



UNIVERSITÀ  
DEGLI STUDI  
FIRENZE

## FLORE

# Repository istituzionale dell'Università degli Studi di Firenze

### **Caring for children with brain tumors in an oncology ward: a**

Questa è la Versione finale referata (Post print/Accepted manuscript) della seguente pubblicazione:

*Original Citation:*

Caring for children with brain tumors in an oncology ward: a phenomenologic-hermeneutic study / Fioretti C.; Lauro Grotto R.; Tringali D.; Padilla-Munoz E.M.; Papini M.. - In: JOURNAL OF PEDIATRIC AND NEONATAL INDIVIDUALIZED MEDICINE. - ISSN 2281-0692. -

*Availability:*

The webpage <https://hdl.handle.net/2158/858897> of the repository was last updated on 2017-10-08T21:23:02Z

*Published version:*

DOI: 10.7363/030112

*Terms of use:*

Open Access

La pubblicazione è resa disponibile sotto le norme e i termini della licenza di deposito, secondo quanto stabilito dalla Policy per l'accesso aperto dell'Università degli Studi di Firenze (<https://www.sba.unifi.it/upload/policy-oa-2016-1.pdf>)

*Publisher copyright claim:*

La data sopra indicata si riferisce all'ultimo aggiornamento della scheda del Repository FloRe - The above-mentioned date refers to the last update of the record in the Institutional Repository FloRe

(Article begins on next page)

# Caring for children with brain tumors in an oncology ward: a phenomenologic-hermeneutic study

Chiara Fioretti<sup>1</sup>, Rosapia Lauro-Grotto<sup>2</sup>, Debora Tringali<sup>3</sup>, Eva M. Padilla-Muñoz<sup>4</sup>, Massimo Papini<sup>3</sup>

<sup>1</sup>Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Italy

<sup>2</sup>Department of Health Sciences, University of Florence, Italy

<sup>3</sup>Lapo Association, Florence, Italy

<sup>4</sup>Department of Personality, Evaluation and Psychological Treatment, University of Seville, Spain

## Abstract

Brain tumors are the most common form of solid tumors in childhood and are characterized by an uncertain prognosis, often meaning tumor invasive surgical procedures in the first steps of the patient's treatment. In a Pediatric Oncology Ward, children with brain tumors are considered a challenge for health professionals, due to the nature of the relationship between the child, the parents, and the health care providers in the initial phase of the patient's illness. Here we present a phenomenologic-hermeneutic study, developed in the Oncology Ward of a Hospital in Southern Spain. All the caregivers of the Ward underwent interviews concerning their experience in caring for children with brain tumors. Interviews were recorded and transcribed with the consent of the participants and were analyzed by content themes. In the present paper, we focus on the experiences concerning the first meeting of the professionals with the children and their families and the principal critical issues related to the communication of the diagnosis.

## Keywords

Brain tumors, staff, pediatric triangle, pediatric psycho-oncology, communication of the diagnosis, group dynamics.

## Corresponding author

Rosapia Lauro-Grotto, Department of Health Sciences, University of Florence, Italy; email: rosapia.laurogrotto@unifi.it.

## How to cite

Fioretti C, Lauro-Grotto R, Tringali D, Padilla-Muñoz EM, Papini M. Caring for children with brain tumors in an oncology ward: a phenomenologic-hermeneutic study. *J Pediatr Neonat Individual Med.* 2014;3(1):e030112. doi: 10.7363/030112.

## Introduction

Brain tumors in childhood are characterized by several peculiarities, both from the point of view of their care and of the psychological and emotional implications. When compared to the case of the disease's onset in adulthood, in the case of any pediatric patient, the care pathway unfolds through the vicissitudes of the so called "pediatric triangle" [1] including at its vertices the health care staff, the child or adolescent and the parents. This complexity factor is especially relevant in the case of chronic or severe illness, such as a tumor. As shown in the last two decades [2-4], the coping strategies that the family puts in place to deal with the disease and its internal dynamics within the pediatric triangle are fundamental for the patient's psychological balance and for the achievement of the therapeutic goals [1]. The complexity of the dynamics within the pediatric triangle is well known in pediatric psycho-oncology [5-9]. A patient who contacts the institution has a variety of needs that relate to his illness, which the institution responds to with professionals, each one with his technical skills. Everyone is implicitly and inevitably accepting to pose and return partial questions and partial answers [1].

The theme of the communication of the diagnosis in pediatric oncology has been treated extensively in relation to its consequences on the psycho-emotional balance of the patient and his family [10]. In the case of a serious illness, the communication of the diagnosis must be carried out by the medical staff by taking into account some important variables: primarily, the degree of awareness of the parents about previously communicated information and what they really want to know about the disease [11]. The pediatrician is essential in the process of communication as he's the one who will lay the foundation of the therapeutic alliance by managing the information, by accepting the outpouring of the parents and by structuring together with them the therapeutic plan [12, 13]. Additionally Buckman [11] suggests that in the "ideal" mode of communication of the diagnosis, the parents can dissolve their doubts and find the most appropriate way to communicate the news to the child as well while being followed and supported by the pediatrician.

There is nowadays growing consensus that the child with cancer requires effective communication with respect to his health condition [14]. It has also been observed that, especially in the initial phase of hospitalization, pediatric patients express

a strong need to be involved in care planning and in the treatments [5, 7]. However less attention has been paid to the starting phase of the therapeutic relationship within the pediatric triangle. If we consider the relevance of the experience that the child and the family develop in the contact with the hospital environment and the expert system, it is necessary to analyze the emotional dynamics and the practices that are adopted in this phase and their implications in the course of treatment [15, 14]. Brain tumor deserves a deeper focus, as this is a particular form of childhood cancer that involves additional problems in the initial phase of the therapeutic relationship. It is a kind of limit-case and therefore some of the dynamics that characterize the initial phase of the therapeutic process can be observed in this context with greater vividness and clarity.

