Esc Anna Nery (print)2013 Jul-Sep; 17 (3):482 - 490

DIMENSIONS OF VULNERABILITY FOR THE FAMILY OF THE CHILD WITH ONCOLOGIC PAIN IN THE HOSPITAL ENVIRONMENT

Dimensões da vulnerabilidade para as famílias da criança com dor oncológica em ambiente hospitalar

Dimensiones de la vulnerabilidad para las familias del niño con dolor oncológica en ambiente hospitalario

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ABSTRACT

The study aims to show the dimensions of vulnerability in the universe of the family, from the viewpoint of families with children with cancer pain in the hospital environment. It is descriptive and exploratory, with a qualitative approach, undertaken in the Hematology and Pediatric Oncology Center of a large hospital in the city of Porto Alegre -RS. Nine families participated, with the Creative-Sensitive Method used for data collection, through the dynamics of creativity and sensitivity, analyzed in line with the framework of Minayo's Content Analysis, in May-June 2010. It was observed that the illness raises situations of vulnerability, imposing suffering, pain, fear, distress, mental and physical strain caused by cancer on the child and family. Thus, Nursing, in appropriating the conceptual framework of the vulnerability, can visualize new dimensions of the health/illness process, helping the ill child and her family.

Keywords: Pain; Medical Oncology; Family; Pediatric nursing; Vulnerability.

RESUMO

Identificar aspectos que demonstrem as dimensões da vulnerabilidade no universo familiar na ótica da família de crianças com dor oncológica em ambiente hospitalar Trata-se de um estudo descritivo exploratório com abordagem qualitativa, realizada na Unidade de Hematologia e Oncologia Pediátrica, de um hospital de grande porte da cidade de Porto Alegre - RS. Participaram do estudo nove famílias, utilizando-se para coleta dos dados o Método Criativo Sensível, por meio das dinâmicas de criatividade e sensibilidade, analisadas conforme o referencial da Análise de Conteúdo de Minayo, nos meses de Maio e Junho de 2010 Constatou-se que a doença traz à tona situações de vulnerabilidade, conferindo à criança e à família, sofrimento, dor, medo, angústia, desgaste físico e mental, causados pelo câncer. Assim, a Enfermagem, ao apropriar-se do marco conceitual da vulnerabilidade, pode visualizar novas dimensões do processo saúde/doença auxiliando a criança doente e sua família.

Palavras-chave: Dor; Oncologia; Família; Enfermagem Pediatrica; Vulnerabilidade.

RESUMEN

Identificar aspectos que demuestran las dimensiones de una vulnerabilidad en el universo familiar en la perspectiva de la familia de niños con dolor oncológica. Estudio descriptivo, exploratorio, con enfoque cualitativo, realizado en la Unidad de Hematología e Oncología Pediátrica, de un hospital de gran porte en la ciudad de Porto Alegre, RS. Nueve familias participaron de este estudio, que se realizó por medio de la recopilación de datos por el método creativo a través de la dinámica de creatividad y sensibilidad, analizada según el referencial de Análisis de Contenido de Minayo, entre los meses de mayo y junio de 2010. Se ha constatado que la enfermedad emerge la vulnerabilidad, trayendo sufrimiento, dolor física y mental al niño y a su familia. Así, la Enfermería, al apropiarse del marco conceptual de la vulnerabilidad, puede mostrar nuevas dimensiones del proceso salud/enfermedad y ayudar al niño y a su familia.

Palavras-clave: Dolor; Oncología Médica; Familia; Enfermería Pediátrica; Vulnerabilidad.

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Submitted on 08/01/2012
Resubmited on 03/27/2013
Accepted on 04/02/2013

INTRODUCTION

The concept of vulnerability, even if not understood in depth by a significant proportion of health professionals, is constantly in use in the scientific literature, with various meanings, depending on the area of study. As a result, the concept of vulnerability is expressed through differing interpretations. The situations of vulnerability affecting the child with oncological pain, and her family, are significant.

