International collaboration for pediatric oncology nursing leadership: Nicaragua and Canada

by A. Orozco, V. Marin, S. Reyes, J. Challinor and B. Carpio

Abstract

In 2005, with financial support from the Pediatric Oncology Group of Ontario, a pilot nursing leadership project linked pediatric oncology nurses from Canada with nurses at the La Mascota Hospital in Managua, Nicaragua. Following consultation with the pediatric oncology team in Nicaragua, a program was developed to strengthen clinical nursing leadership in a clinical setting through continuing education. The nurses believed that care of the patient and family improved due to the increased leadership skills of nurses in the unit and as the profile and credibility of nurses as peers in the health care team became evident. Providing nurses with the autonomy and financing for a project related directly to nursing care represented an important development for leadership in the profession.

Introduction

In 2002, the Pediatric Oncology Group of Ontario (POGO), a collaborative multidisciplinary group representing the five specialty pediatric oncology programs in Ontario, agreed to fund a nursing leadership project for nurses in the seven member countries of the cooperative group in Central America and the Dominican Republic, *Asociación de Hemato-Oncología Pediátrica de Centro America* (AHOPCA). An initial meeting was held in December 2002 in Toronto to discuss the possibilities for the leadership project including ideas such as nursing research, administration initiatives, or educational interventions. Project planning took two years and included choosing a location for the first phase of the project, the recruitment of a Canadian nursing collaboration team, and the establishment of an infrastructure to manage the funding.

The POGO Nursing Leadership Project was designed as an initiative in nursing leadership. It was created in conjunction with a larger collaborative project between POGO, St. Jude Children's Research Hospital, Memphis, Tennessee, and the Monza International School for Pediatric Hematology Oncology (MISPHO) in Monza, Italy. The larger project, named the Central American Pediatric Research Initiative (CAPRI), strives to increase the survival of children with cancer in the AHOPCA member countries. Strengthening nursing leadership was identified as an important strategy of the CAPRI effort.

The nursing leadership project

Setting

The Canadian nursing team, in collaboration with the project coordinator from California (a Spanish-speaking pediatric oncology nurse and member of the CAPRI project), chose Nicaragua as the location to pilot phase one of the POGO Nursing Leadership Project. Factors contributing to this choice included changes in head nurse positions, nursing immigration, political unrest within local units regarding nursing, difficulty with nursing administrations and other obstacles in the larger AHOPCA nursing community.

Nicaragua is a Central America country with a population of 5.5 million inhabitants, 23.4% of whom are illiterate and 56% of whom earn less than U.S. \$9.20 a month (Pan American Health Organization [PAHO], 2009). Children under 18 years of age constitute 49% of the national population, and while reliable statistics are difficult to determine, the pediatric cancer rate is estimated to be 3/1,000 (Dr. R. Ortiz, personal communication, July 30, 2007).

The national referral centre, *Hospital Infantil de Nicaragua Manuel de Jesús Rivera, La Mascota*, is located in the capital city, Managua. Although the treatment regimens conform to international standards, and treatments are increasingly successful (Báez et al.,

A. Orozco, Co-Head Nurse, Pediatric Hemato-Oncology Unit, Hospital Infantil de Nicaragua Manuel de Jesús Rivera La Mascota, Barrio Ariel Darce, Managua, Nicaragua +505.2289.4984 phone and fax.

V. Marin, Social Worker, Pediatric Hemato-Oncology Unit, Hospital Infantil de Nicaragua Manuel de Jesús Rivera La Mascota, Barrio Ariel Darce, Managua, Nicaragua +505.2289.4984 phone and fax.

S. Reyes, Co-Head Nurse, Pediatric Hemato-Oncology Unit, Hospital Infantil de Nicaragua Manuel de Jesús Rivera La Mascota, Barrio Ariel Darce, Managua, Nicaragua +505.2289.4984 phone and fax.

J. Challinor, Assistant Adjunct Professor of Nursing, University of California, San Francisco, USA 's Gravelandseveer 8 1011 KN Amsterdam, Netherlands +31.61003.9792 phone, +1.208.979.9436 fax. Corresponding author: jmchallinor@gmail.com

B. Carpio, Associate Professor, McMaster University School of Nursing, 1200 Main St. W., Hamilton, ON L8N 3Z5 905.525.9140 phone, 905.570.0667 fax.

