

Clinical Nurse Specialist: a model of advanced nursing practice in pediatric oncology in Brazil

ENFERMEIRO CLÍNICO ESPECIALISTA: UM MODELO DE PRÁTICA AVANÇADA DE ENFERMAGEM EM ONCOLOGIA PEDIÁTRICA NO BRASIL

ENFERMERO CLÍNICO ESPECIALISTA: UN MODELO DE PRÁCTICA AVANZADA DE ENFERMERÍA EN ONCOLOGÍA PEDIÁTRICA EN EL BRASIL

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ABSTRACT

The objective of this paper is to report the experience of implementing a model of advanced nursing practice that integrates a clinical nurse specialist into the nursing staff. The authors describe the concept of this model and the process of its implementation in a pediatric oncology reference institution in the city of São Paulo, Brazil. The main result achieved in evaluating the clinical nurse specialist was strengthening of the role of the nurse as a reference professional for the articulation of the various demands of care in assisting the child, adolescent or young adult with cancer and his/her family. The satisfaction of these users due to the closer relationship between the patient, family and clinical nurse in all stages of the caring process also stands out.

DESCRIPTORS

Child
Adolescent
Neoplasms
Oncologic nursing
Practice management
Professional-patient relations

RESUMO

O objetivo deste artigo é relatar a experiência de implantação do modelo de prática avançada de enfermagem por meio da incorporação do enfermeiro clínico especialista na composição do quadro de enfermagem. As autoras apresentam o conceito desse modelo e descrevem seu processo de implantação em uma instituição de referência no cuidado à criança e ao adolescente com câncer da cidade de São Paulo, Brasil. Na avaliação das enfermeiras clínicas especialistas, o principal resultado obtido com a adoção do modelo refere-se ao fortalecimento do papel do enfermeiro como profissional de referência para a articulação das diferentes demandas de cuidado à criança, ao adolescente e ao adulto jovem com câncer e sua família. Também destacam a satisfação dos usuários com o estreitamento da relação paciente, família e enfermeira clínica, em todas as etapas do processo de cuidar.

DESCRIPTORIOS

Criança
Adolescente
Neoplasias
Enfermagem oncológica
Gerenciamento da prática profissional
Relações profissional-paciente

RESUMEN

El objetivo de este artículo es relatar la experiencia de implantación de un modelo de práctica avanzada en enfermería, por medio de la incorporación del enfermero clínico especialista en la composición del cuadro de personal de enfermería. Las autoras presentan el concepto de este modelo y describen el proceso de implantación en una institución de referencia para el cuidado de niños y adolescentes con cáncer de la ciudad de São Paulo, Brasil. Las enfermeras clínicas especialistas evalúan que el principal resultado de la adopción de este modelo fue el fortalecimiento del rol del enfermero como profesional de referencia para la articulación de las diferentes demandas de cuidado para la atención a los niños, adolescentes y adultos jóvenes con cáncer y su familia. También se destaca la satisfacción de los usuarios por el estrechamiento de la relación paciente, familia y enfermero clínico, en todas las etapas del proceso de cuidar.

DESCRIPTORIOS

Niño
Adolescente
Neoplasias
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Relaciones profesional-paciente

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INTRODUCTION

In Brazil, childhood and adolescent cancer is the second most common cause of death among children and adolescents aged between 1 and 19 years, surpassed only by external causes. This mortality profile is similar to the mortality profile of developed countries^(1,2). With respect to nursing, the above situation, in combination with the complexity of the disease and its treatment, and with the repercussions for the patient and his/her family, determines the need for specific qualifications for professionals acting in the area of pediatric oncology to provide safe and efficient care.

A study of the development of nursing in pediatric oncology shows that there is little documentation on the beginnings of this specialty, and its emergence is estimated to date to the late 1940s, when nursing care consisted basically of keeping the child clean, fed, comfortable and free of pain. The opportunities for education and development were limited, and nurses acquired skills and competency through self-teaching and bedside training⁽³⁾. This reality also applied to Brazil.

Beginning in the 1960s, with the development of more efficient treatment strategies, in addition to advances in chemotherapy, infection control and pediatric intensive care, there was a substantial improvement in the survival of these patients. This context fostered the development of an advanced pediatric nursing practice, which, in turn, had a significant influence on nursing in pediatric oncology⁽³⁾.

