

PAPERS

From the land and shadow of death. Voices of children in palliative care

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Abstract

Caring for children diagnosed with life-threatening or end-of-life conditions requires a special, holistic approach within an interdisciplinary team. Love, empathy, patience, kindness, gentleness are virtues that must characterize the people involved in pediatric palliative care. Dialogues with minor patients with fatal diseases, based on open-ended questions, revealed their authentic feelings, concerns, fears, anxieties and faith. They know how to play, respect the medical schedule, be obedient, encourage their desperate parents, pray. The religious assistance offered by the chaplain priest in such situations is indispensable because it speaks to seriously ill children and more, about hope, joy and life in the spirit of God's eternal love.

Keywords: pediatric palliative care, illness, suffering, pain, fear, prayer.

Rezumat

Îngrijirea copiilor diagnosticați cu afecțiuni care le amenință viața sau a celor aflați la sfârșitul vieții implică o abordare specială, holistică, în cadrul unei echipe interdisciplinare. Dragostea, empatia, răbdarea, bunătatea, blândețea sunt virtuți care trebuie să caracterizeze persoanele implicate în îngrijirile paliative pediatrice. Dialogurile realizate cu pacienții minori cu boli letale, pe baza unor întrebări deschise, au scos la iveală trăirile, preocupările, fricile, îngrijorările și credința lor. Aceștia știu să se joace, să respecte programul medical, să fie ascultători, să încurajeze părinții disperați, să se roage. Asistența religioasă oferită de preotul de spital/capelan în astfel de situații este indispensabilă deoarece vorbește copiilor grav bolnavi și nu numai, despre speranță, bucurie și viață în ambianța iubirii veșnice a lui Dumnezeu.

Cuvinte cheie: îngrijiri paliative pediatrice, boală, suferință, durere, frică, rugăciune.

Introduction

What is the meaning of suffering and death of a child? It is a question that will challenge the world to its end. There is perhaps no more difficult subject, and we have no words to express the experience of the child, its parents and often not only theirs. However, it is an unavoidable subject, especially in the context of paediatric palliative care, where the primary task, pain and symptom management, also involves addressing its existential and spiritual components. Research on paediatric palliative care recognizes a significant deficit in data from paediatric patients themselves, with most information about the universe of their experience usually obtained indirectly from relatives and medical, psychological or social care staff. [1, 2, 3] Direct knowledge, in their own words, from children diagnosed with life-threatening illnesses, is indispensable, not only to determine what care goals need to be met and what clinical decisions need to be made to improve their quality of life, but also to recognize the full human dignity of these patients as partners in that inter-human communion that is the life of each of us, regardless of age and health situation. [4, 5] Difficulties in acquiring this knowledge come from children, as their understanding and expression of their own experience

depends on both age and stage of illness; also, several difficulties are specific to the adults involved, primarily their natural concern not to burden the children further. The limits of the clinicians' professional competence are also apparent here, as are the difficulties and limitations inherent in the major tasks and the distressed subjectivity of family members. Of all the adults directly involved, the psychologist and the priest/chaplain stand out as dedicated communicators, not only with paediatric patients, but also with the family and even with the rest of the multidisciplinary team. Of course, through the permanent presence and openness to dialogue of each member of the interdisciplinary care team, they can all become friends to whom the sick child can share some of his or her experiences. At the same time, current experience shows that frequently the fullest and most heartfelt confessions take place in the context of psychological counselling sessions and spiritual dialogue (e.g. in the Sacrament of Confession). It is widely accepted that, with all their natural overlap, the physical, psychosocial, existential and spiritual worlds have their own specificity, which gives the chaplain a distinct place and a well-defined role within the multidisciplinary team. By virtue of this role of communicator par excellence, the chaplain

is also in a special position to gain a deeper insight into the inner world of the experience of paediatric patients in palliative care units, through direct access to their own expression. The priest's practically permanent availability to be present and to listen makes it possible for the thoughts of these children to be expressed more easily and for their voices to be better heard. This is also the motivation of the present research: the desire to make the most of this availability and accessibility, through a micro-study highlighting some existential and spiritual aspects of the experience of paediatric patients receiving palliative care. Based on personal clinical experience as well as a review of the literature [6, 7, 8, 9, 10], I focused on five relevant aspects, one related to the health condition (perception of illness), three existential (concerning one's own suffering, fears and death) and one religious (concerning religious care and the relationship with divinity). The study is part of a wider research that includes the perception of the five aspects mentioned by the health professionals and by the parents of the hospitalized children, research done for a PhD thesis on the role of the priest in palliative care, recently promoted at the Faculty of Theology of A.I. Cuza University in Iasi, Romania. [11]

1. Methodology

The research question is: what are the perceptions of children with life-threatening illnesses about some significant existential and spiritual aspects of their palliative care experience?

