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The experience of suffering: stories told by hospitalized children*

A EXPERIÊNCIA DE SOFRIMENTO: HISTÓRIAS NARRADAS PELA CRIANÇA HOSPITALIZADA

LA EXPERIMENTACIÓN DE SUFRIMIENTO: HISTORIAS NARRADAS POR NIÑOS INTERNADOS

Raquel Candido Ylamas Vasques¹, Regina Szyllit Bousso², Ana Márcia Chiaradia Mendes-Castillo³

ABSTRACT

The objective of this study was to learn about the experience of suffering in hospitalized school-aged children. The methodological strategy used was narrative inquiry, and the Model of Suffering as the theoretical framework. Participants were 14 children. Data collection was performed using semi-structured interviews, guided by the following question: Tell me your story about getting sick and coming to the hospital. Results show that hospital events comprise the child's experience of suffering, represented by five categories: knowing the suffering caused by the disease; enduring to survive the experience of being ill, relaxing from enduring to free their emotions, living the suffering, and floating between enduring and suffering. The suffering or enduring of the child is determined by the context of the experience and by the support or interactions that surrounds them. In conclusion, nurses have the duty to offer children opportunities to express themselves and make the suffering bearable.

KEY WORDS

Child, hospitalized.
Stress, psychological.
Pediatric nursing.
Narration.

RESUMO

O estudo teve como objetivo conhecer a experiência de sofrimento de crianças em idade escolar hospitalizadas. Como estratégia metodológica, utilizamos a pesquisa de narrativa e como referencial teórico o Modelo de Sofrimento. Os dados foram coletados com 14 crianças, através de entrevistas semiestruturadas, norteadas pela questão: Me conte a sua história de ter ficado doente e ter vindo para o hospital. Os resultados mostram que os eventos hospitalares compõem a experiência de sofrimento da criança, identificados em cinco categorias para os eventos narrados: conhecendo o sofrimento causado pela doença; tolerando para sobreviver à experiência de doença; relaxando na tolerância para liberar suas emoções; vivendo o sofrimento e flutuando entre a tolerância e o sofrimento. O sofrimento ou tolerância da criança é determinado pelo contexto da experiência e pelo suporte ou interações que vivencia. Concluímos que oferecer oportunidades para a criança expressar-se e tornar o sofrimento suportável é obrigação da enfermagem.

DESCRIPTORES

Criança hospitalizada.
Estresse psicológico.
Enfermagem pediátrica.
Narração.

RESUMEN

El estudio tuvo como objetivo conocer la experimentación de sufrimiento en niños en edad escolar internados. Como estrategia metodológica, utilizamos la investigación de narrativa, y el Modelo de Sufrimiento como referencial teórico. Los datos fueron recolectados a partir de 14 niños, a través de entrevistas semiestructuradas, orientadas por nuestra pregunta: Cuéntame la historia de haber caído enfermo y haber venido al hospital. Los resultados muestran que los eventos hospitalarios componen la experimentación de sufrimiento del niño, identificándose cinco categorías para los eventos narrados: conociendo al sufrimiento causado por la enfermedad; tolerando para sobrevivir a la experiencia de la enfermedad; relajándose de la tolerancia para liberar las emociones; viviendo en sufrimiento y fluctuando entre tolerancia y sufrimiento. El sufrimiento o tolerancia del niño se determina por el contexto de la experiencia y por el soporte o interacciones que experimenta. Concluimos en que ofrecer oportunidades para que un niño se exprese y transforme en soportable el sufrimiento es obligación de la Enfermería.

DESCRIPTORES

Niño hospitalizado.
Estrés psicológico.
Enfermería pediátrica.
Narración.

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INTRODUCTION

Children's disease and hospitalization can modify their own and their family's daily reality to a greater or lesser extent. Therefore, the experience is seen as a critical and delicate situation for the entire family system and can be an important source of suffering.

It is important to acknowledge hospitalized children's affective, psychological and emotional issues during this experience, as they are part of the child development process⁽¹⁻⁵⁾. The children's answer to the disease depends on their cognitive development, past experiences and knowledge level⁽⁶⁾. The way they communicate and express themselves is potentially influenced by the physical, social, economic and political contexts. If we take time to listen to them, we can perceive the disease's dimension in their life, how it is experienced in a singular way by each individual child⁽⁵⁾.