Collaboration internationale pour le leadership infirmier en oncologie pédiatrique : Nicaragua et Canada

Abrégé

En 2005, des infirmières en oncologie pédiatrique du Canada et de l'hôpital La Mascota, de Managua, au Nicaragua, ont collaboré dans le cadre d'un projet pilote de leadership infirmier. Le projet, qui bénéficiait du soutien financier du Pediatric Oncology Group of Ontario (POGO), avait été mis sur pied à la suite d'une consultation auprès de l'équipe d'oncologie pédiatrique de La Mascota et visait à renforcer le leadership infirmier en milieu clinique par le biais de l'éducation continue. Les infirmières étaient d'avis que les soins aux patients et à leur famille s'étaient améliorés en raison de leurs nouvelles compétences de leadership, de leur crédibilité accrue et de leur participation à l'équipe de santé sur un pied d'égalité. Le fait de fournir au personnel infirmier l'autonomie et le financement pour mener un projet lié directement aux soins infirmiers constituait un important développement pour le leadership dans la profession.

2006; Howard et al., 2002; Howard et al., 2006), many socio-political factors negatively impact survivorship. A large proportion of patients treated at *La Mascota* are from areas far from Managua, and have both economic and transportation limitations. Consequently, many of the children are admitted to the centre with advanced diseases, malnutrition, parasitic and other types of infections. In addition, once children achieve remission some parents are reluctant to engage in the maintenance protocols that are necessary for completion of therapy to ensure survival. According to V. Marin, pediatric oncology social worker and nursing leadership coordinator, families label these treatments as “illness-producing.”

Family members have told us they want to abandon the treatment because they see that the effects of the drugs are complicated and children look more ill. [They] observe the effects of chemotherapy [and abandon treatment] despite the explanations of the staff. In Nicaragua there is a saying that might help to understand this, “The cure is worse than the disease” (personal communication, March 18, 2009).

These factors constitute major challenges for the limited nursing personnel.

The department of hematology-oncology is composed of three pavilions with capacity for a total of 30 hospitalized patients, and an outpatient department that provides 5,000 consults annually, with 200 new oncology cases seen each year including leukemias and solid tumors (Conanca, 2009, p. 3). The nursing staff of 12 professional nurses (nurses with five years of nursing education) and five nursing *auxiliares* (assistant nurses who receive one year of training) are responsible for the care of up to 10 hospitalized patients each, as well as rotating through the outpatient clinics, and work 24-hour shifts followed by three days off.

In a recent study conducted by the Ministry of Health in Nicaragua, half of the nurses surveyed reported stressful working conditions and earnings of less than \$300 U.S. per month in salary (Nigenda & Machado, 2000). The authors also reported that between 1991 and 1997 the number of doctors in Nicaragua doubled, whereas the number of nurses increased by only 60%. A significant nursing shortage is a chronic problem for the pediatric hematology-oncology unit, as it is for the entire country.

Team

A large Canadian nursing collaboration team was recruited due to the scope of the project and language barriers. Canadian nursing faculty from McMaster University and the Hospital for Sick Children experienced in administration, pediatric oncology, and the Central American culture, provided support for the local Nicaraguan team. The Nicaraguan nurses developed, implemented and evaluated the project and eventually presented the results of the nursing leadership project at several international conferences. Two co-head nurses from the pediatric hematology-oncology department of *La Mascota* Hospital in Managua, Nicaragua were designated as the nursing leadership coordinators.

Nursing leadership program development

The nursing needs assessment

In February 2005, a situational diagnosis (needs assessment) was performed with eight professional nurses and three *auxiliar* nurses from the pediatric hematology-oncology unit, physicians, a psychologist and social worker.

The purpose of a situational diagnosis is to discover, or to emphasize, the strengths of the organization as it is well known that it is impossible to develop relying on weaknesses and, of course, also acknowledged is the need to identify problems and their causes, analyzing the meaning, importance and feasibility of solving them [translated by J. Challinor] (García-Romero, Cordera-Pastor & Vargas-Martínez, 1993, p. 558).