A qualitative study, using semi directive interviewing, was conducted between September 2020 and February 2023, in a children's hospital serving paediatric patients in the North-East region of Romania, one of the largest hospitals of this kind in Romania.

The interview guide initially developed was built around thematic units and adjusted as the data collection process progressed according to how the questions were received by the interviewees and how the specificity of the answers received was anticipated.

The interview guide covered five aspects: 1) perceptions of the presence and course of illness; 2) perceptions of one's own suffering; 3) perceptions of fears and worries; 4) perceptions of death; 5) perceptions of the relationship with God and the role and religious assistance. The role of these thematic units was both as a guide for the questions posed to the interviewees and as a heuristic tool for the thematic analysis of the responses. Interviews were interrupted when saturation of responses was reached.

The research took place face-to-face in the palliative care ward of the hospital in question, as well as the Oncology and I.C.U. wards, as palliative care protocols are also applied in these units. The approval of the Ethics Committee of the hospital was obtained for the interviews.

Children with serious, life-threatening illnesses admitted to these wards were interviewed. Ten children were interviewed, 4 girls and 6 boys, of whom 3 were children aged 6-9 years (girls) and 7 were adolescents (1 girl, 6 boys), 9 of them admitted with oncological diseases and one patient with a genetic disease. These are children whose parents gave their consent to be interviewed, who were able to understand and answer the questions asked and who were in a physical condition that allowed them to do so. Selection was done using the snowball technique.

2. Analysis and interpretation

Responses were analyzed using the thematic method. The first stage consisted of open coding by systematically examining the interview transcripts and making memo-type notes. At the same time, information was divided into semantic categories (e.g. illness, suffering, fear, death, religious assistance), followed by the axial coding and selective coding stages, which aimed to determine the semantic categories prevalent in the discourse of the interviewees. As a result of this analysis, a set of 5 documents was produced, 1 for each thematic unit.

2.1 Perception of illness

The analysis of the interviews shows that the way the patients interviewed perceive the disease is directly related to their age group. Thus:

A. Children in the 6-9 age group understand that they are ill, but the seriousness of the situation is not known to them, but only felt, perceived, as a result of the sudden change in lifestyle (from living at home, with extended family, in relation to society, the child had to move with the carer to the oncology ward or to another ward of the hospital for a long period of time, between 3 and 6 months), the inherent sadness of mother, father, siblings and all acquaintances, the invasive procedures to which they were subjected, the psychological environment existing in the oncology wards, I.C.U. and palliative care, where illness and death are part of the daily picture. Children in this age group's knowledge of the disease is often reduced to a list of symptoms:

"My leg hurts and I can't see." (S., girl, 6 years old)

"It hurts if I move too much. [...] It hurts my right side and my spleen because I have an enlarged spleen. When my haemoglobin drops my legs start hurting, my head hurts, it also hurts when I run around the house". (E., girl, 8 years old) Also, in this age group, the language in which children describe their illness is simple, appropriate to their age and understanding:

"My tummy has a lump." (S., girl, 6 years old)

The way these children express their views about their illness shows that they are aware that they have a serious condition, but do not know the final truth about their illness and the stakes of treatment.

B. Adolescents know the diagnosis and understand the seriousness of the situation and are able to explain in detail their illness(es) and the therapeutic maneuvers they are undergoing:

"I had a tumor in my knee that developed very quickly in six months. [...] Being a cancerous tumor there is a risk of it coming back and the best thing is to do preventive treatment." [...] "We did some investigations, we got to the biopsy, [...] they said that the tumor in question was removed." (Ma., boy, 17 years old)

"From one thing evolves into another thing. Diseases have increased. From one disease, several diseases have emerged. So, the first was muscular dystrophy, then came muscle weakness, extrasystoles, proteinemia, heart failure." (A., boy, 16 years old)

In the case of a 17-year-old teenager, the cancer disease that turned his whole life upside down, that made him reconsider and completely change his career plans, the disease that caused him *"unbearable pain"* and because of which he underwent multiple traumatic surgeries, brought out in the young man a fighting spirit, a new, proactive man, focused on positive aspects and actions that have as source the desire to live:

"When I found out the diagnosis, I tried to see what can be done next; I did some investigations, I got to the biopsy to determine exactly what and how so we know what to do next." (Ma., boy, 17 years old)

On the other hand, there is patient A., aged 16, with a life-threatening genetic disease who feels he has reached the end of his physical and mental powers:

"I'm tired of going through so much pain and I would look for ways to escape it, but I can't escape the pain anymore. I mean the pain of the body." (A., boy, 16)

The disease causes him great frustration because he is bedridden, unable to be normal like other children:

"I feel helpless, I feel annoyed because I'm always comparing myself to other kids in physical abilities, not mental ones, and I feel like crying. I watch how they can run, walk, eat freely, have none of my worries. I wish I could go camping, ride my bike, travel. Because I can't do them, I feel anger, depression, nervousness. I feel bitterness because of the above." (A., boy, 16 years old)

For these children, the experience of illness and the pain and disabilities that have arisen is accompanied by a change in their perception of their whole life, repositioned in the context of new and difficult physical, emotional, and social limits, which they seek to understand, adapt to and overcome.

2.2 Perception of their own suffering

As with illness, children perceive suffering and its meaning according to their age group. However, suffering is generally perceived predominantly through the physical manifestations of the disease, i.e. the pain and discomfort caused by the multitude of medical operations and adverse reactions to treatments (chemo/radiotherapy), as well as the disabilities caused by the presence of disease in the body:

"I have physical pain in my hands, feet, ankles, shoulders." (Mb., boy, 17 years old).

"I'm in pain and suffering because I can't walk." (S., boy, 15 years old)

"I can't manage on my own because I can't see, my mother always has to come after me to walk." (S., girl, 6 years old)

"For me suffering is pain." (E., girl, 8 years old)

Two of the adolescent patients consider that the meaning of their suffering is a pedagogical one, to correct, to change their way of life from a carefree, self-centered and irresponsible one to a responsible, empathetic, generous one. They see suffering as a catalyst on the road to maturity, a lesson in life:

"I thought this disease was given to me to open my eyes about my future." (Ma., boy, 17 years old)

"Another meaning is maturation. Before I got here, I didn't believe anything, I was having fun all day, I didn't believe those who suffer. On the one hand it's a life lesson, because years and years later I can explain to my children what I went through, I'd teach them not to become grotesque, to take care of themselves, not to go through rubbish, to have as clean a life as possible. I learned that money should not be spent on nonsense, that we should take care of each other. It's not all fun and games". (M., boy, 16 years old)

The adolescent patient with a genetic disease saw no sense in his suffering, did not understand why his disease is not cured, but on the contrary, it leads to a whole series of other serious diseases. The boy is in a depressive state as a result of not externalizing his suffering:

"I don't see any sense in my suffering. From one thing it evolves into another thing. Illnesses have increased. From one disease, several diseases have emerged. So, first it was muscular dystrophy, then came muscle weakness, extrasystoles, proteinemia, heart failure. The pain of the soul, I don't really look for ways to release it. I hold it inside and don't share it with anyone. I feel helplessness, helplessness because I always compare myself to other children in physical abilities, not mental ones, and I feel like crying. I watch how they can run, walk, eat freely, have none of my worries. I wish I could go camping, ride my bike, travel. Because I can't do them, I feel anger, depression, nervousness. I feel bitterness because of the above." (A., boy, 16 years old)

Another source of suffering is the bullying that children with oncological diagnoses are sometimes subjected to, given that these children often suffer a change in their physical appearance (oedema, redness, alopecia, disability) as a result of chemo/radiotherapy treatments:

"I'm suffering because the kids were laughing at me after my hair fell out from chemo." (A., girl, 9 years old)

Two patients aged 6 and 8 stand out from the rest of the group of subjects interviewed. Although she suffers great pain, excruciating physical suffering that has even led to blindness, the 6-year-old girl shows great mental strength, demonstrating an early maturity. She confesses that her greatest pain is feeling her mother sad, discouraged and crying, and that she is the one who balances the scales with funny role-playing games to cheer and encourage her mother:

"Mother, don't cry! Think of our game 'Filuț, luț, cuț...', it's a silly little game of mine that Mum likes, it's a little game. I say some funny words, puns, do a little dance and cheer her up, I encourage my mom. That's what Mum likes. Come on, baby, please don't cry" (S., girl, 6 years old).