In this way, to live humanly means to live in vulnerability[1], this emphasizing the child with oncological pain, who may feel herself to be incapable of self-care at certain periods in her oncological path, at least in the beginning of life; she may be physically, psychologically and cognitively dependent.

In this condition, the illness, incapacity and suffering are some of the circumstances which impose a state of vulnerability and are conditions which lead to care. For this, the caregiver must be sensitive and qualified to help and to support in the circumstances of vulnerability and, in this regard, the care is extremely important. The efforts seeking to restore health go beyond the physical order, representing support, and permitting the other - the being who is cared for - to be herself, as she is, in her uniqueness[2].

The process of caring for the hospitalized child with oncological pain is an essential component of cancer treatment in itself. Pain relief, and the attention given to the illness's social aspects, must be integrated into the comprehensive care which the child in the process of illness must receive. It follows that being a family member of a child with oncological pain is to be doubly vulnerable, as it is possible to visualize the child with pain, to share the expectation that the suffering will soon stop, to do what is possible, and impossible, to minimize it; nevertheless, it is not actually possible to feel it or even take it for oneself. Pain control in children with cancer, as well as the minimization of the suffering experienced by the family, is part of the being-knowing-doing of Nursing. To this end, the assistential, managerial, educational and research aspects of being a nurse are emphasized.

Faced with this context, questions are raised about the dimensions of the vulnerability in the family universe of the child with oncological pain in the hospital environment, considering this to be an integral part of the care. Thus, the aim was to identify the aspects which show the dimensions of the vulnerability in the family universe, from the viewpoint of the families with children with oncological pain in the hospital environment. Note that this study is part of the dissertation titled: Pain in Oncology: the perception of the family of the hospitalized child[3].

METHODOLOGY

This is research of the descriptive-exploratory type, with a qualitative approach. The setting of the study was a Hematology and Pediatric Oncology Center in a large hospital located in the city of Porto Alegre, in the Brazilian state of Rio Grande do Sul (RS).

The following were invited to participate: families caring for children affected by cancer, hospitalized in the above-mentioned Pediatric Oncology Center, of pre-school and school age, who had the emotional conditions to participate in the stages of the research. As exclusion criteria, there was: to be a family member of a child receiving palliative care. This study considered the family members who were accompanying the child during the hospitalization, this being a minimum of one family member and, at the most, two family members per child.

Of the 17 (seventeen) invitations made, seven (07) family members felt it to be impossible to participate, due to not wanting to leave their children alone; they believed that, without their presence, they would not be well. Of the 10 (ten) who participated, one, however, participated in the dynamic of the first to the third phases, but needed to leave before the discussion even began because the child had hyperthermia and asked him to be called. As a result, the study was made up of nine (09) participants, of whom seven (07) were mothers, one (01) was a father and one (01) was the grandmother of a child with cancer. The Creative-Sensitive Method (MCS)[4] was used for collection of information, through Creativity and Sensitivity Dynamics (DCS). The Creativity and Sensitivity Dynamic (DCS) used was 'Free to create', which consists of offering various game materials, allowing free artistic creation for production of qualitative data, so as to respond to the questions which generate the debate.

In the first step, the participants were received in a room where the research and its objectives were explained to them, and they read the terms of Free and Informed Consent (TFIC). Being in agreement, they signed, and following that introduced themselves. In the second step there was an explanation of how the dynamic would occur, with the presentation of the materials to be used, and time was stipulated for the artistic production to be elaborated. In the third step, through reflection on the guiding questions, the individual artistic production of the dynamic took place. In the fourth step, each participant presented his or her artistic production; in the fifth step, the preliminary analysis of the data took place, with analysis, discussion and collective validation.

The first dynamic lasted for 70 minutes, and the second, for 75 minutes, counted from the moment that the artistic production began. Concomitantly with the undertaking of the workshops, a Field Diary was constructed, so as to obtain, and effectively take advantage of, the information resulting from the period of data collection.

For this study, two (02) workshops were formed with different family members, during the months of May and June 2010. The number of dynamics was established based on the criteria of information saturation, that is, when the ideas transmitted by the participants had been shared previously by others and the inclusion of further participants did not result in new ideas[5].

