

Perspective of young people with diabetes on educational intervention on Facebook®

Perspectiva de jovens com diabetes sobre intervenção educativa na rede social Facebook®

Perspectiva de jóvenes con diabetes sobre intervención educativa en la red social Facebook®

Evelin Matilde Arcain Nass¹

Sonia Silva Marcon¹

Elen Ferraz Teston²

Pamela dos Reis³

Hellen Emília Peruzzo¹

Lorenna Vicentine Coutinho Monteschio¹

Aline Gabriela Bega¹

Maria do Carmo Fernandez Lourenço Haddad⁴

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Corresponding author

Evelin Matilde ArcainNass

<https://orcid.org/0000-0002-5140-3104>

E-mail: evelinmarcain@gmail.com

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Abstract

Objective: To understand the perspective of young people with Diabetes Mellitus on the participation in a self-care encouragement group on Facebook®.

Methods: A descriptive and exploratory study with 35 young people with type 1 Diabetes Mellitus who participated in a group on Facebook®. The data were collected by a semi-structured interview and after was submitted to Thematic Content Analysis.

Results: Three categories were identified: *conventional care offered to young people with Diabetes Mellitus; advantages of using Facebook® for healthcare innovation; and Spirit of community and strengthening of bond from the group on Facebook®*. These show that, from the perspective of young people with diabetes, participation in the group favored the development of spirit of community and strengthening of bond between peers, besides helping to accept the disease and to form a support network. In addition, there was a positive assessment of participation, as young people expressed the wish that other groups with similar characteristics be implemented.

Conclusion: Educational actions on Facebook® are well accepted by young people and can be an important strategy to bring them closer to health services and help them in their self-care actions.

Resumo

Objetivo: Aprender a perspectiva de jovens com diabetes *mellitus* sobre a participação em um grupo de estímulo ao autocuidado na rede social Facebook®.

Métodos: Estudo descritivo e exploratório, junto a 35 jovens com diabetes *mellitus* tipo 1 que participaram de um grupo no Facebook®. Os dados foram coletados por meio de entrevista semi-estruturada e após submetidos à análise de conteúdo, modalidade temática.

Resultados: Foram identificadas três categorias: *assistência convencional oferecida aos jovens com diabetes mellitus; vantagens da utilização do Facebook® para inovação da assistência à saúde, e espírito de comunidade e fortalecimento a partir do Facebook®, as quais mostram que, na perspectiva de jovens com diabetes, a participação no grupo favoreceu o desenvolvimento do espírito de comunidade e o fortalecimento de vínculo entre os pares, além de auxiliar no processo de aceitação da doença e na formação de uma rede de suporte. Além disso, observou-se avaliação positiva sobre a participação, uma vez que os jovens manifestaram o desejo de que outros grupos com características semelhantes fossem implementados.*

Conclusão: Ações educativas na rede social Facebook® são bem aceitas por jovens e pode constituir uma estratégia importante para aproximá-los dos serviços de saúde e auxiliá-los nas ações de autocuidado.

Resumen

Objetivo: comprender la perspectiva de jóvenes con diabetes *mellitus* sobre la participación en un grupo de estímulo al autocuidado en la red social Facebook®.

Métodos: estudio descriptivo y exploratorio, con 35 jóvenes con diabetes *mellitus* tipo 1 que participaron en un grupo de Facebook®. Los datos fueron recopilados por medio de entrevista semiestructurada y luego sometidos al análisis de contenido, modalidad temática.

Resultados: se identificaron tres categorías: *atención convencional ofrecida a los jóvenes con diabetes mellitus, ventajas de la utilización del Facebook® para innovación en la atención a la salud, y espíritu de comunidad y fortalecimiento a partir del Facebook®*. Estas categorías demuestran que, en la perspectiva de jóvenes con diabetes, la participación en el grupo favoreció el desarrollo del espíritu de comunidad y el fortalecimiento del vínculo entre los pares, además de ayudar en el proceso de aceptación de la enfermedad y en la formación de una red de apoyo. Además, se observó una evaluación positiva sobre la participación, dado que los jóvenes manifestaron el deseo de que se implementen otros grupos con características semejantes.

Conclusión: acciones educativas en la red social Facebook® son bien aceptadas por los jóvenes y pueden constituir una estrategia importante para acercarlos a los servicios de salud y ayudarlos en las acciones de autocuidado.

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¹Universidade Estadual de Maringá, Maringá, PR, Brazil.

