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ORIGINAL

Potential of virtual communities as a nurse's communication space on child cancer: qualitative study*

Potencial de comunidades virtuais como espaço de comunicação de enfermeira(o) s sobre câncer infantil: estudo qualitativo

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ABSTRACT

Objective: to analyze the potential of virtual communities of relatives of children with cancer as a communication space from the nurse's perspective. **Method:** qualitative research developed with the Creative Sensitive Method and a virtual field Journal. Three to four people participated in each group, totaling nine nurses specializing in pediatrics and oncology. The data were treated with thematic analysis. **Results:** in the resignification, virtual communities are recognized as powerful spaces for dialog with relatives of children with cancer, sharing experiences through interpersonal relationships of trust and bond creation. These communities are more frequented by women than men, who seek information, acceptance, support, and motivation to face the child's illness. **Conclusion:** virtual communities represent new areas of health education where nurse(s) educator(s) can advocate for the best interest of children by providing the family with qualified and ethically responsible information.

Descriptors: Social Media; Child; Nurses.

RESUMO

Objetivo: analisar as potencialidades de comunidades virtuais de familiares de crianças com câncer como espaço de comunicação, na perspectiva de enfermeira(o) s. **Método:** pesquisa qualitativa desenvolvida com o Método Criativo Sensível e um diário de campo virtual. Participaram três a quatro pessoas, em cada grupo, totalizando nove enfermeira(o)s com especialização em pediatria e oncologia. Os dados foram tratados com a análise temática. **Resultados:** na ressignificação se reconhecem as comunidades virtuais como potentes espaços de diálogo com familiares de crianças com câncer, no compartilhamento de experiências pelas relações interpessoais de confiança e criação de vínculo. Essas comunidades são mais frequentadas por mulheres do que homens, que buscam informação, acolhimento, apoio e motivação para enfrentar o adoecimento da criança. **Conclusão:** as comunidades virtuais representam novos espaços de educação em saúde, onde enfermeira(o)s educadora(e)s podem advogar em favor do melhor interesse de crianças, provendo a família com informações qualificadas e eticamente responsáveis.

Descritores: Mídias Sociais; Criança; Enfermeiras e Enfermeiros.

INTRODUCTION

In social media, 80% of cancer patients connect with their peers for health information, and many build virtual communities(1). Therefore, the Internet has become another place that offers the opportunity to learn and improve communication in health(2).

Access to reliable and qualified health information contributes to the decision-making of parents of children with cancer. Sometimes, healthcare teams do not always provide information about the condition and treatment of these children which meet the needs of their parents. Many seek answers to their concerns in virtual communities among their peers. In this sense, it is necessary to identify and respond quickly to the information needs of these relatives to minimize the adverse stressful effects of child cancer(3). Qualified information can develop skills that give the individual greater decision-making power over his or her health. Well-informed people are empowered, have greater

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control over their lives, and facilitate self-care, increasing adherence to specific treatments(4).

Family caregivers (74%) of children with cancer reported accessing social media to learn more, provide, and receive support and information about diagnosing or treating children with cancer. The nurse's awareness of how the relatives of cancer children use social media is an understanding of these caregivers' ongoing emotional and informational needs. In this sense, it is necessary to invest in selecting reliable sources of information support accessible through social media(5).

The power of the virtual communities organized on the world computer network has drawn the attention of scholars on health information while simultaneously being a territory open to the circulation of false hopes and fake news. The media is an electronic communications space where users live in open or closed communities to share information, personal messages, and content of interest common to that group(6).

The term community suggests some sense of pertaining or repeated contact, sustained social interaction, and familiarity among community members. Therefore, this leads to recognizing individuals' identities and subjective sense of belonging to this specific group. People share affection and maintain social ties, forming a common interactional "space"(7).

There is evidence that social media improve patients' relationship with health professionals. However, nurse engagement still needs to be more significant when compared to the potentiality provided by communities that meet in these media(2). Nurses often occupy these communication spaces with family members and users to share information within an ethically compromised dimension(8). This is likely due to a lack of knowledge of the potential of this new space of interaction and care mediated by educational processes in a virtual community environment.