The nurses who participated in the situational diagnosis were able to identify nursing strengths and weaknesses in the clinical care setting and suggested areas for intervention.

Following the situational diagnosis, the Nicaraguan nurses asserted that they conceived of leadership not as something that is “born” in a nurse, but rather as something that is deliberately sought and practised through informed nursing communication with patients and families. Nursing leadership in both developed and developing countries is challenged by the dominance of a biomedical approach to patient care. Kleinman, Eisenberg, and Good (2006) point out that “biologic concerns are more basic, ‘real’, clinically significant, and interesting than psychological and sociocultural issues. Disease, not illness, is the chief concern; curing not healing is the chief objective” of modern health professionals in both developing and developed countries (p. 146). The true “multidisciplinary team” concept of nurses as equal but unique professionals working together with physicians is often touted, but rarely a reality in most countries (Lockhart-Wood, 2000; Yeager, 2005). “We need nurses leading nurses, nurses leading nursing practice and nurses leading client-centred, interdisciplinary teams” (Ferguson-Paré, Mitchell, Perkin & Stevenson, 2002, p. 4).

Nursing leadership, in the context of this project, is not defined as “administrative hierarchical leadership”, but rather it is defined as individual clinically/patient care-focused leadership skills and traits to be enhanced and capitalized on to positively impact patient and family nursing care. It was the strong opinion of the nurses in the pediatric hematology-oncology department of *La Mascota* Hospital that nursing leadership is a quality that all nurses on the unit should display regardless of their educational background or professional rank.

Leadership does not rest merely with administrators and high-level managers, but also can be developed and implemented at the bedside. Nursing has a responsibility to encourage and support new members of the profession, as they become competent clinicians. Nursing must also make them competent leaders (Valentine, 2002).

The Nicaraguan nurses consider that there is an existing leadership that has permitted the development and management of their current nursing care and that this leadership is built on the concerns and expectations of all members of the nursing team. Seven nurses had received training in pediatric oncology nursing since 1986 with a formal “twinning” program between the pediatric hematology-oncology department at *La Mascota* Hospital and the pediatric hematology-oncology department of the *Ospedale San Gerardo* in Monza, Italy, led by Dr. Giuseppe Masera and the *Ospedale San Giovanni* in Bellinzona, Switzerland (Masera et al., 1998). Therefore, the nurses believed that they did not start from zero with the POGO leadership program, but rather that this effort was a quality improvement initiative to strengthen nursing leadership. As envisioned by the Nicaraguan nurses, advancement of nursing leadership would be achieved by reinforcement of nurses’ knowledge about childhood cancer and improving the communication between nurses and children and parents, as well as other health care professionals to improve the clinical care of patients.

The staff nurses also believed that they lacked comprehensive knowledge about the biology of cancer and cancer treatment and were averse to question physicians about a child’s disease and treatment-related specifics. Therefore, the nurses believed that parents relied on the physicians for clinical information, yet they sought reassurance from the nurses who were not privy to physician conversations with parents and patients. This left the nurses in an untenable position. They could neither confirm nor deny what the parents’ or patients’ understanding was of the clinical situation, and by refusing to communicate on the subject, the nurses believed that the families thought they (the nurses) were badly informed. The staff nurses identified parameters of what was appropriate information to share with the family in distress and skills for communicating with distressed families as areas of leadership that required improvement.

Planning phase

Following the February 2005 situational diagnosis, the nursing leadership team, two co-head nurses, designed a leadership intervention to address nursing concerns about communicating with families in distress, e.g., newly diagnosed child or a child transitioning to palliative care. The staff nurses selected the pediatric oncology social worker on the unit as someone they had observed successfully communicating with distressed families and requested that she be recruited to participate in the intervention. In addition, it was expected that the social worker's collaboration would enhance interdisciplinary practice and communication among nurses, physicians and allied health professionals. The pediatric oncology social worker was invited to become the third member of the nursing leadership coordinators team joining the two co-head nurses. Both professional and *auxiliar* nurses working in the pediatric hematology-oncology service at the time agreed to participate in the project.