Some studies discuss the meaning of the disease and hospitalization process for the children, using their own experience as an information source and also considering the family, jolted by the experience of the child's illness. These studies show that the children stay focused on the care they receive from the family and the health team, can describe the meaning of receiving care, manifest their physical care needs⁽¹⁾, want to be understood and feel loved⁽²⁾, and also supported when obliged to face difficult situations^(4,7).

The disease and hospitalization can entail countless forms of suffering for the children: experience of separation^(4,8), pain^(4,9), physical discomfort due to the disease⁽⁴⁾; the intense handling of the body during inevitable procedures and the disease itself and hospitalization; restriction of daily activities; fear of death, the disease and its worsening⁽¹⁰⁻¹¹⁾. In chronic illnesses, the children's daily life is particularly modified, often by physical limitations, resulting from signs and symptoms of the disease, and they can be frequently hospitalized for tests and treatment as the disease progresses⁽⁵⁾.

Suffering is considered the social response and can provoke several reactions; hence, nurses should be sensitive when delivering care to patients in suffering. To understand and relieve the suffering, nursing professional need knowledge on the suffering experience, as well as answers and the needs of those who suffer.

Hence, greater knowledge and understanding of hospitalized school-age children's feelings, way of thinking and the meaning of their experience becomes fundamental, justifying the accomplishment of this study.

OBJECTIVE

Get to know the experience of suffering among sick school-age children.

METHOD

To conduct this study, narrative research was used as the methodological framework, as its permits understanding school-age children's experiences of suffering in hospitalization situations. Narrative research is the alternative to produce an understanding and explanation of people's stories and, also, the possibility of exploring a singular experience⁽¹²⁾. Essentially, the narrative is the way to examine and interpret human action and the way people attribute meanings to life. It looks at the story itself, so that the research can see how, in the interviews, the respondents impose the order of the experience flow, so as to give meaning to the events and actions in their life⁽¹³⁾.

The way they communicate and express themselves is potentially influenced by the physical, social, economic and political contexts. If we take time to listen to them, we can perceive the disease's dimension in their life, how it is experienced in a singular way by each individual child.

The Suffering Model was used as the conceptual framework⁽¹⁴⁾. The Model was developed to distinguish between the concepts of **enduring** and **suffering**. The authors argue that, despite the interest in suffering, enduring – a strictly related concept – has been ignored in literature. The Model illustrates the relation between the two concepts – ENDURING AND SUFFERING – as two broad and diverging states of behavior and explains the conditions in which individuals migrate inside these two states.

According to the model, enduring is the response that emerges when people have no other choice but to go through the situation. Enduring is described as work; the goal of enduring people is to maintain control and, therefore, they consciously suppress their emotions. When enduring, they are afraid to give in to their emotions and not to be able to go through the experience; therefore, they are extremely focused on the presented, do not let themselves be felled by the devastating past and attempt not to think of possible future developments of what they have tolerated in the present.

Eventually, when they are "ready", that is, strong enough to acknowledge what is being endured, they are touched by the suffering. According to the authors, acknowledging includes understanding that the incomprehensible is actually true and has already happened, but does not imply acceptance.

Suffering is the emotional response to the phenomenon that has been endured or the anticipated response to a lost, destroyed future or to a present/future that has irreversibly been altered because of a past event. According to the Model, the connection between enduring and

suffering consists in the fact that people start to suffer when they are ready to acknowledge what they are enduring; this does not mean that they moved to another stage, but that they can fluctuate between enduring and suffering several times, characterizing a cyclical relation between the two concepts.

Place of study and research subjects – The study was accomplished at the Pediatrics unit of a public teaching hospital in São Paulo City, which offer pre and post-surgery clinical care. Before starting, the Institutional Review Boards of the University the project was affiliated with and the institution where data were collected assessed and approved it under number 578/2006 and 06/06, respectively. Before data collection, the parents signed the informed consent term and the children were consulted as to their desire to participate. Study participants were 14 school-age children who were going through or had already gone through the hospitalization experience for at least 48 hours, independently of the diagnosis. At the time of the research, the children should be physically and psychologically apt to answer the research questions, without discomfort or pain that could alter their narratives.

