

Secrets and truths in the process of family communication with a child with cancer

Segredos e verdades no processo comunicacional da família com a criança com câncer

Secretos y verdades en el proceso de comunicación de la familia con un niño con cáncer

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ABSTRACT

Objective: To understand the experience of families in establishing communication with children in relation to their cancer. **Methods:** This study used a qualitative methodology to analyze interviews in families of children with cancer treated in a health institution in the state of Minas Gerais. We opted for symbolic interactionism as the theoretical reference and qualitative analysis was the method employed. **Results:** Data analysis showed that cancer stigma influences the way that the family establishes communication with their child. The family makes a selection of words to find meaning of normality, keeping information from children about their future and consequently about death. **Conclusion:** This study stresses the need of emotional support as a guide in the communication process between family and child. The family takes messages to the child that express the hope of overcoming their current situation. Thus, it is important to study strategies used by healthcare professionals to assist the family in its communication in respect to the child's illness.

Keywords: Communication; Family Nursing; Child; Cancer; Support.

RESUMO

Objetivo: Compreender a experiência da família ao estabelecer a comunicação com a criança em relação ao seu câncer. **Métodos:** Trata-se de um estudo de abordagem qualitativa, no qual foram entrevistadas famílias de criança com câncer de uma instituição de saúde do interior do estado de Minas Gerais. Optou-se pelo Interacionismo Simbólico como referencial teórico e a Análise de Conteúdo Temática como método. **Resultados:** A análise dos dados identificou que o estigma do câncer influencia na maneira como a família estabelece a comunicação com a criança. A família faz uma seleção de palavras para buscar sentido à normalidade, afastando da criança informações que trazem ideia do comprometimento do seu futuro e, conseqüentemente, a morte. **Conclusão:** O estudo destaca o apoio emocional como fio condutor do processo comunicacional entre família e criança. A família leva à criança mensagens que deixam explícita a esperança de vencer a situação vivenciada. Assim, deve-se pesquisar estratégias usadas pelos profissionais de saúde para auxiliar a família na comunicação sobre a doença da criança.

Palavras-chave: Comunicação; Enfermagem Familiar; Criança; Câncer; Apoio.

RESUMEN

Objetivo: Comprender la experiencia familiar en el establecimiento de la comunicación con el niño con cáncer. **Métodos:** Estudio cualitativo. Fueron entrevistadas familias con niños con cáncer tratados en una institución de salud en Minas Gerais. Se optó por el Interaccionismo Simbólico como referencial teórico y el Análisis de Contenido Temático. **Resultados:** Se identificó que el estigma del cáncer influye en la forma cómo la familia establece la comunicación con el niño. La familia hace una selección de palabras para encontrar la normalidad, ocultando de ellos la información que da la idea de su comprometimiento con el futuro y, por lo tanto, la muerte. **Conclusión:** Se destaca el apoyo emocional como guía del proceso de comunicación entre la familia y el niño. La familia sólo trasmite los mensajes que expresan superación. Hay que buscar las estrategias utilizadas por los profesionales de la salud para ayudar a la familia en su comunicación.

Palabras clave: Comunicación; Enfermería Familiar; Niño; Cáncer; Apoyo.

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INTRODUCTION

During the treatment of childhood cancer, the child is subjected to various exams, prolonged hospitalizations and different types of therapy including chemotherapy, radiation therapy and surgery that sometimes cause limitations and physical and psychological disabilities¹.

The constant visits to the treatment center for inpatient and outpatient procedures expose children to pain and suffering, interrupt their schooling and disrupt both social and family life, thereby affecting their ability and desire to communicate^{2,3}.

All diseases cause suffering and instability in family dynamics, however cancer also generates doubts, fears and uncertainties about the diagnosis, treatment and control, as it is a disease for which the prognosis is poor especially in children. This implies a need for better understanding of the impact of the disease from the perspective of family members, as all are affected^{4,5}.

