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Review Article

Diabetes *mellitus* and the dissemination of information on the Internet: integrative review

Diabetes *mellitus* e a disseminação de informações na *internet*: revisão integrativa

Diabetes *mellitus* y difusión de información en Internet: revisión integradora

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Abstract

Objective: to analyze studies that address the contributions of the Internet in the dissemination of information on diabetes *mellitus*. **Method:** integrative review, in MEDLINE/Pubmed®, Web of Science, Scopus and LILACS databases. The sample consisted of 16 studies, without restriction of time or language, with analysis and synthesis of the results descriptively. **Results:** observational studies with evidence level VI and published between 2009 and 2021 prevailed. Social networks and media represented the main virtual environments used by patients and health professionals to disseminate information and experiences about the clinical condition, promote self-care, maintain treatment and strengthen support networks and social support. **Conclusion:** despite the limited participation of health professionals in virtual communities, the possibilities of cyberspace were evidenced as a scenario of health promotion and interaction with patients, recognizing its potentialities as an interface for health care.

Descriptors: Diabetes Mellitus; Internet; Social Media; Self Care; Social Support

Resumo

Objetivo: analisar estudos que abordem as contribuições da *internet* na disseminação de informações sobre diabetes *mellitus*. **Método:** revisão integrativa, nas bases de dados MEDLINE/*Pubmed®*, *Web of Science*, *Scopus* e LILACS. A amostra foi constituída por 16 estudos, sem restrição de tempo ou de idioma, com análise e síntese dos resultados de forma descritiva. **Resultados**: prevaleceram estudos observacionais, com nível de evidência VI e publicados entre

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2009 e 2021. As redes e mídias sociais representaram os principais ambientes virtuais utilizados por pacientes e profissionais de saúde para disseminação de informações e de experiências sobre a condição clínica, promoção do autocuidado, manutenção do tratamento e fortalecimento de redes de suporte e apoio social. **Conclusão:** apesar da limitada participação de profissionais de saúde nas comunidades virtuais, evidenciaram-se as possibilidades do *ciberespaço* como cenário de promoção da saúde e de interação com os pacientes, reconhecendo suas potencialidades como interface para o cuidar em saúde.
Descritores: Diabetes Mellitus; Internet; Mídias Sociais; Autocuidado; Apoio Social

Resumen

Objetivo: analizar estudios que aborden las aportaciones de Internet en la difusión de información sobre la diabetes *mellitus*. **Método:** revisión integradora, en MEDLINE/*Pubmed®, Web of Science*, *Scopus* y LILACS bases de datos. La muestra consistió en 16 estudios, sin restricción de tiempo ni lenguaje, con análisis y síntesis de los resultados descriptivamente. **Resultados:** predominaron los estudios observacionales con nivel de evidencia VI y publicados entre 2009 y 2021. Las redes sociales y los medios de comunicación representaron los principales entornos virtuales utilizados por los pacientes y los profesionales de la salud para difundir información y experiencias sobre la condición clínica, promover el autocuidado, mantener el tratamiento y fortalecer las redes de apoyo y apoyo social. **Conclusión:** a pesar de la limitada participación de los profesionales de la salud en las comunidades virtuales, las posibilidades del ciberespacio se evidenciaron como un escenario de promoción de la salud e interacción con los pacientes, reconociendo sus potencialidades como interfaz para la atención de la salud.
Descriptores: Diabetes Mellitus; Internet; Medios de Comunicación Sociales; Autocuidado; Apoyo Social

Introduction

Diabetes *Mellitus* (DM) is a complex and multifaceted condition that affects millions of people worldwide, constituting a public health problem because it has a severe impact on the quality of life of the population and because it has individual, social, economic and health impacts due to the need for resources to manage the disease and its complications.[1-3]

In recent years, the incidence and prevalence of DM have increased considerably, causing greater challenges in coping with this condition and reflecting the need for information for the development and maintenance of care, including glycemic control, drug intake, re-education and the practice of physical exercises as essential measures to prevent complications. Living with DM is configured as a continuous management process, which involves changes in lifestyle, adjustments and self-care in practical issues, referred to cultural, social, family and labor contexts, with the purpose of promoting adaptations in the physical and emotional spheres.[1,3-5]