Data collection – Data were collected through semi-structured interviews, guided by a central question, *Tell me your story of getting ill and coming to the hospital*. During each interview, notes were made on the reactions and emotions that emerged on both sides with a view to a better understanding of the moment. To use child-directed language, the interviews were adapted from childhood books⁽¹⁵⁻¹⁶⁾ on themes related to hospitalization and aspects of coping with the bad things that happen in life. This strategy aimed to approach the child to the research theme, facilitate the narrative, and was also a way to *break the ice*. As mentioned, it is important to find ways to approach the children's viewpoints which respect their experiences.

The use of drawings as therapeutic tools and in social science research has been limited for children. Drawing was a useful tool to relax them and conquer their interest and confidence⁽¹⁷⁾. Besides, it served as material to compose the children's verbal narrative. Some of them decided to complete their narratives with drawings on the hospitalization and suffering situation. The dramatization of the situation helped to get deeper into their experience, which might be camouflaged by their little developed speech.

Interviews were recorded and fully transcribed soon after they were held so as to avoid losing significant data.

Data analysis – The narratives were organized according to the story elements: Characters, Scenario, Problem, Actions and Solution. Data analysis consisted in data preparation and organization with a view to their reduction in themes, using a process of coding, condensation and, finally, presentation in a discussion⁽¹⁸⁾. The above-described Model of Suffering served as the framework for data analysis.

RESULTS

Based on the previously presented theoretical model⁽¹⁴⁾, next, the results obtained from the children's narratives are presented.

The child's experience is represented by five categories:

- **Knowing the suffering caused by the illness:** which evidences the arrival of the disease itself, where a new process starts in their life, having to change some daily activities, as the disease is evident, causes discomfort and indisposition and leads to hospitalization.
- **Enduring to survive the disease experience:** when hospitalized, the children see their integrity threatened and react at the moment of hospitalization by enduring the experience, without showing their emotions.
- **Relaxing from endurance to release one's emotions:** when the children's energy is exhausted, representing the moments when they cry compulsively, with attitudes of indignation, protesting and expressing their discontentment.
- **Living the suffering:** when the children understand the disease and perceive that they depend on treatment to get out of the hospitalization situation; this does not mean, however, that they accept being or feeling ill.
- **Fluctuating between enduring and suffering:** when the children do not go through the experience in a linear way, but experience some moments of endurance and others of profound suffering.

Knowing the suffering caused by the illness

Suffering is defined as an emotional response to a phenomenon that has been endured, or an anticipated response to the lost or destroyed future, or to an irrevocably altered present⁽¹⁴⁾.

Through the children's narrative, it can be confirmed how the disease process starts and when the need for hospitalization comes up, as they describe and report the facts, narrating when the disease entered their lives. After the disease arrives, they perceive that this event is not a normal situation, and then a new process starts, which also involves the family nucleus they are part of, having to change some daily activities, as the disease is evident and causes discomfort and indisposition.

I went to hospital because of the disease. I do not manage to get the phlegm out... (AC).

The arrival of the disease imposes the condition of total dependence on the children with regard to the preservation or recovery of health, whose loss modifies their life and entails physical, social and emotional repercussions. The child narrates this loss or the arrival of the disease accompanied by other losses. As they are physically weakened, without being able to do activities they used to be-

fore the disease, they refer to the loss of mobility as a problem in the disease experience.

... staying in bed [...] it is difficult because she is not like the other children, because it's not the same... (O).

That is the new reality for the children. They perceive that everything is different and do not always find what they are looking for, having to adapt to the current situation, even if that bothers them. The restriction imposed by the intravenous medication can also be the triggering factor of the mobility loss.

... it's bad to stay in hospital because I cannot get out of here, because I have to take this medicine in the vein (JV).

The arrival of the disease and the need to start treatment determine a new routine for the children, especially when they need to move to the hospital. The children's withdrawal from their environment and hospitalization in another, which is still unknown, entail the loss of their privacy and daily reality. Hospital routine, structured to guarantee the treatment or cure of the disease invades the children's lives, impeding any possibility for them to exercise their autonomy.

You have to do everything they want, when they want it [...] Everything they do to us hurts (O).

Together with the loss of health and the start of treatment, the children experience the loss of being free from pain. The uncertainty about the arrival of pain or the possibility of having to give in to it is another important aspect in the children's disease experience.

