







## The expert patient's contribution to the empowerment of people with diabetes mellitus\*

Contribuições do paciente especialista no empoderamento de pessoas com diabetes *mellitus*

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### RESUMO

**Objetivo:** desvelar as contribuições do paciente especialista no empoderamento de pessoas com diabetes *mellitus*. **Métodos:** estudo qualitativo, que compreendeu três comunidades virtuais abertas com postagens públicas, em língua portuguesa, voltadas para a discussão do diabetes *mellitus*. Os núcleos de sentido foram identificados por meio de nuvem de palavras, com mútua checagem, entre três pesquisadores utilizando-se da análise de conteúdo. **Resultados:** as interações evidenciaram preocupação com a dimensão clínica da doença e o caráter acolhedor do sofrimento e das angústias. Foi observado, também, que a convivência com o diabetes propicia o saber sobre a doença, tornando essas pessoas propagadoras do conhecimento e garantindo a sua participação no processo de tratamento. Ademais, os diálogos propiciados pelo ambiente *online* podem contribuir para a promoção da saúde, facilitando a compreensão sobre aspectos inerentes ao diabetes. **Conclusão:** os pacientes especialistas se disponibilizam a responder aos questionamentos baseados no conhecimento adquirido com a experiência do adoecer, sustentando suas recomendações no atendimento e nas recomendações recebidas durante o tratamento. **Contribuições para a prática:** espera-se que os resultados possam contribuir para o reconhecimento e valorização de novas abordagens na promoção da saúde e do autocuidado para pessoas com diabetes, como as comunidades virtuais.

**Descritores:** Diabetes Mellitus; Empoderamento; Paciente; Autocuidado; Redes Sociais Online.

### ABSTRACT

**Objective:** to uncover the contributions of specialist patients to the empowerment of people with diabetes mellitus. **Methods:** a qualitative study comprising three open virtual communities with public posts in Portuguese, aimed at discussing diabetes mellitus. The nuclei of meaning were identified through a word cloud, with mutual checking between three researchers using content analysis. **Results:** the interactions showed concern about the clinical dimension of the disease and the welcoming nature of suffering and anguish. It was also observed that living with diabetes provides knowledge about the disease, making these people propagators of knowledge and ensuring their participation in the treatment process. Furthermore, the dialogues provided by the online environment can contribute to health promotion, facilitating understanding of aspects inherent to diabetes. **Conclusion:** specialist patients are willing to answer questions based on the knowledge they have acquired through the experience of becoming ill, supporting their recommendations in the care and recommendations received during treatment. **Contributions to practice:** it is hoped that the results can contribute to the recognition and appreciation of new approaches to health promotion and self-care for people with diabetes, such as virtual communities.

**Descriptors:** Diabetes Mellitus; Empowerment; Patients; Self Care; Online Social Networking.

## Introduction

Cyberculture refers to the phenomenon of technological social convergence, which allows digital means of communication to be established in people's lives and in their community formations. For this reason, technological changes influence the way people conceive of the health-disease process, as well as the user-patient relationship, with implications for the process of managing, caring for and socializing healthcare<sup>(1)</sup>.

From this perspective, there has been a significant increase in behaviors aimed at sharing experiences and knowledge, facilitating the formation of Virtual Communities aimed at different scenarios, including population health. In this scenario, expert patients, who have extensive knowledge about their medical conditions, treatments, and symptoms, and are proactive in sharing their experiences and promoting knowledge and the prevention of illnesses, have stood out<sup>(2)</sup>.

Expert patients are defined as users who take an autonomous stance in the care process through self-care, capable of developing and/or improving skills in managing their health condition and in digital empowerment, enhancing lifestyle performance linked to the virtual environment, being a safe source of information. Based on an understanding of the expert patient's role, health professionals will be better able to establish cooperative contact, with the aim of understanding and discussing the patient's main concerns, priorities, and questions, positioning them as the main person responsible for managing care so that they feel confident in their abilities and able to promote help in their various contexts<sup>(3)</sup>.