The information was analyzed according to the framework of Content Analysis, through the Thematic Analysis technique proposed by Minayo[6]. Four themes were constituted: Oncological pain: the view of the family; Integration of the family in the care of the child with oncological pain in the hospital environment; Dimensions of vulnerability in the world of the family; Cares with the family of the child with oncological pain: tasks of the Nurse. This article presents the results of the third major issue, which may be subdivided into: The reflection on the individual vulnerability in the dyad of family/child with oncological pain; Dimension of the conceptual framework of social vulnerability: the family member of the child with oncological pain; The programmatic dimension of the vulnerability of the family member of the child with oncological pain.

Ethical questions were relevant to this study's development; with a view to not running the risk of invalidating the research, anonymity was ensured to the participants along with the right to withdraw from the research at any time with no penalization or harm to themselves, in line with Resolution 196/96[7]. Equally, their right to privacy was emphasized, there being no public exposure of their person or identity at any time during the research. It was also explained that the information gained during the study would be for exclusively scientific use in the area of Nursing, and that the recordings and transcriptions of the participants' statements would remain in the possession of the researchers for five years, after which they would be destroyed. The anonymity of the participants in the study was, and shall be, preserved, through the adoption of codes for identifying their statements.

The study was approved by the Research Ethics Committee of the Porto Alegre Teaching Hospital (HCPA), under protocol nº 10.0008. The study proposal and the dissemination of the information were validated.

RESULTS

Dimensions of the vulnerability in the world of the family of the child with oncological pain in the hospital environment

The conceptual framework of vulnerability is expressed through various interpretations, there being a variety of situations which affect the child with oncological pain and her family. Thus, for analysis and discussion of the data, the conceptual framework of vulnerability will be used, which cannot be seen only from one single perspective, as it involves the articulated assessment of three axes[8]: the individual component, the social component, and the programmatic component.

Studies of vulnerability seek to understand how individuals and groups of individuals are exposed to a given danger to health, based on totalities configured by summaries, pragmatically constructed based on three analytical dimensions: individualizeable aspects (biological, behavioral, affective), which entail exposure and susceptibility to the harm in question; characteristics belonging to socially configured contexts and relationships, which overdetermine those aspects and, detailed based on these last, the way and the direction in which the technologies already operating in these contexts (policies, programs, services, action) influence the situation - called respectively, the individual, social and programmatic dimensions[8].

The reflection of the individual vulnerability in the dyad of the family/child with oncological pain.

The individual component of the vulnerability refers to the quality and the capacity to elaborate information, incorporating it into one's routine repertoire of concerns. In spite of accompanying the child throughout the path of her illness, it is still not easy for the family to process the diverse information arriving from all sides, ways, people, professionals, and still continue efficiently with the task of being with and caring for the ill person in pain. Even because the fact of being ill and hospitalized is already a circumstance which imposes the state of vulnerability on both the child and on the family - which previously neither knew of, nor understood the illness, but which begins to experience a new world, full of conflicts, rules, impositions, doubts, questions and uncertainties.

> *Thus, after the trauma of the diagnosis and the manifestations arising from the treatment, among them the pain, the hospitalization is an important context to be*

considered and confronted by the child and the family, which previously could not even imagine the size of the context which they were entering. In this way, the discourse below evidences the frustration and the despair of the family members when they experience, for the first time, the hospital context, becoming traumatically aware of the individual dimension of vulnerability.

When you arrive here [...] I myself had not imagined that there was such a place [...] I didn't imagine that there were children like this, when you arrive here, you feel lost and begin to see cases and cases and cases... And the psychological side starts (MOTHER 5).

Vulnerability is characterized by feeling oneself to be unprotected and weakened. In spite of cancer's not being a rare illness, it is stigmatized, in particular by the expectation of feeling pain, even more so when it affects a child, a human being who, often, can become interdependent in the physical, psychological and cognitive senses on her family members who are considered susceptible, who must re-organize themselves to help in coping with the illness and supporting the times when there is pain resulting from it.

