
EVALUATION OF PARENTS' DECISION-MAKING IN ONCOLOGIC PEDIATRIC TREATMENT

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ABSTRACT. Introduction: Decision-making when facing a pediatric cancer treatment deserves a spotlight due to the amount of decisions that parents must deal with during this process, which may often generate emotional stress, doubts, uncertainties and anxieties. Thus, assessing how the health team influences the decision of parents is an important factor to evaluate how much autonomy they have to be able to choose on the numerous possibilities resulting from the treatment. **Objective:** To evaluate parents' decision-making process in oncologic pediatric treatments and to analyze the perception of coercion, the level of moral-psychological development and other difficulties. **Method:** 10 participants were selected by convenience to conduct individual semi-structured interviews, applying the Scale of Perception of Coercion in Assistance and the Moral-Psychological Development Scale. **Results:** Nine mothers and one father were interviewed (n = 10), with an average age of 33.1 years. Six categories were identified from the analysis of content originated from the central theme. There was no perception of coercion by parents and all have shown psychological and moral levels suitable for decision-making. **Conclusion:** It was observed that, in spite of emotional difficulties, parents have proved able to decide on issues related to the treatment of their children, having enough autonomy for decision-making.

Keywords: Decision-making; psycho-oncology; coercion.

AVALIAÇÃO DA TOMADA DE DECISÃO DE PAIS FRENTE AO TRATAMENTO ONCOLÓGICO PEDIÁTRICO

RESUMO. Introdução: A tomada de decisão frente a um tratamento oncológico pediátrico merece um foco de atenção vista a quantidade de decisões que os pais enfrentam durante esse processo, podendo gerar muitas vezes desconfortos emocionais, dúvidas, incertezas e angústias. Dessa forma, avaliar como a equipe de saúde influencia na decisão dos pais se apresenta como fator importante para poder se entender o quanto de autonomia eles possuem para poderem escolher diante das inúmeras possibilidades advindas do tratamento. **Objetivo:** Avaliar o processo de tomada de decisão de pais frente ao tratamento oncológico de seus filhos, analisando a percepção de coerção, nível de desenvolvimento psicológico moral e outras dificuldades existentes. **Método:** Foram selecionados dez participantes por conveniência para realizar uma entrevista semiestruturada individual e foram aplicadas a Escala de Percepção de Coerção em Assistência e a Escala de Desenvolvimento Psicológico-Moral. Utilizou-se o método da análise de conteúdo de Bardin para se realizar a categorização das falas dos participantes. **Resultados:** Nove mães e um pai foram entrevistados (n=10), com média de idade de 33,1 anos. Foram identificadas seis categorias a partir da análise de conteúdo oriundas da temática central. Verificou-se não haver percepção de coerção pelos pais e todos demonstraram nível psicológico-moral adequado para tomarem decisões. **Conclusão:** Observou-se que, apesar de dificuldades emocionais, os pais se mostraram capazes de decidir questões relacionadas ao tratamento de seus filhos, tendo autonomia o suficiente para a tomada de decisão.

Palavras-chave: Tomada de decisão; psico-oncologia; coerção.

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EVALUACIÓN DEL TOMA DE DECISIONES DE LOS PADRES EN TRATAMIENTO PEDIÁTRICO ONCOLÓGICO

RESUMEN. El frente de la toma de decisiones a un tratamiento de cáncer pediátrico merece un foco de atención a la cantidad de decisiones que enfrentan los padres durante este proceso y con frecuencia puede generar malestares emocionales, dudas, incertidumbres y ansiedades. Por lo tanto, para evaluar el equipo de salud influye en la decisión de los padres se presenta como un factor importante para entender el grado de autonomía que tienen que ser capaces de elegir en las numerosas posibilidades que resultan del tratamiento. **Objetivo:** Evaluación de toma de decisiones de los padres sobre sus hijos el tratamiento pediátrico oncológico, Evaluación de la percepción de la coacción, el nivel de desarrollo psicológico moral y otras dificultades existentes. **Método:** Por conveniencia, diez participantes fueron seleccionados para responder a la entrevista semiestructurada individual, aplicando la escala de percepción de coerción de Asistencia y la Escala de Desarrollo moral psicológica. **Resultados:** Se entrevistaron a nueve madres y un padre ($n = 10$), con una edad media de 33,1 años. Se identificaron seis categorías de contenido de origen a partir del análisis temático central. Había la percepción de coacción por parte de los padres y todo a nivel psicológico y moral Mostró apropiado tomar decisiones. **Conclusión:** Se observó que, a pesar de las dificultades emocionales, los padres han demostrado ser capaces de decidir cuestiones relacionadas con el tratamiento de sus hijos, que tienen la suficiente autonomía para la toma de decisiones.