The 8-year-old patient finds the strength to overcome hardship and some relief from her suffering in the fact that she does not feel alone, that she sees many other children suffering around her, some less fortunate than she is: "here are sick children who have no parents to take care of them, no mother or father". She finds relief in drawing, often on the theme of children's suffering. The illustrations are accompanied by messages such as: "even if it hurts, we are strong", "I worship God and the Mother of God". (E., girl, 8 years old)

Despite their situation, their pain and suffering, these children and young adolescents look on and continue their lives without rebellion and without despair, although, as we have seen, they have many fears.

2.3 Perception of fears and worries

In general, fear is an emotion caused by the awareness of real or imagined danger. In the particular situation of the children interviewed in this research, fear is the normal affective reaction to real threats, as well as to traumatic experiences already lived. Faced with a difficult diagnosis, children and parents find themselves together in a critical situation that they find difficult to manage.

The fears and worries of children with serious life-threatening illnesses are diverse and fall under several main themes:

A. Fear of the effects of serious illness on the body, including fear of death:

"I was pretty discouraged when I found out the diagnosis or when I realized that the surgery involved removing the knee." (Ma., boy, 17 years old)

"I was left scarred by the children who died here in the hospital, children I knew." (Ma., boy, 17 years old)

"My biggest worry is the recurrence of the disease, because my leg pain won't go away" (M., boy, 16 years old).

"My fear is that I will die with regrets, with a dream that remains unfulfilled." (A., boy, 16 years old)

B. Fears and concerns about adverse reactions to invasive treatments (surgical, chemotherapy and radiotherapy):

"Another concern is the medication which has caused many side effects." (M., boy, 16 years old)

"I'm afraid of unforeseen situations that may arise during treatment." (R., boy, 13 years old)

C. Fears and complaints about insufficient involvement of medical staff in the therapeutic process:

"I was admitted two weeks ago and after I was admitted, I started feeling even worse than when I left home. There has been no improvement, in fact it has got worse, I feel that not everything that could have been done has been done. There are some nurses and doctors who really care about my condition, but not all of them. Some don't really care that much about me, they just want to get rid of me, to see me gone. I would advise them to take very good care of their patients." (A., boy, 16 years old)

D. Fear for how family members react during hospitalization and while receiving treatment:

Not infrequently, children feel their parents' difficulties and take on the task of supporting and consoling them:

"I encourage my mom, I tell her to stop crying because I'm going to get better!" (S., girl, 6 years old)

"Ever since I got sick, my father has been estranged from the family" (E., girl, 8 years old)

"I think about dying, but I don't talk to the family about it. Not even with my mother because I'm afraid she'll react very seriously. She starts crying because she feels guilty." (A., boy, 16 years old)

"I have several fears: first of all, my mother is afraid that something will happen to me". (E., girl, 8 years old)

E. Fears of social isolation:

Because cancer treatments involve long stays in hospital, children are isolated from their friends, they can no longer go to kindergarten or school, which causes them grief, anxiety and pain:

"I'm afraid of being ridiculed by my schoolmates who laughed at the fact that I lost my hair as a result of chemotherapy." (A., girl, 9 years old)

"I miss my friends and school. I've been bedridden for two years and haven't gone to school. I miss my family, but I've enjoyed seeing them when they visit the hospital and at home." (S., boy, 15 years old)

A particular fear is expressed by an 8 years old girl admitted with her mother in the oncology ward who has noted that there are institutionalized children in the hospital "without a mother and father", whom she considers to be in a much more difficult circumstance than her own, setting an example to all of compassion, empathy, love and mercy:

"I've seen kids like that here in the hospital. I am afraid for them that they are alone, that there is no one to feed them, no one to help them with their homework, they can't go to school or to their friends." (E., girl, 8 years old)

It is found that many of the emotions of parents are felt by teenagers and children alike. They are thus faced with suffering on a variety of levels, but at the same time: physical suffering (as a result of the disease and the secondary consequences of treatment), psychological suffering (as a result of the impact of

the disease on physical appearance, social relationships, etc.) and psychological suffering, unfortunately bearing the burden of guilt for the changes in family dynamics (separations, divorces, misunderstandings) and the mother's inherently sad state of mind.

Despite these fears, worries, and complaints, most children (9 out of 10 interviewed) said they were confident that treatment would eradicate their illness and optimistic that things would get back on track.