Coping with the hospitalization of the child, experiencing the oncological pain, without the necessary knowledge of the treatment, the reactions, the proportion of and existence of other children, following similar paths, makes the family become weak, needing help, the hostage of its knowledge; however, the family finds support in family members of other children who have already been submitted to this dimension of vulnerability.

Experiencing oncological pain while at the same time being thrown into an unknown world, in spite of other people being in a similar situation, it is sometimes possible for the destructuring of the family to occur, to make the family become aware of its vulnerabilities, as the following discourse corroborates

That's why I said that it disrupts an entire family (MOTHER 5).

Becoming the holders of their vulnerability is what makes human beings different from other beings, as in this way, they can adopt attitudes and measures which minimize the situation. This is what the child and family do, on coming face to face with the distressing hospital world: they create ways of coping, with views to a cure and to the re-establishment of the ill person and the family dynamics.

In this way, the child's pain, illness and suffering are situations which confer the state of vulnerability. In the face of this, one may observe that the family still has difficulties in understanding certain knowledges related to care, and that being at home, often, makes it more vulnerable, because the members do not know how to act with the child, in moments of pain, as the following discourse shows

You've got a child at home with pain, or a fever, it's hard, just seeing the fact of the child in pain, you go mad, you don't know what you can do [...] how you should do it, what you're going to do, what medicine you're going to give, which medicine you shouldn't give, because you know that these cases are really sensitive, that you can't just give any medicine. (GRANDMOTHER 1).

As may be perceived, the insecurity in relation to the illness and the child's moments of pain when at home turn times of happiness into times of tension. In experiencing the pain of the child with cancer, the expectation is shared that soon it will cease; nevertheless it creates suffering and imposes the state of vulnerability on the family.

The dimension of the conceptual framework of social vulnerability: the family member of the child with oncological pain

The social component of vulnerability refers to the obtaining of information, the possibility of processing it, and the ability to incorporate it into practical changes, as well as the people's or social groups' ability to react to facing the illness and its events.

Throughout the path of the treatment, there are various factors capable of exacerbating the family's and the child's social vulnerability, once the latter - once in a better condition - begins to re-start her social life, in spite of some restrictions. For the children with cancer, however, at the same time that society is the place of realization, it can also be responsible for triggering pain, as the child continues with some restrictions on leaving hospital, for her own protection. Nevertheless, such restrictions may be assessed by society as threats, as the discourse below describes well:

The suffering of leaving the house wearing a mask... or you're with that headscarf and the people are prejudiced against you [...] our children, any one of them, if you go out on the street with them, everybody stares, there's nobody who doesn't stare. (MOTHER 5).

The pain of being "different" is an unpleasantly embarrassing feeling, for the child and family alike: for the former, the insecurity has been a companion since the diagnosis; for the latter, in spite of all the distress, the expectation of the child returning to her routine, within the normality imposed by society, is great, and also frightening.

The human being is constituted through interaction with other human beings. To the child with cancer, however, this fellowship becomes damaged, depending on how different the child appears, without hair, or using a mask for safety, which - for society in general - is reason to feel threatened.

It is worth noting that the exaggerated concern with children who wear masks in the street is not owed only to prejudice, but also to the genuine fear of contracting some illness, as occurred in the period of collecting information on Swine Flu - it was a constant threat in the population's routine, which increased people's prejudice in relation to the children.

> *Falling ill and not developing the habitual rhythm of one's day-to-day, due to the illness and the pain it causes, are situations of vulnerability of the being which are accentuated, when she takes up once more her life in fellowship with society, as the child perceives herself to be "different"; in hospital, everybody was in the same condition of being "different", but returning to the "polis", society, people's reaction is to distance themselves, which creates pain and suffering.*

> *When we go out on the street... with a bald child, a child with a mask... people stand further away, because of their prejudice [...] Prejudice most of all, because they don't want to even know what that child has [...] And this is a big source of suffering (MOTHER 5).*

From this perspective, it is possible to assert that all the actors suffer: the child, because of feeling different; the family, because of wanting to protect the child from something still greater - prejudice; and society, because it withdraws from a child due to fear and lack of knowledge of her condition - and, also, from prejudice.