One of the coordinators had used Rose Marie Rizzo Parse's (1992) Theory of Human Becoming for her recent master's thesis and the other coordinators agreed it was an appropriate approach for conceptualizing nursing practice in this unit. The nurses chose to use the initial steps in this complex nursing theory, basic listening skills, as a way to begin to address the specific needs and context of patient care in their nursing practice. This model of nursing care extends well past the biomedical model. Nurses in Nicaragua understand the contextual nature and complexity of life that surrounds children and families diagnosed with cancer. For this reason, they chose to enhance their current practice by adopting Parse's theory (to be discussed further). Their goal was not only to improve patient care, but also to lead nursing into a role as an egalitarian partner in the delivery of effective patient care.

The nursing leadership coordinators believed that demonstrating nursing care founded in the practice of human becoming would put the concerns of the person and the family to the front of patient care decisions and develop nursing leadership in the organization. The Nicaraguan nurses' vision of being leaders met Parse's (1997) definition of leadership, as she noted, "Nurse leaders are those who continue to press for something of value, the fortification of nursing as a unique discipline, complementary to other health-related disciplines" (p. 109).

Pre-intervention questionnaire. Nurses were given a pre-intervention questionnaire to solicit their ideas about communication with families. Table One illustrates examples of issues identified by the nurses to be addressed in the intervention. In addition, five nurses

were interviewed at length about their "ideal day" at work and their experiences communicating with families. These interviews were transcribed and translated locally and shared with the Canadian nurse collaborators and project coordinator.

Curriculum content. The nursing leadership coordinators created a program of nursing leadership seminars as a quality nursing leadership initiative. Nurses were not charged for the classes. The objectives of the seminars were to develop leadership in the nursing personnel through continuing education and to enable them to offer greater support (humanistic care) to parents during times of stress. The curriculum content is listed in Table Two.

Implementation phase

A communication skills intervention was provided by the unit social worker and based on adult learning principles of active participation including role play and group work. Actual clinical situations provided by the participating nurses were used as examples in the role-play sessions. There were four different scenarios of 20 minutes each for role-play. Eight role-play sessions were conducted in total to ensure that all 24 nurses had participated. Examples of suggestions for change in communication between the nurse and families were (a) ask the patient and family directly about what the doctor told them today, (b) encourage parents to ask the doctor questions, (c) address the parents' question directly, do not add to it, or refuse to respond, or give an evasive answer, but answer what the parents want to know and make your answers direct.

In a new spirit of multidisciplinary collaboration and communication, a unit oncologist used traditional didactic teaching to provide the requested clinical information about childhood cancer (highlighting leukemia, the most common diagnosis), diagnosis and treatment. There were four teaching sessions of approximately one hour each for the didactic teaching and the content covered five themes of childhood cancer. Attendees of the didactic teaching session included 14 professional nurses, four auxiliary nurses, four clinic secretaries, and two messengers who work on the unit.

In order to facilitate support from the POGO Canadian team, web-based teleconferences were held monthly. The teleconferences allowed for progress status discussion, problem solving, and continual presence of the Canadian collaborators. The conferences were held in both English and Spanish, orally and by texting in the teleconference computer screen. Although this dual language format is tedious, it allowed for more effective communication. Almost daily email was critical for discussion of locally created pretests and posttests, local data analysis results and the infrastructure management of the project, e.g., budgets, payments, summary reports. All members of the Canadian team were included in all written communication and participated in the teleconferences as their schedules allowed.

Evaluation phase

All participants received a short questionnaire regarding satisfaction with all components of the nursing leadership intervention changes in practice, and requesting suggestions for the future.