An expert patient is chosen based on their critical and reflective capacity and their experience of the disease. This choice is made by the adherence of peers, who are also sick, to follow their teachings, or even by the indication of health professionals to identify a patient who meets the specific recommendations of their treatment and commits to sharing their experiences<sup>(4-5)</sup>.

Empowerment refers to inner strength, self-control, self-confidence, independence, a way of living life, considering one's own values and the ability to fight for one's rights, and can be obtained through online communities<sup>(2)</sup>. Therefore, the empowerment provided through virtual communities reflects the participation of expert patients due to the lack of professionals in these spaces, which is why this relationship between self-confidence and health control should be investigated<sup>(2,6-7)</sup>.

The use of virtual communities by people with chronic illnesses is already a reality for seeking knowledge and emotional support and is currently considered to be an alternative tool that can empower the population with chronic diseases and their families, especially people with diabetes mellitus<sup>(6-7)</sup>. When patients are diagnosed with diabetes, they must adapt to a new and often stressful life routine, requiring health professionals to implement innovative strategies. In this sense, learning further information about the health condition requires a great deal of complex care and longitudinality in the perception of the health disease process<sup>(8-9)</sup>.

In this way, the use of virtual communities on social media such as Facebook can provide dialogue about the needs of individuals, facilitating shared care, focusing on priorities defined through negotiation, making adaptations so that they can be easily incorporated into their daily lives<sup>(1,6-7,10-11)</sup>.

This proposition is based on other antecedents, such as access to information and the internet, given the predisposition of a critical sense because of not taking for granted the information transmitted in health institutions. It should also be noted that the use of virtual communities by groups of people with diabetes has provided knowledge, skills, confidence, and self-management of the disease<sup>(10-11)</sup>.

A previous study indicated that online communities provide specialized support for people with diabetes<sup>(7)</sup>. Thus, considering virtual communities as a means of global information, including in the context of people with diabetes, this study aimed to uncover the contributions of specialist patients to the empowerment of people with diabetes mellitus.

## Methods

This was a qualitative study, whose study scenario included the virtual communities on the Facebook platform focused on diabetes, more precisely, the three most relevant ones, considering the number of participants and posts.

To find the communities, two researchers used the keyword “diabetes mellitus”. It should be noted that, to access the communities, the researchers were connected to the chosen social media accounts. Subsequently, in the feed on the home page, the identifier “groups” was selected, and the keyword “discover” was entered. On entering the communities, the number of participants was noted.

The following criteria were used to include the groups: open communities (with no need to identify the researcher, allowing for dynamic observation and data collection), with public posts, in Portuguese, focused on the discussion of diabetes mellitus, with the largest number of participants and posts. Communities with commercial or institutional profiles and no recent contributions were excluded.

The data was collected in January and February 2020 and comprised 8,081 posts and 4,564 comments published by 256,400 members of the communities during 2018 and 2019. The data was extracted using an instrument created by the authors that contained (name of the community, total number of participants, name of the profile/patient expert, posts about diabetes mellitus). In this way, all the posts and comments from the communities were collected using a script for the construction of the matrix text, which was used to read the posts and comments in their original contexts (the script was developed by three external collaborators with experience in the subject). The script was derived from a doctoral thesis and was constructed by a research group in which the study's proponent was a member. The guiding questions dealt with issues involving the participation of expert patients in virtual diabetes communities: What content is expressed in virtual diabetes communities? What is the position of an expert patient on the process of becoming ill and

treatment? How does the expert help other peers? What information can be accessed by the community?

After collection, the matrix text was organized into a filtered text by removing articles, conjunctions, prepositions and other grammatical elements with limited semantic value and correctness according to the cultured norm. This stage was supported by three collaborators who organized the matrix text and then had its content checked by a specialist in the field of linguistics.

To operationalize the content analysis, we used the method consisting of thematic content analysis in three stages: pre-analysis; exploration of the material and treatment of the results; and inference and interpretation. In the pre-analysis stage, the text was organized in Microsoft Word to purify the textual content. On the second stage, categories, recording units and context were chosen. Finally, critical reflection and treatment of the results with inference and interpretation<sup>(12)</sup>.