In the 1990s, a movement in nursing schools, aiming for the inclusion of oncology content in undergraduate courses, triggered the same reflection in the area of pediatric oncology⁽⁴⁾. Thus, even with no formal courses, nurses interested in meeting the demands for the care of this population sought the backup of technical and scientific knowledge in specialized courses of pediatric nursing and/or oncologic nursing.

Currently, despite the supply of conventional specialization courses and the discipline of nursing residence in oncology, nurses continue to express the need for greater depth in topics related to the care of children and adolescents with cancer and their families. The combination of these facts has an impact on the profile of the nurses requested by the services, as well as on the structure of permanent educational programs that assist in the development of an advanced practice related to assistance, coaching, research and management in pediatric oncology⁽⁵⁾.

The Nursing Service of the Institute of Pediatric Oncology (*Instituto de Oncologia Pediátrica* – IOP) from the Support Group for Adolescents and Children with Cancer (*Grupo de Apoio ao Adolescente e à Criança com Câncer* – GRAACC) of the Federal University of São Paulo

(*Universidade Federal de São Paulo* – UNIFESP) has implemented a new methodology of work organization, incorporating activities that included specific advanced practice competencies. In the search for a model that met the institutional reality, we have adapted the North American model of the Clinical Nurse Specialist (CNS), a designation given to a nurse who possesses

broad knowledge (art and science of nursing), strong critical thinking/problem solving/decision making skills, and a high degree of compassion and sensitivity for children, adolescents, young adults, their families and their community⁽⁶⁾.

For the organization and execution of this model, the competencies proposed by the Association of Pediatric Hematology/Oncology Nurses (APHON) were adopted, so that the CNS provides qualified assistance to the patient and his/her family. The competencies include

direct care; nursing consultation; system leadership; collaboration and cooperation with nursing staff and users; coaching; research; active participation in ethical and moral decision-making⁽⁷⁾.

The opportunities for education and development were limited, and nurses acquired skills and competency through self-teaching and bedside training.

This paper describes the process of the adaptation and implementation of the model of assistance of the CNS and the actions developed by the nurses who perform this function at the IOP/GRAACC-UNIFESP. The objective of this paper is to report the experience of adapting and implementing the model of advanced nursing practice by incorporating the CNS in a reference institution for the care of children and adolescents with cancer in the city of São Paulo.

METHOD

To report the experience of the implementation of this model of advanced nursing practice, we have decided to describe the context in which it is being developed, the aspects of its planning and the experience of the action.

Scenario of the experience

The perspective of offering children and adolescents with cancer the same treatment that is offered in developed countries motivated a group of doctors, nurses, businessmen, volunteers and representatives of the community to institute the GRAACC in the early 1990s, whose mission is to *guarantee this population the right to achieve all chances of cure, with quality of life, by means of a treatment within the most advanced scientific standard*⁽⁸⁾. This mission, based on the values of competency, ethics, transparency, solidarity, teamwork and equality in the relationships of all the professionals involved, has led to its consolidation as a reference center in the treatment of children and adolescents with cancer in the IOP hospital, established in 1998⁽⁸⁾.

The increasing demands of this population and the commitment to the idealized mission stimulated these professionals to seek a multiprofessional attendance model that would correspond to these needs and meet its particularities. The proposition of care focused on the child and its family; the concept of dehospitalization, prioritizing outpatient/day hospital attendance; the availability of adequate technical, scientific and human resources; and the training and qualification of professionals have constituted the basis for the adoption of this model⁽⁸⁾.

In this same line of construction, nursing has consolidated itself and has established the mission to

offer nursing assistance to the patient and his/her family, with specific technical and scientific knowledge, based on ethical values and humanization, with the objective to guarantee care and quality of life, ensuring dignity in all phases of the life cycle⁽⁹⁾.

Thus, it has organized its care procedures into pre-established protocols, with comprehensive care as a priority, but still focused on the time-sensitive needs that demand immediate resolution.

The constant demands generated by the complexity of the disease, its treatment and the repercussions for the individuals and their families have motivated nurses to rethink the current type of assistance and the expected competencies at the different levels of assistance offered in the institution. Thus, the nurses responsible for planning, execution and evaluation of the care given to a determined group of patients, according to the type of neoplasia or therapeutic modality, were chosen for inclusion in an expanded, articulate and progressive view in the line of care, characterized as advanced nursing practice. A new method of nursing work organization was chosen for adoption, which included the CNS in the composition of this team.