In this sense, with the advent of the Internet and the popularization of mobile devices, as well as social networking sites, virtual discussion environments have enabled a continuous and intense exchange of knowledge and experiences between users on multiple themes and aspects of life.[6] These are important meeting points in the virtual world that allow covering the most varied subjects, bringing users together with shared values and interests and constituting emerging social aggregations, established by the feeling of belonging to a group.[7]

Social networking sites are often pointed out as a possible area of innovation that can be beneficial to the health conditions of the population.[8-10] The use of social media, for example, has been shown to improve the relationship with health professionals, making people feel strengthened and able to engage in shared decision-making about their care.[11-12]

Thus, the emergence and dissemination of the World Wide Web and online search engines have contributed to websites, blogs and virtual portals increasingly being used as sources of information and advice on care practices.[6-7] The amount of content produced and shared in the virtual environment about health multiplied, being made available in multiple tools and platforms, usually produced in a decentralized way and without editorial control of large groups, by individuals and also by organizations that share common values, objectives and interests.[13]

The recent emergence and growth of virtual diabetes communities brings opportunities and challenges to health professionals and health systems. People with diabetes can now interact with each other regardless of time or place, and this affects how knowledge about the clinical condition is acquired and exchanged.[14]

With access to the Internet increasingly facilitated and broad and in the midst of ignorance and misinformation that permeate the disease, it is common to search for information about diabetes, whether by people with, family members or caregivers.[4,15] Thus, considering the magnitude of the problem, as well as the potentialities of the Internet as an information resource for adequate disease management, this article aims to analyze studies that address the contributions of the Internet in the dissemination of information about diabetes *mellitus.*

Method

This is an integrative review of the literature, conducted through the following stages of investigation: identification of the theme and elaboration of the research question; search in the literature and sampling; definition of the information to be extracted from the selected studies; critical evaluation of the included studies; interpretation of the results; synthesis of knowledge and presentation of the review.[16]

The formulation of the research question was based on the PICo strategy,[17] considering P (Problem) diabetes *mellitus*; I (Phenomenon of interest) the dissemination of information; and Co (Context) interventions carried out on the Internet, websites and digital media. Thus, this review was conducted by the following question: What are the contributions of the Internet to the dissemination of information about diabetes *mellitus*?

The bibliographic survey took place between October 2020 and March 2021, through electronic consultation with the Databases Medical Literature Analysis and Retrieval System online (MEDLINE via PubMed®), Web of Science, SCOPUS and Latin American and Caribbean Literature in Health Sciences (LILACS) via virtual health library (VHL).

For the operationalization of the searches, we used controlled and uncontrolled descriptors, selected after consulting the vocabularies Descriptors in Health Sciences (DeCS) and Medical Subjects Headings (MeSH), and their application was conditioned to the specificities of each base and combination performed through the Boolean operators OR and AND.

It is noteworthy that the search terms were inserted in English, since all journals indexed in these databases present in their articles descriptors in English, with the exception of the VHL, in which the English and Portuguese were prioritized. Chart 1 presents the descriptors, as well as the strategy adopted in MEDLINE, which maintained the standardization of search for the other databases consulted.

Chart 1 - Terms and strategy used to operationalize the search. Teresina, PI, Brazil, 2021.

PICo	Termos de busca
P	Diabetes Mellitus
I	Information Dissemination; Dissemination, Information; Information Distribution; Distribution, Information; Information Sharing; Information Sharings; Sharing, Information; Sharings, Information; Data Sharing; Data Sharings; Sharing, Data; Sharings, Data.
Co	Internet; World Wide Web; Web, World Wide; Wide Web, World; Cyberspace; Cyber Space.
P AND I AND Co	
((Diabetes Mellitus[MeSH Terms]) AND ((((((Internet[MeSH Terms]) OR (World Wide Web)) OR (Web, World Wide)) OR (Wide Web, World)) OR (Cyberspace)) OR (Cyber Space))) AND ((((((((((Information Dissemination[MeSH Terms]) OR (Dissemination, Information)) OR (Information Distribution)) OR (Distribution, Information)) OR (Information Sharing)) OR (Information Sharings)) OR (Sharing, Information)) OR (Sharings, Information)) OR (Data Sharing)) OR (Data Sharings)) OR (Sharing, Data)) OR (Sharings, Data))	

