
SCHOLARIZATION OF HOSPITALIZED CHILDREN FROM A FAMILY PERSPECTIVE¹

Eliane Rolim de Holanda², Neusa Collet³

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² Ph.D in Nursing, Universidade Federal do Ceará. Faculty, Nursing Center, Universidade Federal de Pernambuco, Centro Acadêmico de Vitória. Pernambuco, Brazil. E-mail: elianerolim@yahoo.com.br

³ Ph.D in Nursing, Faculty, Public Health and Psychiatric Nursing Department and Graduate Nursing Program at Universidade Federal da Paraíba. Paraíba, Brazil. E-mail: neucollet@gmail.com

ABSTRACT: This study aimed to investigate the meaning of the experience of the educational process of children hospitalized with a chronic disease from a family perspective. It is a qualitative research, conducted at the pediatric clinic of a teaching hospital. The study included ten families of hospitalized children between seven and 16 years of age. We used semi-structured interviews and the principles of thematic interpretation for analysis. Results showed that families feel distressed by the situation of child's distancing from school due to the periodic hospitalizations and they think that going to school is a desire the children reveal. It was concluded that the hospital class represents an important care strategy. Through the maintenance of the educational process, the children reframe their hospital experience and have preserved their development, improving their self-esteem and quality of life.

DESCRIPTORS: Chronic disease. Hospitalized children. Education. Family.

ESCOLARIZAÇÃO DA CRIANÇA HOSPITALIZADA SOB A ÓTICA DA FAMÍLIA

RESUMO: Este estudo objetivou investigar a aceção da vivência do processo educacional da criança hospitalizada com doença crônica, sob a ótica da família. Trata-se de uma pesquisa qualitativa, realizada na clínica pediátrica de um hospital universitário. Participaram do estudo dez famílias de crianças hospitalizadas com faixa etária entre sete e 16 anos. Utilizou-se a entrevista semiestruturada e, para análise, os princípios de interpretação temática. Os resultados apontaram que as famílias sentem-se angustiadas com a situação de afastamento escolar da criança, em virtude das periódicas internações, e que, ir à escola, é um desejo revelado pelas crianças. Concluiu-se que a classe hospitalar representa uma importante estratégia de cuidado. Por meio da manutenção do processo de escolarização, a criança ressignifica sua vivência hospitalar e tem preservado seu desenvolvimento, melhorando sua autoestima e sua qualidade de vida.

DESCRIPTORIOS: Doença crônica. Criança hospitalizada. Ensino. Família.

ESCOLARIZACIÓN DE LOS NIÑOS HOSPITALIZADOS DESDE LA PERSPECTIVA DE LA FAMILIA

RESUMEN: Este estudio tuvo como objetivo investigar el significado de la experiencia del proceso educativo de los niños hospitalizados con enfermedades crónicas desde la perspectiva de la familia. Se trata de una investigación cualitativa, llevada a cabo en la clínica pediátrica de un hospital universitario. El estudio incluyó a diez familias de niños hospitalizados con edades comprendidas entre siete y 16 años. Se utilizó una entrevista semi-estructurada y los principios temáticos de interpretación para el análisis. Los resultados mostraron que las familias se sienten angustiadas por la situación de retiro del niño en la escuela debido a las hospitalizaciones periódicas y asistir a la escuela es un deseo manifestado por los niños. Se concluyó que la clase hospital representa una estrategia de atención importante. Mediante el mantenimiento del proceso educativo, el niño replantea su experiencia en el hospital, ha conservado su desarrollo, mejorando su autoestima y su calidad de vida.

DESCRIPTORIOS: Enfermedad crónica. Niños hospitalizados. Educación. Familia.

INTRODUCTION

Disease and hospitalization in childhood represent a threatening experience. Deprived of their daily reality, children find themselves in a different environment, where they are obliged to remain separated from their family, friends, school and significant objects. Besides, they are subject to invasive and painful procedures, and suffer from solitude and fear of death.

In chronic conditions, this situation is aggravated as, when the disease worsens, the children are submitted to periodical and/or extended hospitalizations. The hospital starts to permeate their growth and development process, often limiting them in social and intellectual terms.¹⁻³

The inclusion of strategies aimed at making feasible different health service arrangements, with a view to care comprehensiveness, and which enhance subjects' autonomy, is necessary to construct a distinguished form of care logic. Hence, it is fundamental to reorganize hospital care, so as to comprehensively see to the singular needs of families experiencing this reality.