Palabras-clave: Toma de decisión; psico-oncología; coerción.

Introduction

Pediatric cancer represents 0.5% to 3% of all types of tumors in most populations, being leukemia, lymphomas and tumors of the Central Nervous System the most common (Siegel & cols., 2012). While the emergence of neoplasms in adults is usually connected to exposure to various risk factors, such as smoking and lifestyle, many of the causes of pediatric tumors remain unknown. From the clinical point of view, pediatric tumors have lower latency, generally presenting fast growth and higher intrusiveness, while at the same time they respond better to the treatments currently offered (Robison & Hudson, 2014).

According to data from the National Cancer Institute (INCA), it is estimated that in Brazil occur about of 11,530 new cases of cancer in children and adolescents up to 19 years old (Instituto Nacional do Câncer, 2011). The treatment for these young people is complex and includes different forms of interventions, including surgery, hormone therapy, radiation therapy (RT), chemotherapy, target specific therapy or the combination of two or more therapies, according to the doctor's choice (Ramphal & cols., 2011).

In addition to procedures directly aimed at the treatment of the tumor, while hospitalized patients can go through diagnostic procedures, such as laboratory tests, CAT scans, x-rays, MRIs, among others, which might present some risks (Hildenbrand & cols., 2011). These interventions can trigger numerous side effects that must be reported to patients or guardians by means of an Informed Consent (IC). In the case of young patients, i.e. children under twelve years old and adolescents between twelve and eighteen years old, as determined by Act 8,069 of July 13, 1990, this term is signed by the legal guardians, usually the parents. According to Act 10,406 of January 10, 2002, children and adolescents are considered incapable of exercising the acts of civil life, being the legal responsibility of decision-making attributed to parents.

Decision-making involving issues related to assistive processes in health, as in the case of pediatric oncology patients, is based on various skills, such as the possibility of getting involved with the subject, understanding or assessing the types of alternatives and communicating the preferences (Barry & Edgman-Levitan, 2012). Decisions may be made through willingness, when the person involved in the situation makes his/her choice based on his/her interests, disregarding possible external pressures (Martin & cols., 2015). On the other hand, when the decision involves a relationship between two or more individuals, in which there is an element of authority or prestige, the process is understood as coercion (Epstein, 2013). Thus, coercion involves dissuading someone faced with a decision-making process by forcing the individual to do something of interest of who is coercing. In other words, coercion

aims at convincing people who are making decisions to change their behavior by handling their subjective cost-benefit calculation (Stanhope & cols., 2009). In the case of treatments for pediatric cancer, an attitude of coercion of the team could be exemplified as convincing the parents or legal guardians to authorize a treatment that requires consent, even though they are not able to weigh the risks and benefits and end up deciding under the pressure of the team.

Since the ability of decision-making represents the operating or functional side of personal autonomy, a certain level of moral-psychological development is required. This moral development can be understood as the dynamic that governs the process of elaboration of the developing subject concerning the values adopted in situations of social interaction, often aiming at a choice based on aspects of sense and values (Martins & Branco, 2001).

Additionally, when it comes to cancer treatment, it is regarded that besides the ability of decision-making and the individual level of psychological development, the relationship that patients and family will develop with the professionals involved may have a greater or lesser degree of influence on the choices made during the treatment. A clear explanation of the procedures, risks, benefits and alternatives are basic elements for the decisions on the choice of the treatments offered (Goldim, 2006). Conversely, when health professionals adopt a vertical relationship with the patient, they end up assuming responsibility for the change process, resulting in an unequal relationship with knowledge, experience, authority or power, therefore acting in a coercive way.

