

#### **RESEARCH | PESQUISA**



### Use of virtual communities to support people with diabetes mellitus

Uso de comunidades virtuais no suporte às pessoas com diabetes mellitus Uso de comunidades virtuales para apoyar a personas con diabetes mellitus

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#### **A**BSTRACT

Objective: to analyze the support offered by virtual communities to people with diabetes mellitus. Method: exploratory study with a qualitative approach, developed in three open virtual communities, focused on diabetes mellitus, with the largest number of members and posts in Portuguese. The content analysis was performed using word clouds to identify the nuclei of meaning. Results: the most relevant results refer to virtual communities as sites of informational support to improve self-care; and as sites of emotional and spiritual support to encourage behavioral changes. Conclusion and implications for the practice: virtual communities can contribute as scenarios of care for people with diabetes mellitus, providing greater approximation between professional practices and care needs. The understanding of the meanings of the shared information can contribute to the realization of holistic and effective care practices, without, however, being restricted to biological and technicist approaches. It can also constitute a strategy to help people with diabetes mellitus in self-care, highlighting the potential of social media for health as transformative tools for professionals and empowerment of patients.

Keywords: Social Support; Self Care; Diabetes Mellitus; Internet; Social Media.

### **R**ESUMO

Objetivo: analisar o suporte oferecido pelas comunidades virtuais às pessoas com diabetes *mellitus*. Métodos: estudo exploratório com abordagem qualitativa, desenvolvido em três comunidades virtuais abertas, voltadas ao diabetes *mellitus* com o maior número de membros e postagens em português. A análise de conteúdo se deu por meio de nuvem de palavras como recurso para identificação dos núcleos de sentido. Resultados: os resultados mais relevantes se referem às comunidades virtuais como locais de apoio informacional para melhorar o autocuidado; e como locais de suporte emocional e espiritual para encorajar mudanças comportamentais. Conclusão e implicações para a prática: as comunidades virtuais podem contribuir como cenários de cuidado de pessoas com diabetes *mellitus*, proporcionando maior aproximação entre as práticas profissionais e as necessidades de cuidado. A compreensão dos significados das informações compartilhadas pode contribuir para a realização de práticas de cuidado integrais e efetivas, de forma holística, sem, porém, que essas estejam restritas a abordagens de caráter biológico e tecnicista. Pode, ainda, constituir-se em estratégia para auxiliar a pessoa com diabetes *mellitus* no cuidado de si, evidenciando o potencial das mídias sociais para a área da saúde como ferramentas transformadoras para os profissionais e empoderamento de pacientes.

Palavras-chave: Apoio Social; Autocuidado; Diabetes Mellitus; Internet; Mídias Sociais.

### RESUMEN

Objetivo: analizar el apoyo que ofrecen las comunidades virtuales a las personas con diabetes mellitus. Método: estudio exploratorio, con abordaje cualitativo, desarrollado en tres comunidades virtuales abiertas enfocadas en diabetes mellitus, con mayor número de integrantes y publicaciones en portugués. El análisis de contenido se realizó mediante nubes de palabras como recurso para la identificación de los núcleos de significado. Resultados: los resultados más relevantes se refieren a las comunidades virtuales como lugares de apoyo informativo para mejorar el autocuidado; y como lugares de apoyo emocional y espiritual para fomentar el cambio de comportamiento. Conclusión e implicaciones para la práctica: las comunidades virtuales pueden contribuir como escenarios de atención a las personas con diabetes mellitus, proporcionando una mejor aproximación entre las prácticas profesionales y las necesidades de atención. Comprender los significados de la información compartida puede contribuir a la realización de prácticas de atención holísticas y eficaces, sin por ello limitarse a planteamientos biológicos y técnicos. También puede constituir una estrategia para asistir a la persona con diabetes mellitus en el autocuidado, destacando el potencial de las redes sociales para el área de la salud como herramientas de transformación para los profesionales y de empoderamiento de los pacientes.

