

## ORIGINAL ARTICLE

## VIRTUAL INTERACTIONS OF FAMILIES OF CHILDREN WITH CANCER: POTENTIAL SPACE FOR NURSE'S ACTIONS

### HIGHLIGHTS

1. Handling virtual environment requires ethical, scientific, and digital competence
2. Institutional communities are potential spaces for virtual dialogue
3. Virtual communities expand the action and empowerment of nurses
4. Facebook® favors the nurse to act in defense of children with cancer

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### ABSTRACT

**Objective:** to analyze nurses' resignification of the needs of family members of children with cancer in institutional Facebook® communities. **Method:** participatory research developed with the Speak Map and Body-Knowledge dynamics of the Sensitive Creative Method in Rio de Janeiro, Brazil, conducted between 2019 and 2020. Nine specialist nurses in pediatrics and oncology participated in groups of three to four people. Thematic analysis was applied in the treatment of the data. **Results:** dynamic virtual communities favor family members of children with cancer in the search for support, solidarity, and information. In that space, they share experiences of illness, success, losses, and mourning. Challenges mark the community; the nurse can act as mediating information since prepared to interact with ethical responsibility and scientific knowledge. **Conclusion:** In the resignification, these communities are recognized as spaces for dialogue, expanding the locus of action and empowerment of nurse educators and advocates of the best interests of these children.

**DESCRIPTORS:** Social Media; Child; Health Empowerment; Nurses; Family.

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## INTRODUCTION

Cancer is one of the most searched topics on the internet since 80% of patients with this morbidity connect on the world wide web. In social media, people share experiences about coping with their child's disease, create bonds, receive support, and engage in health-related discussions<sup>1-5</sup>.

In social media, users create communities to share information, personal messages, and a variety of content<sup>6</sup>. The social aggregations of these virtual communities maintain public discussions for enough time and human feeling to form networks of personal relationships in cyberspace<sup>7</sup>. They offer the opportunity to learn and improve health communication, which can lead to increased demand for health care, among other aspects<sup>8</sup>.

The way these communities are organized favors interaction, but ethical problems may create difficulties in their daily use<sup>6,9,10</sup>. For example, in Italy and the UK, nursing professionals who used Facebook<sup>®</sup> did so to disclose personal and professional information. However, some posts showed behaviors inappropriate to the posture of a health professional, such as smoking and alcohol consumption, nudity, and sexual content, violating the Code of Professional Ethics of those countries<sup>11</sup>.

Childhood cancer is a sensitive topic to address in a virtual environment, requiring that professionals have prudence, ethics, and commitment to the quality of the information. Studies that deal with this issue in virtual communities point to this scenario as promising in the relationship between family members of children with cancer and health professionals<sup>1,3</sup>.

The social network constitutes a possibility of empowerment, as it allows users to acquire knowledge when they meet with other people and health professionals<sup>12</sup>. In Chinn's perspective<sup>13</sup>, empowerment means growth in personal strength, the power and ability to carry out one's own will, love for oneself, and respect for one another. It comes from real solidarity with and among those seeking community interaction regarding what can expect from the intention, process, and outcome. However, the participation of nurses in virtual communities is little explored in the scientific literature<sup>10</sup>; when found, they are restricted to Resolutions and guidelines for professional behavior in social media<sup>14-16</sup>.

Thus, to increase the empowerment of nurses, it is necessary to know what and how to dialogue in virtual community spaces for family members of children with cancer, a sensitive topic to be addressed in social media. Given the above, the objective is to analyze the nurse's re-signification of the needs of relatives of children with cancer in institutional Facebook<sup>®</sup> communities.

## METHOD

Qualitative research was implemented with the Creative and Sensitive Method (CSM) of art-based research, which has as its structuring axis the dynamics of creativity and sensitivity (DCS) in developing group discussion. The main purpose is to rescue concrete existential situations woven into the sociocultural histories of research participants. In this method, the human experience is accessed in the approach of sensitive topics in an ethical and responsible way<sup>17</sup>. It was chosen the DCS Speak Map and Body-Knowledge for two reasons. First, it was intended to map the human experience as a sensitive topic in time and space. Second, promoting the reflection of this experience on the biological and social body. Both dynamics produced artistic productions guided by the debate generative questions (DGO) and stimulated a group discussion<sup>17</sup>.

