UNVEILING HUMANIZED CARE: NURSES' PERCEPTIONS IN PEDIATRIC ONCOLOGY[1]

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ABSTRACT: This study aimed to unveil the elements of humanized care present in the encounter between the nurse, the family and the child with cancer, to identify these nurses' perceptions regarding the humanization of the care, and ascertain in which situations the nurse perceives that the humanization is anchored in the care. It is an exploratory-descriptive study with a qualitative approach. Watson's Theory of Human Caring was used as a theoretical framework. The data was collected through semi-structured interviews held with nine nurses from a public hospital specialized in pediatric oncology in São Paulo. The results indicated the phenomenon "Unveiling humanized care given to the child with cancer and her family". The theoretical elements emerged from the descriptions of clinical events or situations presented by the nurses. The data permitted reflection on possibilities for construction of the humanistic interpersonal process in the care environment in pediatric oncology and on advances and limitations relating to the applicability of this framework in practice.

DESCRIPTORS: Oncology. Pediatrics. Nursing care. Humanization of care.

DESVELANDO O CUIDADO HUMANIZADO: PERCEPÇÕES DE ENFERMEIROS EM ONCOLOGIA PEDIÁTRICA

RESUMO: Esse estudo teve como objetivos desvelar os elementos do cuidado humanizado presentes no encontro entre enfermeiro, família e criança com câncer, identificar a percepção desses enfermeiros quanto à humanização da assistência e verificar em que situações o enfermeiro percebe que a humanização está ancorada ao cuidado. Trata-se de estudo exploratório-descritivo, com abordagem qualitativa. Utilizou-se como referencial teórico a Teoria do Cuidado Humano de Watson. Os dados foram coletados por meio de entrevista semiestruturada com nove enfermeiros de um hospital público especializado em oncologia pediátrica em São Paulo. Os resultados apontaram para o fenômeno "Desvelando o cuidado humanizado dispensado à família e à criança com câncer". Os elementos teóricos emergiram das descrições de eventos clínicos ou situações apresentadas pelos enfermeiros. Os dados permitiram reflexões sobre possibilidades de construção do processo humanístico interpessoal no ambiente de cuidado na oncologia pediátrica e de avanços e limitações quanto à aplicabilidade deste referencial na prática.

DESCRITORES: Oncologia. Pediatria. Cuidados de enfermagem. Humanização da assistência.

REVELANDO EL CUIDADO HUMANIZADO: PERCEPCIONES DE ENFERMEROS EN UNIDAD DE ONCOLOGÍA DE NIÑOS

RESUMEN: Este estudio tuvo como objetivos revelar los elementos de la atención humanizada en el encuentro entre enfermero, familia y niño con cáncer, identificar las percepciones de los enfermeros sobre la atención humanizada y comprobar en que situaciones los enfermeros perciben que la humanización se relaciona con el cuidado. Este es un estudio exploratorio-descriptivo, con enfoque cualitativo. Se utilizó como marco teórico la teoría del cuidado humano de Watson. Los datos fueron recolectados a través de entrevistas semi-estructuradas con nueve enfermeras en un hospital público especializado en oncología pediátrica en São Paulo. Los resultados indicaran el fenómeno "Revelando el cuidado humanizado ofrecido a la familia y al niño con cáncer." Los elementos teóricos surgieron a partir de descripciones de eventos clínicos o situaciones presentadas por los enfermeros. Los datos permitieron reflexiones acerca las posibilidades de construir un proceso interpersonal humanista en la oncología pediátrica y los avances y limitaciones en la aplicabilidad de este referencial en la práctica.

DESCRIPTORES: Oncología médica. Pediatría. Atención de enfermería. Humanización de la atención.