Table One. Examples of questionnaire responses

- "increase scientific knowledge" of childhood cancer
- develop "techniques to provide care that is *calidez* (meaning "warm" in the Spanish language) and of [high] quality"
- to "have more expert advice" for patients and families
- to "acquire better knowledge for the satisfaction of the [patients and families]"
- the nurses stated that in some circumstances, their responses "bring bad interpersonal relationships with families and a lack of kindness"
- a need for collaboration and teamwork between physicians and nurses to improve the nurse/client relationship
- "...personnel [needed to] communicate better [among themselves] because the work requires continuity"
- "a nurse should not only give the medications, but should know how the patients and their family members are doing"

Table Two. Curriculum content for communication skills intervention

Role play	four 20-minute scenarios based on the nurses' clinical examples
Participant observation	<ul style="list-style-type: none"> • of nursing interventions with parents • of social worker interventions with nurses
Didactic teaching	biomedical teaching of childhood cancer focus on acute lymphoblastic leukemia
Work groups	discussion

Audiotaped interviews with the unit personnel before and immediately following the communication intervention were analyzed by the nursing leadership coordinators and notes were made to capture the active participation and commentaries made by participants during the sessions and outside the sessions. The nursing leadership coordinators used these transcripts and notes to determine the effectiveness of the communication intervention and participant satisfaction. Comments by the staff nurses that reflected concepts of Parse's Theory of Human Becoming, such as "being present" for the family, or listening to the "personal meaning of the situation" for the family, were given particular attention. During the evaluation phase of the project, a Canadian Parse nursing scholar was identified to facilitate interpretation of the outcomes from the perspective of Parse's Theory. It was the intention of the nursing leadership coordinators to continue to develop and implement the concepts of the theory for the nursing care in the unit after this leadership project was ended.

Seven nurses and one *auxiliar* nurse participated in an evaluation focus group for 1 hour 20 minutes to discuss their assessment of the intervention. According to V. Marin, the pediatric oncology social worker and nursing leadership coordinator, positive experiences are important to increase motivation and to improve negative experiences in the context that they facilitate personal growth and of that [we] share a common goal. For example, here [we] heard that nursing work is a continuum and written, verbal and gestural communication can mean better care of patients and their families (personal communication, September 12, 2007).

The participating nurses unanimously agreed that the intervention themes, presentation, and methodology were excellent because they were informative, provided knowledge and refreshed knowledge that was already learned.

Following the intervention, the nurses asserted that they had less fear about confronting the physicians with questions about patient care. The nurses believed that this was directly related to improved levels of self-esteem and leadership. One nurse stated that nurses should literally "open themselves" a little during communication with other personnel, families and patients. Regarding nurses' emotions and communication with family members, it was considered positive to know or remember (for some) that people can express different reactions to a diagnosis and it is important not to pigeonhole people, but to establish empathy according to V. Marin, pediatric oncology social worker and nursing leadership coordinator (personal communication, September 24, 2006).

The *auxiliar* nurses were concerned that the teaching activities were not held on time. This caused them to fall behind in their daily nursing care. However, the nurses all noted the need for further training.

Discussion

It is important to recognize that continuing education opportunities are rare in developing countries. In medical specialties such as pediatric hematology-oncology in developing countries, the physicians are the holders and gatekeepers of clinical information. Physicians have traditionally not been supportive of nurses having an active involvement in talking to patients about diagnosis, treatment, and prognosis (Mystakidou, Parpa, Tsilika, Katsouda & Vlahos, 2004; The, Hak, Koëter & van der Wal, 2000). The nurses believed that without accurate clinical information, they were excluded from meaningful communication with the families about disease issues that were of primary concern to many families when their child was newly diagnosed or transitioning to palliative care. The didactic teaching component of the project was a significant start to provide the nurses with the clinical knowledge they needed to expand their ability to effectively communicate with families.

Parse's Theory of Human Becoming as a theoretical context

Embedded in Parse's Theory of Human Becoming is her explanation of health (1992). For Parse, health is viewed as living one's value priorities and what is of value to a person can only be

known and described by the person. By adopting this view of health, nurses now reprioritize their care based on the values of the person, not the health care team. Parse's practice methodology, known as *true presence*, offers nurses a way to shift from listening as the expert in their patients' health to honouring the wisdom and knowledge of each person or family. Parse explains true presence as "...moving with the ups and downs of the family rhythms while attending in a centred way to the meaning of the situation for each person" (Cody, Hudepohl & Brinkman, 1999, p. 136). It is by listening that the meaning of events or circumstances and value priorities become clearer to both the nurses and the family (Parse, 1999). Value priorities for families are described by Parse as, "*valuing* is the process of living cherished beliefs while assimilating the new into a personal worldview" (1992, p. 37). The opportunity for listening was validated as a nurse stated:

Because the nurse is in the [patient's] room not only to prepare the medication, but also to know the emotional state of the relatives and the patient. Yes, we have the time—while we are giving the medication, we can be talking with the patient.