As for the research participants, the inclusion criteria were defined as a nurse(s) specialized in pediatrics and or oncology, who had been working in the care of hospitalized children for more than a year, who developed research and participated in events and updates; and had skills with digital tools. Exclusion criteria were being a recently graduated professional; being in a residency program; being a retired professional with no clinical, teaching, or research experience; and having no internet access. The participants were recruited in four scientific cafe, held at an average interval of three months over a year, and concomitant with the implementation of the fieldwork (from June to December 2019). This strategy sought to raise awareness of the social media topic among potential volunteers, preparing them to be engaged in the research environment. This public science initiative promotes people's engagement in discussions about relevant health issues <sup>18</sup>.

For the interest of the study, the following themes were presented: use of the social network in the dialogue of nursing care Resolution Cofen No. 554, which establishes the criteria for use and behavior of nursing professionals in social media <sup>14</sup>, health needs and care demands of children with leukemia. Nurse(s) participating in the Scientific Café acted as index persons in the reference chain of the snowball technique, locating key informants from their relationship network, according to the research profile <sup>19</sup>. Of the final sample of 50 people, nine volunteered to participate in the DCS, distributed in three groups with three to four participants. Seven out of nine prepared a virtual field diary (VFD) that subsidized the development of the Speaker Map and the body-knowledge DCS. The research fieldwork was implemented between the years 2019 and 2020.

A hybrid scenario of data production was adopted, combining the virtual community space on 16 Facebook® pages (with institutional profiles of governmental and non-governmental organizations) and a private blog with face-to-face group meetings. The nurses were instructed by the first author to extract, for one week, at least five posts that reflected doubts, questions, and comments from family members, to compose the virtual field diary.

In the face-to-face setting, three meetings took place in a private room, which favored the free expression of the participants. In the Speaker Map DCS, for 65 minutes, the first group (three people) answered the DGQ - "Starting from Facebook®, what 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 body-knowledge DCS took place in two meetings. Participants answered the following DGQ: How to address health needs related to access to technology, attachment, good living conditions, and autonomy in the virtual network to meet the care demands of children with leukemia? The first meeting lasted 88 minutes and was attended by one person from DCS Speaker Map and three new participants. In the second meeting (two months later), three people new to the group participated with a duration of 104 minutes. All meetings were digitally recorded and transcribed in full.

To treat the empirical material, we chose thematic analysis, an analysis technique used to elicit nuances in the narratives of human experiences. The aim was to identify, analyze, organize, describe, and report themes found in a data set <sup>20</sup>. At first, we familiarized ourselves with the empirical material before the narratives were transferred to an analytical framework (AF). Next, the AF was exhaustively read to apprehend key terms and expressions representative of the statement's main subject. For generating initial codes, four procedures were adopted: a) preparation of a glossary of recurring terms; b) formulation of analytical questions containing words from the glossary and key terms/expressions; c) Answers to the questions in the form of a unit of analysis; constitution of a code with an approximation of meanings in a new analytical framework.

The search for themes stemmed from approximating standard language codes associated with the defining characteristics but separately from the singular codes. Then, the codes' themes and defining characteristics were included in a new analytical framework. Through the convergence of meanings of the themes and sub-themes, we applied a new round of analysis movement to emergent knowledge.

The research was approved by the Research Ethics Committee (REC) with Opinions No. 4,447,916/2018 and No. 4,447,916/2020. All participants signed the Informed Consent, and the de-identification of the participants was guaranteed by means of a code for each DCS (speaker map [SM] and body-knowledge [BK]), accompanied by the number corresponding to the encounter (1st KB and 2nd KB).

## RESULTS

The eight nurses and one nurse were between 28 and 57 years old, eight were white and one brown, and their professional education ranged from two to 32 years. All of them had a professional experience in the childhood area, ranging from two to 23 years working in public and private services in Rio de Janeiro's health network. Besides being specialists, three had completed their master's degrees and were pursuing their doctorate, three had completed their master's degrees, and three were in progress.

A total of 198 interactions (posts and comments) and 11 images recollected in the virtual field diary on Facebook® Institutional were used as a reference to produce the collectively produced talking map. The Facebook® posts addressed users' general needs and family members of children with cancer in search of information.

Needs of family members of children with cancer in a virtual community and potentialities for the nurse's action

In the virtual community, people need access to information and support to face the disease to solve doubts in real time with and among the members who belong to that place. The sense of belonging is pragmatic because trust and the bond are maintained for as long as there is a return to technology's interaction mechanisms. Precise information with quick answers to the demands in meeting the needs expands the bonds of belonging and attachment.

*Facebook® is a place where people seek information and support and ask questions. They look for people who have the information; they find other people and health professionals who can help them with a need, in facing the disease, in their daily life with other people, with the institution [...]. Facebook® was the virtual tool to get information (SM Meeting).*

The easy access to the Internet, and the wide availability of the network in different places and at no cost, such as public transportation, facilitates the active maintenance of the community. Besides being a space that conveys information, the virtual community creates a comfort zone keeping the person in anonymity; a common need among people who live in a virtual community.

