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CARE STRATEGIES ADOPTED BY NURSES IN THE CARE OF HOSPITALIZED CHILDREN WITH ADVANCED CANCER AND IN THE SELF CARE

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ABSTRACT
In this study we aimed to analyze the main strategies adopted by nurses, copying in the dying process, in the care to hospitalized children with advanced cancer, and in the self care. This is a descriptive and qualitative research, realized in the Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG), Brazil. Nine nurses took part in it. The data were colleted between January to March 2012, applying semi-structured interview and the Themathic Analysis was used for data treatment. Four categories have emerged, and in this study we present two: the flexibility of nursing care to promote a better quality of life for children with advanced cancer in the process of death and; the self-care adopted by nurses who face the possibility of death of children with advanced cancer. Nurses seek to organize, plan and implement care according to the needs of the child, valuing comfort, quality of life, human dignity and family. They establish strategies for the maintenance of a psycho-emotional balance for the difficulty in dealing with the process of life/death of the child, such as: job involvement, establishing healthy interpersonal relationships, emotional detachment, religiosity and investment in the professional training. The context is complex and suggests new researches aiming to promote intersubjective connections in nursing practices, including thinking and doing, to improve care.

Keywords: Oncological Nursing. Pediatric Nursing. Self Care. Palliative Care.

INTRODUCTION

Childhood cancer is rare compared with tumors in adults, accounting for approximately 2.5% of all cases of cancer in Brazil. However, it is the second cause of death in the age group 5 to 19 years, only surpassed by deaths from external causes, resulted from policies to prevent other childhood diseases, such as the infectious and parasitic disease[1].

In the advanced stage of the oncologic disease palliative care are implemented, involving the assistance promoted by a multidisciplinary team, which aims at improving the quality of life of patients and their families when facing a life threatening illness, through the prevention and relief suffering, early identification and impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms[2].

This phase of the treatment of children is marked by uncertainty, unpredictability, doubts and high possibility of dealing with death, which makes care relationships even more complex, as in the case of the relationships of nurses, for example, with the children and their families[3-5].

Among the types of service in hospice care, hospitalization stands out, since the nurse remains present 24 hours, and when managing care, he establishing an empathic relationship with the child and family, valuing subjectivity, communication and teamwork towards meeting the their needs[3]. Thus, it is understood that the work process of nurses should be structured by means of flexible and dynamic practices in order to facilitate the adjustment of the child and family to the dynamics of the hospital environment and to ensure the dignity, individuality and serenity at this stage of the disease.

In this sense, it is imperative that nurses establish strategies to deal with eventualities and advance in the disorders that permeate the relationships of care for hospitalized children with advanced cancer in the process of

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death/dying, since is understood that the adoption of strategies allows changes in the script of planned actions targeting a specific purpose[6].

Faced with this problem, the following research questions were set: what care strategies were adopted by nurses in the care of hospitalized children with advanced cancer against the dying process? What are the strategies adopted by nurses for self-care in this context?

Thus, this study aimed to analyze the main care strategies adopted by nurses in the coping of the process of dying, in the attention to the hospitalized child with advanced cancer, and self-care.

The study is justified by the epidemiological prominence of cancer, which estimates that in 2012, and also 2013, there were approximately 11,530 new cases in childhood and adolescence, in addition to the need to discuss palliative care in the face of demands for beyond the area of oncology, and cultural, political and structural difficulties[7,8]. Thus, the study based on practical experience of the nurse seeks to contribute to the quality of care when facing the possibility of death by means of the use of the theoretical framework of Complexity[6.9].

