

ARTICLE

HOSPITAL PEDAGOGICAL SUPPORT TO CHILDREN WITH CANCER IN THE LITERACY PROCESS

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ABSTRACT: The present study aims at the general analysis of the pedagogical hospital monitoring carried out in the oncology sector of a public hospital in Recife concerning children in the literacy process. The specific objectives are to verify the knowledge of parents and teachers of oncology about the laws that ensure the continuity of the teaching-learning process in the hospital environment; analyze whether and how the relationship between the school and how oncology teachers occurs in the children's literacy process; investigate the actions of the educator in hospital care in the oncology sector. We conducted research with a qualitative approach, using data collection, decoding, and semi-structured changes as tools. Through the study, it was possible to verify that access to hospital pedagogy offers a child and adolescent in a situation of hospitalization, not only the continuity of the schooling process but offers a perspective for the future, I contributed to a cure so desired, for the continuation of life projects. We emphasize the need to develop new research aimed at contributing to the continuity of the teaching-learning process of children undergoing treatment, especially those who are in the process of literacy.

Keywords: Literacy and literacy, hospital pedagogy, children with cancer.

ACOMPANHAMENTO PEDAGÓGICO HOSPITALAR A CRIANÇAS COM CÂNCER EM PROCESSO DE ALFABETIZAÇÃO

RESUMO: O presente estudo tem como objetivo geral analisar o acompanhamento pedagógico hospitalar realizado no setor de oncologia de um hospital público do Recife no que se refere às crianças em processo de alfabetização. Os objetivos específicos são verificar o conhecimento dos pais e professoras da oncologia sobre as leis que asseguram a continuidade do processo ensino-aprendizagem no ambiente hospitalar; analisar se e como ocorre a relação entre a escola e as professoras da oncologia no processo de alfabetização das crianças; averiguar as ações do pedagogo no atendimento hospitalar no setor de oncologia. Realizamos pesquisa com abordagem qualitativa utilizando como ferramentas de coleta de dados, observações e entrevistas semiestruturadas. Através do estudo, foi possível constatar que o acesso à pedagogia hospitalar proporciona a criança e ao adolescente em situação de hospitalização,

não só a continuidade do processo de escolarização, mas oferece perspectiva de futuro, contribui para a tão almejada cura, para o prosseguimento de projetos de vida. Ressaltamos a necessidade do desenvolvimento de novas pesquisas que visem contribuir com a continuidade do processo ensino-aprendizagem das crianças em tratamento, em especial às que estão em processo de alfabetização.

Palavras-chave: Alfabetização e letramento, pedagogia hospitalar, crianças com câncer.

SEGUIMIENTO PEDAGÓGICO HOSPITALARIO A NIÑOS CON CÁNCER EN EL PROCESO DE ALFABETIZACIÓN

RESUMEN: El presente estudio tiene como objetivo general analizar el seguimiento pedagógico hospitalario realizado en el sector de oncología de un hospital público de Recife en relación con los niños en proceso de alfabetización. Los objetivos específicos son verificar el conocimiento de los países y de los profesores de oncología sobre las leyes que aseguran la continuidad del proceso de enseñanza-aprendizaje en el ambiente hospitalario; analizar si y cómo ocurre la relación entre la escuela y los profesores de oncología en el proceso de alfabetización de los niños; averiguar las acciones del pedagogo en la atención hospitalaria en el ámbito de la oncología. Realizamos una investigación con un enfoque cualitativo, utilizando como instrumentos la recopilación de datos, las observaciones y las entrevistas semiestructuradas. A través del estudio, fue posible verificar que el acceso a la pedagogía hospitalaria proporciona a los niños y adolescentes en situación de hospitalización, no sólo la continuidad del proceso de escolarización, sino que también ofrece perspectiva de futuro, contribuye a la tan deseada cura, a la continuación de los proyectos de vida. Enfatizamos la necesidad de desarrollar nuevas investigaciones que tengan como objetivo contribuir a la continuidad del proceso de enseñanza-aprendizaje de los niños en tratamiento, especialmente los que están en proceso de alfabetización.