"Termos de busca" = "Search Terms"

The inclusion criteria were studies of primary source, without restriction of time or language and that presented the internet, networks or social media as an instrument for disseminating information about diabetes. Theses, dissertations and book chapters were excluded.

The search and selection process was carried out by two reviewers, independently, who after standardization of terms and crosses, reading titles, abstracts and inclusion, obtained an agreement index higher than 80%. The disagreements were managed by the third reviewer, who issued an opinion for a decision on the inclusion of the study.

It is noteworthy that the recovered references were exported to the EndNote® reference manager software in order to identify duplicates, gather and organize all publications. In addition, the list of references of the included productions was consulted, in order to select additional studies that presented potential to answer the question of this study.

A total of 212 productions were identified and after the application of the eligibility criteria, 16 primary studies comprised the sample. The path to identification, selection, eligibility, inclusion and sample followed the recommendations of the

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA),[18] as shown in Figure 1.

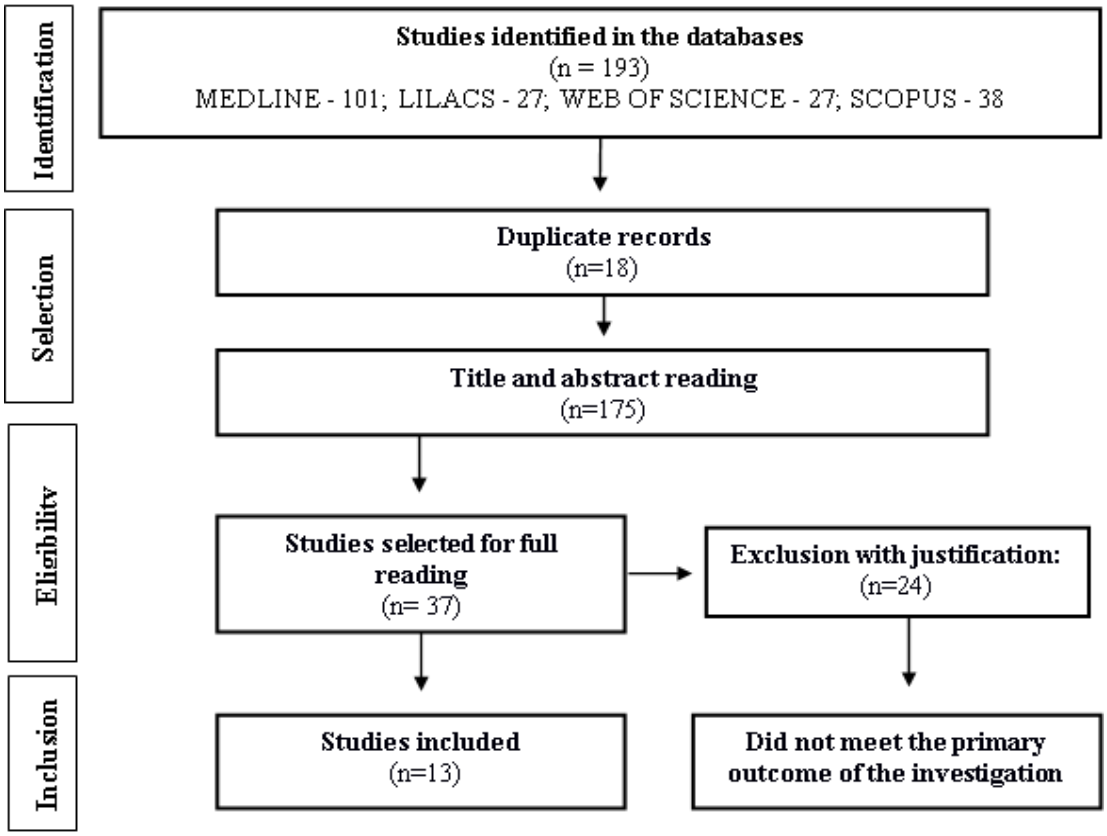

Figure 1 - Flowchart of the study selection process. Teresina-PI, Brazil, 2021

For data analysis and extraction, a validated instrument[19] was adapted according to the variables of interest defined for this study, prioritizing reference aspects (title, journal and year of publication), methodological structuring (design and level of evidence), identification of the information resource, main results and conclusions.

The methodological quality assessment was determined by the analysis of the Level of Evidence (NE), being considered the following classification: I - systematic reviews or meta-analysis of relevant clinical trials; II - evidence of at least one well-designed randomized controlled trial; III - well-delineated clinical trials without randomization; IV - well-delineated cohort and case-control studies; V - systematic review of descriptive and qualitative studies; VI - evidence derived from a single descriptive or qualitative study; VII - opinion of authorities or committees of experts, including interpretations of information not based on research.[20] Based on these criteria,

evidence can be classified as strong (I and II), moderate (III and IV) and weak (V, VI and VII).[21]

Moreover, the protocol of this review was previously evaluated by experts in the method in question. After evaluating the studies in full and composition of the sample, the analysis and descriptive synthesis of the results was performed. The ethical principles were maintained, respecting the copyright carefully by citation of each of them.

Results

The results showed the predominance of observational studies, level of evidence VI, which supported the development and application of virtual communities for the dissemination of information on diabetes *mellitus* among patients and health professionals, being published mostly in the English language between 2009 and 2021, and in journals from different areas and contexts such as nursing, psychology, public health, medicine and computer technologies.