Infant tumors of the central nervous system are the most common form of solid tumors in childhood and the second most diffused malignant form after leukemia in the pediatric age, with a mean incidence on 3.3 cases over 100,000 children [16]. The concept of degree of malignancy of these forms is peculiar, as tumors that appear to be less aggressive can be placed in brain areas that are crucial for life support or can prevent normal development. The prognosis is also very uncertain, ranging from 20% to 70% survival 5 years post onset according to the istochemical characterization of the disease. These pathologies are extremely heterogeneous, a fact that, taken together with the paucity of the evidence in the literature, implies in the professional awareness that *"every case is a single case (...). Diseases are all different, all children are different, parents are all different... So you can imagine the situation... a mystery from beginning to end!"* to say it in the words of one of our interviewed pediatricians [14].

The uncertain prognosis and the variability of this type of cancer are even more difficult to manage, in practical and emotional terms, at the time of communication of the diagnosis and in the initial phase of the therapeutic relationship. Brain tumors are often characterized by an acute episode at onset and the symptoms at diagnosis are generally connected to the raise of intracranial pressure, with headaches, vomiting and nausea [17]. We must therefore assume that in most cases in the run of 24 to 48 hours the parents of children who look absolutely normal are forced to face the diagnosis of a pathology that deeply threatens the psycho-physical development of the child, if not also his survival. The child could be obliged to

undergo a surgical intervention that may last from 6 to 10 hours with an indeterminable outcome, and from which the child might emerge in a state of deep emotional alteration. What is required from the parents, at this point and in the space of a few moments, is to trust and rely on the medical team upon which the survival of their children and the preservation of their future depends.

In other cases, the onset of the disease can be slow and insidious, thus exposing the family members to a long phase of uncertainty, during which the often reassuring response of the health care professionals can lead to episodes of dramatic underestimation of the symptoms – often subtle and difficult to read – on which parents try to convey, with increasing anxiety, for medical attention. The diagnosis, already dramatic in itself, is accepted with extra rage and suffering, coming from the experience of being not believed, and with the anguish of having lost time and possibly valuable chances of care. In assuming the care of these cases, the health professional staff exposes itself to very strong emotional drifts that are often to be faced in the context of a strict contiguity between children, parents, and staff members, under the pressure of heavy organizational demands and in the need of assuming responsibility for very difficult decision making processes.

### **The present study**

The present study, designed according to the phenomenologic-hermeneutic approach [18, 19], intends to explore the interpersonal and relational dimensions in the process of taking care of a child affected by a brain tumor, taking into account both the texture of human relationships which build the therapeutic activity of the staff by promoting or hindering it, and the development of the personal dimension in the context of the professional bond with the patient and his family members [20-23]. We focus on the perceptions of the professionals about the incoming patients and their families, we analyze the practices that are instantiated in this initial phase of the therapeutic process and we enlighten the emotional reactions of the various staff members facing these very complex medical and relational situations. Between February and July 2010 a research plan was developed and implemented in collaboration with the staff of the pediatric Oncology Ward of the Virgen del Rocío University Hospital, Sevilla (Spain). The study focuses on the experience of the first contact between the patient and his family members and the

health care professionals in the Ward. The action-research was designed in the context of a previously established collaboration between the Department of Health Sciences of the University of Florence and the “Departamento de Personalidad, Evaluación y Tratamiento Psicológicos” of Seville.

### **Methods**

#### *Design*

The research was designed according to a phenomenologic-hermeneutic approach. Foundationally, hermeneutic phenomenology explores the individual's context to capture the essence or the underlying meaning of lived experiences as they are brought to light through the experiences of individuals. The experience needs to be described as well as interpreted to fully understand the meaning of the lived experience [24, 25]. The qualitative methodology, mainly the phenomenological-hermeneutic method, is a preferred tool to approach and understand the needs of children with cancer and their families [6, 23, 26, 27].

#### *Setting and participants*

The Head of the Department of Pediatric Oncology assigned to the research team a set of health care professionals who usually took part in the therapy of children affected by brain tumors, according to their different specialities. They were contacted individually by the research team and all agreed to participate in the study. Overall 19 staff members of the Virgen del Rocío Hospital, Seville, were interviewed: 12 from the Oncology Ward (2 oncologists, 1 psychologist, 1 radiotherapist, and 8 nurses), 4 from the Surgery Ward (3 nurses and 1 neurosurgeon), 1 psychiatrist, 1 physiatrist, and 1 intensivist from the Intensive Care Unit. In this paper, we consider only the interviews with the staff members of the Oncology Ward, due to the fact that, as we could note during the study, the multiple perspectives that emerge by comparing the points of view of staff members belonging to different specialities and Wards deserve a dedicated analysis.

#### *Procedure*

The methodology of the intervention was divided into 4 phases.

In the first explorative phase, as a result of non-formal contacts with the Head of the Oncology Ward

of Virgen del Rocio Hospital and preliminarily to the development of the analytical questionnaire, the research team interviewed the parents of children affected by a brain tumor in order to examine, from an external point of view, the Ward procedures and interpersonal dynamics.