At such a time, one can perceive the vulnerability with which society is permeated, the lack of information, or information in excess for some illnesses, with others being forgotten; and also the vulnerability of the family which, in spite of having knowledge of what is to come, outside the world of the hospital, even so is unprepared to process and incorporate the information which it has into its routine, in defense of the child.

> *The prejudice which establishes a distinction between the children with cancer and others causes great suffering for the patient and her family. Mother 5 is emphatic when she addresses the prejudice suffered on the street by her child, which shows the situation of vulnerability faced by the being*

> *Oh, the prejudice! There's a little girl, another child, who arrived in front of my daughter and just stood there, staring at her, like she was an ET, an Extra-Terrestrial [...] and you can imagine what goes through the head of an eight-year-old. There was a man: - Why's she wearing a mask, why? Has she got flu, has she got something contagious? This is how people are prejudiced. (MOTHER 5).*

> *In a certain way, it is when the child leaves the universe of the hospital that she perceives her situation of vulnerability. While hospitalized, the child experiences the various forms of pain (physical, psychological, of the soul) but nevertheless she is not seen as different, but rather similar to the others who are there, as Mother 1 describes below.*

> *So, I think the pain for her is this business of being different because she's losing her hair. Here inside [referring to the hospital] I think she doesn't feel it so much, but outside it gets you down [...] for me it's still difficult to speak about [cries] (MOTHER 1).*

> *One can observe that, of all the significant feelings for the family of the child with cancer, apart from that for the pain to cease, the sharpest desire is for her not to be different from the other children*

> *I think that this [referring to a photo of a smiling child] is what all the mothers want to have... it is the desire of all the mothers... a child who is not different... playing, smiling [...] (MOTHER 5).*

For the family, the desire to see their child smiling, playing, living anew in fellowship with society, without discrimination or fear on either part, is what everybody aspires to. While Mother 5 gave her discourse, the other family members agreed, nodding their heads and, at some points, becoming emotional, due to sharing the same trajectory.

The fact of having a child with cancer leads the family to re-evaluate life with a new perspective, invites them to rethink with new principles for survival, in a society full of pluralities which can place the ill child in situations of vulnerability as she goes along her oncological path.

The programmatic dimension of the vulnerability of the family member of the child with oncological pain

The programmatic component of the vulnerability refers to the assessment of the resources intended for the individuals and health services, for use in control of diseases, as well as to the degree and to the quality of the institutions' commitment, resources, management and monitoring of programs in different contexts.

During the path of the cancer treatment, the child and her family encounter a variety of situations, among which are the health system's organizational weaknesses. The situations of programmatic vulnerabilities are characterized by the consequences of the programs' difficulties, and of the policies which guide them, in terms of the management of resources and the commitment to the health services' organization and quality.

> *Besides all the other concerns reported by the family, the anxiety resulting from the exposure during the treatment and the fear of the pain, one can also observe the period of hospitalization, which is accompanied by distress and total exposure to the uncertainty of whether or not a bed will be found for the child*

> *And that's without talking about when she needs in-patient treatment [...] sometimes she's going to need in-patient treatment and there's no bed, this is something which infuriates you in addition to the pain (FATHER 1).*

> *From Father 1's discourse it may be observed that the access to the health services can be understood as an element of the families' and children's vulnerability, creating physical and psychological strain. Considering that many families seek and/or are referred to centers of excellence for the children's treatment, with the expectation of a cure, of a cease in the pain they often encounter the lack of beds and of solutions to their distress, as shown in the discourse below.*

> *I'm sick of this government, you see people stealing [...] that money could... build hospitals, pay for beds, strengthen the oncology service... for the people with cancer (FATHER 1).*

