabetes (ALZAHRANI; ALANZI, 2019). This same barrier is also perceived by general healthcare patients in Pakistan who use social media – Facebook, Youtube, Google Plus – to seek and share health information (NISAR; SHAFIQ, 2019).

All these presented barriers (RUPPEL *et al.*, 2017; ALZAHRANI, ALANZI, 2019; NISAR, SHAFIQ, 2019) meet the conception of misinformation as inaccurate, distorted, uncertain, vague, or ambiguous information (KARLOVA; FISHER, 2013). Therefore, it is also possible to name them as misinformation barriers. However, the term "diasporic barriers" is adopted instead of "misinformation barriers" to encompass and outline the transitory tensions that particularize the different contexts: on the one hand, LBQ women in the USA who are outside the normativity of motherhood and need to reconcile their practices and needs with the information standards instituted and reproduced in the social media environment (RUPPEL *et al.*, 2017); on the other, the populations of developing countries in Asia who need to reconcile their local sociocultural health practices with the liberal logic of social media (ALZAHRANI, ALANZI, 2019; NISAR, SHAFIQ, 2019).

Furthermore, the term "misinformation" is constantly used to refer to erroneous information (OXFORD, 2017), whether deliberate or accidental (STAHL, 2006). The term "diasporic barriers", on the other hand, makes it possible to link the multiple information difficulties perceived by the subjects – in the use of social media – to the particular experienced transition context. In this review, these types of barriers suggest a greater impact on social media practices in health contexts characterized as significant and personal (CLEMENS; CUSHING, 2010) – health in general (NISAR; SHAFIQ, 2019), health sexual (PATTERSON *et al.*, 2019) (GLIK *et al.*, 2016), elderly (MOULT *et al.*, 2018), diabetes (ALZAHRANI; ALANZI, 2019), motherhood (RUPPEL *et al.*, 2017) – compared to contexts linked to stable routines, such as well-being and dietary practices (BISSONNETTE-MAHEUX *et al.*, 2015).

3.2 Misinformation Barriers

The term "misinformation barriers" is adopted to refer specifically to unstable experiences with information that does not support the truth (KARLOVA; LEE, 2011), whether false information, deliberately manipulated (STAHL, 2006), or information perceived as false in contact with the sources (KARLOVA; LEE, 2011). In this review, incorrect or misleading information was perceived as barriers in the following contexts: US LBQ women seeking information about pregnancy (RUPPEL *et al.*, 2017); Pakistani patients seeking and/or sharing health information (NISAR; SHAFIQ, 2019); Saudi Arabian diabetics who seek and share information about diabetes (ALZAHRANI; ALANZI, 2019).

In the context of the women (RUPPEL *et al.*, 2017), social media were used to address specific issues related to artificial insemination and conception, that is, in the modalities of active information search and exploration (MCKENZIE, 2003). This indicates that the perception of misinformation may be related to a prior awareness of the normative or medical truths of the context. In the contexts of general healthcare patients in Pakistan (NISAR;

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SHAFIQ, 2019) and diabetics in Saudi Arabia (ALZAHRANI; ALANZI, 2019), the use of social media is directed towards general issues of healthcare and diabetes, which can vary between different modes of information search, such as active exploration, non-directed monitoring or by proxy (MCKENZIE, 2003). This indicates that the perception of incorrect information, in these two contexts, may be linked to the high flow of information and limited digital literacy.

In the context of general healthcare patients in Pakistan, this relationship with the flow of information and limited digital literacy is more evident when they perceive the spread of misinformation as another barrier to the use of social media (NISAR; SHAFIQ, 2019). This demonstrates a prior awareness of the possibility of not having critical skills to judge and assess right from wrong, given the information found in social media, and of making wrong decisions about health. In this sense, it is clear that the misinformation barrier is interrelated with another barrier that determines the self-management of health information on social media: literacy.