Amid the uncertainty, the family seeks information to restructure its activities focused on the sick child⁴. In this unexpected context of living with the disease and its meanings, it is necessary to adopt roles and restructure family life⁶. Given this situation, the process of listening and exchanging information generally helps the family understand and cope with the situation it is going through⁴.

When living with a chronic illness, communication is part of the social interaction process with language and listening being used as the key mechanisms⁷.

The communication theory states that there are two modes of communication: nonverbal or psychobiological communication and verbal communication or psycholinguistics. Verbal communication is one in which people use words or written language to transmit messages. Non-verbal communication, on the other hand, is defined by gestures, silence, and body and facial expressions. So communication is a dynamic and complex process that enables interaction, producing effects on behavior, emotions and feelings of those involved⁷.

As communication is an interpersonal interaction in which speech, language and listening are used and are defined as a crucial mechanism, it is believed that children communicate within their cognitive, sensory and motor potentials. They can direct the gaze or body part that has better control and make sounds, thus producing different forms of communication⁸. By living with the child, the family learns to understand their communication process, and, as the interaction between child and family is strengthened, the intercourse becomes more effective.

In the communication process about the disease with the family, it is necessary to address aspects such as the diagnosis, causes, treatment, risks and expected time of treatment and hospitalization. An appropriate language should be used by professionals in order to counsel family members⁷.

The importance of communication and, above all, communication strategies should be valued for proper intercourse in the interaction and interrelationship between the healthcare

professional and the patient and family. These strategies include questioning the knowledge and expectations of the patient and family about the disease and treatment, affirm the professionals concern and interest in multi-dimensional aspects of the patient, be affectionate touch, look, smile, be physically close and listen attentively. Knowledge of such strategies is currently considered lacking in healthcare teams and improvements cannot be achieved over time without appropriate training⁴.

Particularly, in the case of childhood cancer, the establishment of a relationship and communication provide both the family and the child with cancer conditions to adapt to the changes that occur after the diagnosis. Good communications between family and child do not always occur instantaneously; they are the result of an ongoing process that involves interpersonal relationships, with verbal and nonverbal exchanges of different kinds that construct important professional-family-child therapeutic interactions. However, the family is the link with the child and the source of emotional support throughout this experience⁴.

Thus, communicating the diagnosis of cancer to the child as well as the steps of therapy that will be necessary is a difficult task for parents, because together with the diagnosis there are implicit issues of limitations, hardships and even death, as in most cases, this latter is closely linked to the symbolism of the word cancer. Thus, family members need to face up to the fear of the child's reactions about the disease⁹.

The word cancer is still stigmatized, avoided by many and regarded as synonymous of suffering and death. When it relates to a child the impression is even stronger, considered as a kind of punishment; the shock is even greater and involves the whole family, friends and acquaintances. Amid the anguish, the family believes that the child has no cognitive ability to understand the condition, nor do relatives have the ability to provide information to help the parents make sense of the experienced situation. Thus, the literature indicates that doubts about where, how and when to tell the child become part of daily family life, further accentuating the suffering and stress^{9,10}.

Faced with the challenges related to the experience of the family of the child with cancer, we wondered how important communication in this phase of change is in this family context. As communication is present in the daily interactions experienced by the family, this study aimed to understand the family experience in establishing communication with the child in relation to the cancer.

METHODS

This is a descriptive, exploratory study using a qualitative methodology, which included a set of techniques to identify experiences¹¹. Symbolic Interactionism (SI) was used as a theoretical framework, as it constitutes a structure based on human behavior, valuing the meaning that human beings put on the objects with which they interact. It is through this interaction and from the meaning given that individuals develop and execute their actions. This perspective seeks to study the nature of the interactions and actions performed by the individual,

remembering that human beings act toward things because of the meanings these objects have for them and that these meanings are built on interactions¹².