> *In spite of the extant models being constantly structured and restructured as a result of the appearance of new technology, even so they impose situations of vulnerability on the family and on the child with cancer, in view of the fact that the way they face these situations is ambiguous: despair and expectation. Despair, because of the lack of beds, and expectation that new resources may appear as the result of research, with a view to a cure for the illness*

> *It's your child there [...] that money that they're stealing, it could be there... in research, to research this disease, to seek a cure for the disease (FATHER 1).*

> *In addition to their preoccupation with a cure, one can observe in the families that the concern is related to the research undertaken, with a view not only to the treatment of their own child, but also for the others who have been or will be struck by cancer.*

> *Tomorrow or after, this [referring to the correct investment of money] will be for somebody in his family, if he doesn't invest in a hospital, or in research on some disease [...] but everybody is vulnerable to this (FATHER 1).*

Human beings are, intrinsically, vulnerable beings: all are vulnerable to something, at a specific time. One can observe this concern in the discourse of Father 1, as his anger is not only directed at a possible cure for his child. He shows himself to be worried about the others who may one day be affected by cancer, and their families, who will have the same path as he has in facing the illness.

> *It can be constantly observed that the families, in their search for appropriate treatment, travel long distances, using inappropriate transport, in discomfort, and even so, are subjected to long periods of waiting.*

> *What I spoke about, of there not being enough beds, things like that, that's when you get angry [...] you get anxious too. Outside, there are people arriving by minibuses, out there, at 07 o'clock in the morning, often the consultation is at 08, 09 o'clock, you have to wait until 10 o'clock, 08, 09, 10 o'clock at night, wait to be the last to be seen, to be able to return to their city, while in their city there could be a hospital.... An equipped hospital (FATHER 1).*

It is already common to visualize lines of minibuses and buses when one is discussing health institutions. It is increasingly frequent, and frightening, to observe the number of ill people, who accept to travel very uncomfortably in search of specific treatment in other cities. In the case of children, these are accompanied by their parents, who from the time of leaving their own cities through to arriving at the institutions despair of such a situation.

In the path of cancer treatment, there are many obstacles which the family and the child have to face: difficulties, privation, pain, suffering, distress, expectations. In this respect, to change the health care context is a macro question, that is to say, it is necessary for the various social actors to reflect for the implantation of a public policy which is more in line with the social determinants, as the conceptual framework of vulnerability shows us.

DISCUSSION

Vulnerability takes into account the chance of people falling ill, being the result of a set of individual, collective and contextual aspects which entail greater susceptibility to infection and illness and, inseparably, greater or lesser availability of resources of all types for being protected against both[9].

Thus, the analysis of vulnerability allows one to investigate and understand the differences between each one, individually and in the group, and to experience and face the health-illness process[9,10]. A family which relates well to the illness will have greater stability for accompanying the treatment, and will pass on this calmness to the child, especially in periods of pain. The first reaction of many parents, when the treatment begins, is to feel a growing need to protect and care for their child. There are also those who want the child to be always laughing, happy, even when she feels pain[11]. In this regard, it becomes essential to know how to share, and share in, the pain which the child feels; crying and letting her cry with her family is part of the construction of the knowledge of the vulnerable being.

The analysis of the vulnerability confers greater comprehensiveness on the health actions, by strengthening the proposal for interventions which take into account the three dimensions of vulnerability, incorporating the influences exercised by its components. Thus the effectiveness, operationalization and progressivity of the concept of vulnerability can contribute to renewing the practices of Nursing[9,10].

The family generally feels of little use when their children are in pain. Relieving the pain not only makes their child feel more comfortable, but also helps her to sleep and eat better. In cancer treatment, pain is what most reduces quality of life: it can be reduced or alleviated to a significant degree but cannot always be controlled. Preventing the pain from starting or worsening is the best way of controlling it. For this, a special understanding of the child is required. Sometimes the child has pain, but cannot manage to talk about it because she feels afraid[11].