INTRODUCTION

Since the beginning of the XXI century, a strong movement linked to humanization has permeated discussions in the area of health. In 2000, the Brazilian Ministry of Health regulated the National Humanization Program, which has as its fundamental aim to improve relations between professionals, service users/professionals, and hospital/community, with a view to improving the quality and the efficiency of the services provided by the institutions and to promote a new culture of care.[1]

Humanization is a term which is difficult to conceptualize, given its subjective, complex and multidimensional character.[2] The literature describes that "to humanize is to assert the human in the action and this means care because only the human being is able to care in the holistic sense".[3:416]

In this way, in addition to the emphasis on the integrality of the care, there must also be a movement of critical reflection on these relationships, taking into account the subjectivity of the individuals when providing care. This is a process which demands broad and collective emphasis, not only on the one-being-cared-for, the focus of the relationship, but also on the concern with the structuring of the environment and the professionals, such that all may benefit from security and comfort.[4] In addition to this, it involves ethics and esthetics, which presupposes, in addition to technique, sensitivity such that the individuals may formalize consciousness with the care.[5]

In this regard, humanization is a complex process, which involves differentiated standards in the professionals' perception, values and beliefs, for there to be change in behavior. In this unique and intersubjective relationship, there is a unique process, not characterized by generalizations, as different professionals, teams and institutions have distinct processes in the acquisition of skills for more humanized care, as the emerging programs aim to do.[6-8]

This study aims to analyze this uniqueness in the process of humanization, with nurses who work in pediatric oncology. In this context, along with the structure of the child who is still growing and developing, there is the progression of a threatening and stigmatizing disease. In the face of this, the family passes through a destructuration, explained by the change in the routine, by the beliefs which surround the disease, and by the feeling of indignation on seeing the child being deprived of her rights as a result of the suffering caused by successive interventions in the hospital, which create anxiety and stress.[9-10]

Because of this, the child with cancer and her family pass through situations of extreme physical, psychological and social fragility.[11] In addition to the little-welcoming atmosphere in the hospital, the psychological factors which surround the child and the family, such as stress and anxiety during inpatient treatment, are identified as limiting factors in the nursing care, and influence the professional's interaction with the family, causing situations of incomprehension and non-cooperation on the part of the family in the care.

Nursing has an important role in this process, as the attitudes of care must be considered to be factors which minimize these influences and promote humanized care. Factors such as establishing a link of trust and friendship, empathy, and making the patient feel that she is part of the process, that is, considering this process's human dimension, are elements which allow a care which goes beyond simple techniques.[12]

In encountering this environment, the nurse must seek techniques so as to care with art, empathetic skill and plenty of creativity. Furthermore, the diagnosis of cancer involves distinct feelings of suffering which bring profound changes in the lives of the children and their families; as a result of this, the socio-cultural, emotional and spiritual aspects must be cared for and subject to interventions, as decisive contexts in the pathology's progression.[10]

For these reasons, it is necessary to understand the meaning of the care and the subjectivity which surrounds this process, with special attention to the child's universe, preserving her private world and the stages of childhood development, so as to meet their needs so as to achieve well-being, in spite of the condition of having the disease.

In the light of the above, the following objectives were outlined for this study: to unveil the elements of humanized care provided to the family and to the child with cancer, to identify the perception of the nurses who work in pediatric oncology in regard to the humanization of the care, and to ascertain in which situations the nurse perceives that humanization is anchored in the care given.

METHOD

This study is exploratory-descriptive research, supported by the qualitative approach, and

used as its theoretical framework the assumptions of Jean Watson's Theory of Human Caring.[13]

In 1979, Watson developed the carative factors, revised in 1985, introducing the paradigm of Transpersonal Caring, which focusses on the moral ideal and the meaning of the communication and the intersubjective contact through the co-participation of self as a whole.[14] As the theory evolved, the clinical caritas process was introduced, substituting the carative factors. This process includes the sacredness of being cared, the connection of human being to a plane which extrapolates the concrete and visual and the proposition of healing for reconstitution of self as components for grounding the care. The theory considers the nurse-client intersubjectivity based on the idea that one being always has an influence on another, and is based on the humanistic concepts of care, viewing the individual in his or her bio-psychological, spiritual and socio-cultural dimensions.[14-15]

The participants were nine pediatric oncology nurses from a public hospital in the city of São Paulo, who met the following inclusion criteria: to be a nurse, and to be linked to the institution in the study. The subjects were informed as to their voluntary participation, the guarantee of the confidentiality of the information, and on the use of the results only for scientific purposes. These participants were identified by number, so as to ensure anonymity.