Palabras clave: La alfabetización y la educación, la pedagogía hospitalaria, los niños con cáncer.

INTRODUCTION

The literacy process of children in our country is full of challenges. According to Sá and Pessoa (2016), research finds considerable failure rates and a significant number of students who finish the cycle without being effectively literate. According to Morais (2012), being fully literate goes beyond code memorization practices, it is characterized as a movement toward understanding a notational system.

We agree with Morais (2012) and Soares (1998) that the literacy process is satisfactory when the student can read, produce and relate through different oral and written genres with autonomy. However, during the process, students may face some obstacles such as the rupture of the conceptions they had established about the universe of reading and writing throughout their experiences; the elaboration of new concepts, which in many cases generate difficulties in achieving a logical articulation; the use of the same methodology and didactics to teach literacy to different subjects.

The difficulties are intensified in the case of children with cancer, given the invasive and long treatments, the hospital routine, the physical limitations, the constant anguish that permeates the painful medical procedures, and, above all, the separation from the school routine. This distancing causes immeasurable impacts on the child, as an insertion in the school environment and experiences in the social environment are essential for the progress of the literacy process.

Literacy activities and social interactions help to consolidate efficient learning not only of contents and skills but also in the promotion of values, providing the overall development of the person. Kleiman (2002) highlights the importance of students participating in literacy activities in the pedagogical routine by incorporating:

social practices, situated in specific, culturally determined contexts; Focus on collective practice, in which each one participates according to their experience, and their capacity; Diversified practices, according to institutions, objectives, identities, and roles of the participants, etc. Objectives: the accomplishment of specific tasks. Read/write for some other purpose (pleasure, escape, learning, contact, etc.). The privileged basic unit is the text and the production of meaning. In addition to these, there are also genres from the discursive domains of family life, advertising, bureaucracy, commerce, politics, etc. (KLEIMAN, 2002, p.100).

The impossibility of participating in these moments affects the child in treatment, favoring severe losses in the development of significant skills, as a result of which, failure and school dropout become challenges to be faced. Matos and Mugiatti (2009) define this reality as a “Social illness”, caused by the segregation resulting from the disease that calls into question two biases socially considered essential: health and education.

The emergence of the disease promotes the manifestation of a series of negative aspects that permeate the treatment, such as hair loss, indisposition, amputations, dependence on parents, constant feelings of pity for people, and other mishaps that directly affect the psychological development of the child and the learning process. The latter is intensely affected by the interruption of the training process due to the inability to attend the main formal learning environment, the school, impacting the development of intellectual skills and interaction with peers.

To continue the education process, Hospital Pedagogy emerged in Paris around 1935. Currently, it has two methodologies: School Hospitalization and Hospital Class. According to Matos and Mugiatti (2009), School Hospitalization is characterized as a differentiated strategy in consideration of the context that involves the sick student, paying special attention to the peculiarities that involve the disease at that moment, and the level of education of the student. Faced with these factors, an individual pedagogical proposal is created, respecting the needs and particularities of the student, also considering the school environment that the student comes from, through contact with the teacher of the regular class in which he is enrolled. Contact with the teacher at the school of origin is crucial, as it favors the continuity of the teaching-learning process through the exchange of information about the student's advances and difficulties, as well as providing activities that will be applied by the hospital teacher, a creative and playful way.

The Hospital Class performs a service very similar to regular classrooms, together and in a heterogeneous way, considering all the aforementioned specificities. In short, it works in multigrade classes, interspersing moments of teaching regular content with moments of relaxation and games that should also be part of the teaching-learning process, especially social interactions that are essential for the development of significant skills.

To ease the difficulties that sick students face, regulations and laws in favor of hospital pedagogy certify pedagogical monitoring in an attempt to continue the teaching-learning process during the period in which the child is unable to attend regular school. Law 13,716, sanctioned in 2018, the most recent legal support in force, ensures the continuation of the education process of children undergoing home or hospital treatment. The aforementioned Law was integrated into the Law of Guidelines and Bases of National Education (*LDB-Lei de Diretrizes e Bases da Educação Nacional*), guaranteeing the uninterruptedness of studies through differentiated pedagogical and educational support.