The pain here (pointing to the chest) [...] Sometimes I wait for the pain to pass (M).

The loss of family and social context is also present in the children's experience. They perceive this when they perceive the reduced possibilities of being comforted and feeling less vulnerable in the disease and hospitalization experience.

What is making me suffer is to stay here [...] and not being able to leave and I miss my grandma (M).

... My mom helps, she stays with me and holds my hand [...] that helps me... (J).

The losses compose the sick children's suffering and, thus, define the context of suffering they experience.

Enduring to survive the disease experience

The state of enduring can be defined as a result of the decreased emotional response while the person goes through stress experiences⁽¹⁴⁾. Enduring is essentially the ability to take distance from emotions, strengthening the person to do what has to be done in that situation. According to the authors, it is an innate and necessary behavior that allows people to continue exercising their daily functions.

When hospitalized, the children see their integrity threatened and react at the moment of hospitalization by enduring the experience, without showing their emotions. The researchers' observations revealed that, when they get to hospital, they react by remaining quiet and paying attention to everything that is said. Little facial expression is present and mouth and lip movements are discrete; the children speak almost inexpressive and monotonously, using short sentences and with a distant look.

The child seemed very timid, silent... seemed sad; only answered when a question was asked (Observation by M).

These data are in line with expressions of endurance which, according to the Model, occur at different intensity levels, depending on the severity of the threat⁽¹⁴⁾. The children find themselves quite threatened at the moment of the hospitalization and the narratives reveal their efforts to stay strong. They fight, attempting to survive the losses the disease and hospitalization causes and to maintain control in order to avoid causing further suffering to family members. Therefore, they react by enduring. In the narratives, the children reveal that they need to be strong to support hospitalization and defeat the disease.

You have to be strong [...] I think I'm a bit strong [...] You always need to be strong [...] I help myself to be strong... (O).

At different times, they go through this experience and not necessarily accept or agree with the procedures, but endure them, as they believe that they will not be able to stand going through the experience if they lose control.

I'm strong, because I don't cry. You need to be strong when they lose the vein [...] it hurt to get another one, but I didn't cry (Y).

For the children, enduring is not an easy task, on the opposite, it is very hard. When enduring the experience, they fight against their emotions. They do develop some competencies though, which help them to stay strong, to control themselves; they concentrate their energies so as to effectively participate in the experience. They pay attention to what happens around them and to what is said, and learns about the disease and treatment.

I know I can do almost everything [...] After I got ill I cannot play a lot, run a lot, jump... (K).

In order to be able to endure and keep control, the children focus intensely on the present moment of the experience. They do this at all times when they act, enduring the experience: feeling pain or being obliged to undergo painful procedures, like when they cannot breathe, when they have to deal with the uncertainties of the moment and live with important losses.

It's difficult because it hurts [...] we cannot even cry because everyone's watching... (J)

...I couldn't breathe because it hurt so much... (G).

Hence, endurance is the skill that allows the children to experience unpleasant situations, doing what has to be done. Their concentration on the present serves to oppress past experiences or prevent negative thoughts about the future, which is uncertain and misunderstanding to them.

By enduring, the children present a firm attitude regarding their individuality and feelings towards the experience and try to convince themselves that they can cope with and even overcome the difficulties through coping strategies they gained during their hospitalization, like when they say they are strong or affirm that they do not cry when they take medication or when they are going to have a blood test, or because they know that there is nothing else to do but coping and resisting.

By suppressing their emotions, the children reveal the particularity of their experiences, which turns endurance into an individual state. Like in the Model⁽¹⁴⁾, the focus on the present when enduring the experience allowed some children to go through difficult immediate situations and continue taking care of their health instead of giving up or getting emotionally disintegrated, being incapable of continuing with daily events.

Enduring demands much less energy than emotional release or expression, i.e. suffering. The state of enduring allows people to preserve energy, keep control and remain focused on the present to support the unbearable. When people's conditions worsen, fatigue is oppressed and they give up enduring⁽¹⁴⁾.

...you do not manage to do anything, you want to give up [...] I am suffering. But, you know? Sometimes I want to die [...] Because then I wouldn't suffer anymore, I wouldn't have to stay still like this... (O).

Hence, when they can no longer resist the stress imposed by the disease and hospitalization, nor treatment, pain and losses in general, they respond by expressing emotions uncontrolledly, demonstrating irritation and aggressiveness towards the people around them.

