

Suffering in children experiencing a terminal disease: the perspective of parents and professionals

SOFRIMENTO NAS CRIANÇAS COM DOENÇA TERMINAL: PERSPECTIVA DOS PAIS E DOS PROFISSIONAIS

SUFRIMIENTO EN INFANTES CON ENFERMEDAD TERMINAL: PERSPECTIVA DE PADRES Y PROFESIONALES

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ABSTRACT

Little is known regarding the suffering endured by children diagnosed with a terminal disease. The objective of this study was to determine, through the discourse of parents and professionals, the signs of suffering evidenced by ill pediatric inpatients and establish observational indicators. This is a phenomenological and qualitative study. Twenty-six semi-structured interviews were conducted to explore the perspective of parents and nurses in regards to the suffering of children with a terminal disease. Parents and professionals identified the child's suffering with their own. The most frequently identified manifestations were sadness, anger and apathy. Among the reasons for the children's suffering, the parents highlight pain, isolation and uncertainty, with professionals adding the child's fear of dying and of witnessing their parents' suffering. Nurses should provide comprehensive pain management, consider the child's social environment, and encourage communication regarding the end of life.

DESCRIPTORS

Child
Critical illness
Palliative care
Parents
Oncologic nursing

RESUMO

Sabe-se pouco da experiência de sofrimento das crianças com doença terminal. O objetivo deste estudo foi determinar a partir do discurso de pais e profissionais os sinais de sofrimento de crianças doentes na situação de hospitalização e estabelecer indicadores observacionais. Trata-se de estudo qualitativo-fenomenológico. Realizaram-se 26 entrevistas semiestruturadas para explorar a perspectiva de pais/mães e profissionais enfermeiros sobre o sofrimento das crianças em situação terminal. Pais e profissionais identificam o sofrimento da criança com o seu próprio sofrimento. As manifestações mais identificadas são a tristeza, a raiva e a apatia. Entre os motivos do sofrimento das crianças os pais destacam a dor, o isolamento e a incerteza. Os profissionais acrescentam que têm medo da criança morrer e de serem testemunhas do sofrimento dos seus pais. Deve-se realizar uma gestão integral da dor, prestar atenção ao meio social da criança e favorecer a comunicação sobre o fim da vida.

DESCRITORES

Criança
Estado terminal
Cuidados paliativos
Pais
Enfermagem oncológica

RESUMEN

Poco se sabe de la experiencia del sufrimiento de infantes con enfermedad terminal. Se objetivó determinar mediante el discurso de padres y profesionales, las señales de sufrimiento de niños enfermos hospitalizados y establecer indicadores observacionales. Estudio cualitativo fenomenológico. Se realizaron 26 entrevistas semiestructuradas para explorar la perspectiva de padres/madres y profesionales enfermeros sobre el sufrimiento de infantes en situación terminal. Padres y profesionales identificaron el sufrimiento del niño con el suyo propio. Las manifestaciones más identificadas son: tristeza, odio y apatía. Entre los motivos del sufrimiento de los niños, los padres enfatizan el dolor, el aislamiento y la incertidumbre. Los profesionales agregan el miedo del niño a morir y ser testigos del sufrimiento de sus padres. Deben realizar una gestión integral del dolor, prestar atención al medio social del infante y facilitar la comunicación acerca del fin de la vida.

DESCRIPTORES

Niño
Enfermedad crítica
Cuidados paliativos
Padres
Enfermería oncológica

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INTRODUCTION

One of our goals as nursing professionals is to avoid suffering. For this purpose, we need to develop strategies to identify, evaluate and treat suffering when it appears.

Suffering is a state of severe stress associated with the subjective perception of a threat to one's physical or psychosocial integrity⁽¹⁾. It is characterized by the feeling of being threatened, as well as by the exhaustion of personal and psychosocial resources that would allow the person to confront that threat⁽²⁾.