However, the absence of discussions about pedagogical practices directed to the pedagogue's performance in a hospital environment is notorious in the curriculum of teaching degrees, especially in Pedagogy (MOURA, 2014). Faced with the skills invested in these professionals in the current light, the gaps in the training process become immeasurable, considering the multiple functions that involve their activities, above all, work in the hospital environment. According to TUFFI (2011, p.1066):

The teacher has a very important role (...) his performance is fundamental for the success of teaching-learning relationships within the hospital. Therefore, when applying for a vacancy to work in hospital education, teachers should be aware of what will be required of them to perform this function. For his work to meet the expectations of that service, he must have his profile for this purpose.

Based on the above-mentioned elements, there is a need for more intensive work and the development of new research aimed at contributing to the continuity of the teaching-learning process for sick students, especially those in the literacy process.

The general objective of this article is to analyze the hospital pedagogical follow-up carried out in the oncology sector of a public hospital in Recife about children in the literacy process. The specific objectives are to verify the knowledge of mothers and oncology teachers about the laws that ensure the continuity of the teaching-learning process in the hospital environment; to analyze whether and how the relationship between the school and the oncology teachers occurs in the children's literacy process, and to identify the actions of the pedagogue in hospital care in the oncology sector.

PROCEDURES

We started the data collection stage by carrying out a semi-structured interview, individually, previously scheduled, with one of the hospital class teachers. We opted for this technique because it offers flexibility to the interviewer, being able to make adaptations according to the conduction of the process (Lüdke and André, 1986).

All scripts used in the study (observations and interviews) were prepared based on our objectives. In the case of the interview script with the teacher, we prepared to guide questions distributed in three blocks: actions of the pedagogue/hospital teacher, school of origin/hospital class, and laws of hospital pedagogy.

Through the Term of Confidentiality, we preserved the identities of the participants, not showing them, or identifying them with fictitious names in the data analysis and all interviewees signed an Informed Consent Form, which contained essential information about our work, the interviewees declared their participation in the research through the signature.

The interviews were recorded, and later we transcribed the speeches, avoiding the loss of important data. We emphasize that after transcription, the recordings held by the researcher were destroyed.

For complementation purposes, we made three observations of the pedagogues' performance in the hospital class, we planned the observations by defining in advance “what” and “how” to observe (LUDKE and ANDRÉ, 1986, p. 35-36):

The training of the observer must also be foreseen in the planning phase. According to Patton (1980), one needs material, physical, intellectual, and psychological preparation to carry out the observations. The observer, he says, needs to learn to keep descriptive records, know how to separate relevant details from trivial ones, learn to take organized notes, and use rigorous methods to validate his observations. In addition, he needs to prepare himself mentally for the work, learning to concentrate during observation, which requires training the senses to focus on relevant aspects (LUDKE and ANDRÉ, 1986, p. 35-36).

We used the direct observation technique because it allows the researcher to effectively approach the participants, given their immersion in the research field, a tool widely used in qualitative research. After all, “as the observer follows the daily experiences of the subjects in loco, he can try to apprehend their worldview, that is, the meaning they attribute to the reality that surrounds them and to their actions” (LUDKE and ANDRÉ, 1986, p.26).

With the field diary we took note of the observed aspects, we decided to use it because it favored the real description of the environment and the recording of our impressions about what we were observing. In the observation script, we sought to understand how the hospital pedagogical follow-up of children with cancer in the literacy process occurs in the hospital class. We also observed the actions of the pedagogue in the hospital environment and how the relationships between the children's school of origin and the hospital classroom teachers take place.

Finally, we conducted semi-structured interviews with three mothers of hospitalized children to verify their knowledge of the Laws that ensure the continuity of the teaching-learning process for students

undergoing treatment. The script consisted of two guiding questions about the Laws of hospital pedagogy.