It should be noted that vulnerability is not binary - rather, it is multidimensional. In this way, what can leave us vulnerable in one aspect can protect us in another. Vulnerability is not unitary, and this makes us vulnerable in different degrees. Vulnerability is not stable, because the dimensions and degrees of our vulnerabilities change constantly. Therefore, people are not vulnerable all the time, but are always vulnerable in a temporary way to something, in some way or to some degree, at certain points in space and time[9].

Moreover, further, human beings are, in some aspects, much more vulnerable than other living beings; nevertheless they are able to appropriate themselves intellectually of their vulnerability and seek ways of facing it; when they suffer, however, it is necessary to find meaning for their suffering, so as to respond to their vulnerability and save it, to a certain extent[1] .

The illness affects not only the anatomical and physiological structure, but also the cultural aspects, represented by the ignorance of the grounds and reasons for the illness or by not knowing which care and treatments the ill person is receiving[2]. Thus, the pain covers the basic objective of signalling and survival. The despair in the face of uncontrolled pain, and the sense of impotence which this causes, is capable of de-structuring families, triggering disputes, creating disharmony and influencing the quality of the ill person's care and recuperation[12]. In this way, vulnerability is a personal, collective and routine experience[9].

Indeed, the child's vulnerability, in living through the experience of hospitalization, is made up of categories which describe the various facets of the suffering experienced. These encompass inevitable aspects of the experience and the difficulties which accompany them, such as living with pain and malaise, submission to restrictions, the exploration of the body and the undertaking of painful, invasive and unknown procedures[13].

The child subject to chronic pain, as in the case of cancer, develops behavioral and reactional coping mechanisms for the suffering, which facilitate her co-existing with the pain. This behavior, often confused with "simulation", creates a paradigm: the reactional defence mechanisms developed by the child for bearing the pain often lead her "caregivers" to doubt the truthfulness of her complaints[12].

However, when the being falls ill, when he is unable to carry out the habitual routine of his everyday, due to a somatic, social or psychological illness, he perceives clearly the situation of vulnerability of his being[2]; in the same way that, based on the knowledge that each person is made up and is realized through close interaction with other human beings, he creates with them society, that is, *polis*, community, fellowship of life. Much human, personal or family suffering is the consequence of social environment, or, more concretely, of vulnerable social surroundings[1].

In the face of this one may observe that society imposes rules of which we are, to a degree, consensual heirs. The social universe is devastating, as it turns alopecia in prejudice, a mask into distancing, the life of a child and a family into

suffering, with them as protagonists in the pain. In this way, it has to be emphasized that vulnerability is a set of factors which overarch the individual and involve collective, contextual factors. It is necessary to take into account the patient and family's vulnerability and appropriate oneself of it, so as to understand and instrumentalize them for the re-establishment of the child and the family dynamic, minimizing their suffering.

In this regard, the conceptual framework of vulnerability provides an approach capable of generating reflections which can be useful for formulating health policies, based on the population's needs, and for broadening the means of working in health[14].

It is known that universalization, justice and comprehensiveness are mutually referent, each one making demands on the others, such that pragmatism may be made compatible with utopia, and practical realism with the ability to dream. Of the three principles of the Unified Health System (SUS), it seems clear that one - comprehensiveness - has an immediate relationship of creation of diversity and of construction of responses to the tensions arising from it. Comprehensiveness, one of the principles of the SUS, permeates the application of the values of fairness, democracy and effective access to health care within the ambit of technology used in the health practices[8].

It is known that a significant portion of all health programs are directed at children's well-being. Moreover, children's health care, in Brazil, has gone through great transformations, being influenced by its historical period of advances in technical-scientific knowledge, by directives of social policies, and by the involvement of various agents and segments of society[15].

However, one can constantly observe different families and children with cancer who seek treatment in centers of excellence, often far from where they live, travelling enormous distances and changing their routine so as to enter the hospital universe, which in spite of being frightening, has the cure as its supreme goal. These are people who may spend all night travelling to other cities for consultations, in the expectation of better care, and who have to wait for every single person who came with them in their minibus to be seen, irrespective of how long that takes, before they can return to their city.