In this context, SI understands behavior as a set of interpretative factors and processes in which humans conduct their actions through the meaning attributed within social intercourse. This interactional perspective allows you to understand human beings in their dealings with society, with themselves and with each other. Furthermore, the interaction and symbolic communication established by the individual allow perception of meanings, feelings, emotions, behaviors and expectations related to the experienced situation. In symbolic interaction, the human being is considered an individual who experiences continuous interactions, is active and has freedom of choice¹².

This study was performed in a pediatric unit of a tertiary Oncological Health institution located in a provincial city of Minas Gerais and inaugurated in 2009.

A list of names, addresses and data on families with school age children (i.e. aged 6 to 12 years old), who were being treated for cancer of any type for at least three months was provided by the institution. These were the inclusion criteria.

School age was chosen because it is believed that in this period children have already developed cognitive abilities that enable them to differentiate their own ideas from those of others and verbally express these ideas. Children indicate their ability to understand themselves and detect precociously any evidence that is not within the normal parameters that they have established¹.

For SI the child's self develops from interactions established throughout childhood, passing through stages denominated: preparation, play, game and reference group which expand the ability of the individual to define himself/herself as a consistent social object, different from the others¹².

Of the thirteen children who met the selection criteria for this research, three died, two families refused to participate in the study and one family was excluded from the study after the qualifying examination, as after changes in the selection criteria, the child was no longer in the age group proposed for the study (Table 1).

Using the list of names, the researcher contacted the families during consultations in the health facility to explain the objectives of the research and invite them to participate in the study with the date and location being decided by the family.

Data collection took place from March to August 2012 using semi-structured interviews, which allowed researchers to intervene in order to clarify and adjust questions during the process¹¹. These interviews took place in a room provided by the institution. Before the interview, all participants signed informed consent forms.

In light of this knowledge, all the relatives of the children who were present in the institution at the time of data collection were invited to participate, but because someone had to stay with the child, in general we opted for just one relative to participate. In this context, this research is characterized as a family study, as in the

interactional perspective, the family can be defined as "a group of individuals in symbolic interaction, approaching situations with the significant others or reference groups, with symbols, perspective, self, mind and ability to take on roles"¹³.

From this moment, the family members were encouraged to talk about their experience in communicating with the child using the following question: "Did you tell (the child's name) about the disease?" As the interview progressed, other prompts such as "tell me a little more" and "tell me more about how you did it" were used in the interview in order to understand the family's experience in establishing communication with the child in relation to the cancer.

The interviews were recorded, transcribed and systematized according to the method of qualitative analysis. This is a method that employs a set of techniques to understand the implicit meaning of the messages in order to reveal the meanings of communication, developed in three stages: pre-analysis (extensive reading and hypothesizing), exploration of the material (coding and classification in categories), and treatment of results and interpretation (process of reflection)¹⁴.

Transcripts were read in detail to learn how the family was coping with this experience. Subsequent readings aimed to further explore the subject matter that passed through a dismantling and regrouping process called systematization of data. Following this, the data, which were initially separated as themes, were reinterpreted in a process of reflection and analysis of the results. To elucidate the categories, excerpts from the participants interviews were selected and are identified according to the interviewee and family number (example: Mother 1).

All the requisites of Resolution No. 466/12¹⁵ that regulates research involving human beings were respected. This study was approved by the Ethics Committee of the institution (# 05/2012).

The review process took place against the background of the context in which the interaction occurred, that is, the interaction between family and child, family and the extended family, family and healthcare professionals, and family and peers. In this interaction process, we sought to comprehend the processes of communication established between the family and child.