In addition, few studies address nurse behavior as one of the healthcare professionals who work in communities and social media or guidelines for participation in virtual communities(9-11). Therefore, these communities provide lay users and nurses opportunities to share doubts and information. Because of the above, the objective was to analyze the potential of virtual communities of relatives of children with cancer as a communication space from the nurse's perspective.

METHOD

Qualitative research was implemented with the Creative and Sensitive Method of art-based research, which was structured with dynamics of creativity and sensitivity (DCS) as an axis to conduct group work. The participants work together in rescuing concrete existential situations based on their sociocultural histories by accessing human experience ethically and responsibly in approaching sensitive topics(12).

Among these topics is child cancer, approached with the DCS speaker and body maps to know, respectively, how to map human experience as a sensitive topic in time and space and the reflection of this experience on the biological and social body, seeking to answer generated questions (GQ) and generate artistic productions(12).

As the research participants it was defined as inclusion criteria, nurse(s) who Worked in pediatrics and or oncology, were specialists in pediatric or oncologic nursing, provided direct care to hospitalized children more than a year ago; they developed child health research or pediatric oncology and published articles in the area, participated in events and updates in pediatric oncology; they had skills with digital inclusion tools. The exclusion criteria are to be a newly graduated nurse, participating in a single or multi-professional residence program; retired who did not act more in the clinical, academic, or research practice and did not have personal Internet access equipment. The participants were recruited in Scientific Cafe or *World Cafe*, held at an average interval of 3 months over a year. This public science initiative promotes people's engagement in discussions on relevant health issues in the format of a scientific event, expanding the participation of people with the potential to be recruited as research participants(13).

Nurse(s) participating in the Scientific Cafe acted as index persons in the reference chain of the snowball technique, locating key informants of their network of personal relationships consonant with the research profile(14).

The final sampling was 50 people; nine volunteered to integrate the DCS participant group by distributing themselves into three subgroups of three to four people. Seven of nine developed a virtual field Journal (DCV) that supported the work developed in the DCS speaker map and body knowledge.

The hybrid scenario of data production was adopted, combining the virtual community space, located on Facebook pages, with the presence in group meetings. A list of 16 pages of Facebook communities was selected based on the following criteria: an institutional profile and a private blog of open communities maintained by governmental or non-governmental organizations. On these pages, the nurse(s) were guided by the first author to extract, for a week, at least five posts that reflect doubts, questions, and comments from family members to compose the virtual field diary. This material was sent to the field researcher electronically and used in the DCS preparation.

In the face-to-face scenario, three DCS meetings took place in a private room, which favored the participants' free expression. In the DCS speaker map (SM), for 65 minutes, the first group (three people) responded to GQ – "starting from Facebook, which places, people, and technologies can be linked to the health needs of children with leukemia?" – in the form of collective artistic production. Four months later, the second DCS, Body Knowledge (BK), held two meetings to respond to GQ - addressing health needs, access to technology, bonds, good living conditions, and autonomy in the virtual network to meet childcare demands with leukemia. The first meeting lasted 88 minutes and was attended by one person from the DCS speaker map and three new participants. At the second meeting (two months later), three new people participated in the group, lasting 104 minutes. All the meetings were recorded in a digital environment and transcribed in full.

The thematic analysis was chosen to treat empirical material, a qualitative data analysis technique used to elicit nuances from the narratives of human experiences, seeking to identify, analyze, organize, describe, and report themes found in a set of data(15). The thematic analysis is carried out in five phases: familiarization with empirical material, code generation, research and review of themes, designation of congruent themes and subthemes, and report production(15).

Becoming familiar with empirical material requires that the statements be transferred to an analytical framework, which was thoroughly read to apprehend terms and key expressions representative of the main subject of the statement. In the generation of the initial codes, four procedures were adopted: Elaboration of a glossary of terms; Formulation of analytical questions containing glossary words and key terms/expressions; Answers to questions in the form of a unit of analysis; Code formation by approximation of the meanings of the responses of the units in a new analytical framework.

The search for themes resulted from approximating standard codes associated with defining characteristics, separated from unique codes. Then, the themes were included in a new analytical framework, with the defining characteristics of the codes to, again, by the convergence of meanings to form themes and subthemes related to the emerging knowledge of the analysis.