It should be noted that the project received a favorable decision from the institution's Research Ethics Committee (Decision n. 534/2006), in accordance with Resolution n. 196,[16] referent to research involving human beings. The data was later collected, between November 2008 and February 2009, through two-part interviews, the first of which aimed to identify the research subjects, and the second of which was composed of the following semi-structured questions: what do you understand by humanization? Would you tell me about a situation in which you believe you provided humanized care? In the oncology context, what is it that makes humanized care for children and their families possible? The interviews were recorded on cassette tapes and for analysis their content was transcribed in full. Content analysis was used as a strategy, seeking to interpret the data through the following stages: pre-analysis and open coding, exploration of the material for categorization, treatment of the data and interpretation.[17]

RESULTS AND DISCUSSION

The description of the participants

Nine nurses participated in the study, identified by the sequential numbers: N1, N2, N3, N4, N5, N6, N7, N8 and N9.

One of the participants was male, and eight female, with ages varying from 24 to 28 years old. Regarding the time since graduation, the mean was two years four months. The length of service in the area of pediatric oncology varied from two months to one year six months. Of the nine interviewees, three had never worked in another area, and the other six had varying previous professional experience, such as: adult oncology, obstetric center, primary health center, hematology, and screening. Of the religions mentioned, four nurses stated that they were Roman Catholics, four were Evangelicals, and one was a Spiritualist.

The discourses

The study's theoretical elements emerged from the descriptions of the situations presented by the nurses, and were organized based on the 10 Clinical Caritas Processes, in line with Jean Watson's theory.[13]

Practicing loving-kindness and equanimity within a context of caring consciousness

The care must be grounded in a set of universal human feelings, such as kindness, interest in and the practice of love for self and others; this being so, the nurse becomes able to connect with others and with herself.[18] In this regard, aspects emerged from the discourses centralizing these feelings as fundamental for the practice of humanized care in nursing: "being human, treating others with tenderness, love and respect" and "having to exercise one's profession with love, the principal fruit for professional realization."

You have to work with tenderness, with love, that's the main thing. If you don't have love, for what you do, for your profession, [...] *you'll never manage to provide humanized work, everything will be mechanical. Love, tenderness and dedication are essential for humanized work* (N6).

Love for others, for the profession and for self is one of the elements which brings the affinity required for the inter-relation of the self of the nurse with the self of the other (child, family,

community), for the completeness which rules the universe.[15]

Being authentically present and enabling, and sustaining the deep belief system and subjective life world of self and one-being-cared-for

Keeping faith and respect for the beliefs of others is an essential element to connect with one another.[18] Showing the parents and the children that the nurse will always be present, doing her best, shows the importance of ensuring the presence of a competent and dedicated professional alongside the parents and children at all times during the treatment.

[...] *try to converse with the parents and say: look, this is what's happening, and we're here, we're trying. We shall not give up. All the children here are seriously ill, but we try right to the very end* (N4).

So as to assure the family that the care given is adequate, the nurses perceive themselves encouraging the family to have faith and hope in the treatment and in the professionals. Thus, the nurse helps in strengthening the professional-family bond and in maintaining the faith and trust.

Try to understand what is happening in their lives [the family] *and converse, bring it toward faith, for those who believe* [...] *speak about the medical and nursing teams, which are very good, which are experienced, and try to give peace of mind that here he will be treated in the best way* (N1).

Cultivating one's own spiritual practices and transpersonal self, going beyond ego self

In this process, Watson emphasizes the need to experience emotions and feelings in caring relationships, and further reveals that for there to be true interaction, one must act in a sensitive manner. It is this sensitivity which makes the contact transcend the physical/material world, integrating too the emotional and subjective world.[19] The nurse believes that showing sensitivity to the feelings of children and family members reflects the professional's concern with sharing these feelings so as to have empathy and integrate them into the care as a human process, which requires listening skills of the professional.