Among the information resources identified, social networks and media such as the Facebook platform prevailed, which was a favorable tool for the sharing of information and experiences about the clinical condition, the promotion of self-care, the maintenance of treatment, nutritional support and the strengthening of support networks and social support.

Furthermore, it was evidenced that the discussion forums on websites, as well as the messages forwarded via e-mail and the development of applications are expressive realities in the virtual environment, and can directly contribute to greater awareness about the health condition and to the promotion of professional counseling, since these resources have potential for the establishment of connection between users and specialists.

Despite these benefits, it was also found that the content can limit prevention strategies, due to information overload, low recognition of the severity of the disease and limitations in the adoption of changes in behavior and lifestyle.

Chart 2 presents the distribution and synthesis of the studies included according to objective, type of study and sample, year of publication, informational resource, outcome and level of evidence.

Chart 2 - Synthesis of primary studies by objective, type of study and sample, year of publication, information resource, outcome and level of evidence (n = 16). Teresina, PI, Brazil, 2021.

Objective	Type of study and sample	Year	Informational resource	Outcome	LE
To assess the health-related use of Web 2.0 tools by patients with type 1 diabetes.[22]	Descriptive cross section. Adults with type 1 DM (n=289).	2016	E-mail	The use of Web 2.0 and applications for healthcare purposes was considered low. Few health professionals were involved in the dissemination of information about diabetes *mellitus*.	VI
To analyze posts from three Norwegian diabetes Facebook groups made up of patients and healthcare professionals.[23]	Qualitative. 300 posts extracted from three groups, one with restricted access (closed) and two open.	2019	Social media	The posts made by patients involved scientific content, health services, self-management and awareness of the clinical condition. In closed groups, the most disseminated information was related to self-care, while in open groups, awareness about the disease was addressed, mostly by health professionals.	VI
To analyze information sharing and its consequences for the health of patients and families in most Arabic-speaking countries.[24]	Mixed methods. 1,551 Facebook posts from the seven DM-related groups in Arabic.	2016	Social media Facebook	Patients with diabetes *mellitus* are increasingly sharing health information with other users in order to share personal experiences, raise awareness, provide spiritual support, disseminate scientific research and educate about the disease.	VI
To explore information shared in health-related discussion forums and identify approaches used to signal information to	Qualitative.	2016	Discussion forums	Patients with diabetes *mellitus* are increasingly using the online medium to share information about their experiences and that of others with the disease.	VI

