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PROCESSES OF CARE FOR CHILDREN WITH CANCER: A DOCUMENTARY RESEARCH

PROCESSOS DE CUIDAR DE CRIANÇAS COM CÂNCER: UMA PESQUISA DOCUMENTAL

PROCESOS DE CUIDAR AL NIÑO CON CANCER: UNA INVESTIGACIÓN DOCUMENTAL

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ABSTRACT

Objective: to characterize the dissertations and theses available in the Database of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior/CAPES which focus on the processes of care for children with cancer. ***Method***: documentary research performed in the Theses Base of CAPES. The data were collected in the month of June of 2012. The descriptors "processes of care", "Child" and "Oncology" were used. ***Results:*** the sample matched the seven studies, 6 (85.7%) of academic master degree and 1 (14.3%) of doctorate. The Southeast and Midwest regions of Brazil were the most investigated on the subject. Four studies are about nursing, two about psychology and the language sciences. All research are qualitative. ***Conclusion:*** there is little investment in master and doctoral studies working in processes for oncologic care for the child, as well as the need for more research that address the topic from the understanding of the child. ***Descriptors:*** Oncology; Research; Child Hospitalized; Academic Dissertations.

RESUMO

Objetivo: caracterizar as dissertações e teses disponíveis no Banco de Dados da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior/CAPES que versem sobre os processos de cuidar de crianças com câncer. ***Método***: pesquisa documental realizada no Banco de Teses da CAPES. Os dados foram coletados no mês de junho do ano de 2012. Utilizaram-se os descritores "Processos de cuidar", "Criança" e "Oncologia". ***Resultados***: a amostra correspondeu a sete estudos, 6(85,7%) do mestrado acadêmico e 1(14,3%) de doutorado. As regiões Sudeste e Centro-oeste do Brasil foram as que mais investigaram sobre a temática. Quatro estudos pertencem a enfermagem, dois à psicologia e um à Ciências da Linguagem. Todas as pesquisas são qualitativas. ***Conclusão***: há pouco investimento em estudos de mestrado e doutorado que trabalhem os processos de cuidar da criança oncológica, bem como a necessidade de mais pesquisas que abordem a temática a partir da compreensão da criança. ***Descritores***: Oncologia; Pesquisa; Criança Hospitalizada; Dissertações Acadêmicas.

RESUMEN

Objetivo: caracterizar las disertaciones y tesis disponibles en el Banco de Datos de la Coordenação de Aperfeiçoamento de Pessoal de Nível Superior/CAPES que se enfoquen sobre los procesos de cuidar de niños con cáncer. ***Método***: investigación documental realizada en el Banco de Tesis de la CAPES. Los datos fueron recogidos en el mes de junio de 2012. Se utilizaron los descriptores "Procesos de cuidar", "Niño" y "Oncología". ***Resultados***: la muestra correspondió a siete estudios, 6(85,7%) del mestrado académico y 1(14,3%) de doctorado. Las regiones Sudeste y Centro-oeste de Brasil fueron las que más investigaron sobre el tema. Cuatro estudios pertenece a enfermería, dos a la psicología y un a la Ciencias del Lenguaje. Todas las investigaciones son cualitativas. ***Conclusión***: hay poca inversión en estudios de maestría y doctorado que trabajen los procesos de cuidar del niño oncológico, así como la necesidad de más investigaciones que aborden el tema a partir de la comprensión del niño. ***Descriptores***: Oncología; Investigación; Niño Internado; Disertaciones Académicas.

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INTRODUCTION

Different from adult cancer, which usually develops by the sum of several risk factors that the individual is exposed, children cancer has little known embryonic origin, grows faster and is more invasive. However it responds better to treatment and it is considered of good prognosis.[1] This disease represents 0.5 to 3% of all tumors in most populations and in Brazil. It is estimated about 7,000 new cases per year[2]. Among the most common are leukemias, lymphomas and tumors of the Central nervous system (CNS)[3].