After organizing the filtered text, a Word Cloud was created to operationalize the content analysis, using publicly accessible algorithms associated with the Wordart.com website. The word cloud shows the most frequent words in the text, making it possible to relate the feelings printed and disseminated in qualitative studies<sup>(13)</sup>. This category of analysis was used when it was realized that the presence/absence of terms generates factors of meaning in the analysis, given the creation of “nuclei of meaning”, of a matrix registration unit<sup>(12)</sup>.

It should be noted that, to maintain the anonymity of the users, each post included was coded with the term “Post”, followed by an Arabic numeral, according to the order in which it appeared.

The data was analyzed according to its content, based on the stages of organization, coding, categorization and inference of the content of the posts. First, we identified the nuclei of meaning, which represented the most frequent discussions, extracted according to the original text (matrix) with highlighted words, with the frequency of records pointing to the most significant meanings for the purposes of the



sense of empathy with the questions posed, using positive phrases: *What a good thing to know! I'm going to ask my doctor about this medicine* (Post 56). *When I feel like eating sweets, I try to eat a piece of fruit, which deceives the desire to eat sweets, or I drink tea, which seems to give me a feeling of satiety. Do this and let me know if it works for you too* (Post 61). *All you must do is add fiber to the tapioca dough, I make it with oat bran, so you can eat the tapioca we want so much and avoid blood sugar spikes* (Post 217).

Knowledge derived from experience seems highly reliable among group members, especially those with a recent diagnosis, who receive clarification from people who live the routine of the disease and treatment, who have the skills to suggest strategies on how to solve some health demands: *I'm so grateful to have discovered this group, which has people who have been through everything I'm going through and who have helped me to reduce the burden of this disease. You're wonderful people!*" (Post 102). *This group is helping me a lot, I've been able to ask questions about many things, and it's always worked. I thank each one of you* (Post 133). *Now that I've understood that it's a diabetic's right, I'm going to go after my rights and demand that the Health Department provide me with the strips, I can't afford to buy them, and it's my right* (Post 14).

In this context, the informational recommendations made empowerment evident, as the members' posts responded to questions on the subject with propriety, addressing therapy and the reduction of signs and symptoms, also demonstrating the experimental learner's adherence to biomedical treatment, as can be seen below: *We must comply with the doctor's recommendations to control our diabetes well. Those who don't follow what they recommend and overdo it end up acquiring problems with their eyesight, kidneys, and heart, above all. Take care of yourselves* (Post 06). *Avoid exercising during the peak of insulin action and don't apply insulin to areas of the body that will be very demanding during physical activity, as the absorption of insulin will be greater and could cause hypoglycemia during exercise. Be careful* (Post 253). *Guys, no type of tea cures diabetes, many colleagues here in the group have said that they drink tea made from cow's foot, stonebreaker, insulin leaf, cinnamon, but I've investigated this and researched... I've noticed that studies show that in some cases, there is a reduction in blood sugar, but it's so insignificant that it's not worth consuming, mainly because if they are consumed in excess, they can cause poisoning* (Post 23).

It should be noted that the terms: "you have to comply", "those who don't", "end up acquiring problems", "avoid", "don't apply", "be careful", "I've looked into this" and "I've seen what the studies show" demonstrated the certainty and propriety of the message they were trying to convey.

## Category 2: Patient expert of motivational and religious/spiritual behavior

The posts take on an optimistic outlook in the face of having to live with the disease and undergo treatment, with acceptance of the treatment being linked to a better quality of life with the disease: *People, having diabetes doesn't mean that we will have our dreams interrupted, for that, we need to plan, having diabetes goes beyond taking insulin, practicing physical activity and dieting, taking care of our mental health and controlling stress is also fundamental for our health. I've been diabetic for 25 years, I have no sequelae and I live well with it. Let's have faith and cling to God, because only he can give us the strength to go on and face the difficulties* (Post 307).