Our data analysis remained in the central perspective of the research, that is, qualitative, taking into account the opinions of the individuals and the questions raised. We used Bardin's (2011) content analysis technique, performing the aforementioned step in three phases: 1- pre-analysis; 2- an exploration of the material; 3- treatment and interpretation of results. We will detail in the following topics the results of the analyzes carried out.

THE PEDAGOGICS AND THEIR MULTI FACES IN THE HOSPITAL ENVIRONMENT

To deal with the actions of the pedagogue in the hospital environment, we must initially consider that the students they receive are in an extremely peculiar state, directly implying the performance and mechanisms they use to achieve the didactic objectives. It was possible to witness, at different times, the frequent stress generated by the pain caused by the disease, constant medical interventions (numerous changes of chemotherapy medications, temperature measurements, laboratory tests, medical evaluations, auscultations, interruptions due to infusion pump alarms...) during class, during storytelling, activities with textbooks, paintings, and games.

The observations made us realize the complexity that involves the teaching practice in the hospital environment, highlighting the requirement of a series of skills, in addition to the “simple” act of teaching and mobilizing knowledge. In the interview with the teacher, we confirmed the multitasking that involves the pedagogue's performance in these spaces. When asked to define a profile for the hospital pedagogue: “Some characteristics would be to be flexible because everything changes all the time, you need to enjoy studying, be calm about change, be able to resignify yourself in the face of losses, in the face of difficulties, be dynamic ... so, these are some of the characteristics (Professor Paula)”.

We articulated the teacher's speech and the observations we made, with the points listed by Tuffi (2011) when outlining the profile of the hospital pedagogue: emotional stability (control) in the face of situations (moments of pain, losses, frustrations); ability to work in a group, as the field of action is often shared with doctors, nurses, dentists, nutritionists, and other health professionals; initiative and dynamism, especially in the face of multigrade classes where students are in different grades and levels, as well as dealing with a reduced workload in the presence of so many specificities; professional ethics, respecting the needs and particularities of children, as well as the limitations caused by the pathology; affectivity in pedagogical activities, establishing a relationship of trust with children, enabling them to feel free to share feelings, anxieties, showing affection, care and respect, fundamental issues for emotional, social and intellectual development; contribute to restoring the child's self-esteem; instigate being a researcher and adapt to different methodologies, especially those available in hospital pedagogy: school-based hospitalization and hospital classes.

During the observations, we were able to perceive the performance of the characteristics described above in the teachers of the hospital class. The ability to work in a group became constant data in the three days of observations, given the number of interruptions (16) during the classes.

In the multigrade group of the hospital class, despite the reduced workload (each student can only stay one hour a day), interruptions made by doctors to examine children, nurses changing medications, mothers offering water to their children, doctors of joy, volunteers dressed as superheroes, religious groups, and others, which directly influence the dynamics of the classes. Amid storytelling and moments of carrying out activities, it became common to hear the distressing sound of infusion pump alarms going off, the “deep breath” noises of doctors listening to children in the classroom, the torture on the faces of the children when they are “summoned” to undergo laboratory tests.

As a unanimous aspect among the teachers we can mention the ability to resume the class and the focus of the children after the breaks, notoriously already adapting their practices to the context, permeated by different subjects, with different functions, however, incisively articulated, evidencing the professional ethics, initiative, and dynamism, present mainly due to the fact of dealing with the

particularities that permeate the hospital environment: “well, we work inside the oncology hospital, but our role is pedagogical, it is a public school inside the hospital, giving continuity of education for that student who cannot attend their home school in the municipality where they live (Teacher Paula)”.

We perceive that the teacher's roles in these spaces go beyond the pedagogical parameters, expanding the didactic objectives, and incorporating new challenges not prevalent in regular schools. We noticed this when the teachers were concerned about the children's hydration, the faces of concern when questioning whether the treatments were being effective, the times they asked if they were unwell, if they had the energy to continue the activities, in the mobilization for involve the situation of children in activities to alleviate suffering.