There are several treatment modalities, including chemotherapy, whether or not associated with radiation therapy, surgery, immunotherapy and hormone therapy[1], which in most cases require hospitalization of the child in a hospital unit. Diagnosis of the disease and hospitalization generate various emotional conflicts not only in children but also in their family, to experience this process of illness and treatment. Thus, the health team, particularly nursing, for working closer to the patient, must understand that the process of care should not encompass only procedures and techniques, but also the emotional support, empathy, even when there is no more possibility of cure.

The process of care is the way the care is given, it is all activities developed by the caregiver to the cared one on the basis of scientific knowledge, skill, intuition and creativity. This process takes place fully only when it establishes a trust relationship between the caregiver and the cared, and for this to happen, the caregiver should get such confidence, demonstrating responsibility, respect and sensitivity.[4]

To take care of the child, it should be understood his private world and the stages of childhood, holistically on the family-child day, seeking to satisfy his needs, regardless of his current condition. The nursing staff with interdisciplinary team should develop activities with the child and his family, seeking the maintenance of well-being.[5]

In high-technology environments, as hospitals, the care is necessary and important to minimize the coldness and impersonality of the cyber world. However, the professionals end up adopting impersonal, robotic attitudes, and often come along to administrative pressures that prioritize the productivity and performance.[6]

The literature points out that the professional has been away from the relationship with the patient, focusing on technical procedures to the detriment of more affective care, and when it comes to the child the gap is even greater as there are suffering from involvement with the child and his family and the fear that this bond, one day can be interrupted by the death of the patient.[7] It is not correct saying that the technique is not important for the processes of care, but it should not be unlinked emotional care, empathetic, giving the feeling of physical well-being and psycospiritual.

These interpersonal relationships effect in the hospital environment are indispensable for the success of the care actions. In this perspective, it is necessary to reflect constantly about the psycho-affective implications in the process of care, because who cares shares the care and not simply practicing an action actively. Nurses and patients interact during the care in a given context and that promotes a continuous creation process and reproduction of senses.[5]

Given the above, it is considered the process of care for the oncology child, a complex and important topic that needs to be reflected by the health teams, especially nursing, in addition to being the target of searches that seek the improvement of such assistance. With that, the following research questions were listed: what are the characteristics of theses and dissertations available in the database of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) relating to the processes of care to children with cancer? What is being discussed about the process of caring for the child with cancer? Which are the theoretical references these studies use?

To answer the questions, the research aims to:

- Characterize the dissertations and theses available in the Theses of the CAPES related to the processes of care for children with cancer.

METHOD

The present study corresponds to a documentary research, held at the Bank of Theses of CAPES, of CAPES Journal Portal. In this bank, it can have access to information of dissertations and theses defended throughout the country since 1987.[8]

The documentary research comprises the phases: choice of theme, delimitation of goals, elaboration of the work plan, the identification and location of sources to be searched, obtaining and reading the material identified, noting this material through records, analysis, interpretation of data and end writing of the study. These phases occur in a natural sequence and articulated.[9]

The choice for these types of scientific monographs was the theses for being characterized by originality, high level of research and possibility of progress in the scientific area[10]; and for the dissertations being methodological rigour marked by similar to the first ones.[11]

The research was initiated by building a structured Protocol, which has been validated by one of the authors with PhD, being composed by the following steps: delimitation of the topic; objective; guiding questions; search strategies (database and controlled and not controlled descriptors); selection of studies (inclusion and exclusion criteria); strategy for data collection; strategy for critical evaluation of the studies; data synthesis.

For data collection, there were the not controlled descriptor "processes of care"", and the descriptors "Child" and "Oncology", controlled by the Health Sciences Descriptors (DeCS), in the search field "subject", through the "all words" option. The data were collected in June of 2012. Considering that the Theses of CAPES offers only the titles and abstracts of scientific papers, soon after a search was conducted in virtual libraries of universities for development of studies, to find them in full.