Congruently, religion is evidenced as a spiritual foundation for people living with diabetes, serving as social support for patients and their families. Although the participants have already undergone biomedical treatment, they link healing to an immaterial condition, seeking meanings and explanations that go beyond the physical dimension, looking to religious and spiritual involvement as a method of fighting diabetes and a refuge to motivate themselves and continue treatment, as noted below: *Believe in Jesus, only he can work miracles, so have faith! We're going to win* (Post 77). *After I found out I had diabetes, I joined the church and started attending more often. After that, a lot changed in my life, I feel stronger and surrounded by positive thoughts, which I only found there. That's why I'm sending this message to anyone who is discouraged: seek God, and he will be an extra support in the treatment of diabetes. Believe it!* (Post 139).

It was clear that online communities were not only a means of interacting, supporting, and encouraging peers, but also an informal support network. They also strengthened the bond, articulating know-

ledge inherent in care, contributing to diabetes management and favoring the overcoming of adversity, as exemplified below: *I want to share my experience with you so that you can be careful and not go through what I went through. If I had another chance, I'd do everything differently, but unfortunately that's not possible. Young people can also have complications, and I did, I'm on hemodialysis. I played with diabetes. I want to take more care of myself, think more about tomorrow. Furthermore, I'm grateful to God for not giving up the fight. There are days when I'm at my worst, but with the help of God, friends, and family, I've gained the strength to carry on. Today, I can see hemodialysis in a lighter light, but I don't want any of you to reach that point. Be strong and live well today so that you don't have problems in the future. The group is also a place to socialize about good and bad things, but things that have meaning in the lives of each one of us* (Post 46).

## Discussion

It stands out in this study that the expert patient has a connotation of clinical and motivational behavior. This represents the potential application of this agent in the field of virtual communities, especially given the lack of health professionals in this environment and the need for reliable information, mediated by experience<sup>(2)</sup>. The presence of health professionals in this space is a practice that is not yet common, but which can be beneficial for clinical care, especially by reducing distances, speeding up information and reducing costs for areas that are difficult to access. However, caution should be exercised and we should encourage the creation of virtual communities of practice<sup>(15)</sup>.

The experiential learner learns through concrete experience and reflection, which can occur throughout the development of the clinical course of the pathology. It should be noted that this experiential learner takes on a prominent role in promoting the direct engagement of other individuals in practice by causing reflection, using analytical tools (research, information from experts and meaningful learning), allowing others to better understand what has happened and retain the information for a longer period,

while also being able to pass on their knowledge, as observed in this study<sup>(16)</sup>.

From this perspective, it is important that the training of patients with chronic diseases is supported by health professionals so that they can serve as support for other patients and encourage the exchange of experiences. However, it should be emphasized that the autonomy of information from expert patients cannot replace professional conduct and effective guidance, since the condition of the disease is not a sufficient criterion for disseminating correct information about the pathology<sup>(17)</sup>.

As mentioned above, enabling patients to understand their health condition allows for the effective dissemination of care, based on the professional-patient relationship, which allows for adaptations and, consequently, effective patient participation in health decision-making<sup>(18-20)</sup>. From this perspective, health education is necessary to promote the patient's relationship with managers and professionals, so that this relationship can bring about significant changes in services<sup>(20)</sup>.

It is important to train specialist patients because when they become more socially aware, they will use services responsibly, resulting in a reduction in unnecessary demands and health resources<sup>(21)</sup>. On the other hand, despite the challenge of educating specialist patients, this study highlights the current need for changes in the health system, to make the relationship between patient and professional more effective, which consequently favors self-care<sup>(22)</sup>.

Therefore, although no studies were found in the Brazilian context focusing on specialist patients, the literature shows that nursing professionals also need appropriate training to be able to promote the development and instrumentalization of patients, in line with this new global reality<sup>(23)</sup>.

To achieve this, it is necessary to learn how to guide expert patients' searches, advising them on the evaluation of the sites searched, safety issues and the veracity of the information, as well as how to use this knowledge to improve the delivery of healthcare

and the professional-patient relationship<sup>(19)</sup>. This relationship must be based on mutual trust and sincerity between professional and patient to be effective, as the literature has already shown that in its absence, individuals may seek information from unreliable sources and, consequently, generate a false expert<sup>(24)</sup>.