Palabras-clave: Apoyo Social; Autocuidado; Diabetes Mellitus; Internet; Medios de Comunicación Sociales.

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### INTRODUCTION

Web 2.0 or collaborative internet has enabled the evolution of social media, transforming users into content creators, and not only passive consumers. Access to knowledge, previously restricted to specific places, is now widespread through mobile devices that access the internet. From this perspective, behaviors focused on information and social interaction have grown considerably, favoring the formation of Virtual Communities (VC) that have been directed to different contexts, among them, the health conditions of the population.

The term VC was first defined by Howard Rheingold in 1993 as a cultural aggregation formed by the systematic meeting of a group of people in cyberspace. The VC is recognized by the cooperative action of its participants in the sharing of values, interests, goals, and positions of mutual support through interactions in the online universe. In this scenario, the figure of the expert patient stands out, who, by presenting extensive knowledge about his condition, treatment, symptoms, and costs, has an active voice in all aspects involving the sharing of his experiences.

These new spaces, created by the social appropriation of information and communication technologies (ICT), open opportunities for social interaction, acquisition of self-care skills, and use of effective coping modes to manage the stressors related to the condition, since the dimension of anonymity and the feeling of being among peers make communication freer, and narratives acquire special meaning because they are addressed to people who share a common existential experience.<sup>4</sup>

Empowerment comes from the English empowerment, and is the word that best represents the kind of support found in patients' VCs, which can be defined by some terms that make it easier to understand, such as: inner strength; self-control; self-confidence; self-choice; independence; and living in a dignified way according to one's own values and ability to fight for one's rights.<sup>5</sup> In this way, "empowerment" means that VCs offer patients the support they need to have self-confidence, create their own strength and energy to cope with the disease.

Thus, the use of the Internet and social media is considered a favorable alternative to the empowerment of the population with chronic diseases and their families. In this sense, health VCs are presented as a potential strategy to minimize the difficulties in coping with diabetes mellitus (DM).

Considering that the diagnosis of DM brings with it the need to adapt to a new life routine, 6.7 and in view of the difficulties encountered, which can be sources of stress in their lives, 8 one realizes the need to implement innovative strategies based on the use of VC in health institutions, providing opportunities to discuss the individual's needs and propose a shared care, based on priorities defined through effective negotiation, so that they have meaning for the person and, thus, are more easily incorporated into their daily lives.

Studies highlight the use of VC as a possibility of social support for people with chronic diseases, which can favor effective care outcomes.<sup>9-11</sup> At the national level, although VC are widely available, studies exploring their potential are limited.<sup>9,10</sup> At the international

level, the use of VC by people with diabetes has been associated with better knowledge, skills, confidence, and self-management of the disease. Other studies have confirmed the strong potential in favor of knowledge and self-management. <sup>8,12</sup> Nevertheless, the need to harmonize and ensure the safe and accurate dissemination of information is highlighted. <sup>11</sup>

Given this social reconfiguration, associated with the Internet and the use of social media, it is evident the relevance of the institutionalization of these tools, especially by nursing professionals, to monitor the doubts and needs arising from the care, even providing some ideas to mitigate or solve them. Therefore, giving voice to people living with DM and to those involved in their care through VCs can be a strategy to bring out the "unspoken" in health services aimed at the care of this clientele.<sup>a</sup>

Based on the above, this study aimed to analyze the support offered by virtual communities to people with diabetes *mellitus*.

### **METHOD**

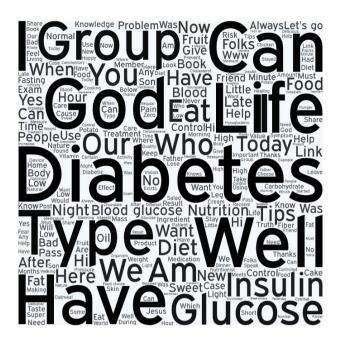
This is an exploratory study with a qualitative approach, developed in the most relevant virtual communities with the highest number of participants and content about diabetes through the Facebook platform.