RESULTS

The process of collecting and analyzing the data identified three categories that made it possible to understand the family experience in establishing communication with the child in relation to their cancer, as follows:

"ESTABLISHING A NEBULOUS COMMUNICATION" which includes the subcategories "Feeling uncertainty about information", "Marked by painful words" and "Sharing the bad news" that correspond to the family's experience on discovering the child's illness; "FINDING SUPPORT BEYOND WORDS" which aggregates the subcategories "Transmitting messages of encouragement", "Being a companion of the child", "Communicating hope", and "Sharing experiences" and "DIALOGUING BETWEEN SECRETS AND TRUTHS" which includes the subcategories "Revealing the diagnosis", "Detailing

Table 1. Identification of children with cancer and participating families

Identification	Data of the child	Study participants
Family 1	Age: 6 years Gender: Male Diagnosis: Acute lymphoid leukemia (ALL) Duration of treatment: 10 months	Mother
Family 2	Age: 6 years Gender: Female Diagnosis: Nephroblastoma (Wilms' tumor) Duration of treatment: 8 months	Mother
Family 3	Age: 6 years Gender: Female Diagnosis: Nephroblastoma (Wilms' tumor) Duration of treatment: 3 years	Mother
Family 4	Age: 10 years Gender: Male Diagnosis: Hodgkin's lymphoma Duration of treatment: 2 years	Mother
Family 5	Age: 10 years Gender: Female Diagnosis: Acute lymphoid leukemia (ALL) Duration of treatment: 5 months	Mother Child's sister
Family 6	Age: 8 years Gender: Female Diagnosis: Triton tumor Duration of treatment: 2 years	Father
Family 7	Age: 11 years Gender: Female Diagnosis: Hodgkin's lymphoma Duration of treatment: 2 years	Mother

the course" and "Understanding the disease process" and describes the family's communication with the child in relation to cancer.

ESTABLISHING A NEBULOUS COMMUNICATION

This is characterized as an exhausting and marked course by fragmented, incomplete, unclear and fuzzy communications; the family seems to be putting together a puzzle to try to unravel the clinical picture of the child. In the process of understanding the language and the information received, the family asks healthcare professionals in an attempt to aggregate information. When faced with the diagnosis of childhood cancer, some find it unbelievable, going back to relatives in an attempt to share the pain of having a child with cancer.

Feeling uncertainty about information

When looking for health services to comprehend the clinical presentation and complaints of the child, the family encounters several obstacles greatly increasing their anguish. The implicit communication process at this stage is incomplete, fragmented and unclear because the communication established with the

healthcare professional does not contemplate their need for information. In this perspective, the family uses an evasive language permeated by uncertainty with the child, after all not even the parents understand the situation. Thus, the communication that the family has with the child at this stage, aims to convince he/she of the importance of collaborating in the process of discovery of the disease, even if a vague communication has to be used for this:

"I (mother) looked at the doctors writing mass, mass, mass, but I did not know what it was or what it meant and no one told me anything" (Mother 3).

"I (mother) spoke to (the child) that we had to do what the doctor asked to find out what she (child) had" (Mother 2).

Marked by painful words

Faced with the certainty of the diagnosis and usually without the child being present, the healthcare team communicates the diagnosis of childhood cancer to the family. When facing such a dreaded disease, the family feels shocked, believes that they

are living in an unreal situation, they find themselves immersed in an unknown reality that causes fear and insecurity. In this situation, they are fragile and do not know how to establish a communication about the disease and treatment with the child, since it is a challenging process and even the family nucleus finds it hard to deal with the information. In addition, just hearing the name of the disease causes panic. Parents revealed how words have the power to transform day-by-day life:

"She (child) stayed with my sister when we (the child's parents) were talking to the doctor. He (doctor) said what she had and we were shocked. It was that cold shower!" (Father 6).

"(...) it affected her head very much (child) and I (the child's mother) tried to convince her, but I was unable to convince myself let alone convince her! It was hard! (...) I heard something, but even I did not believe that. I looked and said it was a dream, that I had fallen asleep and could not wake up. I looked at her and did not believe and said: 'it is not true'" (Mother 2).