This study is inserted in a research line that uses Complex Bioethics as reference to assess different issues involved in the process of decision-making, and aims to understand this phenomenon under the perspective of parents, regarding the different procedures recommended during the oncological treatment of their children, evaluating the level of perception of coercion, the level of moral-psychological development and exploring this process through their perception when faced with the different scenarios of the treatment (start of the treatment, protocol changes, exams, among others).

Methods

Sample and study design

This is a cross-sectional descriptive study of mixed approach that was undertaken between March and October 2014. Data collection was performed in the Chemotherapy Ambulatory of the Clinics Hospital of the city of Porto Alegre (HCPA), a high complexity hospital of the Brazilian public health network, reference in the treatment of pediatric cancer in the study region. Twelve parents of pediatric cancer patients in treatment in the hospital mentioned above, of both sexes and over 18 years old, were invited to participate in this research. Among these, nine mothers and one father (n=10) agreed to participate. The refusal of two parents was due to the lack of availability of time because of their involvement with their children's care during the data collection period. The participants were chosen by convenience and addressed during the chemotherapy sessions of their children, being selected as they consented in participating in the research. No measure of care with the proportion of genders of the parents was adopted, being included as participants those who were willing, regardless of this feature.

All the participants signed the Informed Consent and agreed to participate in this study voluntarily. The study was conducted in compliance with ethical principles, according to the provisions of Resolution Nº. 466/12 of the National Health Council (Resolution 466/12, 2012).

Data collection

Data collection was conducted by a single therapist, specifically trained for this task, in a room at the chemotherapy ambulatory of the hospital, and consisted in the application of a social-demographic questionnaire (with parental data for age, gender, educational level, marital status, religion and current

employment and income), the Moral-Psychological Development tool, the Scale of Perception of Coercion and a semi-structured interview based on six open questions (Chart 1) to stimulate the process of discussion. The average time of the data collection process was 40 minutes and all the interviews were recorded and transcribed for analysis.

In addition to the information provided during the assessment and interview, we collected some data of patients in their medical records, as their ages, gender, diagnosis, date of discovery of the diagnosis and type of treatment proposed (chemotherapy, radiation therapy, surgery, bone marrow transplantation or others).

Chart 1. Script of the Semi-Structured Interview

- 1) In what moments and situations you found yourself in charge of making a decision during the treatment of your child?
- 2) While deciding about a procedure during the treatment of your child, what was the basis for your decision?
- 3) When you had to make a decision during the treatment, do you consider you have received enough information to decide?
- 4) Can you remember your emotional state in the main decisions you have made during the treatment of your child?
- 5) What do you think would have helped you in the decision-making moment? What type of support would you like to have had?
- 6) What was the most difficult decision you have had to make while accompanying your child during the treatment?

Evaluation of the moral-psychological development level

To evaluate the level of moral development of the parents, the Moral-Psychological Development tool was applied before the interview (Loevinger & Wessler, 1970), a self-applicable scale developed from two previous versions proposed by Edela Lanzer Pereira de Souza in 1968, translated to and validated in Portuguese language spoken in Brazil (Souza, 1968). Based on a set of simple sentences, its score allows the classification of individuals in seven different stages of moral-psychological development (pre-social; impulsive; opportunist; conformist; conscientious; autonomous and integrated), described in Table 1.

Table 1. Classification of moral-psychological development according to the mean values obtained using Souza's tool (1968).

Phases of Moral-Psychological development	Score	Characteristics
1) Pre-social	(0.1 – 1.0)	Early development, pre-verbal
2) Impulsive	(1.1 – 2.0)	The individual makes decisions on impulse, based only on his/her desire, not considering the information
3) Opportunist	(2.1 – 3.0)	Overvaluation of desires and valuation of information to reach them
4) Conformist	(3.1 – 4.0)	The beliefs of the individual overlap his/her own desires and justify the contingencies imposed by the environment
5) Conscientious	(4.1 – 5.0)	The individual is able to make decisions in a more autonomous way, comparing wishes and beliefs, though being still prone to embarrassment, since he/she does not have the notion of introjected rules
6) Autonomous	(5.1 – 6.0)	The individual already has introjected rules and is capable of making decisions independently and free of embarrassment
7) Integrated	(6.1 – 7.0)	The individual has the notion of introjected rules; however, he/she sees him/herself as part of a whole, understanding the existing interdependency

Source. Souza, E. (1968). Pesquisa sobre as fases evolutivas do ego. *Boletim da Sociedade de Psicologia do Rio Grande do Sul*, 3(7), 11.