From the idea to the accomplishment of the project

The genesis of the project occurred in the 1990s, based on the personal experience of professionals of the institution regarding the profile of CNSs from abroad and their partnerships with Eleanor Hendershot, RN, BScN, MN, CNS-NP, from the Hospital for Sick Children (Toronto – Canada) and Saint Jude Children's Research Hospital (Memphis – USA), which have been maintained to the present. The project was designed in 2009 together with the department of Nursing Teaching and Development (Ensino e Desenvolvimento em Enfermagem – EDENf) to determine the competencies, profile and selection process and with the administrative/financial department for matters related to costs. The project was then implemented in March, 2010.

The profile for the function of the CNS has ten requirements determined by the nurses of the institution: i) a higher level academic education in nursing; ii) a registration in the Regional Nursing Council of São Paulo State (Conselho Regional de Enfermagem do Estado de São Paulo – COREN/

SP); iii) a *lato sensu* specialist title in pediatric oncology, oncologic nursing or pediatric nursing; iv) past or planned attendance at a *stricto sensu* graduate nursing program; v) membership in the Brazilian Society of Pediatric Oncology (Sociedade Brasileira de Oncologia Pediátrica – SOBOPE); vi) a minimum of two years of experience in the outpatient area, in addition to working in the inpatient units of the IOP; vii) successful completion of the qualification courses in antineoplastic chemotherapy and central venous access in the institution; viii) availability to work 40 hours a week; ix) fluency in English; x) and approval in the internal selection process for this function.

The competencies of the CNS for nursing practice at the IOP/GRAACC have been elaborated based on four essential pillars: qualified assistance, education/coaching (patient, family, professionals), research and management.

In *Assistance*, the competency of direct care, in conceptual terms, proposed by the APHON⁽⁷⁾ was adopted: the CNS interacts directly with the patients and family, aiming to promote their health and/or well-being, as well as to improve their quality of life, characterized by a holistic perspective on the health-disease process. From this perspective, the CNS is expected to be the professional of reference both for this population and for the multiprofessional team, assuming responsibility for his/her professional development and continued education. Among the activities intended for this sphere, the following stand out: nursing consultations; clinical visits; assistance in performing diagnostic procedures and/or follow-up of the established therapy; monitoring the established therapeutic protocols and communication of identified changes to the medical team; participation in clinical case discussions and scientific meetings; telephone triage and follow-up with patients and family members in the diverse stages of treatment. In specific areas, such as bone marrow transplantation, the CNS participates in the execution of technical procedures related to the aspiration and infusion of bone marrow, umbilical cord blood and peripheral blood hematopoietic precursor cells, as well as in the evaluation of complications in transplant patients.

In *Education/Coaching*, the CNS is responsible for the process of the individualized education of the patient/family through assessing the learning needs; the use of specific pedagogical strategies; and the evaluation and reevaluation of the understanding of the supplied information. With respect to the nursing team, the CNS is responsible for teaching the protocols of treatment and specific nursing care. The interface with the members of the multiprofessional team is created through the exchange of information regarding the patient and his/her family. The CNS interacts with healthcare undergraduate and graduate students through lectures, internships and scientific events, putting childhood and adolescent cancer in Brazilian public health into context. Among the activities in this area, the following stand out: the development and/or adaptation of educational materials suited for the age and cognitive capacity of the patients and

family members/caregivers, such as brochures, manuals and instructional toys; the development and implementation of nursing care protocols for the prevention of risks and aggravations during all phases of treatment; participation in multiprofessional clinical meetings; promoting interdisciplinarity by means of case discussion; and participation in the execution of nurse training and development programs for the different levels of professional education.

In the area of *Research*, the topics of investigation emerge from matters arising from nursing practice in pediatric oncology. The CNS stimulates the search for the scientific background of his/her practice through participation in clinical research protocols; development and/or participation in research projects linked to research groups of the Paulista School of Nursing (Escola Paulista de Enfermagem – EPE/UNIFESP); participation in national and international scientific and events related to his/her area of expertise; as well as in the production of scientific articles, disclosing results from studies developed in the institution; and guidance on the final term papers and dissertations of the undergraduate and graduate *lato sensu* nursing courses, respectively.

In *Management*, the activities of the CNS include the following: management of the demands for resources, costs, environment and social support required for assistance to the patient/family; records of information pertinent to nursing activities; and highlighting the indicators of performance and quality of the assistance.

After defining this profile and the competencies for this function, the first areas to be considered with the CNSs were determined based on the needs for attendance in the current institutional scenario. Subsequently, an announcement for the internal selection of nurses eligible for this position was made. To participate in the selection process, the candidate would have to present documentation verifying the required profile and present a work project containing a proposal for action in the specified area, encompassing the four conceptual pillars designated for the CNS, for posterior evaluation by the created judging commission.