METHODOLOGY

This is a descriptive study, in which we adopted a qualitative approach, conducted at the Martagão Gesteira Institute of Pediatrics (IPPMG), which composes the hospital complex of the Federal University of Rio de Janeiro, located in the municipality of Rio de Janeiro, Brazil. In the context of cancer care, the IPPMG is part of the care network in oncology, as Unit for High Complexity Assistance in Oncology (Unacon). Data were collected in the pediatric unit between January and March 2012. For clarification purposes, this unit is composed of six wards, each containing six to eight beds. Two wards are intended for infants (up to two years - A and B), one for children in preschool (three to six years - C), one for children in school age (six to twelve years - E), one to children with onco-hematological disease (F) and a ward for children in pre and postoperative phase (D).

The study included nine nurses who were selected according to the following inclusion criteria: have an employment relationship with the Institute and have experience in pediatric care for at least two years, considering aspects related to the categorization of expertise in nursing practice[10].

The data collection technique used was semi-structured interviews, carried out individually in their own work environment, in a noise free meeting room, in a day and time agreed with the nurses while on duty. The interviews lasted on average 45 minutes and were guided by a script containing the following questions: what are the main care strategies adopted by you, in the care of hospitalized children with advanced cancer? How do you deal with the process of death and dying of children with cancer in your daily work?

Before the interviews the characterization of the profile of nurses was conducted through the questionnaire containing the following variables: age, gender, working Time at the institute and academic titles.

The content of the interviews was recorded on an audio electronic device, in accordance with the participants, and later transcribed in full. Each interview was identified by the letter N, for nurse, followed by the serial number of outputs (N1, N2, N3 ...), in order to maintain the confidentiality and anonymity of information.

Data were analyzed using thematic analysis, following the steps of pre-analysis, material exploration, processing of the results obtained and interpretation, in order to identify the main recurring issues of the experiences of nurses and separate them into themes. This method is considered one of the most appropriate ways to analyze the qualitative research approach to health[11]. From the survey of the categories the processes of analysis and discussion of the data began, based on the literature review and critique of the authors, and in the application of the theoretical framework of Complexity.

To ensure the ethical principles, the research project was approved by the Research Ethics Committee of IPPMG, under opinion number 70/11, following the recommendations of Resolution 196/96 of the National Health Council

RESULTS AND DISCUSSION

With regard to the characteristics of nurses' profiles, most were female, with only one male professional. Three nurses had ages between 31 to 40 years, another three between 41 and 50, two between 51 and 60 years, and between 20 to 30 years of age. The average working time at the institute was 12 years and the shortest time of 05 years and the highest 32 years, demonstrating the large group experience. As to the professional qualification, five are specialists in pediatrics and four in other areas, which include: hospital infection control, biosecurity and intensive care.

Four categories have arisen from the analysis, two of which highlight the complexity of nursing care for hospitalized children with advanced cancer, are presented in this study, namely: the flexibility of nursing care in favor of better quality of life for children with advanced cancer in the process of dying and; self-care adopted by nurses when facing the possibility of death of children with advanced cancer.

The flexibility of nursing care in favor of better quality of life for children suffering from advanced cancer in the process of dying

This category expresses flexibility in the decisions of nurses in the management of care regarding the participation and choice of children, by means of dialogue and negotiation. When children exercise their ability to choose, they rescue their individuality and acquire more confidence in the professional[12]. Among the actions found the following ones stood out: meeting the child's desire to eat something different, see a loved one outside of visiting hours, or even do some activity outside the hospital within their possibilities and clinical conditions.

> We try to work with that child as much as possible in a way that it is pleasing to her, respecting her always, so that, for example, if there is a child who is currently sleeping, and there is a need to redo a bandage on a deep puncture, I will not do it now because I believe very much in humanization, then shortly this kid will wake up, and I will make the dressing, but I will not bother her when she is asleep. (N5)

> We try to ask the patient himself what he would like to do at that moment and then, we take it to the staff, and we sit down to discuss what we can do in order to bring an answer back. (N3)

> The child has a sibling at home and wants to be with this brother, then we provide a cool time, so that he may enjoy this moment with brother mostly. [...] If we can allow some foods when he wants them, sometimes we let him eat fries or a burger. (N8)