You need to puncture a vein, puncture it fast! But when the father wants to talk, wants to talk about the child's problems. At a time like that you listen; sometimes you even cry along with them (N6).

Knowing how to choose the right moment requires the nurse to have the sensitivity to identify when the time is not right for undertaking a specific procedure, especially as this involves children. At the same time, the nurse perceives the necessity to impose limits for the child, with a certain tolerance, so as not to harm her health during the treatment.

You have to wait for the right time [...]. *There was a child in the terminal phase here, and we were going to puncture the catheter, when he said: 'oh nurse, can it wait a little bit?' So I said: 'okay, I'll put the medicine in and puncture the catheter later, okay?' Then I waited about 30 minutes, stayed there chatting, and he gave me a look: 'now you can, Nurse'. So I went there, punctured, and he calmed down to take his medication* (N6).

Developing and sustaining helping-trusting, authentic caring relationships

To develop a helping-trusting relationship, some elements help to establish a caring and harmonious interaction. Consistency is one of the characteristics which help to construct a true relationship, in which the nurse must act honestly and openly.[19] Establishing a relationship with sincerity to have trust is how the professional exercises consistency with the child, going beyond productive work, because he can transcend the rigidity of the function's expectations.

You talk with them first, explain what's going to happen [...] *it might hurt, and it might not! Never lie! People who work with children notice this fast* [...]. *Thus, we can get him to understand and help during the procedure. This is humanizing, it's attention, conversing, hearing* (N6).

Another essential condition to develop a helping-trusting relationship is empathy, explained as the nurse's skill in experiencing the other's private world and communicate to them some degree of comprehension.[19] The nurse notices herself seeing things from the point of view of the child and the family, as a way of expressing empathy, which is fundamental to humanized care.

I always put myself in the position of the other in everything I do, not just at work but for everything [...]. *We try to understand everything the patient is going through, to resolve things in the best way possible* (N7).

The skill of recognizing the other's feelings is a common benchmark for the emotional experience. Even so, nobody can go completely through the other's experience; but people have felt some degree of pain, anger, sadness, guilt and pleasure at

some time or other, and this is a base for a reference for developing this skill, respect and esteem.[18-19]

Another characteristic in this helping-trusting relationship is unconditional positive acceptance, which means accepting the other in a positive way, through small details such as a smile, body posture, caring touch and the ability to listen.[19] Valuing interpersonal communication means the nurse moving to establish a link with the family, with communicational skill, and carrying out humanized care, ensuring the patients' needs.

For humanized care, the conversation, the interpersonal communication is very important. Because, sometimes, ten, twenty minutes talking together, explaining something, consoling, or even just saying nothing, just listening, for the other person who needs to let it out, that's a lot, you know? [...]. *Enough tenderness and patience to listen, I think that's very important.* (N5).

This involvement, which brings the professional closer to the child and the family, in cancer situations, is the fruit of the construction of a relationship of help and trust which involves empathy, consistency and unconditional positive acceptance, and also strengthens a framework in the most fragile times. Being available at the family's side in difficult times means involvement with family members' feelings and the closer relationship established by the nurses as part of the humanization process.

[...] *the patient had died and* [...] *I knew that I wasn't going to see her there, at that time* [at the wake], *she wasn't going to see that I was there, but I felt the need to comfort her mother* (N2).

Being present to, and supportive of, the expression of positive and negative feeling

The acceptance and expression of feelings must be present to maintain a communication channel between people. Not expressing that which one feels leads to inconsistency between thoughts and feelings, which can result in anxiety, stress, confusion, aggressivity and even fear.[19] Giving support to, and respecting, the child and family represents the nurse's efforts to understand them and support them when they present behaviors of distress or anger. Valuing feelings and expressions of happiness refers to the importance of the nurse's emphasizing positive feelings manifested by the child and family.

You must always understand, even when you have a child who kicks and swears. You don't know what is going on [...]. *You see that the mother is suffering: 'you are judging my son and that's not how it should be. He is ill, and we don't know what to do with him'* (N4).