In the context of advanced and terminal illness, many threats to patients' physical integrity may exist: pain and the distress the symptoms produce⁽³⁾, the physical and psychological losses the subject experiences⁽⁴⁾, the diagnostic and therapeutic procedures⁽⁵⁾ or being a burden to other people⁽⁶⁾.

To identify people who are suffering, some authors defend the use of single-item scales, in line with the scales used nowadays for pain. Others have elaborated more complex questionnaires in which they try to cover the distinct dimensions of suffering: physical, psychological, social and spiritual or existential⁽⁷⁾.

Another way to detect suffering is indirectly, through the distinct perception of time in people who are suffering for example⁽⁸⁾, or through the patient's graphic representation about the disease⁽⁹⁾. Patients' verbal demands (analgesia, company, etc.) can also serve as indicators of suffering.

Another sign of suffering can be patients' observable conduct. Developing observational indicators of suffering offers advantages, as this permits access to populations in which verbal expression is confused, limited or almost nil, or contrasts between the patient's verbal information and non-verbal behavior⁽¹⁰⁾.

The way children experience disease and suffering is totally different from adults, also demanding distinct strategies to understand and interpret their discourse and behaviors⁽¹¹⁾. Studies on how terminally ill children experience suffering are scarce, probably due to the ethical and methodological problems involved in pediatric palliative care research⁽¹²⁾.

The perspectives of nursing professionals and parents have frequently been used to approach the reality of severe or terminally ill children. Studies published until date, however, have focused more on parents' needs than on their children's suffering⁽¹³⁻¹⁵⁾.

We believe that parents and professionals' viewpoints can offer fundamental information to get to know children's experience of suffering.

Developing indicators of suffering in the child population can be an effective strategy, as children are not as able to verbally express themselves as their parents, but are very expressive in the non-verbal sense.

The aim in this study is to determine the elements identified as suffering in hospitalized sick children and to establish indicators to detect and interpret suffering in children.

METHOD

We developed a descriptive and qualitative study based on phenomenology, a theoretical-methodological perspective to describe and understand the meaning of health-related phenomena for people⁽¹⁶⁾.

An intentional sample of fathers, mothers and nurses was selected from the hospitalization units of *Hospital Universitario Virgen de las Nieves de Granada* (Spain) between September 2008 and May 2009. The study received approval from the hospital's ethics committee. The following inclusion criteria were used:

Being a father, mother or legal guardian of children in the advanced and/or terminal phase of a disease, defined according to the criteria of the Spanish Palliative Care Society (SECPAL): 1.- Presence of an advanced, progressive and incurable disease. 2.- Lack of reasonable possibilities to respond to a specific treatment. 3.- Intense, multiple, multifactorial and changing symptoms. 4.- Survival prognosis of less than six months.

Only parents of children under 14 years of age and hospitalized during the study period were included.

Nursing professionals who had been working with terminally ill children directly for at least six months and who signed the informed consent term.

Besides the refusal to sign the informed consent term, the following exclusion criteria were established: parents in emotional crisis because their child's symptoms had worsened, because they had received sensitive information on their child's health condition or parents whose children were in agony.

A semistructured interview was elaborated, designed *ad hoc* (Chart 1) and held during a single meeting with each interviewee. Data were digitally recorded and later transcribed.

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Chart 1 – Semistructured interview script

1) In general, what do you consider as suffering?
2) In your experience, what are the alarm bells and signs that your child / the child is suffering?
3) In your perspective, what are the most common reasons for suffering in your child / the child?

To analyze and interpret the data, the sequence proposed by Taylor-Bogdan was adapted⁽¹⁷⁾: 1) preparation of the material through the transcription of the interviews, 2) coding based on the previously defined thematic script 3) data interpretation and description of each category. Two researchers developed the coding and analysis with the help of Atlas.ti 5.2. © software.

RESULTS

In total, 13 fathers/mothers (three fathers and ten mothers) and 13 nursing professionals (11 women and two men) were interviewed.