Assessment of the level of perception of coercion in assistance

For this evaluation, we used the scale of Perception of Coercion in Assistance, validated in Portuguese language spoken in Brazil (Taborda & cols., 2004) and derived from the scale *MacArthur Admission Experience Survey* (Gardner & cols., 1993) composed by 16 questions and developed to assess coercion in psychiatric admissions. The Scale of Expression of Coercion in Assistance is a self-applicable scale composed by five sentences assessing five specific domains of perception of coercion (freedom, choice, idea, control and influence). In each sentence, the participant marks agreement or disagreement with the statement, and the alternative “disagree” suggests the presence of perception of coercion in the domain to which it corresponds. The domain “freedom” refers to how the person felt free to make certain decisions; “choice” refers to how much the person actually chose of what was offered; “idea” considers if performing certain assistance procedure was the person's own idea; “control” refers to the person's perception of control over the decision and, finally, “influence” refers to how much influence the person had over his/her own decision.

Data Analysis

To analyze the data obtained in the individual interviews, transcripts of the narratives were performed, providing greater fidelity to the participants' statements in the course of the research. The assessment was carried out through the technique of content analysis, in which the dialogs transcribed in their entirety were used for identification of units of meaning that were grouped in subcategories. Through this technique is outlined the core of representations found in each category and their interrelation with each other, until the repetition or saturation of expressions of meanings brought by the subjects of the research is established (Bardin, 2004). The information collected through the application of scales were stored and descriptively analyzed using calculation of mean values, standard deviation and percentages with the software Statistic Package for Social Sciences (SPSS) version 18.0.

With the purpose of analyzing the same phenomenon from more than one data source, a data triangulation was performed (Azevedo & cols., 2013), using information extracted from a content

analysis of the semi-structured interviews and the quantitative results extracted from the scales applied, which were analyzed together.

Results

The results of the descriptive analysis of the sample, regarding socio-demographic data of children and parents, are described in table 2. Regarding the Moral-Psychological Development, all the participants presented the ability to make decisions in their best interest (Loevinger & Wessler, 1970), given that the sample had a predominance of people in the Conscientious phase (n=6), followed by the Conformist phase (n=2) and the Autonomous (n=1) and Integrated (n=1) phases. Concerning the perception of coercion, no sample participant marked more than three times the alternative “disagree”, suggesting low level of perception of coercion. The domain in which most of the participants (n=6) indicated a possible perception of coercion was “influence”, followed by “idea” (n=5), “control” (n=2) and “freedom” (n=2). Any participant perceived coercion in the domain “choice”.

Table 2. Descriptive characteristics of the subjects (n=10)

Descriptive Characteristics	Mean	Min.-Max.
Age of children (years)	7.8	3-17
Time of diagnosis (months)	19.4	0-36
Age of parents (years)	33.1	20-43
Characteristics of the Parents	N	%
Gender		
Male	1	10%
Female	9	90%
Marital Status		
Single	2	20%
Married	2	20%
Divorced	3	30%
Cohabitation	3	30%
Education		
Incomplete Elementary School	1	10%
Elementary School	5	50%
Incomplete High School	2	20%
High School	2	20%
Profession		
Housework	4	40%
Unemployed	4	40%
Other	2	20%
Income		
Up to a minimum wage	9	90%
Up to two minimum wages	1	10%
Characteristics of the Children	N	%
Gender		
Male	3	30%
Female	7	70%

Diagnosis		
ALL	7	70%
Wilm's Tumor	1	10%
Neurofibromatosis	1	10%
Non-Hodgkin Lymphoma	1	10%
Type of Treatment		
Chemotherapy	8	80%
Chemotherapy + RT	2	20%

The results of the content analysis of the respondents' statements generated six categories, illustrated in Figure 1. These categories have emerged from the central theme, decision making, according to the themes involved in the questions. Data saturation was achieved with the ten subjects involved.

The first category originated from the main theme refers to decision-making moments related to the treatment. The second category was the basis that parents used to make the best decisions. The third concerns the receipt of information in order to decide on the treatment of their children. The fourth category refers to the emotional state of parents when faced with decision-making moments. The fifth category concerns the type of support parents had or would like to have had during the treatment of their children to be able to decide. And, finally, the sixth category presents what was considered to be the most difficult decision for parents during the treatment. Each of these categories will be detailed below.