²Universidade Federal do Mato Grosso do Sul, Campo Grande, MS, Brazil.

³Instituto Adventista Paranaense, Ivatuba, PR, Brazil.

⁴Universidade Estadual de Londrina, Londrina, PR, Brazil.

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Introduction

Diabetes Mellitus (DM) is one of the fastest growing chronic conditions in the world and constitutes an important public health problem due to the severity of its complications. For effective management and good glycemic control, it is necessary for people affected to be aware of their etiology, treatment and self-care actions, understanding their purpose and importance.⁽¹⁾

Engaging people in self-care practices depends on cultural, educational, and also on skills, individual limitations, life experience, health status and available resources.⁽²⁾ In this sense, the efficient management of the disease in young people can be facilitated through educational activities that value their individual capacity and provide access to information and guidance.

Health professionals, therefore, need to involve young people with DM in educational activities, as they can help them cope with difficulties, improve health behavior, and keep disease under control. Nevertheless, these need to be differentiated from those traditionally offered.⁽³⁾ Insertion of differentiated educational practices with understandable and contextualized language allows young people to have a better understanding of the clinical picture and the importance of treatment and self-care actions.⁽⁴⁾

However, the low participation of the healthy young or those with a chronic condition in activities proposed by health services is a challenge and this interferes with the lack of planning and performance of health actions. In these cases, the internet presents itself as a possible tool to be used, since social networks have changed the nature of relationships between people, and since its inception attracted millions of users, who integrated them into their daily lives and turned it into an important communication platform.⁽⁵⁾

Among online platforms, Facebook® is the most prominent. Brazil is the second country with the largest number of users, behind only the United States. Facebook® is considered a media tool that allows various ways of learning - creation of discussion groups on relevant subjects allows the exchange and construction of knowledge.⁽⁵⁾

Internationally, the use of digital platforms as a tool for health education in patients with DM has been the object of several studies, which has highlighted the benefits of this use.⁽⁶⁻¹¹⁾ For example, it has been identified that an important percentage - about 30% - of patients with 1DM and 2DM use Facebook® as the first source of information about the disease.⁽⁵⁾

This tool has been used to share personal clinical information, request specific disease guidance and feedback, and also receive emotional support.⁽⁷⁾ A study identified that 40% of the patients and relatives surveyed, participants of a group to share experiences and information about DM without official participation of health professionals, reported having benefited from the information and 99% did not suffer any harm by following the group's advice.⁽⁸⁾

A study conducted with 56 students aged 14-23 in a regular group and Internet group, used Facebook® and Skype® as alternatives to regular clinical visits. Both groups showed improvement in disease control, with no difference in acute complications (diabetic ketoacidosis and severe hypoglycemia events), total daily insulin dose and weight change at the end of 12 months of intervention.⁽⁹⁾ The positive factor of Facebook® in the improvement of glycemic control in adolescents is attributed to the fact that it facilitates interaction among young people and exchange of experiences.⁽¹⁰⁾

In Brazil, a study carried out in Rio de Janeiro State evidenced the positive impacts of social media on the interpersonal relationship between doctor and patient, on chronic condition self-management and empowerment for self-care actions development. Ease of access to information, exchange of experiences and social support favored by online connection were highlighted.^(11,12)

Finally, the results of studies point to the possibility of health professionals to use social media to provide support for the education of patients with DM and their caregivers, disseminating useful and safe knowledge and information related to disease treatment and control.^(7,11)

Given the above and considering the high prevalence of 1DM, there is complexity in the management of this condition, especially by young people. There is a low demand for health services from

them,⁽¹³⁾ making it imperative to develop actions that overcome traditional care. To do so, an alternative would be the use of social media as a tool for education and monitoring of the health condition, since they are part of the daily life of young people, and even of health professionals. Moreover, it was defined as the objective of the study to understand the perspective of young people with DM on participation in a self-care encouragement group on Facebook®.

Methods

This is a descriptive and exploratory study conducted with young people with DM who participated in an educational intervention on Facebook®.

The participants of the intervention were intentionally selected from a relationship provided by the Municipal Health Office of the city of Maringá, Paraná State, with the name of the user and their mother, date of birth, SUS (Brazilian Unified Health System – *Sistema Único de Saúde*) card number and illness. The inclusion criteria were to be between 18 and 29 years old, have DM, reside in the municipality, have an active Facebook® account and access the social network at least three times a week. Nevertheless, the exclusion criteria were to have non-existent telephone number and not to be localized in at least five attempts in diverse days and times.