Sharing the bad news

On discovering childhood cancer and in the midst of suffering after receiving such bad news, the nuclear family goes to relatives to share the burden of living with a chronic condition, but excluding the child. It is in this environment that the communication process starts in respect to issues related to looking after the child with one of the family discussion points being related to the issue of whether to tell the child about the illness or not. In the discussion, family members express their fear of the disease and the need to keep the information within the family nucleus as a way of avoiding comments or the need for explanations, thereby preserving the child from remarks about the disease:

"I (the child's mother) went to my mother's house. At the time, I wanted to sit in my mother's lap! I went to her house (the child's grandmother) and I cried with her and my father. Then I went home, because my husband and other daughter were waiting for news. (...) I talked to my husband and he said he did not want to tell her (the child), because he was afraid that she would not cope. Basically, I also had this fear!" (Mother 5).

"I and my husband (child's parents) talked a lot about the treatment, but did not let the (child's name) and my other son participate. We waited for them to sleep and talked in the bedroom, just the two us" (Mother 4).

FINDING SUPPORT BEYOND WORDS

On living with the chronic disease of the child, relatives offer and receive support to face this difficult period. The family try to transmit messages of encouragement and support to help the child cope with this situation. This is not only true in respect to words but also to gestures. These interactions are intermediated

by healthcare professionals who encourage and construct a positive communication with the family and child that encourages and stimulates them to move on. In addition to the relationships established with healthcare professionals, the family stresses the importance of having contact with other families that are going through a similar ordeal; they believe that others can provide more information, help them to develop care as well as offer them support to find the strength to face the hardships.

Transmitting messages of encouragement

In the communication established with the child, the family unit tries to convey messages that encourage the child to cope with the disease. To do so, they select their words using figures of speech, such as metaphors. With this strategy, the family seeks to pass messages that enable an analogy between the child's perception regarding the procedure and the true situation. Thus, when talking about death, the family does not mention cancer as a major risk to the child's life, nor does it use of the word 'death' to give meaning to it. On discussing this issue, they generally look for words to describe it, but more importantly words that stress the importance of treatment for diseases as a whole as a way to avoid death:

"He (child) said, 'Mother I eat, but I throw up. Why am I throwing up? I never threw up! I would say: 'Son, it is because of the chemotherapy. You see that here is a bluish color. The white you have already taken, the orange you have already taken. So these colors are part of a rainbow and this rainbow needs to be completed for your angels to arrive here, go through the rainbow to get to you. So, you have to have a lot of strength to endure this drip feed here because this drip feed will make you have no disease any more. (...) He (the child) said: 'mother what I have kills, doesn't it?'. I (the child's mother) said: 'Son, everyone has a little problem, if you do not heal, if you do not treat this as you are doing, you will not hold out'" (Mother 1).

"(...) I (the child's mother) kept everyone away and I stayed with him (the child) more because I did not want anyone crying next to him" (Mother 4).

Being a companion of the child

Throughout the course of the disease, the family tries to share the child's anguish, fear and anxiety. For this, the family unit shows the child many possibilities of how to live with the limitations of the disease. It offers a variety of entertainments, such as movies, cartoons, games and toys that do not require much physical effort. It also attempts to provide ways for the child to adapt his/her body image. For this, they buy scarves, hats, berets and caps that match the clothes. The family does so, to meet the needs of the child, trying to minimize the suffering:

"I (the child's mother) would not let her (the child) be sad. I showed her that she could live with it perfectly. I bought

several hats and scarves, every day that she put on a dress she would put on a matching hat (she laughs). As she could not play with their friends, I put a toy on the floor, on the bed, on the couch and we played (laughs), so I tried to substitute the games that she could not play at that time for others" (Mother 7).

"When I (the child's mother) said that his (the child's) hair would fall out and that he should choose some caps and berets, to choose the fabrics to make some cute berets, he said: 'Oh I want'. I said, 'we'll do it your way.' His father also told him: 'on the day that your hair starts falling out and we are going to shave, I'll shave mine too'. He said, 'Look dad, you'll have to be bald" (Mother 4).