> We let them choose the venipuncture spot, and we negotiate it to try to make the procedure less traumatic. (N2)

It is important for nurses to listen to children allowing them to express what they see or feel in the experienced situation, once the basis for respect to the exercise of autonomy of people is communication, in particular, listening on the part of the professional, with due sensitivity to the perception of nonverbal communication[6]. With that comes the need to contribute to achieving the wishes of the child, who, inserted in this complex reality, can go through unpleasant situations as for the signs and symptoms of the disease, effects of medications, including restrictions of personal actions in this moment of life throughout the hospitalization process.

> There was a child in terminal phase here, but he still had normal intellectual condition and was physically intact on the outside and he wanted to fly a kite. Flying kites is not feasible, but I can make it possible, all we need is to add a bit of strength and good will of each one, since that will not worsen his condition, and we can make it possible for him to go to the small terrace and fly his kite. (N3)

> There are children who are trapped in the venous catheter all the time of their lives; they know they have no treatment, but they still get stuck in the catheter and sometimes they want to run down the hall, if they have the necessary condition for that, so I heparinize this catheter and leave them as long as they can do without the medications so that they are free to wander off the ward. (N6)

Nurses value the need for carrying out measures to maintain the comfort of the child, to meet the principles of palliative care. Thus, they organize, plan and implement care using playful techniques, such as: playing, storytelling and singing at the time of the procedure. The establishment of a dialogue is essential; then, the nurses talk to the child and explain what will be

done, fostering a relationship of trust and mutual respect.

> We try to play; we sing music of the time; take pictures; we lend the cell phone and; try to make a little toy with the glove. Here we have, in part of the day, doctors of joy, so we try to do our part, you know? We will not be doctors of joy, but, at least, we try to make this child happy. (N5)

> When the child is lucid, engaging, anything is worthwhile. We tell stories, jokes; we sing and pull out that little smile. These things make everything lighter. [...] We have to get closer; we talk; we show him that we are doing this for his sake; we try to give him comfort in any way, either with medication or positioning in bed. (N6)

> We try to ensure privacy; we try to avoid submitting children to unnecessary invasive procedures; we try to provide quality to the life remaining. So, the question of care management is to seek to promote comfort and life quality because they are still alive, you know? We try to be the least invasive as possible and respect the moment and the family. (N2)

The use of the ludic in care relations provides positive effects for nursing care purposes, as it allows children to express their feelings, providing freedom of expression through games, and emotional, psychological and physical well-being. Playing games triggers fun, enjoyment and safety to children, thus softening the stress of hospitalization and the context of the disease. Moreover, the music at the time of the proceedings is also a competent and important management strategy for palliative care, since listening to songs brings positive changes in mood and emotional balance, providing relaxation[3,13].

The establishment of a partnership with the family in order to make care less traumatic, especially in the case of the need to perform painful procedures, is essential, since the family is present at all times in the process of hospitalization of children. Thus, a closer relationship with the family, based on trust and in an empathic manner, was also considered a strategy on the part of nurses that contributes to meeting the needs of children as well as their own family, which makes them an inseparable pair.

> My strategy is to approach mothers, establish bonding, empathy, affinity, trust, so that they can be free to say what they feel, so that we can try to intervene by forwarding them to the psychologist or to the social worker. There are several strategies. (N9)

> I always try to be receptive to the family; I hear what they have to say. Often family members do not want you to say anything; they just want you to stop and listen, and then I sit there to provide them with solace and comfort at that time. (N8)

When the death of the child is near, the family members are the ones who suffer more and are the ones who most need psycho-emotional support for coping with the complex reality. Very often, by the fact that they remain beside the child throughout this process, they feel alone and without support of other family members, either by the distancing from home and family life, imposed by the hospitalization of the child, or by the limits of visiting hours at the hospital[4]. At that moment the nurse plays an important role in supporting families facing the adversities that emerge from the child's hospitalization, which is usually quite long.