The way that technological arrangements are configured ends up in many cases, favoring separation between the moment of the care act and the involvement in its consequences and with the developments in the situation of the patients and communities[8] . The model of vulnerability[14] considers the construction of public policies directed at human beings' needs, working with the communities and carrying out diagnoses on the social groups' conditions in a participative way, as well as the redefinition of the objects of intervention and the critical analysis of the health practices, for their reconstruction aimed at individuals' and the collective's needs.

One may observe that the families of children with cancer face difficulties related to the lack of attention to the child's health in her everyday, as well as to the child herself, regarding the issue of access to the health services, emphasized as a vulnerabilizing element for such families.

In view of this, one can perceive that controlling the child's pain must be part of daily practices of the nurse, involving prevention and ensuring access to the therapy proposed. It falls to the nurse to be attent to the context which involves the child with pain, and to program individually the best care to be offered, using the necessary resources for the re-establishment of the child and the family for the relief of their suffering. The nurse's action involves assistential, managerial, educational and research aspects[12].

The experience of vulnerability is a process marked by continuous events, with phases of greater or lesser intensity, provoking great suffering for the family. It includes causal elements and consequences throughout a period of time which expresses the meaning attributed by the family in the interaction with the illness, the team and the family[16]. The search for comprehensiveness constitutes a fundamental force for avoiding universality being reduced to a mere formality, to a legal franchise of socially devalued practices, and for justice to become an abstract precept, unrealizable in practice[8] .

One can observe the frustrating search for, and the lack of speed in accessing, health resources and services, besides the lack of quality in these. The frustration felt by these families due to there not being health institutions capable of providing appropriate treatment in their cities of origin confers a still greater state of vulnerability on them, as if it is frightening to receive the diagnosis, to be told that treatment is not available in the city where you live is downright terrorizing. In the same way, the child and family must be aware that the minimization and control of the pain is a right which belongs to them, and that the management of this is capable of improving their quality of life.

FINAL CONSIDERATIONS

The child is a being who, from the most tender age, can be exposed to unparalleled situations of vulnerability, adapting as she grows, gradually looming large in the eyes of the family, like a sovereign being, who must outpace it in relation to life's chronological path. As she goes along this path, however, the child may be struck by some utterly unexpected illness, and which - in the case of cancer - is somewhat frightening.

The illness raises anew situations of vulnerability, inherent to cancer, and touches on the fear of pain, which is considered the second greatest fear on the part of the child and the family, second only to death itself. In the face of this, one should stress the important role of Nursing, as

this is the family's first contact when it enters the hospital universe, which on appropriating itself of the conceptual framework of vulnerability can visualize other dimensions of the health/illness process, assisting the child and family in coping with the various painful situations resulting from the treatment.

In the light of the above, the knowledge of the perception of the family members regarding the child with oncological pain in the hospital environment looms large, as do the relationships with the conceptual framework of vulnerability and its possible influence on the path of the oncological treatment. In the face of the dimensions of vulnerability in the world of the family, the individual component stands out, which refers to the family's capacity to develop the information provided during the hospitalization and incorporate it into their care routine. In relation to the social component, what stands out is the prejudice experienced by the families, in relation to the transformations in the children's body image, these reactions arising from the cancer treatment.

In relation to the programmatic component, one should emphasize the social resources which children with cancer, and their families, need. The need stands out for national, regional and local programs of prevention of health risks and programs of care relative to health questions. Equally, there is a need for channeling/improving and/or identifying the needs for resources, so as to strengthen the individuals facing situations which impose vulnerability, in this case, cancer.

In spite of pain's subjectivity, recognizing the uniqueness of the family in the case of the child in pain is of extreme relevance, so as to understand its specific characteristics, accepting its restrictions and possibilities in the act of caring, as these are present in the routine hospital world. Health care is complex, does not possess absolute standards, and depends on the action of each human being, who in his uniqueness subsequently finds himself to be vulnerable. However, absorbing the knowledges, the doings, and the ethics, as well as the subjectivity, into the nurse's practice is essential in the act of caring for the child with oncological pain and her family.

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