Reflecting on the care process for hospitalized children in a comprehensive care perspective implies overcoming practices that are centered on technical interventions in the biological body. Departing from this principle, care needs to focus on the child-family pair, encouraging these subjects' co-participation in decision making through the establishment of a horizontal relation, maintaining the focus on expanded health needs. Besides, care centered on mother and child integrates different professionals and respects the cultural differences of the subjects involved.⁴

In this perspective, when children are unable to attend school during hospitalization, teaching needs to be organized and offered in alternative ways, so as to guarantee compliance with the universal rights to education and health.¹

To avoid systematic interruptions in these children's scholarization or impairments for their course conclusion, in 1994, through the National Special Education Secretary, the Ministry of Education formalized education in hospital classes. This is defined as "pedagogical-educational attendance in health treatment environments, whether in hospitalization circumstances, as it is traditionally known, or in day-hospital and week-hospital care or in comprehensive mental health services".^{5:13}

Hospital classes are responsible for elaborating actions that help to follow the scholarization process of children and adolescents, whether enrolled in mainstream education systems or not, in the basic education context, and who cannot attend school due to the hospitalization situation. These actions aim to guarantee a maintained bond with schools through a flexible and/or adapted curriculum, enhancing students' entry, return or adequate integration into the corresponding school group.⁵

In addition, this strategy also refers to the social inclusion paradigm and contributes to the humanization of hospital care. Living with human diversity, valuing each person and learning through cooperation are basic principles of social inclusion, in which the right to citizenship is understood as the right to equity, including respect for the differences inherent in any human being. From this perspective, education appears as an instrument to construct a social practice, in which one can acknowledge, in each being, talents that need to be developed.⁶

For children with chronic conditions, often, contact with the hospital starts even before they go to school for the first time. Their scholarization process frequently does not start, or it is temporarily interrupted or abandoned. That is why it is important to provide support that allows them to continue participating in the educative process, learning and developing themselves as, after hospital discharge, their social life will continue in permanent interaction.⁷

The hospital class strategy represents that support. The non-interruption of educative processes pedagogical care in hospitals enhances has helped to revert the clinical status of hospitalized children, a fact that increases their self-esteem and their desire to recover. These children's hospitalization should not compromise their cognitive development and scholarization.⁸

Studies^{3,7,9}, however, have appointed low school attendance levels among children with chronic conditions, including difficulties to follow the regular course during treatment. In that sense, this research is justified by the need to further understand the limitations and possibilities of scholarization for hospitalized children, thus contributing to the production of Nursing knowledge. Another justification is the possibility to reflect on the importance of hospital classes and appoint the great scientific gap that exists in this theme.

In view of the above, this study aimed to investigate the meaning of the experience of the educational process of children hospitalized with a chronic disease from a family perspective.

METHOD

An exploratory and descriptive qualitative research was developed, which is concerned with understanding reality, so as to go beyond the phenomena the senses perceive. This type of research is capable of enveloping the subjective and objective, social actors and the midst they are inserted in the analysis.¹⁰

The field research took place at a pediatric 32-bed clinic of a teaching hospital in Paraíba State, Brazil. This clinic is a referral center for the entire State concerning clinical and/or surgical treatment of chronic and rare diseases, attending children and adolescents between zero and 19 years old through hospitalization in different specialty areas. The research problem emerged from the reflection that the care offered did not comprise pedagogical-educational attendance, legally established in Brazil since 1994.

The research subjects were ten families, representing the companions of children or adolescents between seven and 16 years of age, hospitalized due to chronic illnesses. Initially, the families were selected upon the health team's indication and by consulting the patient registration book at the place of study. The inclusion criteria was: being a companion and relative of a child or adolescent with a chronic condition and in the compulsory school-age range.

Data were collected between January and May 2008 through a semistructured interview, using a script that initially addressed subjects' identification aspects, followed by a guiding question that investigated the meaning the relative attributed to the child's distancing from school activities due to the hospitalization.