The inclusion criteria for the selection of the groups were: open VC (which allow the observation of the dynamics and data collection without the need to identify the researcher), public, in Portuguese with the term "diabetes *mellitus*" in the name or description, and with the largest number of members and posts. Communities of commercial or institutional origin and that did not have recent posts were excluded.

Data collection occurred in January and February 2020 and included all posts and comments referring to the years 2018 and 2019. Thus, all posts and comments of the communities were compiled through scripts (developed by three collaborators of the Computer Science department of the Universidade Federal de São João del Rei (Federal University of São João del Rei), previously trained), which enabled the construction of the matrix text, to which we returned to read the posts and comments in their original contexts.

Then, we proceeded to the purification of the mother text in a filtered text by removing articles, conjunctions, prepositions, and the substitution of abbreviated or misspelled words, among other grammatical elements of limited semantic value to the content analysis. It was also necessary to agglutinate terms with variations in gender and number, in addition to grouping words with the same meaning. Then, a word cloud was generated using algorithms from the Wordart.com website (Figure 1).

To operationalize the content analysis, the online tool known as "word cloud" (WC) was used, a resource that allows you to create a word picture from a given text. In the cloud the words that occur most frequently in the text appear in greater prominence. You can choose different fonts, word arrangements and color schemes to facilitate visualization. The WC is, therefore, the



**Figure 1.** Word cloud from the posts and comments from the Facebook diabetes *mellitus* virtual communities. **Source:** WordArt, 2020.

representation of a hierarchical list, visually, for classification purposes.<sup>13</sup>

The WC meets the need to identify which terms are most often discussed and used when discussing a topic, making it possible to draw a map of relationships between the terms and the feelings expressed by them. Extrapolating the illustrative resource, the WC has been used as an option for text analysis in qualitative research, being considered an effective communication tool, adding clarity of ideas.<sup>13</sup>

The data were analyzed, following the concepts of content analysis, <sup>14</sup> in which we proceeded to the identification of "nuclei of meaning", which represented the most frequent speeches. This was done by reading all the original posts in the matrix text that contained the highlighted words. Thus, the frequency of entries pointed out the most significant meanings to the analytical objectives. After the floating readings of the posts in the matrix text, horizontal readings were organized (which sought correlation with the others) in a process of mutual checking between three researchers for the identification and understanding of categories and nuclei of meaning that summarized the objective of the study. The methodological procedures, in simplified form, were systematized as shown in Figure 2.

Despite the public nature of the VCs, this study complied with the precepts of Resolutions 510/2016 and 466/2012 of the National Health Council, obtaining Opinion of Waiver of Analysis No. 05/2019 by the Comitê de Ética em Pesquisa da Escola Nacional de Saúde Pública ("Research Ethics Committee of the National School of Public Health") (ENSP/FIOCRUZ).

### **RESULTS**

The VC selected were: "Controlled diabetes" with 92,800 participants; "Diabetic diary" with 90,500 members; and "Diabetes-diabetic" with 73,100 members. After data retrieval, WC creation, and analysis of posts and comments, the results were discussed in cross-cutting categories such as: Virtual communities are sites of informational support in service of self-care; and Virtual communities are sites of emotional and spiritual support that encourage behavioral change.

### Category 1: Virtual communities are sites of informational support in the service of self-care

In this category, we grouped the information that plays a key role in the context of patients who seek interaction in the communities. People request information in some moments as well as provide information and advice to peers, which help to understand their world and the changes that occur in it and that can contribute to the improvement of self-care.

The frequency of the pronoun YOU shows a search for guidance and recommendations from other patients on aspects of the treatment and management of diabetes. In this category, it is clearly observed discussions about therapeutic aspects through words such as "glucose", "insulin", "diet", "blood glucose", "type" (referring to the classification of the disease), "control", "fasting", "weight", "problem" (concerning complications), "sweet", among others. Thus, information plays a key role in the context of self-care of patients who seek interaction in the communities.