In the second phase, involving data collection, interviews were conducted by trained researchers in an adequate context that was provided by the staff inside the Hospital. To present the project to the participants, in March 2010 a meeting was held at which clarifications on the objectives, intervention, and procedures were explained. At this time, consent to participate was also requested and obtained from all professionals. In this phase the individual testimonies of the operators were collected with the aid of a semi-structured questionnaire. This one can be divided into five thematic blocks, each of which includes several questions presented to the respondents, ranging over the subsequent contents: resources and difficulties of the professional role, the first contact with a child suffering a brain tumor and with his parents, the way for communicating the diagnosis, the feelings that are experienced by the staff members during the various phases of the therapeutic process, the relationship between the respondent and the rest of his/her colleagues from the Oncology Ward, but also with the staff of the other Units involved in the treatment of brain tumors and finally the most relevant personal episodes connected to the care of a child suffering from brain tumors. The interviews were conducted during working hours in a contest made available by the staff and suitable for listening, without preset time limits. The interviews lasted from 35 to 50 minutes. The past research experience has shown that a relationship with a caring person is a framework that facilitates the expression of personal feelings and views and can support the initial elaboration of the emotional contents of the experiences. "This methodology allows to create a space where the operator can find a way to re-evaluate his experiences and a suitable context in order to express feelings and problems that might otherwise remain a source of anxiety in front of which the operator is helpless" [28]. With the consensus of the participants, interviews were recorded and transcribed.

In the third phase, the analysis phase, the research group discussed single interviews over several meetings. An Interpretative Phenomenologic Analysis [29, 30] allowed for the reorganization of the material into themes and phenomenologic categories. The researchers reduced the complexity

of data experience through rigorous and systematic analysis [31, 32]. This type of analysis is based on the process of giving meaning to the world and to the experiences of the participants and seeks to maintain a certain level of attention on what is different, but also to balance this expounding exercise with the commonalities that is shared across the different testimonies.

In the fourth phase, the feedback phase, the phenomenological categories emerged from the analysis were presented to the participants in a feedback group meeting held in June 2011, thus promoting an in-depth discussion of the results. The purpose of restitution to the Ward was to create a common space for the universal and individual emotional events and issues that had emerged in order to improve the responsiveness of families with children affected by cancer of the central nervous system.

## Findings

A complex picture of personal, professional, organizational, and institutional demands emerges from the data. Here we focus on themes concerning emotional and practical resources and difficulties about the communication of the diagnosis to the children and their families, all themes included in the second block of the interview questionnaire.

### *The dimension of urgency*

It is evident in the data that relating to a child with brain tumor is considered to be a very difficult task for the hospital professionals. A crucial difficulty arises if the first meeting with the ill child occurs only after he has undergone neurosurgery, which can have a tremendous impact on the mental and psychological functioning of the patient. In this case the staff is forced to start the relationship without knowing how the child was "before." Many operators declared that they would prefer to see the child before the diagnosis. An oncologist told us:

*"It would be ideal that it (the first contact) happened during the diagnosis. In that way you are allowed to know the child before the surgery. To meet him, to see him, to know how the problem started, and then to see him again after the surgery and then begin the treatment. However there are times when the first contact happens when the children have already been operated on, which is negative because we want to meet them early on, when the diagnosis is made" (oncologist 3).*

Nurses, too, feel the difficulties in meeting the children after the interventions:

*“They come already operated on and you did not meet them before...”* (nurse 3).

Moreover, the words reported by nurse 3 seems to speak about the perception of a child who is so different after surgery, that the ‘true’ child appear to be lost. Often the professionals experience the dramatic change of the children after the intervention. A nurse recalls an episode in which she had a conversation with a child before neurosurgery and just the day after she was not able to recognise him. She expresses her disconcertion when meeting a patient she knew who came back from surgery in a deeply impaired state:

*“Personally I was talking with the child that had come here the day before the surgery: ‘How are you?’ ‘Well! I’m well!’ And the day after he was operated on, then he went to intensive therapy for a little bit of time, and when he returned here was a low child... with a lot of needs... and then little by little they begin to talk... It is different from one child to the next”* (nurse 7).

The need to communicate the diagnosis to the patient and family members in the Department of Oncology before the neurosurgery acquires a crucial importance not only from an emotional point of view, but also in terms of organization of the therapeutic plan. To define the goals of patient care, in the eyes of the professionals it is essential to know the child’s condition prior to the physical and cognitive impairment associated with neurosurgical intervention. An oncologist of the staff said in this regard:

*“When we go and see the child who is already in neurosurgery, this is because we were not told that he was there, then we go and he has already been operated there and we meet the family and the child, it is often in the Intensive Care Unit... and our difficulty is to know how he was before and the extent to which we can make the child return as he was before, when you do not know”* (oncologist 1).

### *The dimension of acceptance*

Professionals also report that after the first meeting with the parents of children with brain tumors, they are often in a state of shock after the communication of the diagnosis. Commenting about their reaction, a nurse told us:

*“I can tell you my personal experience: when you see them entering for the first time and you see their faces you understand that you can’t do anything because in that moment the world has turned against them”* (nurse 2).