I only got revolted after I stopped walking [...] I didn't do anything to feel better. I just got revolted... (O).

Thus, the energy suppressed when enduring ends up being released compulsively. That is why children, during certain phases of the hospitalization experience, cry compulsively, show attitudes of indignation and protest, expressing their discontentment. These protests allow them to release the repressed energy and get rid of what they were enduring. The children in this study narrate their protest due to situations they do not accept or no longer support – when undergoing procedures, when they are alone.

Expressing emotions uncontrolledly can happen sporadically, as a way to get rid of the decision to endure and, when the children have reached the limit to continue controlling themselves in the experience. When someone endures or resists the release of their emotions, they spend a lot of energy and tend to exhaust their energy, crying and

showing their vulnerability when finding that they can no longer bear so much suffering⁽¹²⁾.

Relaxing from endurance to release one's emotions

At some moments, the children's energy is exhausted when obliging themselves to live the experience by enduring. Expressing emotions uncontrolledly represents the moments when they cry compulsively, adopt attitudes of indignation, protest, as their main goal is to express their discontentment.

... I get scared, because it is going to hurt [...] So, I cry, I cry a lot. And they say that it won't hurt and it hurts, then I cry more... (T).

When revealing the relaxation of endurance, the children expose their vulnerability. They experience moments when emotions cannot be repressed. The children's manifestation through crying exposed their vulnerability at the limit of their strength, while going through the disease experience.

It's hurting. Didn't I say it hurt a lot? [...] ask her to stop (referring to the mother). It's hurting a lot. You do it aunty because she's hurting me. Look how I suffer, I'm in pain (JV).

Living the suffering

Children who suffer emotionally are sad. Differently from children who endure, they talk to whoever listens, repeating the story about their suffering. It is as if, by telling her story and giving voice to her suffering, it became real. They live with the disease experience and start to feel more at ease at the hospital. They manage to find ways to replace, even if temporarily, some of the losses they experience. They redirect their energy to activities that make them feel better. Thus, they find themselves ready to use the toys and games at the hospital and seem to adapt to the environment they are in and go back to important activities characteristic of childhood, such as playing.

I read some books the aunties bring, I play with the games... (G).

Little by little, the children understand the disease and perceive that they depend on treatment to get out of that situation. They acknowledge that their condition is different from healthy children. This way, they manage to think not only in the present, but also consider past experiences and hope for the future. Thus, they give a healthy response to the disease and hospitalization experience.

Giving a healthy response represents the sick children being able to reveal their concerns, fears, apprehension towards the different situations they experience in hospital.

The experience helps the children to approach their spirituality. That is where the children find strength to think about the future with hope. It is by living spirituality that they manifest their emotions: crying, revealing fear, seeking hope, believing in the supernatural.

To feel better, I believe in God [...] Believing in God helps to decrease sadness [...] Believing He can cure (AC).

Following their beliefs, the children perceive that they are not alone. They believe in their recovery and start to think about the future and the possibility of a normal life, without having to live with the losses they experience in the present.

According to the model of Suffering, people fluctuate between enduring and suffering until they are ready to accept their losses and move ahead, thinking about the future. Thus, the phases of enduring and suffering can be temporary. The people move between enduring and suffering, according to the energy level, context and available support⁽¹⁴⁾.

Fluctuating between enduring and suffering

The definition of suffering, as an emotional response to endurance⁽¹⁴⁾, helps to understand the intersection between these phenomena and the children's different reactions to the disease and hospitalization. Hence, the children do not go through the experience in a linear way, but live moments of enduring and others of profound suffering. It is as if suffering slipped into enduring and vice-versa.

...I got desperate, I thought I wouldn't hold it anymore [...] the doctor told me to pray to get better [...] I'm going to get better and be able to help my mom to clean the house (T).

Suffering is a very anguishing state in which emotions are released⁽¹⁴⁾. The children in this study attribute their suffering to the disease itself and hospitalization, as, when ill, they find themselves vulnerable and going through situations of loss.

DISCUSSION

The narratives provided the opportunity for the children to tell their stories. Besides, the use of books on disease and hospitalization were essential to facilitate the understanding and analysis of the experience.