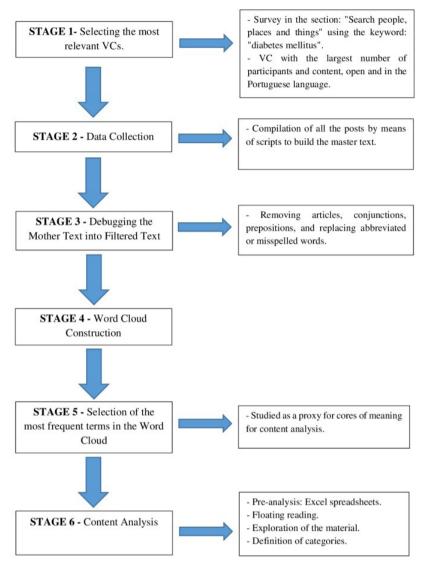
One of the publications reviewed refers to a recommendation made by two clinical posters to another person less experienced in dealing with a hypoglycemic crisis.

The knowledge derived from experience seems to have high credibility among the attendants, especially by those with a recent diagnosis, because it comes from someone who lives the daily life of the disease and treatment and has the skills to suggest solutions to their health demands.

- [...] thank you very much for the tips, we who are at the beginning of this disease need a lot of information. This helps us a lot. Everything that you say has helped me daily.
- [...] I am learning a lot with the group, I wish you a great weekend. friends!

The recommendations made in the informational posts demonstrate a certain level of empowerment. They answer questions with ownership, to convince other members about diabetes therapy, to alleviate signs and symptoms of the disease. These orientations also demonstrate the adherence of experiential learning to biomedical treatment.

You must follow everything right in this diabetes, otherwise you will be full of problems, just like my father, who had it and didn't take care of himself, so he went blind. So, take care of yourselves, people.



**Figure 2.** Flowchart of the methodological procedures of the collection and organization of the research data. **Source**: elaborated by the authors.

It is normal to see the Glyphage XR capsule in the stool, because this medication that has the suffix XR means that it has prolonged release, and, for this, the structure of the pill works like a sponge, which gradually releases the medication, leaving in the end only an empty structure without the medication, which comes out in the stool. So, don't worry, it is normal, dear ones.

People, the insulin leaf tea has no beneficial effect on humans, in other words it should not be consumed by us diabetics. This vegetable insulin has nothing to do with the insulin we take for the treatment of diabetes. I researched several articles and saw that more research is still needed to know its effectiveness and side effects in people, so the recommendation is that we should not use it for our treatment because it has no scientific proof.

The terms used "you have to follow", "otherwise you'll be full of problems", "that's why you went blind", "it's normal" and "so don't worry" demonstrate a sense of certainty and ownership in what they are saying. In another post, the participant issues his knowledge based on experience about plant insulin tea, which seems to be the new fad for diabetes, however, without scientific evidence. These are the experts with experience on the subject.

The posts showed relativization of the prescriptions received through adjustments in food choice, in the amount of carbohydrates, adaptations in the times of taking medications to mitigate side effects, in the dosages of medications, and in the locations of insulin application as ways to achieve better glycemic control.

Hi, I am a user of insulin NPH and Regular, I always applied in the belly, for me it was so painful, after I joined

this group, I learned to apply in other places, and look at the result, thanks God I feel almost no pain now, when I go to apply in other parts of the body, I feel much better. Thank you very much for having accepted me in this blessed group!

Due to some side effects of metformin, daily nausea, swelling, lots of gas, my belly felt like a full drum, reflux, I even thought I was pregnant, constant diarrhea; all of this, three months taking it right after a meal, I found out that taking it an hour later, doesn't give me so much discomfort, it was the way I found to take it.