In the classroom, affectivity permeates the teachers' pedagogical practice. The relationship of trust established between the teachers and the children was evident, which was fundamental for conducting the teaching-learning process. Whenever they completed the activities, the students insisted on showing them what they had done to receive praise and words of motivation. Actions that had a positive impact on restoring the children's self-esteem. At times, we witness the visit of former students from the class, they stopped by to hug the teachers, utter words of longing and expose the positive post-treatment recovery, reinforcing the affective bond existing between both parties, which is maintained even when the treatment ends, permeated by respect and admiration.

This atmosphere prevailed in the teachers' relationships with the children's mothers, which even predominated as companions of Child Oncohematology. They place expressive confidence in the work of the teachers. They were always concentrated close to the class, waiting for the end of the activities, occasionally they enter to check if the children need anything.

Through a WhatsApp group, the teachers and mothers were in constant communication, sharing photos of activities that the children did in the classroom, overcoming and advancing, playful moments of relaxation, and solving doubts.

In one of the statements from the teacher's speech, we note the contrast between the way the teacher is seen at school, and the projected view when he works in other spaces, in this case, the hospital environment:

At school we are protagonists, but at the hospital, we are not so protagonists, because the school cannot harm, de-authorize, disrupt, or unbalance the work carried out by health, so let's do the work from the perspective of contributing, from the perspective of doing so that this student can resume his routine, learn again, but that all this we are going to work with him is not a factor of negligence to damage his health, which at that moment is a priority (Professor Paula).

The impasses that arise in the mediation of the education process in the mentioned place were revealed in the teacher's discourse and verified by us in the observations, with the teachers having the task of managing a range of pedagogical and administrative attributions.

TEACHING PRACTICE AND THE LITERACY PROCESS IN THE HOSPITAL CLASS

Maintaining a connection with the school of origin is essential for sharing information about the sick student's education process. This intermediation occurs because children are hospitalized for months, most of them from the interior of the state of Pernambuco and other northeastern states. It is impossible to go to school in the municipality where the student is enrolled.

Given this context, when admitted to the hospital where the hospital class is located, the parents of children who are from group IV of early childhood education to the early years of elementary school, receive a series of guidelines.

The hospital class teachers get in touch with the school of origin through a referral letter, presenting what the hospital class is, what its role is, and the methodologies used. They also request the student's data, information about the teaching-learning process, difficulties, and the teaching program that the municipality or school follows.

The aforementioned data were provided by the class teachers and also by the mothers interviewed, and it is possible to exemplify in the excerpt below (Isabel's pseudonym):

I received all the guidance, and as soon as she was hospitalized, in the first hospitalization she had here, the teacher called me into her room and started to explain... I didn't understand how the process was going to be, I said: how is it going to be?... her school there, then when she explained everything she said: look, I want to get in touch with her little school in Campina Grande so they can tell me everything, that we follow up so she doesn't miss the year. That's when I understood that it was important (Isabel).

The hospital class teachers flexibly teach all areas of knowledge, adapting to the conditions of the students. During the observations, we were able to follow the process: the activities reach the hospital classroom via email and WhatsApp, the teachers catalog the activities, analyze and prepare the material according to what the school of origin sent, then attach it to the individual student folders. We emphasize that this information is also passed on to parents. Element present in the mother's speech: "the school sends the tasks here because you have to follow the content they give there, which she (the teacher) here, continues to not miss anything (Flávia)".

It is worth emphasizing that the activities sent by the teachers from the school of origin go through a process of analysis, adaptation, and adjustment to the context in which the child is, being the weekly planning day of the hospital classroom teachers (Friday), for these procedures. We emphasize that it is a crucial moment for discussion among the teachers to define the most appropriate didactic actions for each content, above all, sharing the children's concerns, difficulties, and progress, as well as deciding which are the best didactic resources to be used, relevant themes to be worked on and what should be prioritized at that moment for each student.