Certain chronic diseases, including diabetes, are still marginalized and/or ignored by both society and the public sphere, reinforcing stigma and the need for social support. On the other hand, the specialist patient because they know how to deal with and live with adversity, by offering support, without judgment and in a timely manner, can help ease the burden of managing their chronic condition<sup>(3)</sup>. Even so, a paradigm shift can be seen, in which health care leaves the biomedical model and takes a patient-centered approach, which actively participates in the care process, becoming a partner in health care by discussing and sharing knowledge, demonstrating that the specialist patient can redefine the professional-patient relationship, because of new agreements in care that will occur in a more specific, symmetrical, and egalitarian way<sup>(25)</sup>.

The findings show the participation of expert patients as promoters of care by identifying an empathetic language that is easy to understand, linked to experience and committed to elucidating doubts that may arise in the networks and possible shared fallacies. An informal and educational network is then formed, making it easier to identify the warning signs of the disease and the clinical manifestations that come with having diabetes.

In the posts, it was clear that patients' knowledge permeates information attributed to them by health professionals and by their experience with the disease. In this way, even though their guidance comes from their own care, they translate scientific knowledge in a simple and understandable way for their peers, demonstrating their empowerment and leadership, since this information shared in virtual communities can serve as a coping and support resource<sup>(26)</sup>.

By acquiring expertise in their own condition

and actively participating in their own treatment, specialist patients are more confident in managing their condition, treatment, and lifestyle<sup>(2,6-7,10)</sup>. Such ownership of the subject is also notorious when it comes to teas consumed by those with diabetes, with users denying their efficacy, where this information is in line with scientific literature.

It should therefore be noted that knowledge derived from practical experience, however biomedical in origin, has the capacity to translate scientific knowledge, passing it on to others in a clear, simple, and understandable way, which demonstrates the benefits of empowering knowledge<sup>(27)</sup>. In this sense, the study in question observed that the expert patients motivated the participants in the groups to check their blood glucose, gave suggestions for recipes that could be used, and warned about the dangers of insulin leaf tea, among other actions.

An expert patient is one who is empowered in their health issues. In this sense, by obtaining reliable information from professionals, they can facilitate health information and disseminate this content. However, lifestyle changes, disease monitoring and other nuances of this practice should be accompanied by health specialists, contributing to the promotion of self-care and the improvement of health status, since it increases the user's ability to question, inform themselves and draw conclusions to adopt better disease management<sup>(2)</sup>.

Considering care perceived among the experts, a network of care was strengthened, reducing gaps, and strengthening bonds<sup>(7)</sup>. It was possible to see posts about emotional and spiritual support, and it became clear that those who shared their experiences were not only trying to express their feelings, but also to help their peers with coping strategies to manage the disease, which had a huge impact on their lives. In this way, the stories shared, especially between peers, helped to provide emotional support.

Thus, the emotional support shown in the specialist patients' posts highlighted a behavior that health professionals should practice and exercise, which is

to welcome, listen to and comfort people with diabetes, as well as being co-participants in the active process of disease prevention and health promotion in all care environments.

An important finding of this study is related to the doubts and, consequently, the exchanges that took place in the communities surveyed, where the lack of a bond between the health team and the patient with diabetes was evident, as some of the doubts identified should have already been clarified during health care because what was not explained leads users to seek information in alternative places, in this case, in virtual spaces, where the person has the need to discuss with peers the alternatives available to resolve their complaint<sup>(7,28)</sup>.

In category two, it was evident that motivating and religious/spiritual behavior can improve the condition and favor acceptance of living with diabetes, considering that in moments of sadness, patients seek strength and comfort through faith. It was possible to identify a high level of gratitude for the posts that referred to faith and brought up religiosity as a way of facing the conflicts arising from living with the disease and maintaining a social support network, in this case, the virtual community<sup>(6)</sup>.