In this situation it is very difficult to create a good relationship with the parents. In particular, nurses try to establish a relationship that is based on the parents’ needs. In the words of the interviewees the first contact with the child and family must be characterized by acceptance and consideration of the needs. The nursing staff is available to answer questions and face the doubts expressed by the parents; sometimes, however, a temporary attitude of rebellion must be accepted as well:

*“However in the first contact it is very difficult to talk with them. Because, maybe, the parents and also the child are there pent up... You must begin to contact them in a different way. Let’s say that they rebell against the system: all that you do, they quarrel and discuss with you... Nothing seems good to them, you go there with a positive approach, you try to help them, but they don’t accept your help, and therefore it becomes very difficult. Many times after the first contact we comment on the etiquette that we gave them, an etiquette that says e.g. ‘This father is hostile, problematic,’ and you are not aware of the fact that he is not that way. Maybe you are not able to talk with them, but after a week you already see that you can talk with them, and maybe they laugh. It is a normal evolution! So at the beginning it is complicated, but after a while they open up”* (nurse 2).

The experience of profound shock of the family members and the initial rebellion against the disease can be accepted by the nursing staff thanks to the activation of peculiar resources. Among these, the nurses underline the importance of the warm, affectionate, and open attitude that they try to communicate during the first contact. In fact, when the child and family arrive at the unit, staff receives them with an empathic attitude and emotional availability, to meet their needs of comfort and encouragement. In this regard, nurse 1 tells an episode she experienced during a night shift:

*“I saw that those parents could not sleep, and I took advantage of the situation for a moment, I brought the parents out of the room, took them to the office, and spent two hours talking to them. Of course you just cannot help... but you’re talking with them. And they see in you a kind of peace of mind, that you’re explaining things, that you’re giving them hope... then the parents with whom I*

*did this... they were positively impressed throughout the disease. They saw a good person, say, who helped them in the most difficult moment” (nurse 1).*

The first contact with the young patients is invested by a strong emotional charge where acceptance assumes again a central role. Some professionals prefer to contact children with a playful attitude, as illustrated by nurse 5:

*“I make jokes... I ask if they have brothers or sisters... One thing that really works well is asking about their favourite football team! I start making jokes on that, right? What I try to do in the first contact with the children is to try to show them a serene face, a pleasant one, so that they know you are there trying to help them” (nurse 5).*

### *Collaboration between the professionals*

The words of the professionals show that there are two faces in the communication of the diagnosis: on one side, the doctor is always the professional who communicates the diagnosis to the children and the families. Doctors and nurses affirm this practice:

*“In the case of brain tumors, normally the neurosurgeon or the oncologist communicates the diagnosis. They are the ones who stay there” (oncologist 2).*

Another professional tells us:

*“The doctor gives the diagnosis, here actually the oncologist does it. I believe that the group of oncologists or of doctors in general do it fairly well. They perform a series of tests to get to the diagnosis and from there they talk with the parents... Maybe even the neurosurgeon..., but at times it happens that the child is in neurosurgery when a quick surgery is planned, so first thing, they go in the operating room and the parents cannot really access the information until the neurosurgeons operate on the child. So it can also happen that the neurosurgeon leaves the operating room and says, ‘This child has a tumor, called such, that is located in this place’ and he gives the prognosis. And in this occasion, the neurosurgeons give the news... the bad news. But it is always the doctor. The neurosurgeon or the oncologist” (nurse 8).*

However, on the other side, we can say that there is a shared form of communication involving all the types of professionals who participate in

the care. From the words of the professionals, it is clear that the communication of the diagnosis does not happen in a single session with the family and the patient, but develops over time through a real form of multidisciplinary collaboration among professionals. In fact, the doctor is the one who has the burden of bringing the bad news initially, but the nurses and the psychologist are deeply concerned with the promotion of a fair processing of the received information, as they provide answers to the questions posed by both the family and the children and reassure them with respect to the therapeutic procedures. In this sense, the participation of all the stakeholders in the communication of diagnosis, although at different times and with different roles, not only favors the creation of a relationship of trust and an open dialogue between family members and staff, but also reduces the probability that any misunderstanding or confusion from the patient or the family could remain unnoticed.

An oncologist comments on this collaboration:

*“It is a form of shared communication because everyone explains something to them. The neurosurgeon explains to them what I said before, that the child has a little ball in the head. We explain the treatment because they understand it as such, for example, when you do an intravenous treatment you have to explain to them that they must come to the hospital, that you have to put in a cannula to administer the medicine. And for example, the nurses generally come on the topic of the operating room, they bring the masks so the children are familiar with these, they bring all the tools so the children can see that those are the instruments” (oncologist 3).*

For sure, nurses have an important role in the family’s processing of the news of the diagnosis. All nurses express the awareness that they are the professionals who welcome the parents and their doubts and fears after the communication of the diagnosis:

*“They leave the office still blind, they have not yet internalized, maybe they can’t believe it, and with all the doubts that they hide, they always come to us nurses! Because normally the doctor is there in the morning, he gives them the news, and when the parents become aware it is already afternoon or night. Like I said before, the nurses are those who stay the closest to the family” (nurse 5).*

In any case, even in this shared way of communication, each professional appears to

protect the therapeutic relationship built with the patient and family by his colleagues. When providing clarification for a colleague's information to the family, the cornerstone of the intervention is to safeguard the privacy of the exchange that parents have with the oncologist. In this way, by re-learning the news directly from the words of the family, it is possible to assess the degree of understanding that the family and the child have about the clinical situation, and where appropriate, to signal any problem to the colleagues for clarification:

*“When they see me for the first time, they blow off, they cry... and they take it for granted that I know the diagnosis, but I tell them that the doctor told me that there is a sick child, that, approximately, I understand what it is, but I need that they do explain to me what the doctor said. I do so because I don't want them starting to think that the doctor spreads around pieces of confidential information. I prefer that they tell me what they know, in order to understand the level of awareness that have about what's going on. Normally they are aware of the facts, as I see them explaining them very well, but if I see that they say something that I think is not correct, or that is dissonant with what I know about this type of cancer, then I alert the doctor, I say that it is better if he talks with the family once more”* (psychologist 2).