## Category 2: Virtual communities are places of emotional and spiritual support that encourage behavioral changes

In this category, we grouped the knowledge and feelings shared by people with DM to their peers, arising from experiences accumulated throughout their lives. It was possible to infer based on the WC the recurrence of the pronouns "I", "we" and verbs in the first person ("I am", "I know", "I want", "I have", etc.). It demonstrates empowerment to raise awareness among peers, since it derives from those who live the scenario of the disease and treatment. It was also noted the strong influence of spirituality evoked in words - such as "God", "Jesus", "healing", "life" - that represent a source of strength, comfort, and faith in the positive coping with adversity, and stressful events related to the illness process.

The posters publicly assume an optimistic perspective in the face of the condition of having to live with the disease and undergo diabetes treatment. They highlight the changes they have had to experience to find another meaning to life.

People do not think that having diabetes means that it will kill you, on the contrary, it can show you the good side of life, I had a very unruly life, and after I got the disease, I started to take care of myself, to eat with quality, exercise, and today I feel like a happier person, just having to take care of myself more than before. So, we can live longer and without sequels from the disease. Go ahead, warriors, God is with us! I made it, you will make it too.

When the poster mentions "showing the good side of life", he makes explicit the trajectory he went through until he was able to accept the limitations imposed by the disease and the treatment. To perceive this "good side", the temporal dimension given by him is offered with the use of the term "I started taking care of myself". The poster suggests the time interval between the person accepting his condition, submitting to this new routine, and becoming familiar with the treatment as an opportunity to "live longer and without sequelae of the disease". At the end, he mentions words of hope and motivation: "I did it, you will too".

Religion, considered the spiritual foundation of people living with diabetes, stands out as social support to patients and their families, an occurrence evidenced in the following posts:

God is who gives me strength to face all this, if it wasn't for the faith I have in him, I would have already given up fighting.

Following medical guidelines is very important for our well-being, but believing in someone we cannot see, but that we know exists, and that helps us, comforts us, makes us overcome everything. So, my friends, believe in him, only Jesus is capable of this.

The informal support network for people with diabetes, constituted in the VCs, was configured not only as a means of communication for the interaction and strengthening of peers and their families, but also strengthened the social bonds in the sharing of knowledge related to care, helping in the relational needs and in overcoming difficult moments. These social media resemble a therapeutic group, when they state that the sick person acquires more control over his process of getting sick, expanding the idea of health-illness in the case of people with diabetes. The following post depicts part of this interaction:

I thank God for having found this group. It was terrible to find out that my daughter had diabetes, I thought that only our family went through this, that no one was going through the same problem as you, but the group showed me that it's not like that, many parents go through the same problem that I went through. By finding this group on Facebook I felt stronger, one gives strength to the other and so we follow together in the same ideal, giving courage to those who do not have the strength to fight. Despite this suffering they taught me that my son can have a normal life, go to a party, go out with his friends at school, play, because other children with diabetes do that. It was very hard because I did not let my son do anything, and little by little other little mothers showed me that my son is normal.

In many posts, it was possible to get a sense of the participants' social belongings. This is because they produced an important socializing environment by allowing members to meet other people and identify those who were in the same city or very close to them, to offer them social support. Moreover, people used to like and comment on the posts, which resulted in relaxation and a desire to continue the relationships developed in the virtual space into the real world as two inseparable and non-exclusive realities.

Who here in the group is also from Salvador-Bahia? please introduce yourself, I am wanting to schedule a face-to-face meeting to exchange ideas and make good friends, who knows, we may even be meeting periodically to strengthen our group.

If you need a friend to talk to, you can call me in the chat. Count on me to share the little I know about diabetes with all of you! I am always here.

Guys, the glucose meter tape is very expensive, I cannot afford it. Does anyone have one to donate? I need it. If there is a person with a good heart, I'd appreciate it. God bless you.