> I try to show the companion that the fact that the patient has leukemia doesn't mean he will die. So I give him the example that there are many Marias, but each Maria is different. There is Maria Eduarda, Maria da Penha. So, I try to soften things up, showing that each case is unique, so he shouldn't live another person's pain. (N3)

It is necessary, in situations involving the possibility of death of the child, to identify and work with the family in cases where it experiences early mourning. Thus, in the context of interdisciplinary work, the nurse must be available to listen to the family member's needs, anxieties and sorrows, without, however, failing to strengthen hope. We must welcome these families providing them with safety and comfort, maintaining a close relationship by means of conversations that prepare and sustain them face the challenges of the disease and even at the time of death, from the work on the stage of grief[14].

Self-care adopted by nurses when facing the possibility of death of the child with advanced cancer

This category expresses the difficulty faced by nurses before death; the need for capacity building and professional training for dealing with palliative care and the need for coordination

between the labor process and the health of the professional.

Either by the lack of discussions on the theme of death in vocational training or the cultural and historical aspects of life, considering beliefs and principles of people, it is not an easy task to deal with death in daily work, especially when it occurs in childhood[9]. In some cases, work experience is seen as an ally to deal with adverse and unpredictable events including death situations, facilitating their acceptance, meaning that it can help some people to acquire hope and compassion and to improve their self-awareness, becoming more sensitive and prepared to face death[15-16]. However, the subjectivity inherent in human beings does not equal the forms of thought, nor equates modes of each professional to deal with this event in their daily work routine[13].

> Anyway, the process of death of any child is very painful, especially for the family. In fact, it is very painful for everyone, including us, nurses. Actually, the whole team feels it. (N1)

> Death is always a hard thing for anyone, at least for us, Westerners. We don't have a good acceptance of death. (N7)

> There was a time when everyone wanted to run away from that ward where there was a child in terminal phase of life. Today, after fourteen years of experience, I see this process more naturally. I believe death is a natural process; everyone was born and will die someday. (N3)

> Is still very difficult in this last period when the child gets closer to death. You see that the child gets deformed, acquires ascites with ocular bleeding, so, for us, it is also quite shocking, because we see the child degrading in front of us. (N8)

The manifestations of the disease and the representation of proximity to death in the body of the child are striking features of cancer that shock people and are quite noticeable. This situation generates feelings of denial and stigma, which resolves the issue in the agenda, including the academic and vocational training.

Regarding the training of the professional nurse, many universities do not have the formal inclusion of the teaching of oncology in their curriculum, which meets the demand of the population[17]. The gap is even greater when it comes to the topic of palliative care. However, given the need to meet the human being in its multiple dimensions, palliative care is configured as urgent practice to meet the needs of children with advanced cancer.

> I never saw myself prepared to deal with death. I got a support through a course that I did there at the National Cancer Institute for palliative care, when I got to understand a little more this process, and it was enough so that I would not have so much aversion. With this course, I learned that you may not be able to cure, but even in the final stage of life, you still have plenty to do for the individual. (N3)

The previous training on the topic of palliative care is essential so the professional can develop skills and abilities to deal with adverse situations in daily work[12]. Activities such as case discussion in staff, courses, debates or clinical teaching can promote opportunity for opening spaces for exchanging experiences in order to help nurses and other professionals to understand the complex phenomena of human living and dying, helping them in decision making.

Thus, we affirm the need to foster discussions about palliative care, considering the premise of extended care, and the roles of professionals in this specialty, which is presented as new but imperative[8]. Professionals need to be prepared for the multidimensional approach in an interdisciplinary perspective, focusing on their goals far beyond the pathology, without neglecting the possibility of death, which on occasion need not be accompanied by feelings of inadequacy, failure and a sense of failure, but by the gratefulness in the pursuit of doing good[9].