Communicating hope

In the established relationships, the family values the communication maintained with the child and healthcare professionals. The family unit stresses that both healthcare professionals and the child make a combined effort to convey support and hope in order to go on. Through gestures and tone of voice, the family finds the strength to overcome the painful moments, believing that they will win:

"(Doctor's name) sat and explained. He was explaining, explaining, telling how the whole process would be and showing me that there were people who were victorious and that we (the child's parents) could not lose faith" (Mother 3).

"(...) Her (the child's) birthday party was full of people and she just said, 'I just want my cure, I want nothing more mother, just my cure!'. I (the child's mother) did not believe it when she said it (mother crying)" (Mother 2).

Sharing experiences

The treatment of childhood cancer gives the child and family an opportunity to have contact with others who experienced a similar situation. Through information exchange, families are mirrored in each other and with this they seek strength to face the situation.

In this relationship, the family also learns that the child shares his/her experiences, highlighting the importance of treatment and how therapy improves health:

"The support you have talking to other people. Some people were so affectionate, spoke such beautiful words: 'be strong, have faith and you will succeed.' I (The child's mother) got to know other mothers each one comforting the others" (Mother 5).

"(...) He (the child) was talking to a lady (a patient being treated at the institution), 'look you will feel like this, you will feel roasted, and do not worry because you just vomit on the day'. And she said, 'but I feel a bad taste of rotten meat in my mouth, is it like that?' He (child) said:

'Chemotherapy is like that, take a lime and smell in not to feel nausea'. He explained everything, gave her a lecture, so much so she said, 'I'm glad you came here child because you warned me. I'll still have a second round of chemo. I'm in doubt, I'm afraid!' He said, 'No, you will see, you will even improve, your color will improve'" (Mother 4).

DIALOGUING BETWEEN SECRETS AND TRUTHS

To establish communication about the disease with the child, the family prepares and delays as long as possible so that it can reflect on the information received and analyze the best way to talk to the child. Some families talk frankly to the child about the disease but others choose to play down the diagnosis in order to protect the child from negative thoughts that may interfere with treatment. Thus, they think before speaking about the disease and do not mention the word cancer. However, regardless of the words chosen to disclose the diagnosis, the family feels the need to stress the particularities of the procedures. These situations as well as the consequences are understood by the child at the time that he/she experiences them.

Revealing the diagnosis

The context in which interactions occur offer communicational clues that impose direct contact with the suffering and pain permeated in the relationship between family members and the child. This situation leads the child to ask the parents about the change of routine, forcing the family to begin the communication process related to the disease.

Discussions show that some families name the disease, i.e. refer to cancer stating its apparent cause. In fact, the family uses objective comparisons, through which children can imagine, compare and understand their illness:

"(...) (The child's name) says, 'Mother, why I'm like this? Why, mom? My friends are not here!' I (the child's mother) talked to my child: 'daughter, your grandfather on your father's side had the same disease as you. It's called cancer. You're similar to your grandfather, it is genetic. You're just like your grandfather you have the same disease (...)" (Mother 2).

Other families, as they consider the disease delicate and complex, whose name is already a source of denial, do not mention that the disease is cancer, but simply refer to a tumor, small lump or bubo, which are considered diagnoses of lesser impact compared to 'cancer'. Hence, on adapting the language to the universe of the child, the family uses resources to minimize the problem and demonstrate that the child is bigger and stronger than the disease:

For (child's name), I (the child's mother) said it was a tumor and that the tumor was a small lump that was in her belly. So, I did not say the right name. The fear we have of this disease; we see people talk on television of how bad

this disease is. I was afraid ... and my family is afraid just of the name of the disease, we are afraid of the problem, so I tried not to talk, I tried to hide it from her" (Mother 3).

Detailing the course

The difficulty of living through the treatment of childhood cancer and its consequences makes the family communicate with the child about the procedures that will be performed, so that he/she collaborates with therapy. Some families build open communications, naming procedures, that is, replicate what they heard from healthcare professionals. Through playful communication, the family explains the possible side effects, especially related to loss of hair. The parents also clarify about the role of and what is expected from the procedure:

"We explained to her (the child) that for the doctor to remove the tumor, he would have to amputate the leg, because the tumor was already very large. And that in addition to surgery, she (the child) would have to take a little medicine; and that it was this medicine that would finish with the tumor completely. But her hair could fall out because the medication is very strong!" (Father 6).