### *The communication to the underage patient*

Coming to the issue of the communication of the diagnosis to the underage patient, the interviewees took two different positions. In a medical perspective, the oncologists reaffirm that the child should always be informed about the diagnosis, in a way that is suitable for his level of comprehension.

*“So... Pediatrics!... Here there are children aged a few months, up to 14-15 years... then depending on the age of the child, we sit down with him and explain in his own words what's going on... We simply say: 'look... you had pain in the head? Well... this head pain and vomiting you had, this is because we have found that you have a ball in the head and this ball... we'll try to remove it... So maybe you will have to undergo surgery in order to take the ball away, and after we'll see if there will be other treatments to be done.' And we explain it to him according to the child's ability to understand us and according to his age... but always, in one or another way we tell them. Of course, it is different if he's 16 years old or 4, but even if he is very young we always give him a few hints to understand why he is in hospital”* (oncologist 1).

Some professionals, however, underline how difficult it might be to communicate the diagnosis to a child whose comprehension abilities might be reduced due to neurosurgery. Once again, the theme of the physical and neurological consequences of the interventions is central in the collected data. The state of unconsciousness that sometimes follows surgery can limit the possibility to communicate directly to the child about his clinical status. In this regard, a nurse says:

*“Telling the child? The point is that normally the children, when they arrive here, have already been operated on. So... in fact the children are in a kind of comatose state. Maybe before diagnosis children feel symptoms... maybe because their head hurts then they know something... but I do not think that the children are given a lot of information”* (nurse 5).

### *The professional's feelings: healthy positive coping*

When the parents are in a state of shock, they require the opportunity to express their feelings in front of the staff members that are there to support them. On this topic, an oncologist told us:

*“Logically it is a piece of news that... is like an emotional bomb for them. Here in this office many parent have cried... and that's it. I let them cry and after that I always try to give them hope that we can help them”* (oncologist 1).

Nevertheless, professionals have to take care of the families and the patients, but they also have to manage a severe emotional shock for themselves:

*“Then at times you are there in the room and the doctor comes in with the M.R.I. scans and says: 'This here is a tumor...' and maybe it is a tumor as big as an orange in the center of the child's head... And it cannot be removed! It seems impossible”* (nurse 4).

There are a lot of different feelings which the professionals have about the first meeting with children affected by brain cancer and their families: hope, compassion, senses of struggle and rebellion, among others. A nurse told us that the first feeling in her experience is the toughest, as it is the one that reminds her that here is “*still another child, one more suffering*” (nurse 3).

*“My feelings? “Still another!” Still another... yes... because, well, there is no difference if he is young or not,*

*but they all are children, so I think: “So young... and already he starts having all this.” Because he comes here and remains for one year at the minimum. So young and already in this routine? All that he will have to suffer, all that will happen to him...”* (nurse 3).

Faced with this complexity of mixed emotions, some professionals reported an attempt to create a defensive barrier in order to avoid becoming too involved by work experience. This form of protection, as effectively explained in the words oncologist 3, does not always seem to work, but instead clashes with the need to establish a therapeutic practice on the relationship with the patient, even if this means becoming more involved with him:

*“I really live it in such a way that... I try not to be so involved as not to be able to provide any help... but the truth is that after, I become fond of each patient! Each bit of news... every time there is a new child... I do not know how to explain it... they tell me ‘Come, you who are more used to it.’ Well, I’m used to the work, not to the suffering... Is it that bad?... You live with each of them (...) We need to start from scratch to help them... and become attached”* (oncologist 3).

Anyway, it is very difficult for the professionals to manage emotions and to disconnect with the work experience when they live their private life. Some nurses and oncologists report that they always think about job when they are at home:

*“... At your home you cry. You start crying. It is always the same. Either from a song that they are playing on the radio or for whatever other reason. At my children’s school party for Christmas, I saw all these children singing, so healthy, so happy, all so right, and I started crying and I was not able to stop. They were all looking at me and saying: “But what is she doing, that one, is she crazy?” All the world happy and I was crying! And it’s just like that, I start crying, and it happens that way. I was there crying for two hours and after that it went off”* (nurse 4).

## Discussion

The importance of including the perspective of the child suffering from cancer to improve the quality of their care is a topic considered by different studies, and is designed by a qualitative methodology [5-7, 24, 26]. However, considering the triangle comprising child, family and professional staff

that provides care in the field of pediatric psycho-oncology, perhaps this latter group has received less attention from the phenomenological-hermeneutic method. As we wrote in the introduction of this article, our working group has tried to deepen the point of view of health care professionals involved in the treatment process of children with brain cancer (specifically, oncologists, surgeons, nurses, etc.) [14, 25, 33], in particular their perceptions about the patients and their families in the very critical phase of the initial contact with the staff and along the diagnostic process.

The therapeutic approach to brain cancer is among the more complex protocols in oncology as many specialists coming from different disciplines are involved in the therapy from the very beginning. A child with brain tumor therefore might be addressed to the Oncology Ward or to the Neurosurgery Unit first, according to his clinical conditions and to the urgency to plan neurosurgery. This is not usually the case for patients presenting with other oncological pathologies. Most of the members of the Oncology Ward staff signaled that a supplementary source of difficulties arises with these patients when it is not possible for them to meet the patient before he undergoes neurosurgery. Many health care providers affirmed that it is not at easy to get in touch with a child who is in a state of profound emotional distress and suffers from severe cognitive limitations due to the drawbacks of the intervention.