After the subjects granted their authorization, the interview was recorded to guarantee data reliability, based on the apprehension of the subjects' discourse. The data saturation criterion was used to close off data collection, which involves the knowledge the researcher achieved in the field, that (s)he was able to understand the logic of the group studied.¹⁰

The interviews were fully transcribed and the empirical material was analyzed based on the

principles of thematic analysis, including the following methodological steps: ordering, classification and final analysis of the data.¹⁰ The testimonies were subject to exhaustive and repeated reading, asking questions to apprehend relevant structures. Next, with a view to the final analysis, the most relevant themes were regrouped, which permitted constructing the empirical study categories. In this excerpt, we aim to address the following core of meaning: meaning of the educational experience of hospitalized children from a family perspective.

In compliance with National Health Council Resolution No. 196/96¹¹, approval for the research was obtained from the Ethics Committee at the research institution, under protocol No. 140/07, and all interviewed subjects were consulted as to their desire to participate and signed the Informed Consent Form. To guarantee anonymity, patients were identified as follows: interviewee 1 (E1), interviewee 2 (E2) and so forth, until reaching interviewee 10 (E10).

RESULTS AND DISCUSSION

Subjects

Most of the accompanying relatives interviewed came from poorer social classes, with low education levels. Concerning parenthood, six of them were the children's mother, while the remainder was, respectively: father, sister, aunt and grandmother, with nine female and three male companions. Ages ranged between 18 and 55 years, with 40 as the predominant age. Six out of ten companions lived in the rural area and the remainder in the urban region. Seven interviewees lived in small cities located in the interior of Paraíba State, while only three lived in the capital.

The children whose family members participated in this research were five boys and five girls, who attended public municipal or state schools, except for one who was not studying. Considerable variation was found in the duration of hospitalization at the clinic but, in general, it ranged from nine months to five days. These children's mean hospitalization period ranged between 15 and 30 days, except for children who were hospitalized once per month (in case of thalassemia), who on average spent eight days in hospital.

The children's diagnoses were: idiopathic thrombocytopenic purpura, thalassemia, acute lymphoid leukemia; rheumatic fever, juvenile rheumatoid arthritis; nephrotic syndrome and

pheochromocytoma. All of these represent chronic conditions that imply periodical and sometimes extended rehospitalizations. They do not impede studying though.

In view of the child's current age, the age when the disease was diagnosed and the school level in course, six of the children were delayed, that is, they were taking an inadequate school year for their age range according to MEC (Brazilian ministry of Education) recommendations, in line with Law No. 9.394/1996, which sets the guidelines and bases for national education.¹² It was verified that these delays were due to the loss of contents and regular distancing from school, motivated by frequent hospitalizations. The other children had either discovered the diagnosis/disease recently or had minimally attended school and hospital, i.e. for now, they had been able to control and live with the limitations the chronic condition imposed.

Meaning of hospitalized children's educational experience from a family perspective

Together with the family, the school plays an extremely important role in the establishment of children's personal and social identity.¹³ Especially for chronically ill children, maintaining activities that recover the routine of their life before the disease, like school activities for example, represents concrete possibilities to keep up their hopes of survival through the construction of their own future.

When referring to the scholarization of hospitalized children, we are not only referring to the traditional sense of systemized knowledge production, but to school as a place representative of childhood. According to their reports, however, we perceived that the children's families did not always value this experience: [...] *she has always been very diligent to study. But I was even telling her that week: 'oh kid, if I were you, I would only study this year!' And she said like: 'oh mom, I don't know why, right, né? Sometimes I really just want to study this year!' (I2); I merely ask God to cure my daughter. I am only concerned with her health, but I know that she's losing classes (I4).* These testimonies indicate how some parents conceive the participation in school life of children with chronic illnesses. Sometimes, they say: *'I even wanted to take him out and not let him go to school anymore! It's no use studying!' (I3).*

It is known that mothers' ability to take adequate care of their children depends, among other factors, on their own education level.³ As the

children are under the parents' care and monitoring, this fact intensifies the importance of family characteristics in school delay. School delay refers to the difference between the year the child is taking or has concluded and the year it should be taking, without any subjects failed. Not complying with expected and recommended levels entails harm that jeopardizes the quality of learning, the child's development and creates problems related to that child's self-esteem and school and professional trajectory.¹⁴

The Brazilian educational system displays severe qualitative deficits, so that it often naturalizes high repetition or poor school performance rates, mainly among low-income students. This situation pictures the devaluation of education in some Brazilian States.