In this direction, we emphasize that people need to engage in care situations, as they are processed by means of multiple relationships and interactions between human beings. However, the report below elucidates that the estrangement can be a strategy to deal with the process of death and dying of the child, related, for example, to the very vulnerability of their peers.

> Actually, I'm kind away of the whole process. I try not to get involved. I don't get myself too much involved with the process itself. When the

> child is in the process of death, I shift my attention mostly to the mother. (N4)

The family care is paramount, since it should be looked upon as a care unit. However, the attention of the nurse should be given to the child and his family, in an articulated and simultaneous manner, also considering that one of the needs of the family may be related to the very ability of nursing staff to meet the child with competence in good time, with good humor, with good communication and empathy[3,18].

Among the different forms of nurses dealing with the phenomenon of death of the child, is their own immersion in the work as a refuge, which is a means of occupying the mind and has an objective and practical nature. In addition, healthy interpersonal relationships among team members contribute to a more peaceful and harmonious environment, which increases the ability of people to show themselves up available to the other, favoring the subjective expression of care, and the essential intersubjective ties to humanization .

> Oddly enough, I take refuge working. In fact we never have a job, we have two, three, so from here I go to another job and there I try to talk to my co-workers. We talk; laugh at other things to try to minimize that sorrow that we feel regarding this child. (N5)

It should be emphasized that the creation of a healthy work environment is favored by the attitude of the professional nurse, his leadership and managerial style, as well as by the way he establishes relationships and interactions with members of the nursing staff and other health professionals. Thus, consciously, from the recognition of subjectivity and before all the elements that cause stress, the leader nurse can work together to ensure that the management practice happens in a humane way, for the health of the worker. This should be a concern at the possibility of psycho-emotional and physical overload, in the face of unpredictable and predictable situations that permeate nursing care[19].

The emotional unpreparedness and the difficulty in maintaining balance at the possibility of death of the child and suffering of his family are important factors that generate stress, in addition to the dynamism and the need to cope with changing situations. It is noteworthy that the National Policy on Humane Care and Health Management (HNP), of the Unified Health System (UHS), includes the construction of a space for social, professional and interpersonal relationships for the quality of life at work[20].

We also highlight the reference to religion and faith as ways of dealing with the process of death of the child, as they help to comfort, to reduce anxiety, to neutralize stress, as well as being associated with the hope of a possible change in prognosis[3,19]. The practice of religious principles is one way that nurses have found to accept and support the event of death in daily work.

> It's true. Faith in God, absolutely, brings comfort. is the best way to handle it. (N1)

> It is clear that religion brings comfort. I'm Catholic, so my religion allows me to believe that suddenly he is going to a better place. (E2)

The various beliefs surrounding the death subject are means that man, as the only living being with this awareness, finds to deny it, as for example, to believe in a prolongation of life beyond death[9]. From this perspective, we think on the limitations of this study and the need to carry out further studies, since it is a subject with many myths and taboos that must be addressed in other scenarios, given the diversity and multiple identities of human beings.

FINAL CONSIDERATIONS

Nurses working in oncology are inserted in a complex and challenging situation facing the possibility of dealing with the process of death and dying in their daily work, often marked by pain and suffering. When this experience is related to child care, the work environment becomes more difficult due to several factors, with an emphasis on socio-cultural issues, as well as to the lack of preparation in vocational training for dealing with the unpredictability of this context.

Thus, it is understandable that nurses provide different strategies that help them in the practice for maintaining the emotional and psychological balance. Among the strategies we include: refuge

in work, the establishment of healthy interpersonal relationships at the work environment, emotional detachment, practice of religiosity and investment in professional training.

Nurses organize, plan and implement care according to the needs of the child, in order to maintain the comfort; promote quality of life and human dignity, establishing strategies and explain how to dialogue honestly about the procedures; use playful techniques such as playing and singing, which refers to life outside the hospital; respect the child's time in a flexible manner; negotiate and facilitate choices; preserve the autonomy of the child; grant wishes as far as possible, according to their clinical condition; in addition to establishing partnerships with the family, seeking also to suit their needs.