"I encourage my mother; I tell her to stop crying because I will be fine!" (S., girl, 6 years)

2.4 Perception of death

Although the objective of this approach was to probe the deepest and most authentic thoughts and feelings of children, ethical and deontological principles required not to address the subject of death in interviews with sick children.

From the interviews conducted, there is a general positive mentality among seriously ill children. They are convinced that if they are patient enough and endure the countless treatment protocols, they will get better and resume the normal, carefree life they had before their diagnosis.

However, the topic of 'death' came up spontaneously in the discussions with the children interviewed, especially following the previous question.

Thus, patient A., aged 16, admitted to the I.C.U. ward with complications of the underlying diagnosis (muscular dystrophy), says: "My fear is that I will die with regrets, with a dream that remains unfulfilled". The boy stands out for a dichotomy in his thinking: on the one hand he strives to follow all the recommendations and treatments administered, to seek solutions to the complications of his disease, and on the other hand he thinks of death as a terminus point that could prematurely interrupt the course of his life, before seeing his dreams and hopes fulfilled: "I wish I could go camping, go cycling, travel". He admits that he thinks about death but says he doesn't want to discuss it with his mother because he doesn't want to see her suffer: "I don't talk about death with my mother because I'm afraid she will react very badly. She starts crying because she feels guilty". There is an extraordinary gentleness in the teenager who, despite realizing the inevitable, tries to spare his mother, feeling her sensitivity.

Patient Mb., 17 years old, who has been in the oncology ward with leukemia for 10 months, talks about death in response to the question about fears and concerns: "My biggest fear is not being near my family, that is to die. Sometimes this frightens me". The young man's words convey the idea of the fear of death as a rupture of his family, of uprooting, of destroying the bond, until then considered indissoluble and indestructible, between son and parents, brothers and sisters, grandchild and grandparents. Through death, the young man fears the disintegration of the entire tapestry of his family's life, of the familiar comfort zone. The thought of going through death in a suspended and unknown space and time, in an unknown and mysterious existence, impossible to express in words, causes him anxiety ("it frightens me"). "Not being near my family" shows the fear of being "torn away from the place where he has learned to live".

Patient Ma., 17 years old, admitted to the oncology ward with a tumor operated on his knee, talks about death with ease, but his speech has Christian overtones, being punctuated by mercy and empathy towards the children who died in the oncology ward while he was admitted: "I was marked by the children who died here in the hospital, children I knew". Asked how he

feels about the deaths of those children, he tries to explain it by emphasizing God's will: *"That's about how God's will is"*. Even if the answer seems to be a common and general one, the fact that it is given in the context of the Oncology Department of the Children's Hospital prompts us to ponder. Can a child, a teenager, know what God's will is? Can he obey it? Does he fully understand it?

2.5 Perceptions of the relationship with God and the role of religious assistance

A. Relationship with God

Spiritual suffering is something that cannot be ignored. It is expressed by children through different attitudes or states such as: existential suffering, loss of meaning, rebellion and acceptance, relationship with God.

For most inward teenagers and young adults, God appears a constant presence in their thoughts, through whom they receive support and strength. Illness, for many of them, matures them before their time, so that the relationship they develop in the intimacy of their soul with God indicates a desire to seek meaning in the suffering they endure, meaning related to immediate concerns, but also going beyond them.

"I worship God and the Mother of God. I say 'Our Father' and then I pray for what I want most. I pray for health for myself and my whole family." (E., girl, 8 years old);

"I pray to God to give me health to get well." (S, boy, 15 years old)

Children reveal a certain inclination towards prayer and trust its results:

"We pray in the morning, in the evening, we have hope in God and in the Mother of God". (S., girl, 6 years old)

"I pray to God with the prayer 'Our Father' [...] without God we can do nothing."(R, boy, 13 years old)

"Throughout this period of suffering I was helped by the Guardian Angels to whom I pray." (M., boy, 16, years old)

"I pray with the prayer 'Our Father' and in general I devote a special time to prayer". (Ma., boy, 17 years old).

