

PAEDIATRIC ONCOLOGY NURSING CARE IN LOW- AND MIDDLE-INCOME COUNTRIES: A NEED FOR BASELINE STANDARDS



SARA DAY, (LEFT TO RIGHT) DEPARTMENT OF NURSING EDUCATION, ST JUDE CHILDREN'S RESEARCH HOSPITAL, MEMPHIS, TENNESSEE, USA AND SCHOOL OF NURSING, UNIVERSITY OF ALABAMA AT BIRMINGHAM, USA; **JULIA CHALLINOR**, SCHOOL OF NURSING, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CALIFORNIA, USA; **RACHEL HOLLIS**, LEEDS TEACHING HOSPITALS TRUST, UK; **LINDA ABRAMOVITZ**, UCSF MEDICAL CENTER, HELEN DILLER FAMILY COMPREHENSIVE CANCER CENTER, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, USA; **YULIANA HANARATRI**, THE INDONESIA ANYO FOUNDATION, JAKARTA, INDONESIA AND **REHANA PUNJWANI**, CHILDREN'S CANCER HOSPITAL, KARACHI, PAKISTAN

This article looks at the Baseline Standards developed by the International Society for Paediatric Oncology (SIOP) for paediatric oncology nursing care in low- and middle-income countries. The Baseline Standards lay the foundation for effective care and address barriers such as inadequate staffing levels, lack of support, limited access to nurse education and unsafe nursing environments.

More than 160,000 children worldwide are diagnosed with cancer annually, resulting in about 90,000 deaths, and the majority of these deaths occur in low- and middle-income countries (LMICs) (1, 2). Over the past two to three decades, advances in molecular diagnosis and oncological treatments have greatly improved overall survival rates in children with cancer (83%) in high-income countries (HICs), where adequate hospital infrastructure, continuous professional training, and up-to-date resources are readily available (3). The large majority of cases of childhood cancer occur in LMICs, where late diagnosis and limited access to appropriate management and effective therapy have resulted in survival rates of 20% or less (4, 5). Even more discouraging is that the gap in survival rates continues to widen as curative therapies and national paediatric oncology strategies are developed by health-care professionals in HICs, but not implemented in LMICs (6). The problems caring for children with cancer in LMICs are being addressed with growing interest by international medical organizations due to recent shifts in paediatric global health care emphasis (7-9). Improved

prevention and treatment of childhood communicable diseases permits increased efforts in other areas as evidenced by initiatives from the NCD (Noncommunicable Diseases) Alliance and World Health Organization (WHO) (10-11). According to the NCD Alliance (2014):

"NCDs, including cancer, are a major cause of preventable mortality, morbidity and disability amongst children in LMICs. Many of these children die prematurely because of late diagnosis and/or lack of access to appropriate treatment; those fortunate to survive, often experience significant hardship and disability as a result of living with a chronic health condition that is not optimally managed" (10).

Many strategies have been offered to improve the survival rate of children with cancer in LMICs, including community awareness efforts (12), adapted protocol-driven care (13), and improved interdisciplinary care in local settings (14). The need for competent paediatric oncology nurses is one aspect of care that is universally acknowledged as essential to all such strategies (14-15).

The development of baseline standards for paediatric oncology nursing care in LMICs described in this article lays

the foundation for effective care by addressing barriers such as inadequate nurse staffing levels, lack of support, limited access to nurse education and unsafe nursing practice environments.

In a document that sets out the strategic direction for nursing services, the WHO acknowledges nursing staff globally, which comprises by far the largest group of health-care providers, is poorly staffed, lacks training and is not well deployed. WHO further recognizes nurses as “front-line clinicians” who are critical for improving health-care access and success in general (16). Several large-scale studies in a range of HICs settings have concluded that nursing education and staffing contribute to improved patient outcomes, including reduced mortality (17–19). A systematic review of research on the relationship between nurse staffing and patient outcomes commissioned by the Agency of Healthcare Quality and Research determined that a strong evidence base links inadequate nurse staffing levels to longer hospital stays, increased risk for complications and an increase in mortality (20).