The particularities that involve the hospital sphere make pedagogical planning a great dilemma for teachers, achieving didactic objectives in the face of the entire context that surrounds the environment; on the other hand, the specificities of students, a daily workload of only 1 (one) hour that each student spends in the classroom demonstrates a great challenge. About this point, Teacher Paula claimed:

It is interesting to mention the need to be resilient, not to be a rigid professional (...) when we study planning, we understand that planning is a flexible instrument, so in the classroom, it will be much more flexible, given the specificity, before the peculiarity of the work, before this class. So, we go... find the child one way and then we'll find another. If you do a whole plan for that student, with a pedagogical time of one hour, which is the oriented one, and then he has the access hand that he writes free and then he has access to the writing hand, then you will not be able to do a writing activity with him that day or at that moment. So we will need to reorganize, so the child was in a certain way and then there was an incident... and then, when you are going to carry out the activity, you are going to look for ways, strategies, methodologies to organize that student's life, which are activities significant because the time we have to work with him is short (Teacher Paula).

The teacher's statement is related to what Fonseca (2008) defends about the systematization of planning in the hospital class, which must be adjusted to the needs and what calls the students' attention, running the risk of facing paths that, although not planned, may cause changes in their development and learning process.

We point out that the teachers also work dates of historical events (we follow the week of black consciousness), through playful activities, always respecting the state of the children. We know that given the intense treatment, moments of indisposition, fatigue, and nausea are frequent in the classroom routine, the teachers were always alert to these situations, frequently questioning the students about how they felt.

Upon arriving at the oncology sector, the teachers pass by all the beds to check the conditions of the children and make an assessment (they record the name, year of teaching on the board and whether or not they will be able to go to class) on which students are in conditions to move to the classroom to participate in the class. Those who are unable to get out of bed, perform activities adapted to their clinical situation, in their room, with one of the teachers. Matos and Mugiatti (2009)

define this type of methodology as school-based hospitalization. We found that in the hospital classroom, the two methodologies of hospital pedagogy are implemented: the hospital classroom and school-based hospitalization. In addition to monitoring during the observations, this data was reinforced in the speech of the mothers interviewed “when she can go to the little room when she can't, the teacher goes to the bed and teaches there (Isabel)”.

We observed the application of the school hospitalization methodology when faced with the impossibility of children getting out of bed (in some cases this occurs under medical order). On the second and third days, the two methodologies were used, those who could go to the hospital class, were, those who were unable, to receive care in bed.

According to the teacher:

When all children enter the classroom, they undergo a diagnostic evaluation, because even if they are in the second year, for example, we even have several in the second year... it will provide a basis for how the contents will be worked on (Teacher Paula).

In the classroom, the diagnostic evaluation is a key element, it guides the way the teachers prepare and conducts the students' work plan. We stress that, according to the teachers, they can be enrolled at any time of the year, and their performances are recorded in individual reports.

In the case of children who enter childhood oncology without actively enrolled in a school, it is carried out in the municipal network of Recife, specifically in the school installed on the university campus where the class is located.

When asking Professor Paula about the literacy process of children in the hospital class, we got the following answer: “In the literacy process, we work like in the network, phonological analysis, starting from what the child understands of this phoneme and grapheme relationship, then the people are working on phonological awareness and we are expanding the writing and learning process” (Teacher Paula).

Faced with our experiences in the classroom, in the literacy process, we realized that the perspective of literacy is aligned. Each day of the week, a specific area of knowledge (discipline) is worked on, and a schedule with this distribution is fixed at the door of the classroom; however, literacy practices are daily, transversally, permeating all disciplines.

The teachers start from the children's prior knowledge to incorporate everyday situations into activities so that they can understand and exercise the social function of reading and writing. We witnessed, for example, the construction of a family tree (through charades, children had to guess and name the degree of kinship); the production of the daily textual genre; construction of stories collectively, each day the children created excerpts of the story and the teacher recorded it on the board, to later produce a book with the stories produced by the children in the hospital class and publish it; storytelling problematizing situations that permeate life in society, such as prejudice, racism; word production activities with the movable alphabet, writing the names of geometric figures, making “abayomis” dolls, searching for African names for the dolls in the black awareness week; and others, highlighting the importance of literacy practices in the process of appropriating the alphabetic writing system.