In conclusion, we highlight that it is important and necessary for nurses to seek a way to manage the nursing care that values the human being in its complexity and multidimensionality, considering the context of the child and his family in the dying process. Thus, the complexity of the issue requires investment in training and new studies emerging from practical contexts of professionals and which assist in constructing models of care.

ESTRATÉGIAS DE CUIDADOS ADOTADAS POR ENFERMEIROS NA ATENÇÃO À CRIANÇA HOSPITALIZADA COM CÂNCER AVANÇADO E NO CUIDADO DE SI

RESUMO

Neste estudo objetivou-se analisar as principais estratégias de cuidados adotadas por enfemeiros, no enfretamento do processo de morrer, na atenção à criança hospitalizada com câncer avançado, e no cuidado de si. Estudo descritivo, qualitativo, realizado no Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG), Brasil. Participaram nove enfermeiros. Os dados foram coletados entre janeiro e março de 2012, por entrevista semiestruturada e foi utilizada a Análise Temática para tratamento dos dados. Emergiram quatro categorias, das quais duas estão apresentadas neste artigo: a flexibilidade do cuidado de enfermagem em prol da melhor qualidade de vida da criança com câncer avançado em processo de morrer; e o cuidado de si adotado por enfermeiros frente à possibilidade da morte da criança com câncer avançado. Os enfermeiros organizam, planejam e implementam os cuidados de acordo com as necessidades da criança, valorizando o conforto, a qualidade de vida, a dignidade e a família. Estabelecem estratégias para a manutenção do equilíbrio psicoemocional pela dificuldade em lidar com o processo de morte/vida da criança, tais como: envolvimento com o trabalho, estabelecimento de relações interpessoais saudáveis, distanciamento emocional, religiosidade e capacitação profissional. O contexto é complexo, sugerindo a realização de novas pesquisas que fomentem conexões intersubjetivas no pensar e fazer o cuidado de enfermagem.

Palavras-chave: Enfermagem Oncológica. Enfermagem Pediátrica. Autocuidado. Cuidados Paliativos.

ESTRATEGIAS DE CUIDADOS ADOPTADAS POR LOS ENFERMEROS EN LA ATENCIÓN DE LOS NIÑOS HOSPITALIZADOS CON CÁNCER AVANZADO Y EL CUIDADO DE SI

RESUMEN

El estudio tuvo como objetivos analizar las principales estrategias de cuidados adoptadas por enfermeros, para hacer en el proceso de la muerte, en la atención de los niños hospitalizados con cáncer avanzado, y el cuidado de si. Estudio descriptivo y cualitativo, realizado en el Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG), Brasil. Participaron nueve enfermeros. Los datos fueron recogidos entre enero y marzo de 2012, por entrevista semi-estructurada, y el análisis temática fue utilizada. Emergieron cuatro categorías, y en este estudio se presentan dos: la flexibilidad de los cuidados de enfermería para mejorar la calidad de vida del niño con cáncer avanzado en el proceso de la muerte; el cuidado de si adopatados por enfermeros para afrontamento de la posibilidad de la muerte de los niños con cáncer avazado. Los enfermeros organizan, planifican y implementan la atención de acuerdo con las necesidades, valorando comodidad, calidad de vida, dignidad y familia. Las estrategias para mantener el equilibrio psico-emocional son: implicación con el trabajo, establecimiento de relaciones sanas, desapego emocional, religiosidad y inversión en la formación profesional. El contexto es complejo y sugiere la necesidad de nuevas investigaciones que contribuyan para conexiones intersubjetivas entre pensar y hacer los cuidados de enfermería.

Palabras clave: Enfermería Oncológica. Enfermería Pediátrica. Autocuidado. Cuidados Paliativos.

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