While access to clinical trials and affordable medicines has been fundamental to improvements in survival in resource-rich countries, so too has been the development of paediatric oncology as a distinct nursing specialty. Specialized nursing education, appropriate staffing levels, and adequate equipment and resources are needed to support this complex nursing practice. Paediatric oncology nursing care requires an extensive knowledge of paediatric cancer and advanced clinical skills (21). Hospitals in HICs provide comprehensive education and clinical training to newly hired paediatric oncology nurses and offer education on an ongoing basis. In contrast, paediatric oncology specialty education is generally unavailable for nurses in LMICs, and limited educational experiences may be diluted by mandatory nursing rotations to a variety of clinical settings within the hospital (22). Graduate nurses in LMICs often have a diploma degree and they serve as vocational nurses. In many LMICs, there are still few nursing graduates with a bachelor degree performing professional nursing duties. This affects the clinical nurse’s ability to make critical decisions. In addition, a professional nursing career ladder for staff nurses is not always well defined in many LMICs to regulate the role and functions of the oncology nurse (and ultimately promotion) in accordance with their competencies.

Yet LMIC nurses, with less preparation, have a wider scope of practice than nurses caring for children with cancer in HICs (23). There are several explanations for this. Limited medical personnel on night and weekend shifts requires

LMIC nurses to independently make critical patient care decisions (24). In many LMICs, nutritionists, psychologists, social workers and pharmacists do not provide services to children and young adults with cancer. Thus, the nurses are responsible for providing symptom management, psychosocial and nutritional support and preparing chemotherapy drugs (25–26). Children commonly present with late-stage cancer in LMICs which requires advanced palliative care skills that most nurses lack (27). Additionally, nurses in LMICs contend with limited resources when providing care. Basic equipment such as intravenous (IV) pumps, digital thermometers and monitoring devices are often not available.

There is increasing recognition by many clinicians that high-quality specialized nursing care and nursing participation in clinical decision-making are essential to improving the survival rate of paediatric oncology patients in LMICs (28). Effective communication and partnerships between nurses and doctors is central to improving holistic care; unfortunately, in many LMICs this is not common practice. Paediatric oncology nurses from LMICs should be encouraged to act collaboratively with other health-care team members. In order to function as a strong partner in delivering cancer treatment, paediatric oncology nurses must improve their knowledge and skills. As nurses in LMICs gain experience and expertise caring for children with cancer they must maintain their moral responsibility to provide safe and ethical care as they are challenged by severe shortages, of pain medications and chemotherapy, and a hospital hierarchy that does not allow for nursing autonomy.

Nurses are at the bedside 24 hours a day and play a key role in monitoring the patient and family’s understanding of the disease and treatment plan. An effective treatment plan needs to be acceptable, understandable, and described in a way that resonates with patients’ life priorities (29). This requires having a nurse present at informed consent conferences or when a diagnosis is disclosed. This involvement is critical, permitting the nurse to hear what the family has been told and allowing the family to recognize the nurse as a valued member of the care team. Later, when the family has questions, the nurse can answer accurately or make appropriate referrals. Nurses have the potential to be advocates for their patients, and give voice to the child and family to ensure that the health-care team understands their perspective. The nurse’s ability to educate the child and family about the treatment plan is critical to reducing abandonment of care, a leading cause of death in LMICs (30–31). Although some nurses would like to assume an

advocacy role as part of their nursing practice, this can be challenging in LMICs due to barriers such as hospital regulations, administrators, paediatricians and even peer groups, since nursing's scope of practice is not always well defined. However, despite these barriers, LMIC nurses caring for children with cancer can develop their role as a patient advocate by carefully documenting their nursing care, using effective communication with patients and families, as well as working as a team member. The nurse's ideas and suggestions will be better received if they speak clearly with strong body language while advocating for the child and family. The paediatric oncology nurse should know the regulations and laws of the local health services to be a more effective advocate.