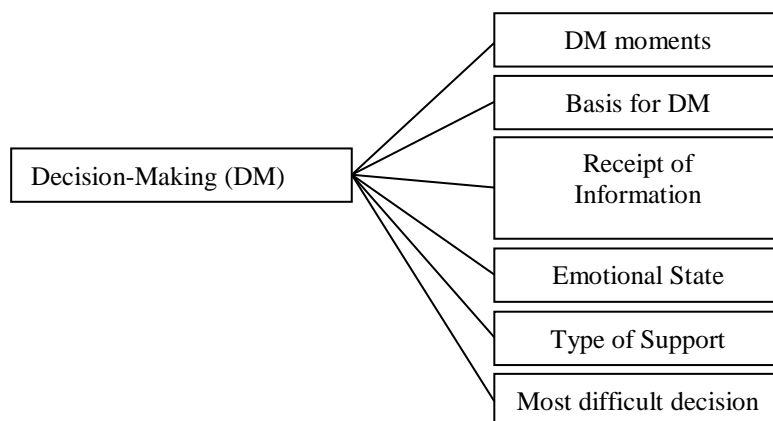


Figure 1. Main theme and categories found

Category 1: Decision-making moment

In this category were perceived the moments when the parents found themselves in charge of making a decision concerning the treatment of their children. It was observed that starting the treatment was the most cited moment by the parents (n=6). They also reported as moments of decision the need for distinctive medical assistance (n=3), changes in treatment protocol, catheter insertion and surgery. About the start of the treatment, a participant (P) stated: *"I had to make a decision at the time, because they give you an option, innit? But then, I chose to treat her. It was the moment when I had to choose,*

wasn't it, do it or don't. (P4)" This statement exemplifies the choice between performing the treatment of their children or not as one of the first decision-making moments parents were faced with, usually accompanied by feelings of anxiety and fear, and without much time for preparation due to the aggressiveness of the disease.

The search for distinctive medical care concerns the fact that parents initially had sought public health posts and had not found a proper diagnosis, making necessary to resort to private medical care:

"It was like this, it'd been three weeks I was in my city and he was ill. Then I took him to the station, 'oh, mother, it's a flu with a sore throat'. Ok. I gave him the medicine for a week, but the boy didn't get better, he had fevers and started to swell up, with swollen lymph nodes (...). Then I took him to the doctor, paid for the consultation, and he examined him and said 'mother, his case is serious'" (P2).

Category 2: Basis for decision-making

In its entirety, parents reported thinking about the welfare of their children to make the decisions. This well-being is strongly linked to the possibility of healing with the proposed treatment, as illustrated in the statement of one of the participants: *"... I thought like that for his sake, innit? He is going to be 'mistreated', it's an aggressive treatment, yes, but it's all for his sake, for his health.* (P2)" This statement also shows risk assessment by the parents about the aggressiveness of the treatment; however, the search for the cure carries great weight on the risk. The following report, given when parents were asked about what they mainly based themselves on to decide about the treatment for their children, corroborates this notion:

On her life. Continuing her life, only this. The doctors explained the situation of each problem she had and I decided about her life, about keeping her alive. If I didn't do it she might not survive, it's her life, I think (P9).

In addition to thinking about the welfare of their children, two parents reported previous experiences to make a decision, especially regarding adverse effects of medicines used in the treatment, as seen in the following statement *"In the way that, in other situations that she had not taken this medicine, she reacted in a different way, the anesthesia went off more quickly, she recovered better, the time spent in the waiting room was way less, understand? (P1)".*

Category 3: Receipt of information

All the parents reported that they received sufficient information to be able to make the best decision possible. However, two participants stressed the difficulty of assimilation at the time of deciding upon receiving the information, even if not resulting in an inability to decide, as illustrated in the following statement:

I received it, but did not get it, about the disease, you know? It didn't sink, you know, I thought as soon as I arrived 'My God, does he have this disease?' in my head. And then we came back like that, calmer, 'No, he really needs this. He must get the treatment' (P3).