3.3 Literacy barriers

Literacy barriers refer to resource constraints or individual and collective provisions to determine the extent of sources, effectively and efficiently access information, and critically assess information and its sources (BRASILEIRO, 2019). The literacy barriers faced by young people in the United Kingdom, in accessing information and support for sexual health online, are restricted to the absence of guidance on specific sources and the difficulty of finding locally relevant information (PATTERSON *et al.*, 2019). While the absence of guidance on sources indicates both the lack of knowledge about the health information scenario (LLOYD, 2014) and the need to build online informational support (BRASILEIRO, 2019), the difficulty of finding locally relevant information reinforces the lack of knowledge about the information scenario, but above all, it problematizes finding information that is presented as redundant.

Lack of knowledge about the scenario of online information on sexual health raises uncertainties about the information accessed on social media (BRASILEIRO, 2019), as well as insecurity in terms of engagement with sources and decision-making. Finding redundant information means that, although plural, social media tend to reproduce a common information value (GONZÁLEZ DE GÓMEZ, 2012) about sexual health. The lack of knowledge of this online scenario, therefore, prevents the transition of information standards and the connection with relevant information suited to local realities. In this case, the online informational support constructed in a situational and negotiated way allows us to significantly know the extent of the sources and find relevant information (BRASILEIRO, 2019).

Finding appropriate information is also a problem in the health context of adolescents susceptible to high-risk behavior in Iran (related to smoking, physical inactivity, alcohol consumption, risky sexual behavior, among others). Another difficulty considered in this context is to determine the quality of the information found during preliminary searches (ESMAEILZADEH *et al.*, 2018). This barrier can be linked to uncertainties arising from the lack of knowledge about the health information scenario (LLOYD, 2014), which fragment the information value and can prevent the designation of quality.

All of the identified literacy barriers are interrelated with diasporic barriers, as they emerge from the unstable situations of the subjects in a new informational environment about health on social media, which, in turn, demands new skills. This indicates that online information literacy is not likely to be fully constructed by previous formal structures (HICKS; LLOYD, 2016), but above all, it needs to be constructed situationally in context and in collaboration (LLOYD, 2014). Such collaboration, in turn, presents challenges and dilemmas

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to the self-management of health information as it requires negotiation between multiple conflicting objectives (BRASHERS *et al.*, 2002). In this sense, literacy barriers are interrelated with interaction barriers.

3.4 Interaction barriers

Interaction barriers correspond to intersubjective and situational dilemmas and challenges that involve the articulation between self-management information practices (BRASHERS *et al.*, 2002) and face-work dynamics (GOFFMAN, 1967). In this review, the interaction barriers identified by the studies were grouped into two topics: (a) the concern with the loss of privacy and reputation during online practices of information searching and sharing (PATTERSON *et al.*, 2019; LIAO, 2019; NISAR; SHAFIQ, 2019; ALZAHRANI; ALANZI, 2019; BERNARD *et al.*, 2019; ESMAEILZADEH *et al.*, 2018; GLIK *et al.*, 2016; WITZEL *et al.*, 2016); (b) discomfort with online acts of threat to the face during avoidance practices (NISAR; SHAFIQ, 2019; BERNARD *et al.*, 2019; RUPPEL *et al.*, 2017). Both themes are configured as barriers to self-management of health information on social media.

Concern about the loss of privacy and reputation (a) is a barrier present in most of the included studies (9/11). Part of these studies reveals users' concern with privacy in general: US social media users who share personal and health information (LIAO, 2019); Pakistani health care patients seeking or sharing health information on social media (NISAR; SHAFIQ, 2019); people diagnosed with depression and anxiety disorders from Germany who use the internet (BERNARD *et al.*, 2019); and Senegalese adolescents who seek information on social media about health (GLIK *et al.*, 2016).