Experiencing and evaluating the action

The area of EDEnf received the first CNS, followed by pain and palliative care; central nervous system tumors; bone tumors and retinoblastoma. These CNSs have quickly become a reference in the institution for the follow-up of treatment of the above-mentioned populations. This position has demonstrated the need for the CNS to acquire new technical and scientific knowledge to better perform this function by incorporating specific knowledge. As a result of this position and the growing demand in the different aspects involved in the line of care, the CNS has widened and incorporated new responsibilities, managing the care of this population together with the healthcare team.

Assuming responsibility for decision-making on the care to be given to the client and his/her family has encouraged obtaining more effective answers and results in treatment.

Strengthening the bond between the CNS, the patient and the family and sharing decisions on care with the other nursing and healthcare team members has rendered their activity more visible and pro-active, optimizing the planning and execution of caregiving actions.

The appreciation of the CNS by patients and families is demonstrated by the closer client/family/nurse relationship in all stages of the caregiving process, exemplified by the constant requests in moments of guidance and shared decision making, resulting in strengthening of the bond between the patient/family and the CNSs. This appreciation has enabled the expansion of this model of nursing work organization to the areas of bone marrow transplantation; radiation therapy and diagnostic imaging; and leukemia and lymphoma during the period from 2011 to 2012, resulting in the current existence of eight CNSs.

Several factors have favored the implementation and development of this project, such as the philosophy of the institution and the nurses; the commitment of the group of CNSs; and the unrestricted support of the managers, clinical staff and nursing team. These factors have enabled the advances in safe and qualitative care given to a clientele whose disease condition requires a highly qualified team to address the diversity and complexity of demands arising from the disease, the treatment and the rehabilitation and social reintegration process. Also as a result of this implementation, a further advance has been the participation and publication of works at scientific events, emerging from the needs of the daily professional practice, of individual authorship by the CNS or together with the multidisciplinary team.

In view of the innovative character of the proposal and the characteristic challenges of each project being implemented, there was a need for adjustments in diverse spheres of competencies of the CNSs, to meet, primarily, the demands from the areas of assistance and coaching. As a consequence of this decision, the activities envisioned for the spheres of competency related to research and management are still below expectations. The search for a balance in the development of competencies in the four pillars proposed for the action of the CNS is the challenge being currently confronted.

Another demonstrated challenge is the estrangement of some members of the healthcare team from this new proposal of action by the nurse. In the perception of one CNS, for some doctors, nurses, nutritionists, social workers and physiotherapists, *constant coping with the presence of the nurse, participating in the treatment together with the patient, has been seen as an invasion of their professional space*. This situation has been overcome gradually by means of multiprofessional meetings discussing the specifics of action of each professional with regard to the demands of care for the population seen at the IOP and, especially, the aim to integrate the CNS into the nursing team work organization. This strategy, linked to the positive evaluation of the received treatment, verbalized by patients and family members, has contributed to the resolution of this matter.

The perception of the need to use indicators to evaluate the impact of this model of nursing work organization in the quality of assistance to the patient/family has been the objective of the reflection and discussion of this group, as the next stage to be implemented.

FINAL REMARKS

The aim was to reflect on and raise debates about the trajectory and contribution of this institutional project to improving the quality of the nursing assistance in the context of pediatric oncology. For this purpose, a description was sought of the role of CNSs in the context of assistance, science, education and management.

The need for treatment that is individualized, qualified, humanized and based on the needs of each patient and his/her family has led us to the design of this new model of nursing work organization.

The possibilities that have emerged during its construction and the relationships established between the CNS/

patient/family and the CNS/healthcare teams have encouraged its growth and receptiveness. Over the years, it has been undeniable that, as the group of CNSs organizes itself around the common goals, it has resulted in strengthening, cohesion and solidity in the search for solutions concerning assistance to the child, adolescent or young adult with cancer and his/her family.

The experience reported here indicates that the CNS can be a working model for the nurse who wishes to positively influence the responses of his/her patients and family members through the care given in diverse situations, as well as to improve the processes that compose the system of treatment of this clientele.

We believe that the nursing team of the IOP/GRAACC-UNIFESP has successfully implemented this model of work organization, resulting in qualified nurses, trained and committed to care, and a pattern of respectable organizational competency comparable to similar international institutions that have served us as references for assistance, education and research in pediatric oncology.

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