"(...) The comic was like this: I (the child's mother) took a large sheet and in each box I drew a lot of small squares; and in each small square I indicated days of chemotherapy and counted them for him. I drew a rainbow and a little angel for him to understand what he was going through. I depicted a walk to the hospital and a little boy getting medication" (Mother 1).

Understanding the disease process

In the interaction with the child, the family learns, through verbal and non-verbal communication, how much he/she is affected and confused not only in respect to the diagnosis, but even more so about the physical transformation. They perceive that the child seems to feel shame, fear and anguish on recognizing their limitations and mutilation, victim of a chronic disease that has significant consequences. When this happens, the child's mood oscillates between aggressive behavior and isolation. In an attempt to circumvent the situation, the family communicates with the child with respect; however, they speak firmly, setting limits and showing the child that the disease is no reason nor excuse for rude behavior. At other times, the family demonstrates difficulties in establishing communication with the child in order to alleviate the suffering. This accentuates the family's suffering:

"For her (the child), even though she does not speak, it was a shock, because her life was transformed. (...) She cannot do anything. (...) When she is aggressive towards me, I (the child's sister) spoke to her. I show her that I did not like her attitude. I say: Like that no! It is not because you're going through all this that you can do things wrong" (Sister 5).

"(...) But it is living, struggling every day and learning every day. It took a long time for her (the child) to be aware of the disease. When we (the child's family) are at home, there are times that she closes the door of her room and says: 'Mother, I do not want to see anyone'. I open the door to talk to her but I cannot. I (the child's mother) think that... (pause) there are times when she must feel something, I'm going to talk to her and she says: mother leave me alone, please" (Mother 2).

DISCUSSION

An analysis of the interviews shows that the family's experience in communicating with the child with cancer occurs as a dynamic and integrated process. The family faces a number of obstacles to unveil the clinical picture and establish communication with the child about the illness. In this interaction, emotional support becomes the central theme that permeates throughout the whole experience.

Childhood cancer has a great emotional impact on the family, but parents do not express their own feelings to save the child and they seek emotional support in the extended family, the healthcare staff and other caregivers in an attempt to understand and cope with the situation.

The results of this study corroborate the findings of a study on the psychosocial needs of families and their everyday life with a child with cancer as the family pulls together in difficult times, establishing a support network that spans the institutional wall and expands to the community¹⁶. The core concerns focus on the future of the child¹⁷.

Family communication is characterized by an open relationship where there is freedom for mutual communication of thoughts, feelings and fantasies. In the interaction established within the family, members value the possibility of sharing the fear of losing the child. The experience of having a traumatic diagnosis such as childhood cancer unites family members, who reassess their values and the priorities within the unit itself. The strengthening of family ties is very important to alleviate suffering¹⁸.

In this context, the relevant issue in the data, which is intrinsic to support, is the constant selection of words used by the family to communicate with the child. The care of the communication is associated with the desire to protect the child from the anxiety caused by multiple uncertainties related to the diagnosis, procedures and the future.

A review of the literature on the attitudes of physicians towards breaking bad news as well as the perceptions and preferences of parents, demonstrated that the selection of words is an effective strategy to contain uncertainty; this is seen by the family as a source of emotional support for the child. This strategy constitutes a significant protective factor for those who have to face bad news¹⁹. Thus, the family direct their resources to work with the meanings of the disease.

Taking care with communication is related to the meaning the family attributes to the disease and its experience and involves

everything they saw and heard about cancer. Furthermore, the possibility of death, which appears so early in the life of an individual, increases the family's distress²⁰. Thus, the family attempts to give a sense of normalcy by limiting information. It does this to try to prevent the child from suffering any discrimination in respect to the disease.