peers.[25]					
Qualitatively evaluate communication content in Facebook communities dedicated to diabetes.[11]	Qualitative. 480 users in a series of 690 comments on posts from the top 15 Facebook groups focused on diabetes management.	2011	Social media Facebook	Patients with diabetes, family members and their friends seek to share information, ask for guidance about the disease and receive emotional support. Information related to the management of the disease, the importance of physical activity, self-care and forms of treatment were disseminated.	VI
To examine online diabetes health communities available to teens with type 1 diabetes.[26]	Qualitative. 18 diabetes websites.	2014	Online medium	Patients sought general information about the disease, guidance on management and treatment, exchange of experiences, self-care actions, beliefs and psychological support.	VI
To investigate the content, quality and popularity of type 2 diabetes information available on YouTube.[27]	Descriptive cross section. 100 type 2 diabetes videos available on YouTube.	2018	Videos	Out of 100 videos, 45 were rated as helpful and 23 as misleading. Mean reliability and content scores for useful videos were 3 and 5, respectively, and 6 videos met ≥ 4 of 5 reliability criteria. Overall, misleading videos were more popular than helpful videos. Culturally adapted videos were just as likely to be misleading and had similar scores compared to non-culturally adapted videos.	VI
To investigate the use of web-enabled electronic touchscreen information kiosks as a tool to provide culturally and linguistically appropriate diabetes information to Latino audiences.[28]	Qualitative. Focus groups.	2009	Kiosks*	Public usage data and interviews with focus group participants showed that users found the kiosks and their functions useful and usable, although usage was moderated by the presence or absence of a health educator; participants also preferred the seated multifunctional kiosk model.	VI
To investigate the motivations	Mixed method design with	2009	Application and email	The web application favored disease control and self-care,	VI

and experiences of patients with type 2 diabetes with the web-based application.[29]	usability testing and interviews. 43 patients with DM2 (n=43).			constituting an important means for disseminating information mainly related to the treatment of the disease. Patients showed interest in contacting professionals through e-mails, as they received information about lifestyle, healthy behavior and emotional support.	
To analyze health communications across ten diabetes-related Facebook pages to identify messaging features that predict user engagement.[30]	Qualitative. 500 posts from ten Facebook pages (n=500).	2016	Social media Facebook	It represented an important means of disseminating information about the clinical condition. The most publicized topics were related to self-care, forms of treatment and improved quality of life.	VI
To use a semantic approach with a focus on diabetes-related websites.[31]	Qualitative. 430 diabetes-related websites (n=430).	2019	Sites	430 sites were identified, and five sets of words were tagged with 38 different tags from six different dimensions, in which poor performance was evidenced using tags to determine diabetes-related site sets. This reflects the reality of the community: a set of different types of sites that create a mixed space.	VI
To review public diabetes Facebook groups and their content.[32]	Descriptive cross section. 34 public diabetes Facebook groups with 193,458 members.	2019	Social media Facebook	Thousands of members included in groups created to provide emotional support were identified. The topics most commonly addressed in the groups were related to nutrition and patient self-care.	VI
To develop a diabetes care support system so that patients can integrate self-care activities needed in different contexts.[33]	Methodological study.	2012	Application	The system developed in this study provides care support function for diabetic patients and healthcare professionals. It is based on a set of self-care scenarios designed to describe the dynamic condition of the patient's daily care activities, including health problems and technical solutions.	VII