UK young adults seeking sexual health information (PATTERSON *et al.*, 2019) relate concerns about the loss of privacy to the risk of embarrassment (GOFFMAN, 1967): being seen seeking sexual health information; leaving traces on social media about content related to sexual health; and fear of shame or embarrassment (PATTERSON *et al.*, 2019). Such barriers are related to diasporic barriers as they emerge from the transitory conflicts between the little experience of young people and the dynamic online environment of sexual health information (PATTERSON *et al.*, 2019). Concern about the loss of privacy in the context of diabetic patients in Saudi Arabia (ALZAHRANI; ALANZI, 2019) and in the context of participants in healthcare interventions in the United Kingdom (WITZEL *et al.*, 2016) is linked to personal data security issues. These UK social media users (WITZEL *et al.*, 2016), and the adolescent students from Iran (ESMAEILZADEH *et al.*, 2018) also link the loss of privacy to reputation[1] – specifically to the risks of disclosing personal information.

These barriers show the face-work (GOFFMAN, 1967) as a conflicting objective against the information objectives about health on social media (BRASILEIRO, 2019). Likewise, the need to manage online acts of threat to the face (b) is also in conflict with the practices of avoiding information and interaction. In this regard, Pakistani patients point to the fact that overexposure on social media turns them into targets of compliments or complaints as a barrier (NISAR; SHAFIQ, 2019). For people diagnosed with depression and anxiety in Germany (BERNARD *et al.*, 2019), these barriers are associated with social comparison cues and ambivalent contacts. People in this context (BERNARD *et al.*, 2019) as well as LBQ women from the USA (RUPPEL *et al.*, 2017) also associate such barriers to unexpected responses or comments when they are not requested.

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[1] Participants in sexual health interventions also relate concerns about the loss of privacy to the risk of assuming a stigmatized identity, which can imply involvement with sexual health interventions on social media (Witzel *et al.*, 2016)

All these interaction barriers demonstrate that social media platforms, while they can promote connection with a variety of health information, they may also pose threats to reputation and require cautious practices (BRASILEIRO, 2019) involving the preservation of the face (GOFFMAN, 1967). This justifies avoiding seeking and sharing personal health information, to maintain reputation and comfort – an attitude based on shared moral feelings (COLLINS, 2004), which is interrelated with individual emotional barriers as it prevents engagement with sources (people) on social media, as it occurs, for instance, with the fear of embarrassment (PATTERSON *et al.*, 2019).

3.5 Emotional barriers

Emotional barriers are related to feelings of anxiety, fear, discouragement, among others, which interfere with the individual's ability to make decisions, establish consensus, select and appropriate relevant information sources, as well as the willingness to face an adverse situation (BRASILEIRO, 2019). In this review, such barriers are perceived in the context of people diagnosed with depression and anxiety disorders in Germany who use the internet in their daily lives (BERNARD *et al.*, 2019). In this health context, two circumstances were identified: (a) lack of support to recover from mistakes and overcome emotional difficulties; (b) contents that resemble disturbing experiences or negative affections (BERNARD *et al.*, 2019).

The first (a) reveals that the state of emotional vulnerability experienced in significant and personal life contexts (CLEMENS; CUSHING, 2010) demands informational and emotional support for the development of information resilience (LLOYD, 2014). However, people face difficulties in building this support on social media, given the challenges and dilemmas regarding the negotiation of multiple competing goals (BRASHERS *et al.*, 2002). The second (b) indicates that the state of emotional vulnerability influences the perception of content associated with low emotional energy experiences (COLLINS, 2004) in the context of social media, which, in turn, prevent facing barriers and building information resilience.

Emotional barriers can, therefore, determine the lack of motivation to use social media in the search for health information, even when other situational or contextual barriers related to information are not evident, such as literacy or misinformation barriers. This indicates that studies on E-Health need to include emotional issues in their research agenda – involving user practices, interactions and behaviors – regarding the uses of social media.