The family believes that the meaning marks people with cancer in unwanted and unexpected ways making it difficult to live with these scars. The mark may be stigma or death, and although the significance of the disease is often ambiguous, its consequence can be modified by the environment in which the patient is inserted, that is their cultural context. The family changes its resources to work with the meanings of the disease, seeking a sense of normalcy; it is afraid of direct communication of the child with other individuals. The family believes that, as they know their child better and have more interaction, the vocabulary is easier and shared. The family chooses to receive information about childhood cancer and then transmit it, thereby exerting greater control over the situation, which consequently leads to protection of the child. It is also important to remember that the culture and family values have significant roles in determining the most appropriate way to convey the information to the child²⁰.

Emotional support is transmitted to the child through messages that portray the positive side of the situation. The acceptance and hope for a satisfactory outcome in relation to the disease are used as instruments to deal with the treatment.

The choice of words is associated with the desire to protect patients not only from the bad news, but also from the feeling of anxiety caused by many uncertainties related to procedures, the diagnosis and the future. The selection of words is an effective strategy to contain the uncertainty; this is seen by the family as a source of emotional support for the child²¹.

The stories and comments about the disease in the different contexts of the family, such as previous experiences with children and adults affected by cancer, have an important influence on the words that are used in the current communication with the child. Moreover, the word cancer is still a stigma that for many should be avoided as it is synonymous of suffering and death. When it affects a child, it has an even stronger impression, a kind of punishment, and the shock is greater affecting the whole family, friends and acquaintances²⁰.

In this context, words, objects and actions are symbols that are used intentionally in social interaction, employed in communication to represent something for others. When interacting with others, the human being receives stimuli that cause changes in the elements involved in the context of the situation¹². Thus, it is in the presence of each experience and the meanings of the interactions that the family develops measures to minimize the suffering of the child.

In a qualitative study to understand how cancer therapy is seen by children and adolescents with the disease, it is clear that the desire for a victory and a satisfactory resolution of the disease becomes the main and sometimes their only goal²⁰.

From this difficult present, the future is desired and dreamed for by the child with hope being essential to overcome the physical and emotional stress²².

CONCLUSION

The family's experience with regard to communicating with the child about cancer is a cautious process that goes hand in hand with the development of their therapy. The revelations are made not so much as to make the diagnosis clear, but to conduce the child to contribute to therapy and believe that everything will pass. The future is evoked in the present as a way to give meaning to suffering and to the hardships experienced in the course of treatment.

Interactions built on companionship between individuals is required to cope with the difficulties encountered during the care of children with cancer, with emotional support being the principal feature in the communication that the family establishes with the child. The support offered to the child is the adoption of a protectionist language, by passing information that suggests the situation will be overcome.

The list of established interactions includes nurses who can act by encouraging the family to face the situation, empowering it with explanations and information, and facilitating contact with peers and with other members of the healthcare team. As they are always close to the family unit, professionals can identify the difficulties encountered in establishing communication with the child and help them to build this relationship.

Understanding the family's difficulties enables planning to fill in the gaps in understanding and of care. Thus, it is believed that the family and healthcare professionals can enhance a child's ability to understand and to answer their questions in the search for comprehension.

Much still needs to be understood about the process of communication and interaction: what stimulates, what makes communications difficult within the family, between the family and professionals and with the patients themselves, with their personal, age, cultural and social characteristics. For nurses, whose interaction with the child and his family is the main tool, there is much to investigate, to thereafter establish the best care plan.

The limitations of this study are related to the family's perception of longitudinal changes in the child's development and changes in the form of communication, which were not investigated. Although communication in the family perspective was requested, it involved just one family member. Moreover, this study explores family communications with schoolchildren; there is a need to investigate communication from the perspective of children of other age groups.

Given the above, this work shows how imperative it is to carry out detailed studies on communication, considering the need to prepare healthcare professionals to become a source of support for families experiencing chronic diseases.

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