Explore the experiences and perceptions of gestational DM reported by women in online parental support forums.[34]	Qualitative. 646 posts in 137 topics from 282 users.	2020	Online forums	The content of the posts was limited to prevention strategies as it involves the following aspects: gestational diabetes is not a serious diagnosis that warrants concern; low recognition of the importance of behaviors or lifestyle in controlling the disease; lack of recognition of the increased risk of type 2 diabetes.	VI
To map and characterize online Hebrew discourse on diabetes during the first period of the COVID-19 outbreak and the period before.[35]	Mixed method. Descriptive and Qualitative Transversal.	2021	Social media and online forums	During the COVID-19 pandemic there has been considerable growth in informational discourse on diabetes.	VI
Explore online experiences of acquiring information about COVID-19 among people with DM2 and variable e-Health literacy.[36]	Qualitative. Adults with type 2 DM (n=107).	2021	Social media	Challenges capable of compromising disease prevention and control were identified, such as information overload and conflicting data. The coping strategy involved behavioral change.	VI

*The health kiosk helps people register, self-check-in, take health checks (which are the most important processes), review their health reports, and receive health data via email or apps, which can be used as a medical kiosk in hospitals to serve patients (connecting to the EMR system), or it can be facilitated as a health post in rural areas to serve the public to do health checks for chronic diseases, it also helps people to do interactive diagnoses with doctors online through the telemedicine system.

Discussion

In recent decades, internet tools have evolved constantly, and social media has been presented as alternative platforms for sharing and searching for information related to the health conditions of people with diabetes *mellitus*, as well as for promoting self-care and strengthening social support and support networks.[22,24]

The predominance of studies with low evidence force (level VI) such as observational design, although not establishing a cause-and-effect relationship, is a relevant method for care practice because it takes less time and cost, being constantly

used to indicate prognosis, evaluate results of exposure to risks and gather evidence capable of supporting care with safety, effectiveness and quality.

In this review, the identified online resources were constantly used to seek advice, connect with specialists and people with similar conditions and experiences, share questions and concerns about treatment options, or understand professional diagnoses.[24]

A study conducted in Spain with 309 people with type 1 diabetes mellitus (DM1) analyzed perceptions of internet use through applications and software guided by health professionals. The analysis of the content discussed there identified that men, with an average age of 42.8 years, are the ones who most access social media for this purpose. They usually share posts about quality of life and health-related aspects, in general, in a lay way, without professional guidance.[22]

In Saudi Arabia, similar results were evidenced, in which the information shared generally related to quality of life, aspects related to health status and experiences. However, unlike research in Spain, most posts were made by women, aged between 40 and 60 years.[24]

With regard to the means for communication and exchange of information between patients and health professionals, e-mail has become the most used tool.[22] Considered an "old" tool in the midst of the constant process of elaboration and dissemination of social media, e-mail is still used as an expressive means of communication to maintain contact between patients and specialists.

The evaluation of social media or specific applications for people with diabetes, such as Facebook, Twitter and Instagram guided by health professionals was also verified, suggesting clinical utility and feasibility for the dissemination of information about the disease, care strategies and prevention of complications.[37]

It is noteworthy that the sample, in its entirety, addressed directly or indirectly the use of social networking sites, especially Facebook, revealing that this platform represents a widely disseminated tool, which allows different forms of interaction for information and content sharing. A Norwegian study, analyzing group posts about diabetes on Facebook, found that the most talked about topics were health services, self-management and awareness of the disease. However, the evidence highlights the

need to harmonize and ensure the safe and accurate disclosure of information.[23] Similar data were found in other production sat in the United States of America (USA).[11]

The increasing use of social media, such as Facebook, for the dissemination of information among people with diabetes, seems to be related to easy access, as well as to the low cost related to the development of communication strategies with the patient. However, care strategies are essential, due to the dissemination of false news and without scientific evidence that can cause negative effects on the emotional scope of affected individuals.[30]

In the USA, 34 public groups focused on instrumental and emotional support for people with diabetes, without guidance or participation of qualified professionals, were found, being associated with the decay of the groups found, while the shared information became discredited and invalid.[32]

The massive production and propagation of fake news - Fake News finds fertile ground on social networking sites and can induce patients to errors in personal decisions and health care.[38] Therefore, it is recommended that the patient always check the propagating source of the content. Combating fake news requires investments in education and digital literacy and for institutions to increase the level of reliability of information accessible to the entire population.[39]