B. The role of the priest

The priest's visit to wards where children with life-threatening illnesses are admitted is desired and expected by young patients, regardless of age:

"The presence of the priest in the hospital helps me a lot. Without God and without a priest we can't do anything" (R., boy, 13 years old); *"It's good to have a priest in the hospital because he is very wanted"* (M., boy, 16 years old); *"it helps me, it gives me a good feeling, especially when I am receiving Holy Communion"* (S., boy, 15 years old); *"it helps me to feel a bit better, especially because he gives me Holy Communion every week"* (L., girl, 13 years old); *"it helps me to feel a bit better"* (A., girl, 9 years old); *"in my opinion, the priest is absolutely necessary in the hospital, knowing the suffering and the troubles of the patients"*. (M., boy, 17 years old)

The priest is perceived by children especially as one who lifts the mood, encourages, restores optimism and courage:

"The priest is important in the hospital because he gives us advice, he relieves our suffering" (S., girl, 6 years old)

"The priest in the hospital is important because he helps us; he listens to our problems and we feel the help because he reassures us. He visits us and we talk". (E., girl, 8 years old)

"The presence of the priest in the hospital is very welcome, because it encourages patients to feel better, to trust in themselves and that God can help them with their health, especially through Holy Communion." (Mb., boy, 17 years old)

"I see the presence of the priest as an opportunity and a joy because we realize that we are not alone, that someone is helping us to fight [...]; the presence of the priest shows the presence of God which gives me a feeling of well-being and courage". (Ma., boy, 17 years old)

"The priest in the hospital helps us to pray as much as possible, to soothe our soul. It helps us to be closer to God, because we can talk to him more openly".(M., boy, 16 years old)

"The role of the priest in the medical team is to alleviate the suffering of children and their mothers. After Confession and Communion, I felt I had someone to share my sins, my inner suffering with." (A., boy, 16 years old)

In the oncology ward of the hospital, every week, on Fridays, in the specially arranged spaces, the Holy Mass is celebrated for these children and their relatives. Also, every Saturday of the year, children admitted to the oncology and palliative care wards, as well as other wards as appropriate, receive Holy Communion. The moment is awaited with joy and hope, with seriously ill children and their carers preparing especially for it:

"We're eagerly awaiting for the priest to come and give us The Holy Communion. When we know that the priest is coming with the Holy Sacraments, we prepare ourselves as when someone important comes. When the priest comes, it's like we're waiting for the Good Lord. [...] After taking Holy Communion I feel better. I feel a relief in my tummy." (S., girl, 6 years old)

Discussion and conclusions

Children affected by life-threatening illnesses interviewed are aware of their medical problems and their immediate implications at the level of understanding of their age. Although they do not make sense of their suffering as adults do, their maturation can be observed ahead of time. This is due to several reasons such as deprivation of childhood exuberance, change in physical appearance, reduction in daily activities, minimization of social relationships, sometimes bullying, hostile or exclusionary behavior by schoolmates or playmates, situations of abandonment, desertion, loneliness, helplessness, disappointment or depression. Children usually manage to adapt to new realities to some extent and even develop a certain balance of mind and strength of character. Their fears cover a wide range including fear that not everything possible has been done to cure them, fear of the adverse effects of illness and treatment, fear of relapse, fear of unforeseen situations, concern about the difficulties their parents are going through, of social isolation, of being rejected by their peers and friends, of dying without fulfilling their dreams. For seriously ill children, the thought of going through death in an unknown space and time, in an unknown and mysterious existence, impossible to express in words, causes them anxiety. They also sense the feelings, the deep concerns of parents worried about the uncertainty of the evolution of their illness. Despite these difficult conditions, children often display an optimism specific to their age, but also a certain strength of character typical of people who have gone through a traumatic experience. An example of this is the encouragement they seek to convey to their own parents.

Of course, children could cope more easily with these situations if they were provided with the services of one or more psychological counsellors/clinical psychologists (it should be noted that during the recent pandemic, period in which most of the research was carried out, the children's hospital in question did not dispose of the services of this professional category).

As far as he is concerned, the priest has an important role in the paediatric palliative care team [12]. Because, in many situations, doctors do not have the time to listen to the life stories of families and children, it is the priest who has the availability and responsibility to be there for them. To listen patiently and attentively, without time limitations, to understand, to comfort, is part of the priestly vocation. The priest can more easily reach the soul of children and parents, support them in dealing with bad news and offer the spiritual perspective long awaited by the interlocutor. While the medical team intervenes at the level of the body, e.g., with medication, the priest's intervention addresses the soul, with dialogue, but also with prayer and the sacraments. Paediatric patients are showing a significant interest in having a living relationship with God. Even if they are in pain, they pray, are optimistic, love their parents and respect the medical staff. Certainly, there is light glimmering in their shadowy land.

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