### DISCUSSION

The clinical and informational publications are inserted and shared in the VC on issues involving different therapeutic dimensions of DM. These are more detailed information about diabetes and are disseminated by those who have been undergoing treatment, diet, and medications for longer than those who require information and clarification. This type of publication has knowledge derived from the experience of living with the disease and dealing with the many limitations inherent in the treatment and all that it involves in relation to their body and social behavior. It is, therefore, someone who has "experiential learning".

Experiential learning is a learning process resulting from concrete experience and reflection that usually occurs during a given activity. It differs from traditional knowledge in which the learner plays a relatively passive role in the teaching-learning process. <sup>15</sup> In experiential learning, the learner assumes a prominent role. The role that emotion and feelings, derived from experiential learning, play in this process is relevant. The direct engagement of the individual in the practice and his subsequent reflection using analytical tools allow the learner to better understand what happened and retain the information for a longer time. Thus, he is also able to pass on this knowledge. <sup>15</sup>

The valorization of the patient's experience with chronic disease has come to occupy a prominent place in the context of adherence to the treatment of chronic diseases, previously centered on a model of patient submission to medical power. The equally important expertise of care providers and patients have led to the idea of recognizing the patient's right to make decisions that make sense in the context of their lives rather than the goals determined by health professionals.<sup>16</sup>

Currently, participation in patient groups organized in the virtual environment is an evident reality. Participants in VCs have access to information about their disease, which gives them greater autonomy in making decisions about their health condition, for the discussion of their case with the physician, displacing, in part, the asymmetry that, for centuries, has characterized the doctorpatient relationship.<sup>17</sup> Whoever performs clinical publications seems to be, equally, under the biomedicine perspective. However, they do not submit to the professional authority of the physician. The knowledge he gains through daily practice of treatment, internet searches, and sharing in digital media brings him closer to the typical expert patient.<sup>18</sup>

Searched by people who are sympathetic to a particular subject, this knowledge is built through the experiences of each

one, by searching the literature, by contact with health professionals and people who have gone through the same situation through interaction in online and offline groups. This process has been studied over the years and, based on the research conducted, the concept of expert patient or, as some authors translated it into Portuguese, "informed patient" was defined.<sup>18</sup>

In the context of chronic non-communicable diseases (NCDs), patient empowerment influences and promotes lifestyle changes that contribute to self-care and improved clinical and psychological outcomes, since it increases the user's autonomy to acquire a critical sense about their health condition and the ability to manage it. <sup>19</sup> In this context, the broad and easy access to information through the Internet is relevant because, through this channel, users acquire knowledge, awareness of their condition, and the necessary behaviors for diabetes control.

It was possible to verify that, in the VCs, there is a search for information by the other members of the community as a strategy for better disease management, since "what is not said" by health professionals leads users to seek virtual spaces as an alternative for disease management. The person desires to discuss with the group the possibilities that he may have for the resolution of his complaint.

Living with a long-lasting disease such as diabetes, and the paths taken to seek care in health services place the subject in a delicate relationship, permeated with many unsaid. The unsaid can be understood as all the information that is distorted or omitted in speeches, attitudes, texts, behavior, or any other form of expression or manifestation. This omission or distortion may be voluntary or involuntary, conscious, or unconscious, and be assumed or not, but it is invariably considered a source of misunderstandings and conflicts that affect coexistence, or else, causes or effects of a lack of knowledge whose overcoming is supposed to be enriching.<sup>20</sup>

It calls attention to the issue of doubts and exchanges that occurred in the researched communities, in which data analysis showed flaws in the relationship between the health professional and the patient, since the doubts pointed out would be easily clarified through an effective dialogue in which the professional is willing to answer all questions, welcoming the person and seeking to understand the cultural, social, psychological, and economic aspects of this individual.

The knowledge derived from practical experience differentiates the clinical poster from other patients and health professionals, including physicians. Even though his orientation is biomedical, he can translate scientific knowledge into a simple and understandable form for the user. He is empowered with knowledge derived from the experience of living with the disease and undergoing treatment.