Although the prevalence of Fake News is considered to be high on social media, a study in England revealed that there are discussion groups on social media that include health professionals and specialists to provide guidance on health-related aspects. It is noteworthy that the sharing of information and experiences is the most addressed content in discussion groups.[25] This evidence was also verified in two other studies conducted with adolescents with DM1.[26,40]

Discussions in online forums were also evidenced. There is social media being generated outside social networking sites, such as online forums, with specific communities for diabetes on the internet, which focus on sharing experiences and information about the pathology. In general, they are open and there is the presence of health professionals, family members, friends and people with diabetes. This fact could be observed in a study conducted in Portugal.[31] A similar study obtained equivalent results regarding the content addressed in the discussion groups on websites.[29]

The development of software as applications intended to obtain information by users with diabetes was also found in the analysis process. An American study revealed that, despite the initial low acceptance, alternatives to obtain safe information are necessary and effective for the outstanding public.[28] An analogous finding was found in a Taiwanese article, in which the Web 2.0 Diabetes Care Support System software presented itself as an alternative to social media in obtaining secure information.[33]

Still, a Canadian study approaches Youtube as a health information resource for diabetes *mellitus*. In this platform, many patients and health professionals have channels for disseminating knowledge, tips and current events on the theme that involves diabetes.[27]

Similarly, different studies evaluating discussions on diabetes in online networks and forums showed that despite the considerable growth of posts during the COVID-19 pandemic and its measures of isolation and social distancing, the content often has limitations capable of impacting on disease prevention and control.[34-36]

These events were mainly associated with information overload, generally conflicting that directly had a direct effect on patients' behaviors and lifestyle, as well as in the recognition of the risk and severity that this health condition presents.[34,36]

Thus, it is considered that new information and communication technologies (NTICs) can play a fundamental role in the access and dissemination of information and, consequently, for individual and collective empowerment.[41] In the field of health, empowerment is closely related to information. The possibility of producing content, establishing digital social networks and accessing a multitude of content, makes the internet an important medium for empowerment.[42]

Access to information through the Internet allowed the emergence of the informed patient – a consumer/patient with information about diseases, health conditions, diagnoses, symptoms, treatments and medications. Studies on this new actor in the health area suggest that the acquisition of health information would result in a citizen/patient empowerment. As a part, he would become less willing to abide by unilateral medical decisions, leading to changes in this relationship. Among the possibilities pointed out, the rise of the informed patient could lead to the deprofessionalization of the physician, transform the doctor-patient relationship or

preserve and condemn, simultaneously, the authority and status of the medical profession.[43]

Thus, it is considered that the internet and social networking websites function as disseminators of information, of true or non-true order, produced and consulted by patients, family members and caregivers. Despite the contributions evidenced, the low cost and easy access, the incorporation of these resources in health practices is still incipient, revealing new studies directed to these environments to ascertain what has been shared by users, as well as to contribute to the development of self-care and the maintenance of health and quality of life.

The limitation of this study refers to the predominance of studies with low evidence force because it does not allow establishing cause-effect relationships. Also, the absence of Brazilian productions on the theme stands out, which made it impossible to compare the evidence with the international context.

Conclusion

It was identified in this review that the main informational support identified was the Facebook platform, in which contents related to self-care, treatment, nutrition, social support of patients and disease management are addressed. Despite the limited participation of health professionals in virtual communities, the possibilities of cyberspace were evidenced as a scenario of health promotion and interaction with patients, recognizing its potentialities as an interface for health care.

Due to the evolution of internet tools, people with diabetes mellitus, family members and health professionals use virtual environments as an important information resource capable of contributing to the sharing of knowledge and experiences about the disease and to self-management of the care inherent to this health condition. The use of applications, networks and social media, software and online discussion forums, although used less frequently, proved to be important tools for the dissemination of information.

The scarcity of experimental and near-experimental studies in relation to the use of the Internet by people seeking information on diabetes mellitus evidences the need for further scientific research on the subject. Thus, it is considered that this gap needs to

be explored, in view of the high incidence of diabetes and the growing habit of researching health information on the Internet.

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