The feelings explain thoughts and behaviors and, therefore, the one who is caring must be attent to the feelings of the other in the maintenance of health and in people's responses to the situation of the disease, as a way of profound connection with the spirit of the person being cared for and of the being who cares for the other.[13,15]

Creatively using self and all ways of knowing as part of the caring processes; engaging in artistry of caring-healing practices

The creative resolution of problems must ally knowledge and intuition as part of the caring process. The scientific method for nursing practice has a value equal to the fundamental nature of nursing (caring for the other), which involves the humanistic approach.[18-19] Considering the child's specific universe so as to understand her reflects the concern with practising care directed at the child's needs, taking into account particular aspects of development, so as to improve understanding and interaction.

For the child, everything is new, everything is a surprise, but it's only in that very moment, you know? When you are going to puncture them, it is suffered in that moment. Five minutes later they're jumping around! So, you have to enter this world too, which is a world we experienced (N4).

Another meaning identified in the discourses was the use of ludic tools to interact with the child, and there is a similarity with what was described above, as in both we noted the professional's concern in trying out a different approach for the child, in considering humanized care. The nurses describe strategies which they use to get closer to the child's world.

I think that this is humanizing the care, and we do this with routine things, letting them give us injections, pretending they're puncturing the vein, making this a little more tranquil for them (N3).

Engaging in a genuine teaching-learning experience that attends to wholeness and meaning, attempting to stay within the other's frame of reference

The nurse must be genuinely dedicated in a practical experience of teaching-learning.[19] Offering the patient information which is necessary to

understand the treatment represents the role of the professional as educator in the attempt to make the child and family understand each aspect related to the treatment, reducing the anxiety and stress resulting from the uncertainties and doubts. For the nurse, it is necessary to promote educational meetings and discussions with the team, to have discussions about the treatment, and also about aspects related to the process of humanization among the team members.

There have to be discussions in the work institution [...] *for everybody to grow together, because otherwise it is how I told you: it comes down to personal criteria; each does what she thinks is best, and there's nothing scientific about that* (N3).

Creating healing environment at all levels, whereby wholeness, beauty, comfort, dignity and peace are potentiated

This process is related to an environment made available by the nurse to promote and restore health and prevent disease.[19] In nearly all the discourses, these aspects appear as a necessity to have a holistic view of the child and family. In this way, it was possible to identify the professional's concern in seeing the patient as a complete human being, rather than as a health problem.

Humanization, for me, means treating the patient in the best way possible, respecting equally the psychological, spiritual and bio-psycho-social parts, complete [...], *always considering the patient as a whole, and not as a sick part* (N9).

For Watson,[14] this is the big difference between the perspectives of traditional science and of human science. The first is normative, reductionist, mechanistic, centered in the method and in the illness of the physical body. Human science does not consider the knowledge as a product but rather as a process of discovery, it being transpersonal, metaphysical, centered on the phenomenon and the illness seen as a response to personal human conditions.[14]

Assisting with basic needs, with an intentional caring consciousness, administering 'human care essentials' which potentiate alignment of mind-body-spirit, wholeness in all aspects of care

This process is based in a hierarchy of care, considering each person in the global context. The hierarchical needs were composed in the following way: survival needs, functional needs, integrative needs and those of search for growth. For Watson,[14] attending the lower-order needs may not help the human being in regard to self-realization.

You have to explain what's going to happen, what might happen to the child, that hair falls out, that she'll lose her appetite when she does the treatment, and care for this too [...]. *We explain, we understand when she doesn't want to eat, we encourage, but we don't force, because if she doesn't want to, she really doesn't want to!* (N8).

The pediatric oncology nurses express the need for a complete attendance, going beyond functional or integrative needs – they present holistic thinking for the care of the child and family.[14,19]

Opening and attending to spiritual/mysterious and existential unknowns of life-death

In spite of the spiritual aspect's importance for caring practice, this element did not emerge spontaneously in the discourses obtained. The nurses were not encouraged to talk about this matter, because it was not explored among the study's objectives. However, the nurse values the link for the recognition of self, of the child and the family's self, and also as strengthening in the professional work. In this process, it is fundamental to try to investigate the experience of the other.