The Model of Suffering⁽¹⁴⁾ can serve as an instrument, offering orientation to understand this journey of suffering, for the children as well as for the pediatric nurses.

According to these study results, this suffering is articulated with a real-life drama. Its narratives reconstruct the children's lives, who describe the alternative resources they used to get stronger for the experience of suffering.

Daily hospital events compose the children's experience of suffering, as they were not part of their daily reality until then. These are new, marking moments that entail many restrictions for routine life. Hence, the children's suffering or endurance is determined by the context of the experience and by the support or interactions they are faced with.

When people are enduring, professionals should not use empathy, as people are not emotionally available to accept it and, in this sense, empathy can provoke hardly healthy emotional reactions⁽¹⁹⁾.

Hence, in the endurance phase, the children should not be touched, as touch becomes yet another challenge for them to endure, as they are no longer prepared to accept the experience or express themselves emotionally. Thus, it can also be affirmed that stimulating the expression of feelings is not always the best intervention for hospitalized children. Assertions supporting their behavior should be expressed though, such as compliments for their efforts.

On the other hand, when the children are suffering and emotionally strong to express themselves, they need to talk, tell their story, talk about their feelings. At those moments, the expression of feelings should be stimulated, and that can be done through adequate resources for each age range.

The children's behavior needs to be met with attention and sensitivity – as that is what indicates the extent to which and how they are enduring or suffering – and they should be provided with different interaction and care styles, including: staying beside them silently when they are retracted, or acting more actively, for example: taking the child on one's lap, talking, playing, offering them different forms of comfort when perceiving that some children seem to be more at ease in hospital.

This research shows that, by staying in hospital with their children, mothers help them to tolerate the experience. As seen in a Brazilian study, mothers stay with their children, serving as their voice, defending them, facilitating interactions, in short, maintaining the family bond, preparing them for death if that is the case, supporting their children during procedures, giving information, helping them to deal with the losses and, at the same time, facilitating to allow the children to tolerate hospitalization well⁽⁴⁾. Consequently, the children manage to preserve themselves in their place, feel protected to continue enduring and surviving the experience. This study underlines the value of observation as a strategy for nurses to find out what is happening with the children, whose non-verbal behaviors need to be taken into account to receive care. Nurses need to develop skills to observe child behavior, appearance, the children's reactions indicating suffering or enduring, so as to offer them more individualized and comprehensive care.

This study identified relevant spirituality aspects the children revealed, who attributed spirituality with the strength to think of the future with hope. They use spiritual help to support traumatic events of the disease and hospitalization. A study developed to understand the spirituality experience in adolescents with genetic illnesses indicates that it is imperative for pediatric nurses to be alert and develop skills to communicate and assess patients' spiritual dimension, as they describe the disease experience and give meaning to it through connections and spiritual relations, manifested by the anxiety for relationships, for bonding inside the hospital and to continue being what they were before the hospitalization⁽⁷⁾.

In the conception of another international study, the child's spirituality is scarce in relation to the multicultural society and, nowadays, this care aspect probably is not ef-

fective and satisfactory⁽²⁰⁾. According to that author, research involving children in the spirituality area is difficult, not only due to ethical issues, but also because of vulnerability for children to deal with the traumatic events of life.

CONCLUSION

Nursing is starting to explore and acknowledge suffering as a care need – and knowledge expansion on this concept is a great advancement.

This paper mainly contributes by the possibility to get to know children's experiences from a different viewpoint than those used so far. Seeing the children's experiences, focusing on their behaviors and reactions towards suffering brings us closer so as to offer care centering on the children and their families.

By using narrative research, this study establishes its importance as a method, which permits knowledge on school-age children's experience of suffering during the

hospitalization and disease phase. It enables them to understand how their life is changing. The use of narrative research can grant health professionals a deeper understanding of how the children experience the disease and hospitalization.

Research on intervention forms to comfort the children's suffering is recommended, highlighting not only those forms that explore new ways of helping them to bear their losses inside the hospital, but also forms that propose new pain relief interventions.

It is health professionals' obligation to investigate each child's opinions, desires and values, at the children's convenience, including even the most timid and silent ones, who should be given the opportunity to express their opinions and participate in decision making.

The constant search for learning needs to be an ongoing movement, reformulating awareness and emotional resources, beyond the skills that guarantee care, supported by human conducts and compassion.

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