It was identified by consulting the literature that the provision of social support during the course of chronicity in online environments promoted both mutual support and adherence to treatment, by favoring welcoming, requests for help or during the exposure of outbursts and frustrations, corroborated by the present study, emphasizing these findings<sup>(1,6-7,10-11)</sup>.

The limiting factors of diabetes have a negative impact on patients' lives, in which health professionals, even if they are specialized, are unable to measure the associated disabilities. At this point, the posts played a decisive role, since the testimonies were able to encourage other people in the same situation, such as the posts that addressed the importance of current professional recommendations for controlling the disease, linked to the emotions and experience of those who undergo/are undergoing adversity. This high-

lights their commitment to caring for themselves and others, as illustrated in this study.

It should be noted that although specialist patients indicated life-saving procedures, they also recommended to other participants the need to seek appropriate professional assistance, demonstrating the need for strategies that include health professionals in this discussion space<sup>(7)</sup>. In this study, health professionals were not identified in the virtual communities, which is an important gap for information security, continuity of care and strengthening of care.

Nowadays, there is a lot of evidence that encourages the implementation of person-centered approaches, such as shared decision-making, which can favor the patient's experience of illness, have an impact on the quality of care and improve the results to be achieved<sup>(29)</sup>. Therefore, it is necessary to build care collectively, including the patient in shared decisions, making them an active participant in the commitment mediated by the multi-professional team<sup>(26)</sup>. In this way, the recognition of effective conduct requires the guarantee of fundamental principles of investigation, evaluation, and proposition about health conditions, resulting from the ability of their peers to associate information, apply it in their daily lives and safely inform other people with diseases, a model that is applicable and even recommended by the guidelines of the Brazilian Unified Health System<sup>(24)</sup>.

Finally, it highlights that the formation of the expert patient does not necessarily imply a break with the continuity of health care or the need for clinical follow-up, but rather favors the expansion of a care network that can reach people who sometimes don't have access to specialists and can be directed to a flow of information.

As such, there is a need for research around virtual communities and expert patients, with a focus on continuing education and the inclusion of health professionals in its debates. The incorporation of advice mechanisms, supported by feedback, evaluation, and information veracity guarantee mechanisms, is encouraged, and is a potential field for the use of artifi-



cial intelligence. The professional-patient relationship must therefore be ensured, and self-care links strengthened.

## Study limitations

This refers to the fact that the study did not analyze posts and comments in closed groups. As such, the discussions analyzed may not represent all the interactions in the diabetes scenario.

## Contributions to practice

It is hoped that the results will contribute to the recognition and appreciation of new approaches to health promotion and self-care, such as virtual communities, since it was possible to observe that these communities can intervene positively in the lives of patients with chronic diseases, more specifically in patients with diabetes. In addition, it demonstrates the need for reflection, especially on the preparation of health professionals to deal with these new social actors, who are specialist patients, training them in health care and encouraging health promotion strategies in the context of diabetes.

## Conclusion

It was found that the specialist patients were willing to answer questions based on the knowledge they had gained from the experience of becoming ill, in other words, they based their recommendations on the care and recommendations they had received during treatment. They were welcoming when explaining their experiences, aiming to strengthen other members in times of distress or uncertainty, and encouraged self-care and adherence to treatment because they have experienced what others are experiencing, checking posts, ensuring legitimacy for peers, favoring the validation of expert patients with greater life/disease experience, by sensitively perceiving the

transformations in other people due to illness, and fostering help mechanisms, reaffirming their position and ensuring credibility in digital communities through empowerment.

## Authors' contribution

Conception and design or data analysis and interpretation: Alencar DC, Vasconcellos-Silva PR.

Writing of the article or relevant critical review of the intellectual content: Alencar DC, Alencar AMPG, Ibiapina ARS, Campelo LLCR, Cruz Neto J.

Final approval of the version to be published: Alencar DC, Alencar AMPG, Ibiapina ARS, Campelo LLCR, Cruz Neto J, Vasconcellos-Silva PR.

Agreement to be responsible for all aspects of the work: Alencar DC, Alencar AMPG, Ibiapina ARS, Campelo LLCR.

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