According to the interviews, the problem cannot be limited to the issue of establishing the therapeutic relationship as the fact of not knowing the patient in his standard way of functioning and behaving can be a relevant limitation even when defining the specific goals of the therapeutic plan, especially those related to quality of life issues. In a concrete plan, these kinds of problems enlighten the complexity implied by the intrinsic multidisciplinary characterization of the process of caring for a child with brain tumors, one that is often set in place under the absolute urge of a lifesaving intervention. If we consider the participants’ words from a psychodynamic perspective, the opportunity to get in contact with the child before surgery, when he is still looking like a healthy child, suggests the need to remain in contact with a kind of an image of a “good and whole object”. Recovery is often seen as a kind of *restitutio ad integrum*, and the possibility to keep in mind a concrete image of this *integrum* (the child as an intact, unbroken object) could provide support to the healing faculties of the staff members in a deep

psychological sense. According to a psychodynamic point of view we would say that when the child gets worse and his physical conditions deteriorates, an inner image of the child remains, who says: “*Well! I’m well!*,” as nurse 7 reported, as a good and lively object that preserves and protects the therapeutic bond [34]. From a different theoretical and methodological perspective, the study Jackson and colleagues [35] conducted in a pediatric hospital in Melbourne also discusses the feelings of parents in the early days after diagnosis, thus, the need to establish effective communication between staff members and parents to provide the best possible care to children diagnosed with brain tumor.

Nurses express their discomfort in facing families just after the communication of diagnosis, when they can feel how shocked they are and that is not possible to do anything for them, “*because in that moment the world revolves around them*” (nurse 2). Testimonies show that is important to create a gradual relationship, based on the parents’ needs, allowing them to digest the difficult information over time and to experience a complex range of emotional states: anger, rebellion, despair, but also, in the end, confidence in the professionals.

Although health care providers report a certain degree of personal and professional satisfaction with respect to the relationship with patients and their families, they appear to be aware that the construction of a positive therapeutic alliance is the result of an extended process that often begins with the rebellion of the families against accepting of their present situation. This difficulty in the first contact hinders the possibility of developing a family-centered care, which is a highly relevant approach in pediatric oncology, chiefly for nurses. Thus, MacKay and Gregory [36], utilizing person-centered interviews to collect data, interviewed 20 nurses of the Oncology Ward of a pediatric hospital in West Canada. The purpose of this study was to identify how pediatric oncology nurses implemented family-centered care (FCC) into their practice, what facilitated and enabled pediatric oncology nurses to implement FCC, and which barriers and challenges were present in their settings when implementing FCC.

Hill and colleagues [37] also developed a qualitative methodology that focuses on how fathers view and understand their roles in families with a child with acute lymphoblastic leukemia: specific training of professionals, not only of nurses, in implementing FCC, could alleviate some of the difficulties highlighted in the interviews.

In order to cope with the experience of these families, the healthcare staff has developed a way of communicating that is shared by all professionals with the intent to meet the fears and doubts that arise in parents and children through full availability to answer questions and review the information as it is understood by the parents about the diagnosis over time in different occasions. By engaging in these practices, parents are supported in their reworking through information provided by the doctor and other health care providers.

In this way, all professionals will demonstrate their availability to be seen as a constant presence that can be supportive and trustworthy in the hard times that follow the diagnosis. In the study by Clarke and Fletcher [12], the main problems of communication between professionals and parents were analyzed, especially in the early days about diagnosis. Parents usually began their narratives of the defining moments in the months, weeks, or days prior to the diagnosis. The authors reported on parents’ views about one of the defining moments in the stories.

#### *Communication with the parents*

This level, called by us “communication issues,” includes the parents’ issues with how the communication was made at diagnosis, contradictions and confusion, feeling whether they are getting the “right” amount of information, if they received good or poor communication, if they feel listened to, and errors in medical information. With respect to the theme of the communication of diagnosis, staff members expressed discordant opinions to Clarke and Fletcher [12] about who communicates the diagnosis and about which two aspects of the communications emerged. All professionals agree that it is always a doctor who informs the children and the parents about the clinical situation. In some respects, in the view of almost all the members of the staff of care, the physician receives the family in his office and explains to them the problem that has emerged by explaining the nature of the illness and the type of the treatments required. However, some health care providers believe that, in practice, there is a shared form of communication between different type of professionals (oncologists, neurosurgeons, nurses, or psychologists) who contribute to explaining the diagnosis to the child and parents, thus vastly enriching the communication [38].

Nurses recognize their role as important in this phase of the disease. Being the professionals

who spend more time in the care of the patient and his family, it is often the nurse, as well as the psychologist, who can help the parents to really become aware of the diagnosis already received. In this form of multidisciplinary communication, however, professionals respect the protection of privacy of the patient-physician relationship in order to preserve the trust that is a crucial point of the therapeutic alliance. The psychologist in the Pediatric Oncology Ward at the Southern Spain hospital, for example, usually requires to be informed directly by the family about the patient's clinical conditions, in order to avoid any suspicion that the doctor could spread around confidential information. This suggests that the communication between the family and the team takes place along two different temporal levels. The first, a synchronous one, is characterized by the bad news that the physician brings to the parents and the child, which is recognized by all professionals as the official communication of the diagnosis. A second plan, however, unfolds in a diachronic way through several communications that are developed more continuously over time, with each designed to provide more detailed information and clarification of various aspects from the different professional figures. It is at this second level of communication that the family has time to digest the bad news of the disease, gradually adding information and clarifying those that are not yet fully internalized. In the latter case, every member of staff has his specific role: the doctor explains the dynamics of therapies and their possible consequences; the nurse takes care of the patient and clarifies the doubts day by day thus strengthening the efficacy of the communication; the psychologist watches over the correct understanding of the information and the holding of therapeutic alliance.