4 DISCUSSION

The results demonstrate that the barriers to health information on social media are multiple and vary according to the health contexts and situational motivations that emerge from them. Some of the presented barriers are recurrent and corroborate the findings of previous studies, such as the concern with privacy and reliability (ANTHEUNIS *et al.*, 2013). Others are presented originally from the perspective of transition, such as the tensions and conflicts that make up the diasporic barriers.

Therefore, presenting them in a transversal way under the approach of information practices (LLOYD, 2010), in a perspective of the transition of significant and personal health contexts (LLOYD, 2014) (CLEMENS; CUSHING, 2010), allows situating the dynamics of these barriers and their impacts on the entire process of self-management of health information. In this review, this approach involved the articulation among barriers, motivations, contexts,

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and social media, which supported the indication of the mesh of (meta) interrelated barriers: diasporic, misinformation, literacy, interaction, and emotional.

Although the included studies reveal the multiple barriers (Chart 3) perceived in different contexts, it appears that the approach based on information practices is not central in these studies. Furthermore, the investigation of barriers explicitly linked to social media is central to only three studies (LIAO, 2019; NIMAR, SHAFIQ, 2019; ALZAHRANI, ALANZI, 2019). This finding indicates that the investigation of barriers to health information on social media tends to be secondary - as a result of studies on behaviors in the use of health information on the internet - or restricted to the analysis of difficulties related to some of the material aspects of social media.

The study of barriers, on the other hand, when articulated to contexts, motivations, and social media, is configured as an alternative for understanding the dynamics of health care involving social media (ANTHEUNIS *et al.*, 2013) as it allows revealing other complex subjective and situational issues, such as, for example, the multiple meanings that information can take, the multiple information objectives and the multiple responses that subjects can present in interaction situations (BRASHERS *et al.*, 2002). In this sense, the mesh of interrelated barriers can be configured as an analytical resource for complex issues about health in social media.

In the included studies, the barriers are presented from the perspective of socio-technical aspects common to the materiality of social media, such as, for example, public availability, the possibility of change at any time, the global audience, the immediacy of information, the ease of use, contextual relevance, information overload and excessive spam (AGARWAL; YILIYASI, 2010). However, the adoption of this perspective, by itself, may not encompass all the barriers that emerge from the use of social media in the transition process in the health context, since it leaves aside barriers that are inherent to the transition context itself and, therefore, precede the barriers of a technological nature. However, it is noteworthy that some of the studies (PATTERSON *et al.*, 2019; GLIK *et al.*, 2016; RUPPEL *et al.*, 2017; WITZEL *et al.*, 2016) manage to indicate an integration between this socio-technical perspective and the contexts of transition.

The motivations for the use of social media presented in some studies (NISAR; SHAFIQ, 2019; ALZAHRANI; ALANZI, 2019; ESMAEILZADEH *et al.*, 2018; RUPPEL *et al.*, 2017; GLIK *et al.*, 2016; BISSONNETTE-MAHEUX *et al.*, 2015) are in line with the motivations presented in the literature, such as the need to increase knowledge about the disease, express emotions, share experiences, obtain advice, find answers to specific questions and make contact with doctors (ANTHEUNIS *et al.* ., 2013; DE MARTINO *et al.*, 2017). Others are presented in an original way, such as combating stigma and managing impressions (LIAO, 2019). However, in general, the presented motivations are not related to the situational character of self-management information practices (BRASHERS *et al.*, 2002), which can impede understanding of the situational barriers of the context. In addition, some studies (PATTERSON *et al.*, 2019; BERNARD *et al.*, 2019; MOULT *et al.*, 2018; WITZEL *et al.*, 2016) reveal that the subjects do not have motivations regarding the use of social media to seek health information, due to the negative perceptions associated with them, such as the lack of trust and credibility (SOUSA; ALMEIDA, 2016). This indicates that pre-existing barriers in the dimension of users' experiences, added to the tensions of the transition context, influence the motivations for the use of social media in health. Therefore, they should be considered by interventions – based on digital media – of institutional and public policy actors to optimize public communication strategies in health.