The parents' mean age was 36.8 years ($\sigma= 5.2$), ranging between 31 and 42 years, while the children's mean age was 5.3 years ($\sigma= 4.1$), ranging between seven months and 14 years

The professionals' mean age was 44.8 years ($\sigma= 11.4$), varying between 29 and 62 years, and they had been working in pediatric care for an average 17 years ($\sigma=14.4$), ranging between one and 37 years.

Three main categories were established related to the interview questions: concept of suffering, signs of suffering and motives for suffering.

Concept of suffering: for the interviewed parents and professionals, defining suffering is complicated. Both groups tend to identify suffering more with emotional issues like feeling, state of mind etc. than with physical issues.

Parents and professionals appoint the lack of control over the situation and the accompanying feeling of powerlessness as characteristic of suffering. Some differences exist though between both groups: to define suffering, the parents use their own experience, instead of their children's, as a reference. Professionals, in turn, tend to use more elaborate and theoretical definitions of suffering, mostly selecting the proposal to identify it as *a response to a life-threatening situation* (Chart 2).

Signs of suffering: parents and professionals agree when appointing the signs of suffering they detect in the children. Both groups mainly identify suffering in the children through verbal and non-verbal language, facial expression, behavior and attitude. These manifestations can reflect sadness, apathy and anger.

Chart 2 – Interview excerpts about the Concept of Suffering

Informants	Interview excerpts
Parents	<i>...I don't know how to describe it, as you feel exhausted, you feel defeated, powerless because you can't do anything, that's what I feel most ... (PA.03)</i>
	<i>It is a mixture of restlessness, ignorance... I get very anguished when I don't have punctual information about what's happening, it's uncertainty (PA.04)</i>
Professionals	<i>a threat that is considered vital, that is, the child thinks, asks you "Am I going to die" although his question does not have the transcendence we adults can do, but you know there's a road there that comes to an end. (PR.06)</i>
	<i>the state of mind, the mental and spiritual pain and mainly the absence to be able to control... to master the situation he's going through (PR.08)</i>

Sadness is externalized through facial expressions and crying; parents and professionals identify apathy through inactivity, silence and isolation; the children express rage through verbal and physical aggression, fundamentally directed at their parents and professionals (Chart 3).

Chart 3 – Interview excerpts about the signs of suffering

Informants	Interview excerpt
Parents	<i>You see her facial expression, you see that she's more sad... the crying and sadness the face shows you... you notice it, of course you notice it (PA.05)</i>
	<i>She shows the rage by grabbing me, kicking me, I know it's a response to the rage she feels inside, because she's affectionate ... (PA.09)'</i>
Professionals	<i>perhaps one of the first signs is silence, little desire to talk, to empathize, to transmit nothing. That lost look when you enter the room and they watch the void and they are hardly responding to what you are explaining or doing at that moment. Right? Or to the encouraging words you are trying to transmit (PR03)</i>

Motives for suffering: although parents and professionals agree that physical pain is the main motive for their children's suffering, some important differences exist in their discourse.

The parents highlight three main motives for suffering: a) the physical pain the diagnostic/therapeutic techniques produce, and the anticipation of this pain b) The children's separation from their habitual environment: school, family, friends, etc. c) Uncertainty towards the near future (hospital discharge, physical sequelae, cure, etc.)

The professionals add other motives for suffering the parents do not address. In the professionals' discourse, as opposed to the parents, the *fear of dying* is underlined as one of the main motives for children's suffering.

The professionals refer to the children's own perception of their immediate context (relative and health professional). According to the professionals, children suffer

when they are *spectators* in situations that may go beyond their ability to understand and perceive that their parents try to hide their concern from them.

Professionals also indicate that children consider the physical sequelae of the disease and/or treatments very important, emphasizing the deterioration of their own image as the cause of this suffering (Chart 4).