The invitation to participate in the study was done by telephone contact (number located on the online register), at which time they were informed about the purpose of the study and type of participation desired, and investigated the use and frequency of access to Facebook®. For those who accepted the invitation, a personal meeting was scheduled on the day, time and place of their preference.

Of the 99 individuals included in the study, only 35 were included in the study, since 32 individuals did not meet the inclusion criteria (no diabetes or age above 29 years), 12 were not located and 20 did not participate, alleging lack of time or interest.

The inclusion in the group “Diabetes: let’s talk?” Only occurred after personal contact, when it was clarified the rules of postings and operation

of the group. For effective inclusion, it was necessary for the young person to add the researcher to his Facebook account®. At the same time, data on socio-demographic characteristics were also collected. The Self-Efficacy Diabetes Scale - Short Version (measures psychosocial self-efficacy for self-care management in DM)⁽¹⁴⁾ and the *COMPASSO* protocol (allows the individual to identify the barriers in their adherence to self-care practices in DM) were used.⁽¹⁵⁾ In this communication, data from these two tools will not be addressed.

The group worked in June and July 2017 with the purpose of disseminating specific content about DM, promoting the exchange of experiences and dialogue between the young people and between them and the researcher. It was developed in the private format and allowed participants to view, comment, and post. Only the researcher could include new entrants, terminate activities and remove the group from the social network, according to the platform’s commands in order to maintain the group’s composition and objectives.

The researcher’s role in the group was to encourage participants to practice self-care by posting videos, informative texts and clarifying doubts. The tools applied in the personal contact and the comments of the registered participants in the group subsidized the researcher’s posts. The main barriers identified to address the contents were: difficulty following the food plan, performing physical activity and making correct use of medicines.

Data regarding participation in the group were collected in August 2017 by a self-administered online questionnaire prepared by the researcher based on the study objectives. It consists of six open-ended questions that addressed young people’s perspectives on educational practices developed by health professionals to guide self-care and group functioning.

The data were entered into the Microsoft Word® program and submitted to the Thematic Content Analysis, following the three pre-established steps: pre-analysis, material exploration and data categorization.⁽¹⁶⁾ Three categories emerged: *conventional care offered to young people with Diabetes Mellitus; advantages of using Facebook® for healthcare innova-*

tion; and *Spirit of community and strengthening of bond from the group on Facebook*[®].

Brazilian and international research ethics norms with human beings were respected (*Certificado de Apresentação para Apreciação Ética - Certificate of Presentation for Ethical Consideration* (CAAE: 62834816,4,0000,0104)/Research Ethics Committee; Opinion 1,963,605).

Results

The mean age of participants was 21 years. The majority were female (21), single (34) and had already completed or higher education degree was in progress (21). All participated in the activities until group closure. One of the young people had already participated in educational activities about childhood diabetes and three were enrolled in related pages on Facebook[®].

From the content analysis, three categories emerged, whose deponents and examples of extracts from the speeches that compose them are described in chart 1.

Chart 1. Categories presentation

Participant	Speeches Excerpts	Category
F19 24 years	<i>In the health center they have already told me to take part in the meetings they promote for diabetics, but I cannot participate because of work.</i>	Conventional care offered to young people with Diabetes Mellitus
F23 16 years	<i>I know there are meetings with lectures, tips and guidelines, but I do not like to participate in this type of activity, I am very shy and do not like to speak in public.</i>	
M18 24 years	<i>I took part as a child of a group that promoted meetings and lectures. But I remember going a few times, I found it boring ... I had no other children or young people.</i>	
M5 24 years	<i>I participate of another group on Facebook[®], but in that we only deal with the exchange of inputs, this I found more complete.</i>	Advantages of using Facebook [®] for healthcare innovation
F31 19 years	<i>I already followed a page on diabetes on Facebook[®]. I find the quickest and most practical way to have access to information, and the content stays there, and you can review as many times as you want.</i>	
M10 22 years	<i>The fact that the group is online made it much easier, I always have my Facebook[®] open, so I saw it fast when I had something new.</i>	
F16 24 years	<i>I felt free to participate at any time and from anywhere, I did not have to stop doing something or move to a specific place with date and time.</i>	
F14 17 years	<i>I had been advised when to use insulin, but I only followed all the steps after watching your video and understand why each step.</i>	
F3 22 years	<i>After I was instructed, I started to change the insulin application site. I understood that applying constantly in the same place creates a barrier in this area, disrupting absorption.</i>	
F26 20 years	<i>It was good to remember that there are more people my age in situations that are the same or similar to mine.</i>	Spirit of community and strengthening of bond from the group on Facebook [®]
F12 19 years	<i>It was great to be part of a group where people live with the same difficulties as I do.</i>	
M29 23 years	<i>I thought it was nice to be able to talk to someone who knows what's going on, because it shows that you're not alone.</i>	
F22 18 years	<i>I saw the group as a support. When I had a problem with the driver's license for diabetes, the first thing I thought was to post there in the group to see if anyone had had this problem and how it was resolved.</i>	
F3 22 years	<i>I thought it was cool how the group happened, I think they should create more groups on Facebook[®].</i>	
M20 19 years	<i>The next groups should have a longer duration, I found two months little.</i>	