The selection of the research was based on pre-established criteria: 1) inclusion criteria: dissertations and theses available electronically in full about the processes of care for children with cancer produced between 2003 and 2012; 2) exclusion criteria: dissertations and theses that do not address the topic relevant to the scope of the research; animal studies; studies with adults and adolescents.

The systematic evaluation of each selected study has been carried out according to the following indicators of data collection: academic level (masters or PhD); development study place; year of publication; area of knowledge; methodological design; topic addressed; theoretical referencial.

The results and the characterization of selected studies were presented by figures to facilitate the visualization of the final data.

RESULTS

The research resulted in the selection of 15 studies, among theses and dissertations, by the descriptors used. Subsequently, based on the inclusion criteria, the number of studies was reduced to seven, being this the study sample used. The difference between the total quantitative studies and those who have been selected for analysis was mainly by the impossibility of accessing them in full, as well as the theme not being centered in the child.

In relation to the academic level, six (85.7%) searches are related to the academic masters and only one (14.3%) to doctorate. It was also observed that the research with approached topics gained more esteem from 2008.

Figure 1. Distribution of the studies according tu the year of publication. Natal/RN, 2012

The Southeast and Midwest were the most regions producing studies about the processes of care for children with cancer, while the northeastern region has only one. The University of São Paulo and the University of Brasilia had 2 works (28.6%), the Catholic University of Pernambuco, the Federal University of Mato Grosso and the Federal University of Rio de Janeiro have developed only 1 (14.3%) work on the subject.

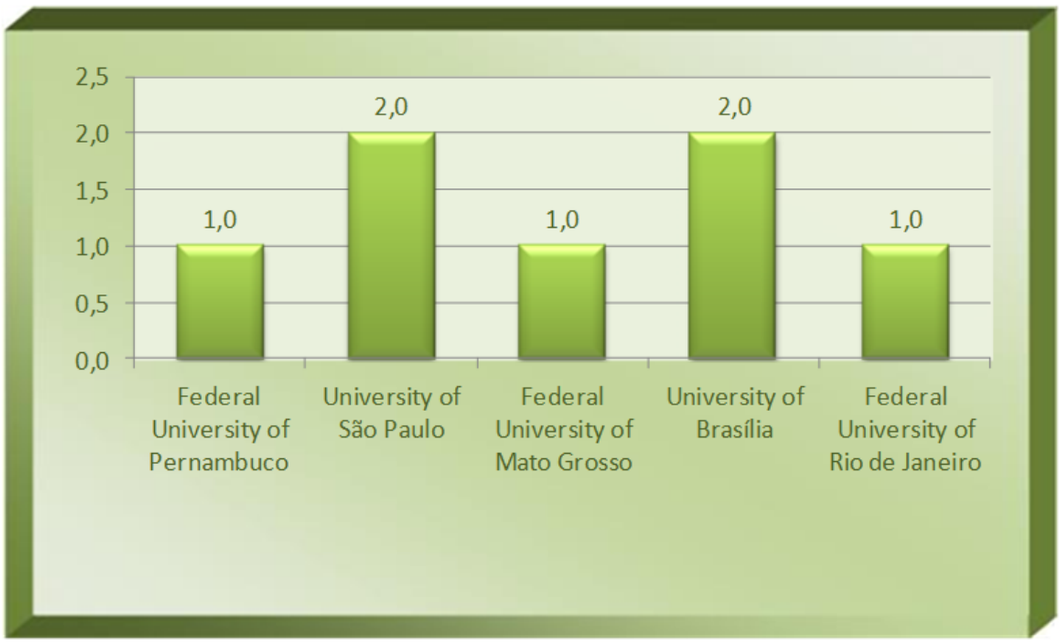

Figure 2. Distribution of the studies according to the place of development. Natal/RN, 2012.