Some limitations of this literature review need to be pointed out. Although the research terms have been designed to cover the studied object, it is recognized that they do not cover the

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terminology used by other studies related to the same scope. This is because the object of barriers can take on multiple terminological variations within the scope of communication and health information studies, such as, for example, difficulties, obstacles, challenges, restrictions, impediments, etc. It is also recognized that the use of a single database restricts the selection of relevant studies. Although this understanding is explicit in the PRISMA model, a single database was chosen for convenience, considering that the study does not intend to be framed as a "systematic literature review", but rather as an "exploratory review" (scope).

The mesh of presented barriers was based on the barriers (difficulties, restrictions, impediments) perceived by the empirical subjects of the included studies, according to the highlighted and reported evidence. Thus, this mesh can be constituted as meta-barriers and may present limits as to the representation of the empirical reality of the barriers described in Chart 3, as it involves the perspective of researchers regarding the articulation between barriers, reasons, contexts, and media. Furthermore, the barriers may be related to other meta-barriers not included in this mesh, but which are present in information practices, such as, for example, network barriers, related to the limits of weak or strong connections in social media, which can determine the scope of the information (JOHNSON; CASE, 2012; BRASILEIRO, 2019); technological barriers, related to the dimensions of the interface[2] and information architecture, which can influence the trust and credibility of health information (SOUSA; ALMEIDA, 2016; BRASILEIRO; FREIRE, 2012).

From this literature review, therefore, the mesh of presented barriers based on the results, although limited to certain categories, allows a deep understanding of the multiple barriers that impede the utilization of social media in health information practices. In addition, this mesh offers paths to alternative information strategies to be developed in the context of social media to overcome and redefine the barriers faced in the transition process in health contexts. For further studies, this study suggests expanding the meta-barriers that group and relate the mesh.

5 FINAL CONSIDERATIONS

Social media platforms, although facilitating the access and sharing of health information for lay users or patients, impose difficulties on the processes of self-management of information, self-care, and decision-making. These difficulties result from the articulation between the difficulties associated with the dynamics of digital platforms and the difficulties that emerge from the contexts of healthcare transition.

Understanding these difficulties, therefore, is not a simple task, as it involves multiple and complex dimensions that permeate the materiality of the platforms. In this sense, the analysis focused on barriers is configured as an alternative strategy to unveil or reach the underlying layers related to the use of social media for information purposes in health contexts. This review demonstrated that the barriers perceived by lay users, identified from the literature, constitute and connect a mesh composed of meta-barriers: diasporic, misinformation, literacy, interaction, emotional.

This mesh indicates that the beneficial use of social media for health information purposes presupposes the overcoming of these barriers – and other possible ones – during situational practices of transition in health contexts. In other words, facing one specific barrier

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[2] Although they have not been categorized as meta-barriers, some technological barriers can be observed in some of the included studies, such as difficulties in navigating the websites of large organizations due to non-intuitive design (Patterson et al., 2019) and unfriendly interfaces and broken sites (Bernard et al., 2019).

is not enough, the whole mesh must be tackled. In this sense, health information interventions on social media must consider the relational incidence of these barriers to promote information resilience. We believe that these digital interventions should articulate situational and collaborative practices among subjects who face common experiences with the contingent mediation of specialists and/or health professionals.

We expect that the results of this review are useful for researchers and professionals involved with the topic of health information in social media. We hope that the presented barriers, juxtaposed with other particular structural barriers[3], can be considered as a starting point for further analysis related to the new information challenges imposed from March 2020, resulting from the Covid-19 pandemic.

CRediT

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[3] Sociocultural, political, and economic contexts can impact how subjects cope with barriers. Therefore, carrying out empirical studies in the Brazilian context is relevant, which is now marked by the dispute of information across different actors, such as politicians, media, market, influencers, etc.

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