The Institutional Review Board approved the research with opinion no. 4.447.916 and was implemented according to the ethical guidelines provided for in Resolution no. 466/2012, of the National Health Council. All participants signed the Informed Consent, and the disidentification of participants was guaranteed using code for each DCS (speaker map [SM] and body knowledge [BK]), accompanied by the number corresponding to the meeting (1st SM and 2nd BK).

RESULTS

The eight nurses and one nurse were between 28 and 57 years old, eight white race/ethnicity and one brown, time of professional training ranging from two to 32 years. Professional experience in childhood ranged from two to 23 years of public and private service activity in the health network of the city of Rio de Janeiro. In addition to the specialists, three had completed their Master's degrees and were studying for their doctorate; three had completed their Master's degree, and three had their course in progress.

One hundred ninety-eight interactions (posts and comments) and 11 images collected in the virtual field diary on Facebook Institutional (Figure 1) were used as a reference for producing the collectively produced speaker map. In the cloud of words, the strength of the community is revealed in the centrality of the image expressed by the words network, social, child, information, marrow, professionals, and institution.

Figure 1 - Words cloud of common terms from DCS Speaker Map and Body Knowledge. Rio de Janeiro, RJ, Brazil, 2022

Facebook posts addressed the ability of users to communicate and participate in a virtual community, revealing it as a potential space for the nurse to interact with relatives of children with child cancer in the disinformation approach. In this sense, the power of Facebook virtual communities has emerged from narrative analysis as a place to share family experiences.

The capacity of virtual community communication

The information and virtual communication technology in health has integrated the lives of people who access pages and profiles of virtual communities, wishing to know them and to be welcomed, regardless of the geographical region where they live. They form heterogeneous and dynamic cultural groups if there are relationships of trust and a sense of belonging. In this way, the virtual community has the power to receive, contain, or accommodate various demands from different sources.

> *They (people) meet there. One person lives in one state, another in another, and creates a virtual link through the Facebook page. It is a group, virtual, heterogeneous, dynamic space. This virtual possibility of living with others, the child, and the family. Today, everyone has a social network...*
>
> *They connect at any time; they can go back any day, share and consume information. (SM meeting).*
>
> *The social network enables the lay public to access information quickly and at the touch of a hand. (1st meeting BK).*
>
> *We see on the social network that there was the support of unknown people who did not know the child. (SM meeting and 1st BK meeting).*

The public creates spaces of coexistence and a sense of belonging in these communities because when connected to the Internet, it shares, consumes, and accompanies the flow of postings with information of interest that may be appropriate by the nurse(s) in public enlightenment. Therefore, the technological potential of the virtual community expands because there is a host ease of access to information with quick answers to doubts.

> *Today, technology is deeply rooted worldwide; it is part of people's life. (SM Meeting).*
>
> *In the social network, families feel welcomed, have quick answers, and access to information... concerning the disease; it has more resolution. (2nd BK meeting).*

Interpersonal relationships with health professionals are extended in this network by leading its users to transform the roles of these professional caregivers into friends, uncles, aunts, and expressions related to the family bond.

> *(For community users) doctors, nursing professionals turned care friends. They are called uncle and aunt. I saw this established link with the physician expressed in the virtual network... It creates a connection in this virtual network with unknown people through the pages of that institution. (1st CS meeting).*
>
> *The link was related to people, unknown people... (SM Meeting).*

Trust relationships strengthen the bond that expands among unknown people by involving different relatives of children who have become ill with cancer. In the community, they find strength, support, and motivation and thank the institution and professionals caring for their children. Thus, cancer as a "cursed disease" is faced daily, evolving to cure or death.

> *The bond with unknown people was there, with the team taking advantage of the moment. Link to collect information and trust. They want to link with the person who commented: 'That's it!'... It gives strength: 'You and your child will be able to overcome!' It motivates: 'that's right.' They thank the institution and the professionals who took care of the children. They express how they feel that the child has evolved into healing, that... 'brother died! Cursed disease!' (SM Meeting).*

Virtual communities are frequented by different people who anonymously post comments, photographs, and reports of experiences as bone marrow donors.