With regard to the area of knowledge of the studies developed, four belong to nursing, two psychology area and one is related to the area of Language Sciences.

All research are qualitative, being three of descriptive character (42.9%) one descriptive with phenomenological approach (14.3%), a case study (14.3%), a descriptive exploratory study (14.3%) and a narrative research (14.3%).

Before the analysis of selected studies topics, it was found that two of them discuss about the experience and the feelings generated in the family who have a child with cancer; two studies refer to the performance of nursing staff in the children with cancer; one research of coping strategies of children with cancer; one study deals with the feeling of family with child in palliative care and the perception of physicians about this practice; and finally a single study brings an analysis of the narratives of children with cancer and their families, as well as doctors who care for these children. It is noteworthy that only two studies showed theoretical reference, one of them being a nursing theory (theory of Dorothea Elizabeth Orem – self-care theory) and another, the theory of Elizabeth Kübler-Ross (The stages of dying).

DISCUSSION

The literature has shown growth in terms of quality and quantity in the research of Brazilian post-graduation, highlighting the success obtained by courses with pride for the Brazilian Academy and public authorities.[12] In this perspective, the topic of cancer has been much exploited by different healthcare professions, especially when it comes to new forms of treatment and care. There is a regularity of published scientific articles on the subject from 2002, coming from above all of theses and dissertations.[13] However, there is a small number of studies that address the processes of care for the oncology child, showing only a slight increase after 2008.

The research on masters level academic prevailed over the doctorate, which is consistent with the reality of the Brazilian post-graduation, in which the master is the kind of academic postgraduate graduating people and fastest growing in the country[14]. The doctorate is still little diffused when compared with the masters, being one of the causes cited in the literature the considerable number of masters who do not continue their studies upon completion of masters[12].

The Academy plays a central role in the generation of new knowledge. The scientific literature has been benefited with substantial resources from research funding agencies, with the goal of keeping the graduate programs and fund research manifested in thesis and dissertation defenses.[15] It is worth highlighting that the level of investment received by the graduate program and their age can influence and influences on their quality.

The location of the research development reflects a national scenario in which stand out the productions in the southeast of the country, as seen in Figure 2, appearing the Midwest with the same number of publications, despite that region present less contributions to scientific research.[1] Therefore, there is a predominance of research that follow the same order of Brazilian Federative regions as regards the distribution of post-graduate programs in the country,[8] being the Northeast region with the

newest production on the addressed topic.

Also, in the place of realization of the studies, it is noting the predominance of studies developed in public institutions, highlighting the importance of the public system in Brazilian post-graduation where 80% of these types of courses are allocated in federal and state universities,[16] a reality that has been built over the years, considering that since the founding of the first graduate programs in Brazil, the courses were limited to the public sector, except for a few exceptions.[12]

As to the area of knowledge to which they belonged, studies nursing stands out with four projects developed, followed by the psychology and finally the area of language sciences. This it can be confirmed by studies that indicate a growing importance for the area of Oncology Nursing in recent years[17], followed by the field of psychology, mainly due to the "current" perception of humanization of assistance, the professional-patient relationship, as well as their physical and psychological implications in the process of care.

It is shown concern for issues related to perceptions, behaviors, feelings, relationships, support requirements, among others, gaining greater visibility from the Decade of 1990, with the emergence of a socio-cultural nature productions. And it is especially in this kind of research which has been the highlight of the sub-area of nursing.[13]

The research has as one of its functions to contribute to the knowledge and enhance the professional practice so that this is more qualified and based on scientific knowledge. The dissertations and thesis were analyzed in their entirety, using qualitative research, being three of descriptive character (42.9%) a phenomenological approach with descriptive (14.3%), a case study (14.3%), a descriptive exploratory study (14.3%) and a narrative research (14.3%).