Category 4: Emotional state

In this category, it was found that all the parents had some emotional distress at the time they had to decide regarding the treatment of their children. Reactions like sadness, fear, nervousness and feeling of helplessness were reported by participants as the most frequent during this process. The following report features some of the feelings experienced by the parents at this time:

When you discover your son has it, it seems like your world has ended, you know? It seems like everything is cracking and your son is dying. It was the sensation I had. But after the doctor gave me the news, when I received it like that, it seems as a strength grew inside me and I started making my decisions, and no, I won't change them, if I have to say somethings, I will (P4).

The emotional impact generated from the discovery of the diagnosis and the emergence of feelings mentioned above were often reported in conjunction with the need for intervention of a mental health professional, as the following statement describes: *"I was in the bottom of the well. Look, I was seeing a psychologist and all, you know, I took antidepressants, because it's not easy. I say, only who passed through it, knows. And we think it's never going to happen with us, innit? (P2)"*

Category 5: Type of support

When asked about the type of support they would like to have had to decide on the treatment of their children, most participants (n = 6) commented on the support of the family as being essential in the decision-making moment, as the following report demonstrates:

Ah, at that time it was my mother who stood beside me, like that, she didn't want to put me down, make me blue, innit? My brother, I thank my brother 'til today, and my mother. They stood in my place, though I, of course, I'm her mother, I must have stayed there, but my brother already knew, he's family, participated and also he went through all that for me (P7).

Many participants talked about the support they have received at the time, but not about what they would have liked to have. This may be because during the period of hospitalization, only one relative of the patient is allowed to accompany him/her, which is usually the father or the mother, not being allowed the entrance of other family members or friends to visit. However, the participants reported that, despite being present, the support of the family could have been more frequent during the decision-making process, besides the emotional support provided.

Category 6: Most difficult decision

In the report about the decision considered the most difficult during the treatment of their children, some parents (n=3) mentioned catheter insertion (venous access) as being the most complicated moment. This procedure is performed in the early days of treatment, so that chemotherapeutic drugs can be administrated through the catheter. The signing of the terms of consent for initiating the chemotherapy treatment was also reported as a shocking moment, as illustrated in the following statement:

The most difficult one was when they told me my daughter would have to go through chemotherapy. This was the most difficult one for me... because then we would get to the worst part of the treatment, because she would lose her hair and would not accept herself like that (P4).

Assessing the impact of the decision to start the treatment on their children was described by participants as a distressing moment: *"... when she starts losing her hair, losing weight, it'll be complicated. I think this will be a little more complicated, because she is strong now. And then she'll start feeling the treatment... (P6)".*

Discussion

All participants of the sample demonstrated the ability to decide on the treatment of their children, thinking about their best interest. The results obtained in the scale of Moral-Psychological Development justify this statement, being similar to those found in previous studies (Raymundo & Goldim, 2008; Wittmann-Vieira & Goldim, 2012), demonstrating that participants were able to make decisions in a more autonomous way, looking after their desires and their beliefs. Moral-psychological development allows the expression of the ability to make decisions, concerning precisely what is considered the best interest, and it is important for the reflection on the actions to be carried out and the assessment of possible risks of an impulsive and non-rational choice.

With respect to the perception of coercion in assistance, the values found indicate a low perception of coercion in terms of deciding on the treatment of their children. The opinion of the health team was regarded as important and parents demonstrated enough autonomy to give their opinions concerning the recommended treatment. The mean values obtained in this sample do not differ from those obtained in other situations of assistive service (Bittencourt & cols., 2014; Protas & cols., 2007). It is important to highlight that none of the parents answered that the choice to perform the treatment was not their own. This result corroborates what was observed in the autonomous ability to decide, which can be verified through the triangulation of the scales applied on parents' statements.

The moments pointed by the parents as those when they found themselves in charge of making a decision were starting the treatment ($n=6$) and seeking distinctive medical assistance. Regarding the start of treatment, signing the informed consent and allowing the team to perform the due treatments were some of the tasks associated with this stage. Thus, it is indicated that the type of relationship parents have with the health team must be evaluated, as well as the knowledge of the team about the clinical picture and the empathy and expertise showed in the resolution of these cases, so that parents can make a decision more clearly (Pyke-Grimm & cols., 2006).