Chart 4 – Interview excerpts about motives for suffering

Informants	Interview excerpt
Parents	<i>If there's an anesthetic cream, why don't they put on this anesthetic cream before a prick? My son, who knows the treatment, asks for it: "I want them to put on the cream ". He doesn't want to suffer. And this suffering adds up to and precedes the pain, which is what would come afterwards ... (PA.12)</i>
	<i>The separation from the family, from their environment, from their friends... she's very shy and meeting unknown people..., new faces every day which change with the work shifts ... (PA.09)</i>
	<i>She's thinking about Christmas, about what's going to happen at Christmas, which is her birthday. Today she said "I won't be here in the hospital on Christmas Eve, will I?..." (PA.13)</i>
Professionals	<i>I believe the thing is that the child sees no exit from his disease, they're ready, they see that they don't get well, that the other children are better, that they continue the same, that it's still hurting, that they see no way out, that they believe they're going to do and that they know they're going to die. (PR.10)</i>
	<i>I think it's when the child doesn't understand what's happening, when they don't know what's happening. They feel bad, feel weird and see weird behavior in the people around them, mainly the parents who are their references, because they get to know us here, they may not know how we usually are but they do know their parents, even very small children, who do not talk, they see an attitude and notice a weird feeling, weird behavior in their parents, in the people around them, in the people that give them strength (PR.04)</i>
	<i>the pain and the image of her seeing herself without hair. The same as L. (girl) thinking that they were going to put on a wig, they had to cover up the mirror, it was something horrible to her, seeing that her hair was falling out and that they were trying on wigs, she yelled, yelled. The pain and the worsening (PR.02)</i>

DISCUSSION

For parents and professionals, suffering exists when there are visible signs or a cause they identify as justified. Anthropological studies have shown that the visibility and interpretation of pain and suffering are culturally determined⁽¹⁸⁾. Manifestations of suffering are not universal; To identify indicators of suffering in children, their sociocultural context needs to be taken into account.

Witnessing their children's suffering and being unable to do anything to avoid it makes the parents suffer. For them, it is essential to maintain a protective role, even if their children are under other people's care. They need to participate in their care and provide them with everything they need, thus affirming their parenting role^(14,19-20).

Mainly parents, but also professionals need to be the strong people children should rest on: they cannot show sadness, fear or insecurity in front of the children^(14,19). The professionals reveal that one motive that makes hospitalized children suffer is to perceive that their parents are emotionally vulnerable, despite their attempts to hide it. In this sense, the parents' support for their children is conditioned by their ability to cope with the situation.

Both parents and professionals identify manifestations of sadness, apathy and rage as signs of children's suffering. Sadness, however, is interpreted as a *normal* and *understandable* manifestation of the disease condition the children are in. Apathy, on the other hand, provokes feelings of powerlessness, mainly in the children. The children's manifestations of anger and aggressiveness towards their parents and the health staff, finally, are badly tolerated, perhaps due to the feelings of guilt these arouse in both groups.

We cannot affirm that a child who cries or hides under the sheets suffers less than a child who yells or aggresses, although some conducts are more socially tolerated than others. Suffering is a subjective experience that happens in a social and cultural context⁽¹⁸⁾. Therefore, an indicator of suffering will not be the children's conduct, but the changes in comparison with their habitual behavior.

Parents and professionals highlight pain as the main motive for their children's suffering. The pain the parents refer to, however, is caused by the health professionals' interventions. The children experience this pain as an aggression, which the smallest ones are unable to understand and which arouses rejection and rage.

The children expect the nurses who deliver care to them to be technically competent to treat the pain⁽²¹⁾. In a study that explores the view of a good nurse according to hospitalized children, for them, the ideal nurse *does not harm them*⁽²²⁾.

The parents, on the other hand, signal that their children's suffering starts when they perceive the pain-evoking stimulus, not when the painful situation is being produced. This anticipation of pain, a product of past painful experiences, is reactivated by the actual or imaged presence of the stimulus situation.

In pain assessment, not only clinical (intensity, location...), but also emotional and situational parameters should be considered, which together characterize the painful experience.