The research confirms the found in the literature regarding the methodology of studies, there is a marked tendency for the development of qualitative research, and descriptive approaches, which enable the understanding of experiences, emotions, feelings and behaviors that pervade the health care process in Oncology.[17]

On the thematic analysis, it was shown the prevalence of work to rescue the importance of family in the process of taking care of the oncology child, as well as the care that professionals should direct these people, through understanding of their troubles and doubts of the illness of the child. It is worth mentioning that the nursing fit two works that deal with this topic, and one refers to psychology.

The family/caregiver stress is related to the amount of tasks that involve the care, requiring energy expenditure to deal with feelings inherent in this process. It implies the disruption of their daily activities, such as: work, study, sleep, leisure, humor, sex and social life, financial, misfit among others[13]. Due to all this, it is noted a considerable investment in research that aims to understand and assist the families during the process of illness and treatment of the child.

Also on the subject of studies, two of them spoke about the role of nursing staff. In this sense, the literature points out that the intentionality of the researchers is pointed mainly to investigations with clients, professionals from nursing staff and family. Therefore, there is a concern of this professional class with aspects related to assistance and the organization of the process of care, reflecting the demands that contribute to the complexity of the processes of interaction with clients, nurses and families.[17]

During cancer treatment, the child sometimes needs to be hospitalized in a hospital unit. This process has a negative meaning when the hospital is described as a place of limitations, as determined by the presence of hospital technology, restriction of spaces to play, and distance from family and friends. The fear of hospitalization is triggered by invasive procedures and the possibility of pain.[13] Given this, it is important to understand the process of illness and hospitalization in children's vision, since this will be the direct recipient of care health team, however, only two studies have addressed this issue.

From the dissertations and thesis mentioned, two were beyond family and child experience with cancer, the experience and perception of professional who assists both. It is known that the Oncology sector workers suffer an immense workload and emotions coming from the daily battles of family and children who fight against cancer. And training institutions are not always prepared to "teach" the essence of care in Oncology. With this, there are already studies that point to the shortage of professionals, such as those in nursing, in the fields of Oncology, since even possessing expertise in that area, they choose to migrate to another that is not so stressful and that does not involve so much suffering.[18] So, the burnout syndrome,

professional/emotional wear, is one of the most important causes for the shortage of these professionals.

Health workers must be prepared to be aware of what is happening and what may occur with patients and, therefore, requires not only professional competence, but sensitivity, insight and intuition. To show available to patient and family is a precious factor. The enlightened family, well cared for and supported may collaborate very care.[5]

Therefore, knowing as professional experience the care for children with cancer and their perception about, it is fundamental for creating counter strategies, so that it can offer a cozy, humanized assistance, without, however, bring all the suffering for himself to the point where physical and emotionally wearing and so decrease the quality of care.

As for the theoretical reference, among the studies analyzed, only two explained the theories published their research. The theories used were a nursing theory, theory of Dorothea Elizabeth Orem – Self-care Theory, and the other was the theory of Elizabeth Kübler-Ross-The stages of dying.

Nursing theories are assisting the profession to focus on their problems and concepts, therefore, represents the knowledge of those nurses.[19] However, they are little known and rarely used as foundation of practice. Thus, in the Brazilian reality, the adoption of theories as the foundation for the production of scientific knowledge is scarce and limited almost exclusively to the Academy and a few University hospitals,[20] which confirms the result of this research, which pointed only a study of nursing, one of four, who addressed a nursing theory.

CONCLUSION

There is little investment in the master and and doctorate level, who are working the porcesses for oncologic care for the child, despite the discreet increase in number of searches on the subject in recent years. The topics found on three actors were present in the process of care: the family, the child and the professional, being the largest focus of family attention, for this to be the point of support of the child.

It was noted, therefore, that the feelings and anxieties of the child and his vision on caregiving is still little explored. It is important to highlight that, to understand what is the point of view of the receptor is essential for multidisciplinary qualified and humanized assistance, therefore, the need to develop further studies involving the topic in the child concept.

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