Thus, children who go through periodical hospitalizations will face difficulties to go back to school. During their treatment, hospitals and schools need to be more concerned with school monitoring. School is a full part of children's lives and, especially for sick ones, it can help to consider themselves more included.

Although some accompanying relatives expressed doubts about the importance of scholarization, in view of a chronic condition in childhood, most of them expressed their anguish about the child's school situation due to the frequent hospitalizations, as identified in the following testimonies: *look, one thing I always tell my children a lot is about the importance of studying! To achieve things, you have to fight! (I6); I find studying very valuable because, without that, you're nobody! Today, you need to have finished secondary school even to work as a garbage collector! [...] I usually say that studying never ends! Never, never... it cannot end (I9).*

It is important to highlight that the families' stimulation of scholarization can be weakened when they do not find a network to support and encourage educational environments in the hospital context, in school and in society.¹⁵ In that sense, the inclusion of hospital classes into the pediatric hospitalization units will enhance partnerships and dialogical mediation among professionals designated to the pedagogical function and health professionals that help to make these activities feasible at the hospital.

Members from the same family expressed opposite perspectives on the sick child's scholarization, and this was not only related to the disease, but to the father's perception that all

members had to work in agriculture to be able to survive in economic terms. *If it were for her father, nobody would study anymore at home! Everyone should be working! The thing is that nobody knows what value agriculture will have from now on. And if you have studied that's something else! I don't know, I don't feel well because... if I haven't been able to achieve the best for myself, that doesn't mean that I will not want to best for my children either, right?! If they have the chance to study, I think that what's right is to study* (I7).

The accompanying relatives also expressed feelings of concern with the unease the children themselves demonstrated because of their distancing from education. *Ah, I feel like... not guilty, because I'm not guilty of her disease, right? But I feel a very great weakness because, all the time, she's saying: 'mommy and my class? Mommy and how is school?'. Then I feel kind of bad, right?! She asks a lot, she loves to study!* (I9).

One relative whose child was not enrolled in mainstream education also demonstrated this same concern. *I have never been to school, dear! Who raised me didn't put me in school! And I would like her to study, so that she wouldn't go through what I do!* (I10).

In this case, although the companion did not have the opportunity to study, based on her own experience, she acknowledges the negative effects this privation entailed for herself. This supports the idea that experience and the "course of life" interfere directly in the transmission of cultural inheritances and behavioral standards, like: greater commitment to studying, reading habits, contact with music and arts. Thus, children who receive adequate resources, stimuli and care for their development since the initial years of their lives will achieve a better cognitive and emotional formation.¹⁴

Accompanying relatives' understanding about the importance of education is fundamental when returning to school after discharge. In partnership with the hospital, families should provide schools with all information needed to facilitate the school reinsertion process, so that the children are seen as students instead of patients. Similarly, schools can contact the hospital to maintain what the child learned during hospital classes.

In that sense, whether hospitalized children value studying or not greatly derives from the stimuli the family provides. The following reports illustrate, from the accompanying relatives' perspective, aspects concerning the hospitalized

children non-valuation of studying. *He is very absent-minded and does not care about studying! [...]* I know various people who have the same illness as he and like to study! [aunt remains silent] (I3); *He is kind of lazy! My mother's always hot on his heels! He's also kind of revolted by life! He says that he doesn't want to study anymore and that he doesn't want to do anything anymore! He's always repeating that he knows he's gonna die!* (I8).

When families consider that children do not want to study, this may involve their subjectivity, which the hospital routine hurt, lacking cognitive and psychic stimuli, leading to a lack of motivation. Hospitalized children's self-esteem is often suppressed by the illness and by the feeling of impotence the family itself and the health team may be feeding.

In human beings, hospitalization provokes a state of permanent threat. To understand the developments of this fearful event, children are obliged to incorporate, into their knowledge universe, the non-familiar, the discomfort of pain, the therapeutic procedures applied and the uncertainty of one's possible finiteness.¹

In that sense, children need to be equipped to go through the hospitalization experience with greater acceptability, granting them the opportunity of personal growth.¹⁶ Therefore, they need to attribute a new meaning to the conception of hospital functions and broaden its concept to that of an environment intended to help with recovery, rehabilitation, cure or dignified death, envisaging "[...] a space where life happens, where everything that is a part of life is accepted".^{16:71}