As the Nicaraguan nurses learned to practise true presence, a nurse reported, "I got to know a lot of things from the relatives and the children. I like it and I always do it."

It was hoped that adopting Parse's theory would help the nurses meet their need for enhanced skills necessary to listen to the families, as they spoke about the experience of having a child with a new diagnosis of leukemia, a relapse of the disease, or a child who had been newly placed on palliative care and, thereby, meet the nurses' ultimate goal of enhancing the quality of patient care. Indeed, the nursing personnel now had an improved understanding of the experience of the patients and their families by applying the listening techniques they had learned in the role-play and reflective exercises. In addition, the disease and treatment information served as a knowledge base for accurate conversations with the parents/guardians. This increased knowledge improved the confidence of the nurses, as they practised true presence with the families.

Many challenges in practising true presence were faced by this group of committed nurse leaders. Poor and under-educated families are often forced to the background as health care teams, despite limited resources and personnel, strive to provide basic oncology care and to cure the many patients who arrive in late stages of disease. In addition to insufficient resources, poverty, concomitant diseases, and cultural beliefs also contribute to the complexity of treatment of children with cancer in developing countries. Despite the rapid and dramatic advances in the medical treatment and survival rates of pediatric cancers, treating children with cancer remains a challenging and demanding area of nursing worldwide, but particularly so in resource-poor settings. Leadership is particularly essential in these countries, as nurses attempt to strengthen their unique and key roles in health care teams.

Providing nurses with the autonomy and financing for a project related directly to nursing care represents an important development for leadership in the profession. In addition, nurses in resource-poor countries need the support of nurses from developed countries with the history of working towards autonomy and peer-recognition in their own settings. International collaboration is essential for ongoing successful nursing leadership programs. The resources that international collaborators bring to a project, as well as the international recognition of the work of the local nurses facilitates nursing leadership development.

The profile and credibility of nurses, as peers in the health care team, is particularly important at a time that many countries are moving toward for-profit health care. The unique contribution of nursing to the quality of care available to the community must be made visible through the generation and dissemination of valid information that demonstrates the benefits of nursing leadership in the health of the public and, particularly, the most vulnerable members of society—children and the poor.

Lessons learned and recommendations

In May 2006 during the end of the data analysis and evaluation phase, one Canadian nursing professor travelled to Nicaragua and spoke with the nursing leadership coordinators. For the purposes of data analysis, it was necessary to clarify the limitations of the project and the use of Parse's Theory of Human Becoming. The coordinators requested more direct support from the POGO nursing team to avoid feelings of working "alone" in the project. There is no doubt that time zones, language barriers, distance, and work schedules for both the Canadians and Nicaraguans limited the direct support available from the POGO team. Future consideration of such challenges in the early design phase of similar projects is recommended. Concrete changes in nursing practice identified by the coordinators following the intervention were: (a) an increase in referrals to ancillary health professionals; (b) an increase in interest in patients; and (c) a willingness to ask more questions about patient care. The nurses demonstrated a new willingness to share information and concerns reported by patients and families with one another, as well as the multidisciplinary team. The nurses also expressed more interest in continuing education and training, and believed that the physicians should be included in the nursing initiatives.

This project was conceived as phase 1 of a comprehensive nursing education and leadership plan for the nurses of AHOPCA in Central America and supported by POGO. Unfortunately, phase 2 was not realized, as funding was redirected to a separate project. 🌿

Authors' note

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Correspondence concerning this article should be addressed to Julia Challinor, 's Gravelandseveer 8, 1011KN, Amsterdam, Netherlands. E-mail: jmchallinor@gmail.com

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