We witnessed a continuous stimulus to reading, always at the end of classes, the children were invited by the teachers to go to the reading corner, available in the classroom, where the books are arranged. They selected a copy and took it to the beds to read it. The teachers always suggested books, generally literary genres and informative books on how to deal with cancer, on oncology, with colloquial and playful language, but also, they left the children free to choose the books that most attracted them. In the case of children who suffered an amputation, the teachers made a point of taking them in their arms and taking them to the reading corner to choose the book, a moment that reveals the affection that permeates the work of the teachers. As for the children who are unable to get out of bed, the teachers selected and took the books to them, who were waiting anxiously for the visit.

Whenever the students returned the books, the teachers asked what they had thought of the reading, and if they had liked the book. It is worth noting that the hospital class reading corner is a

relatively new space, opened in August 2019.

In addition to the planned themes, during the classes, questions arose mainly related to the writing of words. The teachers appropriated these questions to promote new challenges, encouraging the group to help their colleagues to solve their doubts, with the mobile alphabet always ready for these word production situations.

Given the way children are organized in the class (in most activities each table accommodated five students), the interaction between them was constant. During the activities, those who were in more advanced writing hypotheses helped those who were at the beginning of the process, generating conflicts and reflections about the functioning of the SEA. We emphasize that the teacher's mediation in this phase directly influences the meaning that students will attribute to reading and writing skills. Regarding this issue, Kleiman (2007) highlights:

The difference between teaching practice and teaching so that the student develops a competence or ability is not a mere terminological issue. At school, where a conception of reading and writing as competencies predominates, the activity of reading and writing is conceived as a set of progressively developed skills until reaching an ideal reading and writing competence: the proficient writing user. Literacy studies, on the other hand, start from a conception of reading and writing as discursive practices, with multiple functions inseparable from the contexts in which they develop (KLEIMAM, 2007, p.02).

LAWS OF HOSPITAL PEDAGOGY: THE DICHOTOMIES BETWEEN THEORY AND PRACTICE

Despite the legal contributions in favor of hospital pedagogy existing since 1969, unfortunately, there is the impracticability of legal vehicles. On the one hand, there are the public authorities that do not show the slightest interest in executing what the Laws, decrees, guidelines, normative instructions, and regulations preach; on the other hand, there is the population that is unaware of the rights guaranteed through these devices. Consequently, there are gaps in the propagation of this information, resulting in the absence of mobilizations and demands in favor of the cause. To circumvent this neglect, the hospital classes in practice are supported by special education laws. According to the class teacher:

Regarding the legal framework, it is still fragile, in general, the MEC before 2000, was much closer, it even has the document (hospital classes and home pedagogical care guidelines and strategies) (...) at the national level the In hospital classes, they seek to be linked to special education in general, so we end up using the entire framework of guaranteeing the right in this perspective of inclusive education (Teacher Paula).

The teacher interviewed knew about the legal framework of hospital pedagogy. During the interview, she performed an overview of the “legal timeline”, starting from the first legal provisions, to those that are currently in force. We relate this condition to the fact that she was a pioneer in this field in the State of Pernambuco (the first teacher, from the only hospital class in Pernambuco), justifying the level of ownership when referring to the historical/legal path.

Concerning the municipality of Recife, the teacher stated that even though there was a municipal decree governing hospital classes, there were numerous challenges encountered in the implementation process:

At the municipal level of Recife, when I went there so that we could implement the hospital class, one of the struggles was to ensure legislation, there is a municipal decree that institutes the hospital class, from 2015, and there is also the normal instruction that came out in September 2015, because one institutes the hospital class and the other informs, explains, guides how this hospital class will work. Now, each state, the MEC does not have this direction and as it has not yet managed to reorganize all this part, each state does it its way (Teacher Paula).