In the hospital environment, education can assume a recreation proposal in the search for new routes, which positively influence the response to the hospitalization, as it "[...] recovers the possibility that the option to play with knowledge will make the child levitate and turn it into an instrument to gain autonomy and reconstruct his/her life".^{16:72}

Children, however, do not always apprehend chronic childhood conditions as an impediment to their scholarization process. The families perceive these feelings and express them, to the extent that going to school is a desire the children reveal. *I though that he wouldn't like studying, but he cries to go to school and is always asking me for the school material* (I1); *She's always saying: 'daddy, I want to get well to be able to study again soon!'* (I4); *He does not like to lose a class, he likes to be present in*

the classroom, if you'd ask the teachers you'd see (I6); He says: 'mommy, I don't want to lose this year! Do you think you're the only one who works? I wake up early to go to class, I go every day and return on foot, 'cause it's kind of far and that's one year of work! I really cannot lose class!' (E9).

In these testimonies, the children's requests to their families to continue attending school and be with their friends are evidenced. They demonstrate that they experience this distancing from school negatively, acknowledging the long hospitalization periods as a limit to their scholarization and socialization. Not attending school symbolized being excluded from a space for exchange and learning, causing longing and anxiety.

The scholarization theme represents the recovery of self-esteem for hospitalized children and appears as a reference to normal life and to the identity of healthy children who, hence, are not in hospital. Hence, it is not academic contents children seek when they ask their mother for school material, but the feeling of belonging to the social group of their age range.⁹

One mother particularly mentioned her child's telephone conversation with her school. In that conversation, the importance the child attributes to studying can be perceived, even to the detriment of the difficulties the disease imposes. *This week, he called his school to find out about his classmates, to know how classes were going, whether they were good, and I saw him saying: 'with God's help, not this year, I'm losing this year, but next year we'll be together again!' He was saying that to his classmates there! (I5).*

When hospitalized children ask to go to school and get their friends back, that's because they need life in society, among their peers, struggling against the experience of getting ill and being hospitalized.¹⁷ The experience dimension of getting ill, however, cannot be diagnosed, but merely felt, together with the children, when we allow ourselves to listen to their affective and cognitive processes, observing their interactions and cooperating with their constructions.

In this context, hospital classes represent a singular vital experience, concerning the possibility of symbolically recoding the hospital context and experience, as it are not just the medicines that cure. Despite the limitations their health problems trigger, we are talking about living children, and who need multiple stimuli to develop their potentials.¹⁸

The children's possibility to study in hospital avoids content lags and possible school exclusion/evasion. Families and schools lack information and clarifications about the legal right to pedagogical-educational accompaniment during hospitalization. Some schools even stimulate the children to give up that year and only restart studying when they are released from clinical treatment, in the belief that, thus, they are facilitating their healing process to regain health.¹⁸

The continuity of the scholarization process not only helps sick children to cope with this period, but also contribute for them to feel socially included and not punished for having a chronic condition.

Due to a long trajectory of exclusion and non understanding that hospitalized children are entitled to follow the school curriculum during their hospital stay,¹⁹ however, merely visualizing their restrictions remains common practice in society. This represents a deeply segregationist view that needs to be overcome.

Schools need to respect differences, welcome everyone, further learning and attend to everybody's needs. In view of this context, the partnership between education and health is reaffirmed as an indispensable target for comprehensive and humanized childcare.

Another important aspect that was revealed in the interviews is some accompanying relatives' perception about the legal security medical declarations granted them with regard to school approval, due to the absences they endorsed. These relatives considered medical declarations as a problem-solving instrument that repaired the classes lost during the children's hospitalization, as follows: *ah, now it's excellent! This public school helps him so much! Each time we go back they say: 'Bring the declaration', and then I take it. He was absent 25 days last year and the teacher and director arranged it all, then he took the tests (I3).*

These same relatives, however, showed neither understanding about the qualitative impairment to the themes addressed in the classroom due to the distancing from school, nor any perception of legally guaranteed rights to education "[...] to students unable to attend classes due to health treatment".^{20:3}

On the opposite, other interviewees expressed awareness about the fact that medication declarations do not repair the learning lost during hospitalization in qualitative terms: *even if we take a declaration and everything, it's what the teachers*

say, right? There's no way he could follow. Even taking the test, even doing tasks, it was difficult (I6); The advantage of the declaration is just that he won't get the absences, because you know that's a reason for failing. At least it serves to know that he really wasn't going to school because he was playing, but due to the hospitalization. But, unfortunately, he loses the classes (I8). The relatives knew that, if they needed this, they could count on legal support to achieve the child's approval; in practice, however, they understood that the contents lost needed to be somehow replaced or learned for the children to be successful in future years.