*Today the Internet is a public space in Wi-Fi. It's a space where people don't have to put their faces [remain anonymous] and feel more comfortable asking questions. [...]. So, social network has a very important role in disseminating information, which people before had more difficulty seeking. (First BK meeting).*

The moments of joy and achievements represent the need to share successful experiences in access to treatment and services. In the virtual community, people share stories about what they have lived through or are supportive of those experiencing childhood cancer and celebrate the beginning and each stage of treatment. In the communities, they feel the need to remain confident and safe to share experiences that they have lived in person, with emphasis on getting successful treatments, access to tests (blood, imaging, CT, MRI, etc.), and transportation services for out-of-home treatment.

*Today, on social networks, they celebrate that 'the marrow took, shared joy'; 'Day zero of*

*treatment' for when they start a new stage. Children and families share, 'Today was exam day!', 'ambulance ride day!' [out-of-home treatment]; lots of blood tests, imaging. (First BK meeting)*

In the meeting of subjectivities, concern is expressed for the problems of others; they respect each other, virtually embrace each other, and appreciate each other's accomplishments, which strengthens the group as a unit and increases the bond.

*Everyone wishes for improvement for those who are going through this process of getting sick with cancer. A place where they could share experiences that helped them become strong: 'I have been through, 'my son has been through, he was cured' ... They share places: 'through this place, I was cared for and supported' (SM Meeting)*

*There is the virtual hug; messages of support: 'I wish you well ... get well ... everything will be all right.' 'We are rooting for you... praying for you! (First BK meeting)*

There are expressions of gratitude and recognition for the health professionals who contributed to the success of the child's care, treatment, and recovery. By sharing the experience of the death of loved ones in the community, they seek to awaken feelings of empathy and solidarity in processing mourning and grief. Therefore, it is a space that serves as a counterpoint in the virtual network approach to death.

*They wish the best for the doctors and the team to be healthy enough to take care of their children and others. They wish the best for the institution for all the support and all the treatment they received[...]. They bond with the institution; they thank the institution and the professionals caring for the children. They express how they felt that the child evolved to healing, that the "brother died! Damned disease!" (SM Meeting).*

Facebook® virtual communities are privileged spaces for disseminating information that meets the demands and needs of family members of children with cancer, if they are occupied by professionals who assume roles of communicator in health, adopting a language understood by lay people.

*Information technology is an essential tool. As health professionals and specialists, it's our role to disseminate coherent information, which can be assimilated by the layperson, without generating big problems [expectations], bringing issues so that we can get these people to reach the reference units more [earlier]. (First meeting BK).*

The health professional can be a safe source of access to reliable information on the Internet. The nurse, as part of this set, is endowed with credibility to interact in virtual communities with family members and disseminate health content.

*[The user] doesn't know where the information comes from; they look at the first site that appears [of his search]. To say where it is reliable to search, you need guidance from a health professional. As mothers use Facebook® more, the health professional should use this social network to disseminate [information]. Why can't we as nurses disseminate [health] information? (Second meeting BK).*

It is necessary to be cautious, reflect and think before interacting, and responding to the demands of the users of the communities. Therefore, it is necessary to know the needs of the people who attend that community to overcome difficulties in addressing sensitive issues related to signs and symptoms of childhood cancer and bereavement.

*It's paramount to be careful about what will be said in the social network, that uncertainty the person has of the signs and symptoms. Nurses need help identifying themselves as professionals in the social network; it brings the information before realizing the person's need and if they have understood the message they are passing on. (First meeting BK)*

*What worries me is how to approach this family in this moment of mourning [...]. Social media is not for that. You will have to use the media as an intermediary to approach a*

*conversation with them. The fact that social media is not enough is impersonal. (Second meeting BK).*

There are many challenges to interacting in virtual communities, such as lack of time, schedule incompatibility, and overload of demands. Valuing one's own experience as a health professional in the care of children with cancer helps to interact in these environments, respecting the limits that are of the virtual communities and the nurse(s) themselves.

*On the web, your schedule never matches the person. You go to bed at three o'clock, and at six o'clock in the morning, that mother is awake and sends you a question. You would have to always have someone to respond to the demands that arise. It is one more task, in addition to many others. We are going to interact with how many children and how many families? [...] Can you imagine if we interacted with everyone? Since it demands time, we must take it seriously, and it is not informal (Second meeting BK).*

Communicating in health requires that the nurse be a member of that community, adopting responsible and ethical behavior. Empowerment is built in respect, mutuality, and reciprocity in forming affective ties and bonds. It is not something that can be learned from books but requires the ability to read and interpret reality to determine the manner and extent of engagement.