In the emotional and spiritual support posts, it was possible to analyze that the sharing of these experiences sought not only to express feelings, but also to assist the other participants in facing challenges inherent to the management of care arising from the disease through their life narratives. The experiences shared by peers seem to have more impact for the patient.<sup>10</sup>

The experience with the disease - when narrated and in association with other accounts - promotes resources for the construction of thought whose result is the expansion of knowledge about the disease and the consequent empowerment,<sup>3</sup> which may or may not reflect in the decision-making processes of people with DM. The empowerment of the patient indicates that he/she has the authority of knowledge because he/she is part of the disease phenomenon, incorporated to his/her subjectivity.<sup>21</sup> The experiential knowledge about the disease considers subjective and practical aspects that are generally excluded from scientific and biomedical knowledge. This knowledge guides mutual aid groups (such as patients' VCs), patients' associations, and social movements in health.<sup>22</sup>

The words encouraging the self-care of the person with diabetes can be understood as facilitators of submission and biomedical guidance and can also play an inhibiting role in treatment evasion. In the analyzed groups, this was possible because the participants had the possibility to interact with the perspective of other people living the same health condition and facing the same restrictions imposed by the disease and treatment. These are environments in which the participants are free to describe their experiences without necessarily having a prejudiced or negative reaction. They are reports shared, above all, among peers. Reciprocal support was the guiding principle of emotional support. Its orientation obeys the biomedical parameters and may contribute to treatment adherence.

The spiritual support to the patient can contribute to the improvement of his condition and to the acceptance of the process of living with the disease, considering that, in moments of suffering, he resorts to this type of support as a source of strength, comfort, and faith. This comfort is necessary for him to be able to deal with the situation and demonstrates the relevance of this practice for health in the strengthening and recovery of patients with chronic diseases. <sup>23</sup> A result that was also observed in the context of the studied VCs, since in discussions related to a certain problem, the poster thanked the members who met his demands and referred to faith, exposing his religiosity.

Faith can be used as a coping strategy for the disease and treatment of people with chronic diseases because it can increase the self-determination of VC members. This is because, even facing the restrictions imposed by the disease to their daily lives, patients believe in the possibility of a good life associated with a greater resistance to stress.

It is necessary that the focus on spirituality in the care of people with diabetes be reinforced, seeking the development of important aspects such as self-esteem, happiness, optimism, hope, faith, satisfaction, and the strengthening of social and family relationships to support the person. Spirituality transmits to the person and his/her family security, serenity, and, in a certain way, control over the stressful situations they go through during the treatment.<sup>24</sup>

Social support for chronically ill patients in the virtual environment was analyzed in studies, which identified that the interaction between VC participants promoted mutual support

between people. These surveys concluded that the mutual support verified between people in the groups influenced treatment adherence. Social support for people with chronic diseases was verified through welcoming, asking for help, sharing grief, frustrations, and motivational messages.<sup>8-10</sup>

The Internet introduces a new spatial and temporal perception, promoting a dynamic specific to cyberspace that profoundly affects the social field.<sup>25</sup> This is corroborated by the social support evidenced in these spaces that seem to influence the people who receive and those who offer the support, enabling the understanding that individuals need each other for self-management.

Only those who undergo the limitations imposed by diabetes know how much the diagnosis of the disease negatively impacts their lives. The health professional does not have this same experience. No matter how much they study and specialize in the disease, they don't feel it or live with the restrictions imposed on their daily lives. The motivational poster has gone through this ordeal. At this moment, the poster's word plays a decisive role. It impacts the unmotivated users of the group and, with its own testimony, encourages its virtual friend for life. This poster, who is a more psychologically informed patient, emphasizes the importance of adherence to therapy, reinforcing the prevailing biomedical recommendation. He is empowered with emotions and feelings of those who have gone through existentially difficult situations.