In general, the concrete needs of their child's problem absorb the parents and they need time to reorganize their daily reality, which is when they stick to the child's education. Some families, nevertheless, in an overprotecting attitude, trying to save the children from any kind of effort, whether physical, intellectual or social, do not allow them to attend school after discharge, even when they feel physically well for this purpose.¹³

Concerns with organic issues and hospitalizations gain that much importance that the parents often find no alternatives that can reinsert the children into mainstream education, resulting in school abandonment. This can be due to a wide range of reasons, apprehended from the interviewees' testimonies:

The belief that the child became intellectually limited due to the disease: *he's going to learn how to read and write. But it will be very difficult for him, because he doesn't know anything! [...] he likes and wants to learn but, like, with all the medication he took, and many other things he's gone through too, it's complicated, for him and for me too [...]. He won't manage and I know he's gonna suffer a lot!* (I1).

Insecurity about the child's physical condition: *whenever she went to school I got worried [...]. I didn't let her go! I didn't let her because, where could she go when she got pale like a paper? How would she be able to study like that? That's why she lost yet another year in school (I2); Now, at the beginning of the year she lost class because, when it was raining, I didn't let her go, because she feels great pain in her ankles (I9); I'm afraid she'll get those red stains. I think it's better to let her get older to go back and study (I10).*

According to the subjects' reports, when families for some reason do not acknowledge the sick children's development potential, expectations regarding their accomplishment skills decrease. In response, children feel their parents'

message and react equally discouraged, or manifest hostile behavior.

We perceived that concerns with the children's physical/emotional integrity stand out among other preoccupations, such as education. If they parents do not feel that their children are being well attended in the school environment, they will definitely keep them at home, against their will and health professionals' recommendations.

Inserting school classes into pediatric units results from the formal acknowledgement that hospitalized children, independently of how long they stay at the institution, have educative needs and are entitled to citizenship. Being hospitalized will always represent changes in the children's daily lives, which scholarization is an important part of. Besides recovering the sick children's self-esteem, pedagogical actions in the hospital context cooperate towards their return to the school universe and are essential with a view to comprehensive care delivery.

FINAL CONSIDERATIONS

The main goal of this study was to investigate the meaning families attribute to the educational process experience of children hospitalized with a chronic condition, as this directly interferes in their quality of life. As it progresses, chronic conditions in childhood can significantly alter children's development, as it restricts their social relations and distances them from their family, friends and, mainly, their school.

The results showed that, due to different physical health-related concerns, some parents do not grant due importance to the continuity of children's education, even after treatment, resulting in school abandonment. Most accompanying relatives, however, demonstrated their anguish because of the children's school delay due to frequent hospitalizations. They also expressed feelings of concern with the unease the children themselves manifested because of their distancing from education, revealing the desire to go to school. Another important aspect is the awareness some accompanying relatives demonstrated about the fact that medical declarations do not repair the learning lost in qualitative terms, but are merely useful to help with the legal security of school approval, due to the absences endorsed.

The families' dual interpretation of the situation can weaken any processes to claim this right in society. It is highlighted that the scholarization of

hospitalized children has not received sufficient attention from the public power. In Brazil, especially in the North and Northeast, the implementation of this educational modality is just beginning.

In this perspective, hospital classes need to be inserted in all hospitalization units that offer pediatric care, so as to contribute to better coping with hospitalization and to support the cure and recovery process. Being ill removes neither patients' intellectual capacity, nor their critical sense.

These research results highlighted that the hospital class strategies has represented an important care technology, enhancing ill children's self-esteem and protecting their development; respecting their needs in the disease context; humanizing treatment; recovering daily reality and promoting meetings that grant another meaning to the hospitalization experience.

Brazilian literature on pedagogical practice in pediatric hospital contexts is scarce. Therefore, we believe this research contributed to explore new horizons, presenting important findings to direct future research on the theme. In view of the above, new studies are recommended, addressing the gaps appointed here to support evidence-based health and education practice.

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