The search for distinctive medical care occurs mainly because of the inefficiency in the basic public health network, forcing parents to afford the costs of private medical care, especially to have a diagnosis and subsequent access to public services. A study with users of the Public Health System (SUS) pointed out that the search for means of care other than those offered by the public network gives the impression that these are insufficient for the needs of patients, presenting difficulty of access, bad customer service and low resolution rate (Oliveira & cols., 2009). Therefore, for the parents who participated in the study, seeking a private service was an important decision so that their children could receive initial assistance suitable for the cases. It is worth noting that, because the treatment was performed in a public hospital, its costs were fully covered by the Public Health System.

All the participants reported always thinking about the welfare of their children to decide on these and other issues. The idea that they are doing the best they can to get a cure makes the parents accept the associated risks. It should be noted that through the Moral-Psychological Development scale it was possible to establish that parents were able to decide considering their best interest. However, this interest does not always appear as the desire of the children, so that parents do not delegate to them the charge of deciding, preventing their autonomy in the belief that they are not cognitively and emotionally capable of choosing on their treatment (Killen & Smetana, 2015; Teixeira & Braz, 2010).

Thus, to decide what they consider the best for their children, the participants pointed out the importance of receiving enough information. Therefore, the information provided to parents directly by the health team constitutes the primary basis to understand the process of treatment, according to what was previously found by Kilicarslan-Toruner & Akgun-Citak (2013).

However, this exchange of information is not manifested in a vertical relationship, where the team is strong enough to prevent parents from questioning the decisions. When, in the scale of Perception of Coercion in Assistance, parents presented high level of disagreement with the affirmation that they were responsible for the idea of starting the treatment and that they had more influence than anyone else about performing the treatment or not, it becomes clear that they consider the opinion of the team about these issues, especially regarding the idea of starting the treatment. It was noted that only the

health team has the knowledge to indicate whether or not a treatment should be performed, and they have major influence in the decision due to the technical aspect.

This issue can also be verified in the statements of the participants when asked whether they received enough information to decide on their children's treatment, and all of them stated that, despite the difficulty of assimilation, they felt that the team managed to convey sufficient information so they could make the best decision, also denoting a good degree of comprehension about the diagnosis and the treatment.

Regarding the emotional state, reactions as persistent sadness, pessimism, hopelessness, guilt, helplessness, decreased energy and difficulty in concentrating are frequent in this population (Kohlsdorf & Junior, 2012), corroborating the data found in the present study. Through the analysis of the participants' reports, the sense of helplessness and sadness were the most quoted by parents, though they did not configure as a hindrance to the decision-making process. Maybe this issue is better explained by the type of emotional support that they have received during the process of treatment of their children, where family support to deal with their feelings was not an impediment in the decision-making process. The impact of the disease causes each family member to develop new skills and tasks in the familiar daily life to resolve conflicts resulting from the hospitalization and the impact of the disease on physical, psychosocial and financial aspects, including a series of decisions to be made (Angelo & cols., 2010).

Final considerations

The evaluation of the process parents are faced with to make decisions about the treatment of their children and its variables proved to be important to encourage a more welcoming practice of the health team regarding these moments. Deciding on the best way to conduct the treatment of their children was considered a difficult process, fraught with emotional aspects, inflicting a sense of helplessness in parents faced with decision-making moments. However, the results obtained make it possible to infer that, despite the difficulties encountered, the parents in the sample analyzed found means to deal with their sufferings, as well as to choose the best alternative for the proposed treatment.

Information provided by the team, family support and the concern with the welfare of the children were presented, in this study, as important variables so that parents could decide when faced with the demands imposed by the illness. The opinion of the health team proved to be essential for parents' decision-making; however, it was not featured as coercive, making the participants feel free to decide. The understanding of the situations through information, as well as the feeling of freedom to ask in case of doubt, proved useful so they could assess the best decision to be made more coherently.

As a limitation of this study is the impossibility of generalization of the data obtained in the research because of the small number of participants, being in a study with good internal validity. Due to the size of the sample, it has not been possible to perform correlation analyses of variables such as gender and educational level and income of parents as possible factors associated with the decision-making process, as it has not been possible to relate time of treatment of the children with other variables. Thus, it is important that new studies be performed, including correlation of these items.

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Received: Apr. 20, 2016

Approved: Oct. 18, 2016

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