Institutions need to restructure their care practices and should be guided by the logic of care to accompany a more autonomous patient in self-care. An assistance that goes beyond a relationship conducted in the sense of exchange and adjustments of care, since it implies a qualitative change in the support offered, aiming to meet the needs and priorities established by the person with diabetes. It is up to the support system offered by the health team: the welcoming, listening, and dialogue in the sharing of experiences in the care of the person with diabetes. It is essential that the person with DM knows that there are professionals trained and committed to their care.

It is worth noting that, although the experts' patients make "prescriptions" of conduct based on their experiences, there are recurrent recommendations to other participants to seek assistance from qualified health professionals.

Another aspect evidenced in the posts refers to the instrumental support, verified through the exchange of supplies among the VC members. Those who had medications and supplies that were no longer used during therapy promoted donations and exchanges among the other members, helping to reduce the cost of treatment, which still represents a major barrier to treatment adherence.<sup>27</sup>

The analyzed posts revealed the important role that health professionals play in empowering the user in the online environment for a health-promoting care, even though they are absent from the intermediation in the analyzed VCs. Their role goes beyond the other difficulties encountered to guide the necessary and appropriate measures that each user and/or community can take according to their reality. It is known that the practice of self-care

is focused on a dialogical relationship, in which professionals and patients must understand that its success depends on shared negotiation. Therefore, it is necessary that professionals develop a practice based on interaction and exchange of experiences between members of the health team, to offer comprehensive care that values self-care as part of life.<sup>28</sup>

# CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

Virtual communities can contribute to this practice by acting as scenarios of care for people with diabetes, providing a better approximation between professional practices and the care needs, since they can offer interactions for informational, emotional, and spiritual support. The findings showed that the predominant care practices have neglected particularities and aspects of the context in which people with diabetes are inserted, failing to listen to them and isolating them from their daily lives, increasing consumption and choices disengaged from the process of living with DM.

Participants seem to find, in the groups, strategies of support and acquisition of experiences, which generate well-being and greater confidence in dealing with the disease. Some posts assume a more welcoming posture, triggering their experience to comfort other participants in moments of anguish or doubt a word of comfort in a moment of despair and tension. Others are more concerned with the clinical dimension and respond to doubts and questions from the knowledge they have developed from the practical experience of living with the disease.

In general, they sustain their recommendations in the biomedical order, since they reiterate, in their speeches, the results obtained by medicine in the treatment of the disease, or the information validated by medical knowledge. The emotional support evidenced by the VCs in the analyzed posts plays a role that the doctor and medicine have failed to play welcoming, listening, and comforting people with diabetes. The fact of having lived what the other lived gives the poster legitimacy among his peers, which becomes a central actor in the initial process of adherence to therapy.

The findings of the study may contribute to the recognition that VCs can reveal gaps for a better approach to assistance, relationship with users, or care provided to them - which suggests the development of activities in social media by the Brazilian health system. The use of online communities by people with diabetes has proven to be complementary to face-to-face follow-up in health services and seems to fill a gap that provides tacit knowledge not readily available in the clinical environment. In these places, horizontality is the guide for interaction and freedom for the expression of aspects perhaps unspoken in institutional spaces, which can, there, be expressed, reflecting on improvements for a comprehensive care.

The limitations of the study are related to the subjectivity of the researchers in the content analysis. To reduce interpretation bias and ensure the credibility and reliability of the data analysis, it was used the validation by three researchers in a process of mutual checking. Even though we sought objectivity in interpreting the data, since we analyzed only three virtual communities, the findings cannot be generalized.

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<sup>&</sup>lt;sup>a</sup> Since this is a very recent area of knowledge, the translation of some terms may make it difficult to understand. For example, although in Portugal the word mouse is used, in Brazil the Anglicism mouse is preferred to designate the pointer interaction device on the computer. We preferred to use more classical terms of the area to precisely designate the concepts that were initially described in English, however, still respecting the official Portuguese language standard, highlighting the terms that have not yet been widely incorporated into dictionaries.