Discussion

Among the study limitations, the fact that the educational intervention was carried out with a limited group of young people and for a limited time was highlighted. In any case, the results allow to affirm that the formation of groups in social networks, with the purpose of encouraging self-care practices, can constitute an important strategy to approach young people who live with some chronic condition to health services.

When talking about the experience of participation in the group, the young people referred to the conventional care offered in primary care. This is characterized by individualized consultations and educational activities in groups by "disease", that is, brings together people of all ages with the same health problem. They said that the schedules of these activities coincide with the work shifts, involve traditional methodologies and are little attractive.

It is observed that these results corroborate with the literature when portraying that the existence of difficulties in the access to health actions, as well as in their organization, are factors that contribute to the low demand of the young people for the Primary

Health Care services.^(13,17) Thus, care for people with DM is usually focused on face-to-face clinical meetings, medical and nursing appointments,^(3,14) and it is necessary to rethink and implement care strategies for individuals with chronic conditions that are attractive to young people.

Educational activities are presented as the best way to educate young people with DM about the importance of self-care.⁽¹⁸⁾ When these occur in a group, the benefits can be enhanced by allowing the exchange of experiences, redesign of conceptions and production of new knowledge.^(19,20) A study carried out in Portugal with 30 young people identified that they shared their experiences with greater ease in group activities, which highlights the benefits of these activities in living with diabetes.⁽²¹⁾

A systematic review study pointed out that in the case of diabetes, all forms of intervention including health education activities are beneficial, be it individual or in group, face-to-face, by telephone or the internet; be performed by professionals or between pairs of patients; daily, weekly or monthly, with or without the involvement of the patient's family, being in all formats.⁽²²⁾

Nonetheless, it must be considered that for young people, face-to-face meetings in conventional environments are not always attractive. The proof of this is that although the participants of this study were aware of the existence of educational activities, with face-to-face meetings at the health units, they did not feel encouraged to participate because of barriers such as location, time and methodology used in their conduction.

With regard to the category *Advantages of using Facebook® as a strategy for healthcare innovation*, it was observed that participants assume that the advancement of technology has made social networks used for social interaction, search for related information health and exchange of inputs. They recognize that social media can be accessed quickly and practically, as well as enabling other activities to be carried out in parallel. They also point out that Facebook® can be an important and effective tool for health education and care, and it can raise awareness of the importance of correctly following care related to insulin use.

Regarding this, the fact that the study group took place on a digital platform made it easier to participate. This is because in this platform there are no financial, organizational or geographical constraints, in addition to the extent to which young people embrace this technology.⁽⁹⁾ Similar results were found in a study of 227 young people with 1DM residing in Northern Ireland and England, noting that the five most cited reasons for not participating in structured diabetes education programs were: “other things to do”, “lack of time”, “it was not possible to take a break from school, college or work.” They also reported having learned about diabetes from other sources and being able to cope alone with the disease.⁽²³⁾

In this sense, considering that digital genres are already part of the daily life of young people and that the new forms of communication are increasingly consolidated, it can be concluded that they can constitute educational tools of great value for health needs, especially for the younger audience. The increasing use of digital technologies suggests the adaptation of primary care with the aggregation of “electronic care” technologies.⁽²⁴⁾

A study carried out in the city of Fortaleza, Ceará State, with 35 adolescents, identified that this generation prefers virtual relationships because they feel more at ease and with more freedom to express their feelings. They assert that the fact that they are not physically close to information sources encourages them to ask questions and to search for health information.⁽²⁵⁾