It may be very useful for nursing professionals to incorporate interventions like emotional control training, relaxation, distraction or active participation techniques into their care plan, as resources to enable children to better cope with the pain and reduce the feeling of aggression⁽²¹⁾.

Among the motives for suffering, parents and professionals also highlighted the children's isolation and rupture with their habitual environment and uncertainty towards the future. When hospitalized, they are distanced from their friends, siblings, schools and obliged to adapt to a new context, with new faces every day, physical isolation measures, strict times etc. The children may be concerned with their absence from school, with lagging behind and feel that *they are not normal*⁽²³⁾.

Observing the children's behavior, considering their social relations in the hospital environment, especially the relation with other children and the use of common areas like the classroom, the playroom or similar areas, can indicate suffering if difficulties emerge to adapt to the context, symptoms of social isolation when there are no impediments, or hostility towards the presence of other children.

Finally, according to the adults, another motive for suffering is uncertainty, in accordance with existing literature⁽⁴⁾. The interviewed parents reveal that the children express uncertainty with regard to situations like hospital discharge, surgical interventions, always short-term situations. As opposed to the professionals, however, they do not make any reference of uncertainty towards the medium-term future, nor towards the fear of death. Parents do not mention this, neither when talking about themselves nor when referring to what their children express. We believe that parents may keep this theme silent, in view of studies in adult populations indicating the fear of death as a frequent source of suffering⁽²⁴⁾, although these studies should be expanded to child populations.

The parents' disbelief that their children may die results in a very generalized situation, in accordance with different studies^(13-14,20). In this sense, the fact that the parents do not talk about death in any way may be due to the desire to focus on the immediate, on *doing things*, in which they can keep up hope⁽¹⁴⁾.

This is in line with the results of an ethnography, in which patients and relatives' need to cling on to a false belief in recovery is described, as a way not to openly acknowledge the adverse reality lying ahead of them and the consequences it may entail⁽²⁵⁾. In our study, considerable influence from sociocultural factors may exist as, in Spain, like in other Mediterranean countries, an attitude exists that is opposed to open and direct communication

with the patient, in which death and dying are avoided and silenced themes⁽²⁶⁻²⁷⁾.

In conclusion, the analysis of the parents and professionals' discourse about their perception of the terminally ill children is a very useful information source to further elaborate knowledge on the particularities of children's experiences of suffering. We need to stop and consider the nuances of suffering in this phase of life in order to be able to evaluate and plan the care each child needs individually.

In conclusion, we have summarized the main recommendations for health professionals as a result of our study: changes in children's conduct need to be considered in comparison to their habitual behavior. The emotional support parents grant to their children needs to be valued, as well as whether the children perceive their parents' vulnerability and, in this case, if this affects them emotionally. For pain assessment, not only physical, but also emotional and situational parameters characteristic of children's pain experience need to be considered. It is very important to evaluate children's social relations in the hospital environment, especially the relation with other children and the use of common areas. Finally, it is crucial to assess the children and their parents' expectations with regard to the disease.

CONCLUSION

When parents try to define what they consider as suffering, they are talking about what makes them suffer at that moment: uncertainty, powerlessness and lack of knowledge. Professionals, in turn, tend to use more elaborate and/or theoretical definitions of suffering.

Despite the absence of a consensus between parents and professionals to define suffering, both interpret the same signs of suffering in children. Signs of suffering include sadness, apathy and rage.

On the one hand, parents allude to issues of loss (what the child has lost due to the disease) and fear of medical procedures. Professionals, on the other hand, refer more to matters of uncertainty *What is going to happen to me?* and fear of death, which the parents do not mention.

Both parents and professionals are able to identify terminal children's suffering. Parents' profound emotional involvement in this advanced disease situation, however, can distort the understanding of their children's suffering by mixing it up with their own experience of suffering. As professionals, we should heed any manifestation or cause of possible suffering, in children as well as their parents.

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