*It's a great challenge because this universe has other ethical issues. What kind of condition can you give correct suggestions and proper guidelines? You need to feel supported by the institution where you work [...]. I see the social network as a great tool, but I would not feel comfortable and reassured beyond: 'Look for the specialized hospital.'* (First meeting BK)

*It is not written in the books [how to use social network]; it's from the professional, from reading and interpreting how he will use it. (Second meeting BK).*

To develop a community, people need to take the time to reflect and discuss together the group process, share scientific information, and interact with the people who belong to this group.

## DISCUSSION

The democratic environment of Facebook® virtual communities favors the welcoming of unknown people with different needs of access to information and support in facing the disease. The set of needs redefined by the nurse(s) can be summarized as follows: access to information; support for coping with the disease (virtual embrace and welcoming); resolution of doubts in real-time and with a sense of belonging; preservation of anonymity; maintaining confidence and safety; thinking before interacting to act with caution and scientific knowledge.

Therefore, a comfort zone is created by seeing their demands met with pragmatism and immediacy. The nurse has the credibility to share information if he/she understands this place as a space where users have information needs and demands. In this sense, re-signifying the virtual community as a nurse empowerment space emerges from active engagement with others whose values are shared in the community<sup>13</sup>.

It is a place of social relationships, but certain behaviors increase the vulnerability of those who disclose and an entire professional class. In this sense, a relevant finding of this study is that acting in a virtual community requires professionalism, knowledge, and respect for one's dignity and that of all people who frequent a virtual community. It is a space marked by challenges, where the nurse can act as mediating information if he/she is

prepared to interact with ethical responsibility and scientific knowledge.

These communities make unlimited online information on any subject available to everyone with access and competence to use it<sup>21,22</sup>. In Brazil in 2019, searching for health information on digital media was the second most searched topic<sup>22,23</sup>. Recent research documents that patients and their caregivers use social media to share disease experiences and engage in discussions about health and cancer<sup>1,2</sup>.

The virtual community creates opportunities for interaction among its users, sometimes anonymously, because they identify with its content and purposes. The bonds are formed by discussing subjectivities, psychological support, empowerment, and mutual motivation under challenging moments. However, lack of time, incompatibility of schedules, and overload of demands can be challenging for nurses to play the role of health communicator.

People with health problems can benefit from participating in virtual communities without revealing their identity, protecting themselves from stigmatization. People can get answers and emotional support, while face-to-face social networks may need help to provide them. This mode of organization favors family members who seek support, solidarity, and information. Furthermore, there is a sense of control over the help-seeking process, which can meet patients' need for autonomy with benefits on subjective well-being with a health outcome<sup>5</sup>.

To develop a community, people must stay together for some time. They may only meet sometimes but need a regular, agreed-upon time to be together, either through a face-to-face or a virtual meeting room with audio and video. Only some people must be present every time their group meets, but everyone needs to know when and where the group meets<sup>13</sup>.

In that space, they can share experiences with illness, success, losses, and bereavement. Nevertheless, not all subjects are ethically plausible to be professionally approached in virtual communities when it refers to an individual demand involving a sensitive topic such as, for example, diagnostic confirmation, referrals to services, or even bereavement therapy.

As limitations of the study, we highlight that the virtual field diary was prepared using Facebook® pages, the only social network used by nurses in this study. Moreover, gender limitation was marked by a predominance of women and one man's participation as a research volunteer. The dynamics were not carried out with the families of children with cancer on Facebook®.

## FINAL CONSIDERATIONS

In the nurses' re-signification of the needs of family members of children with cancer, the institutional Facebook® communities are recognized as virtual spaces for dialogue to meet the needs for welcoming, trust, safety, and caution. Thus, it is possible to expand the locus of action and empowerment of nurse educators and advocates of the best interests of these children. These communities represent a new place of care to be appropriated by empowered nurses who share values in favor of the best interest of the members of that community as well. It was found that there are mutual benefits from the shared experiences, while also opening windows of opportunity for nurses to interact with family members of children with cancer.

Working in virtual communities requires competence and ability to use digital tools together with scientific knowledge and an ethical and responsible approach. There is a need for training, qualification, and education of nurses, so that they feel safe and

comfortable in this new space of caring by health education. In this way, the locus of action and empowerment of nurse educators and advocates for the best interest of children with cancer is expanded. Developing an atmosphere of respect and trust in the community is a challenge to be overcome through group coexistence for a certain period, not always available to those who are part of the group, so that one can reflect and discuss based on a process that is group-based.

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