With the enactment of Law 13,716 in 2018, to ensure nationwide pedagogical hospital monitoring for basic education students unable to attend school due to health treatment, at the hospital or home level, the hopes of hospital class teachers, precisely because the device is added to the LDB, which is the most relevant law in our country concerning education:

We are in the perspective of transforming this pedagogical work into a teaching modality...the change at the national level of the LDB of 2018, indicates more strongly the right of this student who is undergoing treatment to continue education but still needs greater regulation, of guidelines, of normative instructions that ensure this right is ensured (Teacher Paula).

The three mothers interviewed stated that they did not know about the Laws of hospital pedagogy before their children were admitted to the classroom. Information about these Laws, the importance of the hospital class, and how it works, was provided by the teachers when the children started treatment in childhood oncology:

I never heard that she would have the right, you know?! I found out after a few months that it was their guaranteed right, about the school, I didn't know the class either, I only found out that the school would exist exactly on the day my daughter was hospitalized, that the teacher talked to me (Bruna). I just found out here, I didn't know it existed. When I got here and I saw it, I said: my God! like this... everything, everything is new, I had never been there, I had never been in a hospital like that for children with cancer. I came to see everything here (Isabel). No, I've never heard of it (Flávia).

Given the mothers' reports, we reflect on the consequences that the absence of disclosure and especially the implementation of what the legislation promises, to offer to the public which leaves schools to undergo treatments. The principles set out in the Federal Constitution that treat education as a universal right are called into question: "Education is everyone's right and the duty of the State and the family, it will be promoted and encouraged with the collaboration of society, aiming at the full development of society, for their personal development, their preparation for the exercise of citizenship and their qualification for work" (BRASIL, 1988). We realize that from the moment the individual is facing a process of illness, he is forced to cruelly face the neutrality of the State and social impartiality.

FINAL CONSIDERATIONS

We know that receiving a diagnosis of cancer generates immeasurable impacts, especially when it comes to childhood illness. The family dynamics and the child's routine change, the insecurities that permeate the evolution of the disease and the prognosis arise, and the conception of finitude that unfortunately is still intrinsically linked to cancer.

Access to hospital pedagogy provides hospitalized children and adolescents with not only the continuity of the education process, but also promotes perspectives for the future, contributes to the much-desired cure, and to the continuation of life projects: "hospital classes do not it is simply to continue education, it has other factors, it contributes to the improvement of the patient who is undergoing treatment, it reduces pain, anxieties, fears... (Teacher Paula)".

The Semear hospital class projects children into another universe, in the short daily workload available, in a playful way, intersperses regular content with games, respecting the particularities of each child. It brings out the potentialities that exist within each subject, minimizing the stress that permeates the hospital context, this reverberates in the meaning that students attribute to this space:

My daughter prefers the school here to the regular school, you see... and she is here because of the treatment, but the little school leaves her so well that she prefers... she says: I like the little school at the hospital. I think it's because she distracts, it's not just the same as in the normal school, it's not the same literally (Isabel).

We found that enabling the continuity of the literacy process of these children is crucial to maintain the connection with life in society, important mechanisms for the overall development of the individual, with repercussions on cognitive, emotional, affective, behavioral, and social aspects. Our research enabled us to perceive the emerging need of children unable to attend school to participate in effective literacy practices, in addition to guaranteeing a right, access to practices that involve reading and writing skills have repercussions on the visualization of new perspectives that often are wiped out

by the diagnosis. Given this, we found that the contributions go beyond the bias of education, the literacy process of this very peculiar public is seen as synonymous with hope and resistance.

We emphasize the urgency that exists around the emergence of new research in favor of hospital pedagogy, the propagation of pedagogical follow-up, and the creation of public policies that put legal contributions into practice. In this way, rights are assured, within the scope of national, state, and municipal. It becomes essential that we, as a society, fight to claim the effectiveness of these guarantees.

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Autora 2: Coordenadora, participação na análise dos dados e revisão da escrita final

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CONFLICT OF INTEREST DECLARATION

The authors declare that there is no conflict of interest with this article.

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