> *On Facebook are professionals in the cancer area, patients... There, it is impossible to know if they are family members, children, patients... or students from some health discipline interested in the subject... I saw a report from a bone marrow donor. But on the institutional pages, there are people there, and you understand you are a family member. (...). They may be the professional members of the team. (SM Meeting).*

The bond can occur between one person and another, known or not, involving relatives of the child or adolescent who are experiencing illness by leukemia. In this network, they navigate people interested in the subject, professionals, and academics of some courses in the health area. Therefore, it is a place of social relationships. This plural place requires attention, caution, and wisdom because it is not known who is the person with whom it is interacting.

> *Facebook is who has interest, professionals in the area, patients... It is impossible to know if one is family or the other is ... The family, the child, the patient... or the scholar of some course in the area who is interested in the subject. In social media, no patient or child uses institutional Facebook. But it could have a teenager using it as a tool because they understand the importance of this technology... (SM Meeting).*

Virtual communities are built by different people (health professionals, guardians, and relatives of children with leukemia) who access and post comments, photographs, and reports of experiences as bone marrow donors, for example. Therefore, with different needs and demands.

> *I saw a report from a bone marrow donor. But I saw on the institutional pages people who are there, and you understand that you are a family member. (...). They can be the professionals themselves, the team members themselves. So I was in doubt who they would be (the people responsible for these postings), the relatives agreeing with that. (...) (SM Meeting).*

In the cultural environment of the virtual community of Facebook, women need to attend and interact more than men. In this context of female culture, there is an emptying of male power. The father's participation is restricted to entering and viewing the post without commenting.

> *Most of the postings are from mothers or women who have experienced cancer in one of their family members or have been accompanied by caregivers or mothers concerned with some cancer-related symptoms. They seek support on the network of other mothers' sites and spaces. This female cultural issue is perceived as (...) We do not see the father in social and virtual spaces. (...) Most posts are about women and family members. You don't see the father solving doubt... (1st BK meeting).*

> *.... They enter just for the matter of entering or to see what is posted, no posts (no extra ones). They don't make or have few comments, they don't interact, it's a little busy...* (SM Meeting).

The power of the virtual community is in the communication and participation capacity of the most varied users interested in some subject that motivates them to interact, such as child cancer, regardless of whether people are known or not and where they live.

DISCUSSION

The capacity of the virtual community makes it a powerful interactive tool. However, there are challenges and limits to its use since the communication capacity is because they are heterogeneous and dynamic. They are spaces of coexistence that favor the sense of belonging. Facebook, as one of the social media, favors the approximation and creation of a bond between people who reside geographically in regions closer to or far, extending interpersonal relationships beyond where users live.

Regarding geographical distance, virtual communities approach the internet network and create links from different places. The public creates spaces of coexistence, trust, and a sense of belonging in social media because people when connected, share, and consume, accompany posts with information of interest on the condition of the child and adolescents with cancer. They create bonds between those who live near or far, extending interpersonal relationships beyond the place where they live. People participate in these communities as part of their regular and ongoing social experience, seeking to be welcomed, counseled, and supported in their network of friends. The social worlds are becoming increasingly digital, with social activities and interactions on the Internet and other media mediated by technologies, which requires the mediation of reliable scientific information(16).

Due to their heterogeneity and dynamics, virtual communities democratize the dissemination of information, such as being medulla donors, allowing patients and caregivers to connect directly by seeking and sharing information that is not mediated or filtered by health professionals or specialists.

Similar results regarding access to information by these communities were identified in a study conducted in Iran analyzing the need for interaction of the health team, physicians, and nurses in communicating information that meets the expectations of relatives of children with cancer(3). With the increased internet use to search for health information, social media has become a prominent platform for communication and the exchange of information on cancer(17). Cancer research has examined the type and nature of health-related communication in these media through content analysis of social media posts, links, likes, and comments. People use social media for social support, sharing experiences with the disease, and seeking advice, opinions, or answers to their questions. During the implementation of the protocol for the treatment of children with cancer, family caregivers have many doubts about the number and interval of regular visits to the clinic, risks, and recurrences of hospitalization to be compatible with other demands of work and family life. When they move away from friends and family to dedicate themselves to the follow-up of this child in treatment, the leading social support networks *online platforms* become a potential tool for busy family members to seek information and support(17).