#### *Communication with the child*

Coming to the issue of the communication of diagnosis to the child, once again it clearly emerges that the staff worries about the relational difficulties due to the condition of temporary cognitive disability that the child can be forced to face. On the one hand, the position taken by the staff of care is to acquaint the patient of his disease while consistently adopting the terms and conditions that are most appropriate to his age and to his understanding of the situation. From another point of view that position is not always pursued because sometimes the children are in a comatose-like state.

With regard to the emotions experienced by the health care providers in this first phase of the treatment, professionals express the need to take care of the families, but also to take care of themselves when they are confronted with such hard experiences in their daily life. Some professionals try to protect themselves from the most painful experiences implied by their working practice by "getting a shield" or by maintaining a certain degree of emotional detachment from the children with brain tumors. However, professionals, who are well aware of the importance of the relational aspects in their work, tend to avoid this illusory protective barriers and get deeply involved at an emotional level.

#### **Conclusions**

The aims of a phenomenologic-hermeneutic study is to stimulate a reflection about practice in those who are involved in such complex relational and professional issues, and possibly to facilitate the exploration of the links between self-reflection and good practice. By analysing the life experiences of health care professionals who demonstrate such a deep involvement in their professional goals and such a delicate attention to the personal implications for themselves, the families and the patients, it is therefore possible to enlighten some points that could deserve deeper attention in clinical practice.

First of all, we would like to stress the relevance of providing enough space and care, both in mental and organizational terms, for the multidisciplinary team to elaborate the emotional implications of the clinical situations that are faced day to day when coming in touch with such dramatic circumstances as those implied by a diagnosis of brain cancer in a pediatric patient. We would like to describe this need by a metaphor that emerged during one of the last group meetings we had with the participants in the last phase of the study: each painful experience, each piece of bad news, each loss, each therapeutic failure is destined to be preserved not only in the memory but as a kind of 'open wound' in the psychic body of the staff members, both at the individual as well as at the group level. Now it is evident that bandages and protections must be provided in order to allow the professionals to continue in their therapeutic efforts, so that the 'open wound' will not be kept in full sight all time long; and yet these psychic wounds deserve attention and care in some moments at least, in order to avoid complications and further, unjustified suffering for the staff.

The second point we would like to stress is the complexity that emerges when the communication of the diagnosis is seen as a psychological process and not only as a mere interpersonal act: the family in fact has to be introduced to a new reality, the one of being a family with a child suffering from a brain cancer. It is not a matter of 'knowing', it is a matter of facing the 'meaning' of this condition, its implications both in practical and in psychological terms, its sense. It is of course true that the physician who is in charge of a given patient and family is the one who has the responsibility for the communication. Nevertheless, from the data we can see how each one of the staff members who gets in touch with the family and the child is implicitly or explicitly required to support the parents' inquire for meaning and implications. The nurse who is providing details on the rules that govern routinary events in the ward, as well as the sanitary operator who is showing to a mother how to clean the hair of the child after surgery, the neurosurgeon who is explaining the possible long term consequences of the surgery, all these are indeed deeply involved in the process of explaining to the parents what it is like to have a child with a brain cancer. In this perspective, the effort to share the same view on what is going on among the staff members, despite the differences that constantly emerge due to the professional role and to the personal preferences and beliefs, becomes indispensable and a valuable working tool for the multidisciplinary team. The family sees itself in the professionals' eyes, and therefore the degree of integration in the team is a fundamental protection for the psychological integrity of the parents facing such traumatic events, and by their interposition for the patient himself. We suggest that responsibility for such a sharing process should be considered as a mandatory aspect of an effective leadership in these contexts.

### Declaration of interest

The Authors declare that there is no conflict of interest.

### References

1. Valentini V. Condivisione dell'esperienza del reparto di oncematologia pediatrica in un gruppo di supervisione. In Papini M, Tringali D (Eds.). *Il pupazzo di garza. L'esperienza della malattia potenzialmente mortale nei bambini e negli adolescenti*. Florence: Firenze University Press, 2004.
2. Kazak AE. Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. *J Consult Clin Psychol*. 1989;57(1):25-30.