Online communication impacts on society and influences people's lives, given the diversification and acceleration of information, accessibility and services that reach users. The collaborative environment, triggered by the ease of information exchange via the Internet, served as basis for technological evolution of virtual social networks.⁽²⁶⁾ On the other hand, the possibility of involving a larger number of participants, since there are no impediments related to temporal and spatial factors, besides the preservation of anonymity, are aspects valued by the young.⁽²⁷⁾

In this direction, a study conducted in a closed group on Facebook® with 52 young adults, North Americans, smokers, addressing knowledge and

prevention of diseases, showed active participation. Positive feedback on study procedures led the authors to conclude that Facebook® may be a viable and efficient way to conduct groups with young adults.⁽²⁸⁾

Regarding Diabetes, a randomized clinical study conducted in the Republic of Macedonia with 56 people aged between 14 and 23 years, identified that patients approved communication with health professionals through social networks to obtain knowledge and information about the disease. It also observed that the control of diabetes in the participants of the online group was similar to those who attended regular visits to the clinic.⁽⁹⁾

Thus, Facebook® has been explored as a learning environment with pages directed to the posting of specific contents and formation of groups destined to exchange of inputs. This reinforces that the use of innovative educational strategies is important in care for people with DM, since it provides knowledge and social interaction, and this reflects in their attitudes and skills in self-care practices, favoring the understanding of their role in health care.⁽²⁹⁾

The use of social networks in nursing work processes is recent and has been used to research, teach and assist the most different profiles of individuals.⁽³⁰⁾ It should be emphasized that social network channels can encourage participation, involvement and continuity of care of both those receiving assistance and those who provide it, since they are efficient, ubiquitous and easy to use platforms. In addition, these platforms could contribute to more resolute health promotion interventions and reduce social inequalities in health, since they are tools that are available and accessible to all.⁽³¹⁾

The participation of young people who experience the same health problem in an online group contributes to the acceptance of the disease. It is a space to provide and receive technical, emotional and medical support. In addition to that, support can extend to an extra experiences online forum, physically connecting its participants.⁽³²⁾ This space of exchange, especially for the young, can constitute an opportunity to re-signify the chronic disease, as well as to recognize among the shared difficulties some self-care strategies that can be adopted to improve their quality of life.

The participants of this study assessed that the group allowed the development of the *Spirit of community and strengthening of bond from the group on Facebook®*, since it favored the online conviviality with people of the same age group and with the same health problems, communication private and collective relationship with a health professional and the sharing of specific experiences related to DM. The association of these characteristics, according to them, favored the acceptance of the disease and the formation of a support network, leading some participants to express the desire that other groups with similar characteristics be created, but without definition or time limitation.

Support networks - a set of meaningful relationships to the individual, in health situations, and especially in periods of illness - generally provide better adaptation and conviviality with a chronic illness, contributing to self-care practices and helping to reduce personal barriers to limit health care.

Dissemination of information through social network is conducive to the development of support not only due to the exchange of information in the virtual environment, but also to sharing of experiences, helping integration of participants, group engagement and strengthening of feelings as self-realization, identity and belonging.⁽³³⁾ Nonetheless, given the possibility of divergence between the information posted in these groups and those recommended, mediation by professionals would minimize dissemination of wrong health practices.⁽³⁴⁾

In the nurses' daily routine, the use of different technologies can produce significant changes in the self-care capacity of people with DM, highlighting the importance of technical and clinical knowledge of nursing interventions.^(3,35) In this sense, the young people studied reported better adherence to treatment with the use of this technology.

DM is a serious public health problem and there is a lack of disease monitoring and follow-up by health services, especially in the case of young people. This is associated with inadequate adherence to the proposed treatment program, contributing to the worsening of the disease. It is inferred that the use of virtual technologies is useful to health professionals in their difficult task of supporting and assisting young people with 1DM.

Conclusion

The results of this study show that the self-care encouragement group developed on Facebook® and educational actions carried out were well accepted by the young with DM who also expressed the wish that more groups of this nature and with no closure period be implemented. These results indicate that this tool can be an important strategy to be used by the health services in approaching young people, especially those with chronic conditions, helping them to clarify doubts, correct adherence to treatment and, consequently, disease control.

Collaborations

Nass EMA, Marcon SS, Teston EF, Reis P, Peruzzo HE, Monteschio LVC, Bega AG and Haddad MCFL contributed to the study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and final version approval.

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