In the cultural environment of the virtual community of Facebook, women attend and interact more than men, sharing the same values and keeping an active and attentive listening. With other users, they form a unity of thought and mutual support experiences, friendships constituting a feminine culture. They share experiences and establish relationships of virtual friendships, seeking support to constitute a female culture of participation in communication through virtual community. Empowerment is manifested by the active engagement of women who share the same values. They keep an active and attentive listening to their senses while expressing respect and reverence to other users, forming a unit of thought. In this movement, active engagement occurs with other people who share the same values founded on real solidarity with and among those who seek the interaction's intention, process, and outcome. Therefore, empowerment requires listening to one's senses, being attentive and active to the senses of others in a conscious way, and adding strength(1).

Social media help women users solve problems and challenges, raise their voices, convey perceptions, and share experiences. Social media provide women with new ways to communicate and interact through improved knowledge and skills. Female empowerment includes views of women views on various social and cultural issues that helped raise their current social status. Through these channels, women expressed themselves freely, regardless of the global context(18). Data from the ICT [Information and Communication Technology] Census Home 2020 show that women (57%) access the Internet more in search of health information than men(49%)(19).

Interaction in virtual communities with the same sense of belonging and group identity can provide more egalitarian communication between the child's family and the health professional. With access to qualified information, families of children with cancer can increase their knowledge of the disease. As a result, they can communicate with the health care professional more because they can better understand what is happening and feel more confident in their relationship. Therefore, this leads to recognizing individuals' identities and the subjective sense of belonging to a specific group(7).

When the nurse uses social media wisely and prudently, she becomes a tool to promote public health personal and professional development and contribute to better professional-patient interaction.

However, when used without caution and knowledge, the dangers of these technologies to health professionals and patients are enormous. Even though these professionals know how to use social media to interact in virtual environments, they need to visualize these media as tools capable of being applied positively in healthcare(20). It is crucial that they occupy this space based on ethical guidelines, scientific evidence, and best practices and that they interact in online or virtual communities linked to the social media of health institutions. Moreover, community involvement requires attention, collaboration, and solidarity in building cultural identities that bring people closer together. In this way, nurses can educate parents about evaluating information obtained through Facebook using evidence-based guidelines. Providers can encourage caregivers to use Facebook as a tool for communication, information, and support for families of children with cancer(10).

As a limitation of the study, the access to virtual communities of a single social media was highlighted to extract posts in the composition of the virtual fieldnotes. There is a potential to transfer the findings to nurse(s) familiar with social media; however, it is impossible to generalize that all nurse(s) can participate and interact in virtual communities. The limitation of gender, with the predominance of women and the participation of a man as a participant in the research, is highlighted. The dynamics were not carried out with the family members of cancer children who attend virtual communities on Facebook. More research is needed to expand the knowledge about the potential of virtual communities as a space for communicating information on child cancer.

CONCLUSION

From the nurse's perspective, virtual communities have proved to be a communication space among relatives of children with cancer, who are more frequented by women than men. These women communicate with unknown people, friends, and health professionals by sharing information, and experiences, remedying doubts to deal with difficulties facing the disease. In this way, they are empowered and strengthened. In the communities, a sense of belonging favors the bond of reception and the ability to find solutions to problems.

The use of Facebook proved feasible, effective, low-cost, and fast in obtaining answers. Users of virtual communities have a high capacity for communication with each other and with health professionals who need to be better used to disseminate information about child cancer.

However, care must be taken to ensure that this space is not seen as a substitute for the therapeutic meeting of educating and caring in health. People living in these communities can benefit each other from the experience while creating opportunities for family interaction of children with cancer and health care professionals, in particular, nurse(s).

As an implication, the recognition of the technological potential of the virtual communities of this social media and the appropriation of this space as a tool of virtual interaction are highlighted. In addition, advocacy can be promoted in favor of children's best interest by sharing scientific evidence and good healthcare practices with relatives of children with cancer ethically and responsibly. Therefore, the virtual community's technological potential and communication capacity need to be better exploited to disseminate health and disease information. Permanent education in using social media for professional communication with health system users contributes to increasing the nurse(s)' qualification.

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CONFLICT OF INTERESTS

The authors have declared that there is no conflict of interests.

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