There was that attachment [...] *we* [team and family] *are a second family, when he* [the child] *died, this feeling created was something which comforts me and gives me energy to continue the work* (N8).

In spite of this, it seems to us that there is a lack of skill for helping the patient and the family to explore the meanings which they give to the experience of illness and death, in the spiritual dimension within the context of oncology.

The nurse's perception on humanized care brings fundamental elements for human relationships and is consistent with Jean Watson's caritas processes,[19] as well as with the discussion on care and humanization, which is growing, with the National Humanization Policy (Humaniza/*Sistema Único de Saúde* - SUS),[1] addressing aspects such as: people's individuality, attentive listening, the valuing of beliefs, of communication and of genuine presence.[6] Considering human relationships as manifestations of subjectivities, these ingredients form part of the sensitization of professionals and of the institutions to entrench the existential and human aspect in the health encounters. This

being the case, the focus of a constant work of consciousness-raising of the teams is necessary, for attending the child and family, given that the hospital routines are rigid and remain distant from the families' needs.[6,20]

A theoretical framework such as Jean Watson's Theory of Human Caring, for the practice of the care given to the children and families who face cancer, can guide the nurse's practice. This is an important resource to go beyond the rigidity of the functions which stifle the care encounter, thus promoting a dialog which is more sensitive to the physical, biological, psychological, emotional and spiritual human needs.

FINAL CONSIDERATIONS

Jean Watson's theory leads us to think about the existence of self, about the love as a manifestation of care which transcends the physical aspect of this process. In using the ten elements which make up the clinical caritas process, we understand that the nurse needs to risk him- or her-self to undertake an analysis, a transformation within, for the promotion of humanistic care to be possible.

This care involves strengthening the link between the professional, the family and the child. Some feelings need to be evident, such as tenderness, love and respect for the other and for the profession. In the same way, it is necessary to commit oneself to establishing a relationship with empathy and creativity, to encourage faith and hope in the treatment, to act with sensitivity and flexibility in the approach with the child, to accept the expression of feelings, to invest in communication and to hold meetings with the team to think about the care offered, so as to ensure the family's needs in the best way. This being so, the nurse displays a fundamental role to guarantee that the caring encounter involves consciousness and sensitivity in interactions with the other.

The nurse who experiences the context of pediatric oncology knows essential human elements for bringing the care closer to the client, as Watson's Theory calls for, but little appropriates benchmarks for the care. Thus, it becomes more difficult to conciliate formal and grounded strategies to help with the suffering of children and families. This theory, because it comes close to the perception of humanized care brought by the nurses, may be a path for these professionals to develop interventions in attending the families' needs and their adjustments to the disease.

The subjectivity of the care actions involves focussing on the human interactions, which are in constant change, requiring the professionals who promote the care to have preparation and critical reflection. This study opens this possibility based on the knowledge of the perception and experience of the nurse in the care for the children and the families who live through the experience of cancer. It is an invitation to reflection and a proposal to change the way of thinking about nursing, through the valuing and the perception of self and other in caring relationship.

The tenth clinical caritas process – Opening and attending to spiritual/mysterious and existential unknowns of life-death – seems relevant to us for the context of oncology, in which the nurses deal with the questions of life and death. According to Watson, if the nurses are not capable of looking within themselves and facing their own questions related to the losses, they will not be capable of helping the other to discover the meaning of the difficult event which they are experiencing. Thus, we consider this process to be overriding for true humanistic care, especially in the contexts in which we need to work with people who are in the process of dying.

"Unveiling humanized care: nurses' perceptions in pediatric oncology" represents the intellectual exercise undertaken in the course of this work, of deepening the knowledge in Jean Watson's Theory of Human Caring and analyzing the statements using this framework as a base. This study brought us a new knowledge in relation to care and will, without doubt, bring great benefits to our future clients and families, the target of our caring actions.

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