3. Kazak A, Christakis D, Alderfer M, Coiro MJ. Young adolescents cancer survivors and their parents: adjustment, learning problems and gender. *J Fam Psychol*. 1994;8:74-84.
4. Pelcovitz D, Goldenberg B, Kaplan S, Weinblatt M, Mandel F, Meyers B, Vinciguerra V. Posttraumatic stress disorder in mother of paediatric cancer survivors. *Psychosomatic*. 1996;37:116-26.
5. Björk M, Nordström B, Hallström I. Needs of young children with cancer during their initial hospitalization: an observational study. *J Pediatr Oncol Nurs*. 2006;23(4):210-9.
6. Griffiths M, Schweitzer R, Yates P. Childhood experiences of cancer: an interpretative phenomenological analysis approach. *J Pediatr Oncol Nurs*. 2011;28(2):83-92.
7. Söderbäck M, Coyne I, Harder M. The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *J Child Health Care*. 2011;15(2):99-106.
8. Axia V. *Elementi di psico-oncologia pediatrica*. Rome: Carocci, 2004.
9. Weisner TS. Ecocultural understanding of children's developmental pathways. *Hum Dev*. 2002;45:275-81.
10. Jankovic M. L'importanza della comunicazione di diagnosi di malattia al bambino. In: Papini M, Tringali D (Eds.). *Il pupazzo di garza. L'esperienza della malattia potenzialmente mortale nei bambini e negli adolescenti*. Florence: Firenze University Press, 2004.
11. Buckman R. *La comunicazione della diagnosi in caso di malattie gravi*. Milan: Raffaello Cortina, 2003.
12. Clarke JN, Fletcher P. Communication issues faced by parents who have a child diagnosed with cancer. *J Pediatr Oncol Nurs*. 2003;20(4):175-91.
13. Comisión de psicología de la Federación española de padres de niños con cáncer. *Psiconcología pediátrica: valoración e intervención*. Madrid: Federación española de padres de niños con cáncer, 2007.
14. Papini M, Tringali D, Lauro-Grotto R. *La nostra era una vita normale*. Ancona: Sorbello Editore, 2011.
15. Massaglia P. Il vissuto e l'assistenza ai familiari nelle differenti fasi della malattia tumorale del loro bambino. In: Bertolotti M, Haupt R, Jankovich M, Masera G, Massaglia P, Massimo R, Saccomani R (Eds.). *L'assistenza ai bambini malati di tumore*. Milan: Raffaello Cortina, 2010.
16. Sinzig M, Gasser J, Jauk B, Hausegger KA. [Brain tumors in childhood]. [Article in German]. *Radiologe*. 2008;48(10):946-54.
17. Jankovich M, Conter V, Ferrari E, Colombini A. Diffusione e classificazione dei tumori infantili. In: Saccomani R. (Ed.) *Tutti bravi. Psicologia e clinica del bambino malato di tumore*. Milan: Raffaello Cortina, 1998.
18. Husserl E. *Die Krisis der europäischen Wissenschaften und die transzendente Phänomenologie*. Den Haag: Nijhoff, 1936. [It. transl.: *La crisi delle scienze europee e la fenomenologia trascendentale*. Milan: Il Saggiatore].
19. Papini M. *L'ultima cura. I vissuti degli operatori di due reparti di oncologia pediatrica*. Florence: Firenze University Press, 2009.

20. Bleger J. *Psicohigiene y psicología institucional*. Buenos Aires: Paidós, 1966. [It. transl.: *Psicoigiene e psicologia istituzionale*. Loreto: Libreria Editrice Lauretana].
21. Carli R, Paniccia MR. *Analisi della domanda*. Bologna: Il Mulino, 2003.
22. Correale A. *Area traumatica e campo istituzionale*. Rome: Edizioni Borla, 2006.
23. Dixon-Woods M, Young B, Heney D. *Rethinking experiences of childhood cancer: a multidisciplinary approach to chronic childhood illness*. London: Open University Press, 2005.
24. Woodgate R. Feeling states: a new approach to understanding how children and adolescents with cancer experience symptoms. *Cancer Nurs*. 2008;31(3):229-38.
25. Tringali D, Lauro-Grotto R, Papini M. The perspective of the nursing staff on terminal sedation in pediatric onco-hematology: A phenomenologic-hermeneutic study. *Palliat Support Care*. 2013;11(6):465-72.
26. Stewart JL. "Getting used to it": children finding the ordinary and routine in the uncertain context of cancer. *Qual Health Res*. 2003;13(3):394-407.
27. Fochtman D. Phenomenology in pediatric cancer nursing research. *J Pediatr Oncol Nurs*. 2008;25(4):185-92.
28. Papini M, Tringali D. *Il pupazzo di garza. L'esperienza della malattia potenzialmente mortale nei bambini e negli adolescenti*. Florence: Firenze University Press, 2004.
29. Reid K, Flowers P, Larkin M. Exploring lived experience. *Psychologist*. 2005;18(1):20-23.
30. Mantovani G, Spagnoli A. *Metodi qualitativi in psicologia*. Bologna: Il Mulino, 2003.
31. Smith JA. Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychol Health*. 1996;11(2):261-271.
32. Smith JA, Osborn M. Interpretative phenomenological analysis. In: Smith JA (Ed.). *Qualitative psychology: a practical guide to research methods*. London: Sage, 2003.
33. Lauro-Grotto R, Tringali D, Papini M. Close encounters with caregivers: the case of pediatric brain tumors. *Psychooncology*. 2007;16(9):264-65.
34. Klein M. Notes on some schizoid mechanisms. *Int J Psychoanal*. 1946;27(Pt 3-4):99-110.
35. Jackson AC, Stewart H, O'Toole M, Tokatlian N, Enderby K, Miller J, Ashley D. Pediatric brain tumor patients: their parents' perceptions of the hospital experience. *J Pediatr Oncol Nurs*. 2007;24(2):95-105.
36. MacKay LJ, Gregory D. Exploring family-centered care among pediatric oncology nurses. *J Pediatr Oncol Nurs*. 2011;28(1):43-52.
37. Hill K, Higgins A, Dempster M, McCarthy A. Fathers' views and understanding of their roles in families with a child with acute lymphoblastic leukaemia: an interpretative phenomenological analysis. *J Health Psychol*. 2009;14(8):1268-80.
38. Zonza M. Narrative Based Medicine and Neonatology: an interpretative approach. *J Pediatr Neonat Individual Med*. 2012;1:49-52.