Community and primary health-care providers' awareness of early cancer symptoms is essential to address the overwhelming numbers of children who arrive at the hospital with advanced disease. Well-trained paediatric nurses working in the community can help detect children with cancer before their disease is so advanced that their only option is end-of-life care.

The vision of the International Society of Paediatric Oncology (SIOP) is that all children and young adults have access to state-of-the-art cancer treatment and care (32). To achieve this goal, nurses caring for children and young adults must be well prepared and have adequate resources.

The IOP PODC Nursing Working Group was created in 2010 (with members from 23 countries) and joined existing working groups under the SIOP Paediatric Oncology in Developing Countries (PODC) Committee. The Nursing Working Group "promotes the key role that nurses play in cancer care for children and young people, and aims to both support and learn from nurses working in developing countries" (33).

A set of baseline standards for the provision of nursing care was developed by the Nursing Group within SIOP in order to highlight the fundamental role of nurses in improving the care and survival of children with cancer. Development of the standards was a priority for several reasons. Nursing quality assessments from paediatric oncology units in LMICs documented a consistent lack of paediatric oncology nursing education, adequate staffing and basic resources (34). Nursing Working Group members from LMICs included experienced staff nurses from Ghana, South Africa, Colombia, Argentina, India, Cameroon, Pakistan and Ethiopia. They corroborated these findings and described other challenges in their daily work when they met together with HIC partners in a workshop designed to address education and training needs of nurses working in

paediatric oncology. One of the outputs of this workshop, held at the SIOP Congress in 2012, was an agreement to initiate work on the development of a position statement by the group. In December 2013, a final draft was completed. "Baseline standards for paediatric oncology nursing care in low- to middle-income countries: position statement of the SIOP PODC Nursing Working Group", was submitted to *Lancet Oncology* and published in June 2014 (35).

The Standards

- ▶ **Standard 1:** A staffing plan based on patient acuity levels is utilized. A nurse to patient ratio of 1:5 for general paediatric oncology units and 1:2 for critical care and transplant units is recommended. Nurses who have been trained and gained experience in oncology should remain within the paediatric oncology service and not rotated to other wards or specialities.
- ▶ **Standard 2:** All new nursing employees receive a formalized paediatric oncology induction (orientation) programme to include two weeks of theory and clinical skills training followed by 3–4 weeks spent with an experienced nurse preceptor. The induction programme should include specific learning objectives. Evidence of successful completion should be obtained before new nurses provide direct patient care. Content should include: review of paediatric cancers, administration of chemotherapy and management of side effects, management of venous access (central and peripheral), control and prevention of infections, administration of blood products, management of neutropenic sepsis, early detection and treatment of oncology emergencies, assessment and management of pain, nutritional support, education for patients and families, palliative care including death and dying and spiritual and psychological issues.
- ▶ **Standard 3:** Nurses receive continuing education and training to maintain and increase their paediatric oncology clinical skills and knowledge. A minimum of 10 hours continuing education and training per year is recommended.
- ▶ **Standard 4:** Nurses are recognized and acknowledged as core members of the multidisciplinary paediatric oncology team, as evidenced by inclusion in patient rounds and all meetings with patients and parents/caregivers when the diagnosis and treatment plan are discussed.
- ▶ **Standard 5:** Nurses have the resources needed to provide safe paediatric oncology care, to include: Intravenous pumps, hand washing/sanitizing supplies

and isolation supplies. Nurses prepare chemotherapy only if a pharmacist is not available, personal protective equipment and a biosafety level two cabinet are available, and periodic screenings for secondary cancers (related to exposure to antineoplastic agents) are provided.

- **Standard 6:** Evidence-based paediatric oncology nursing policies and procedures are in place to guide the delivery of quality nursing care. Because of the scarcity of nursing research in LMICs, funding for locally directed research is the next step to create relevant nursing policies and procedures.

Discussion

To close the survival gap that exists between children with cancer in HICs versus LMICs, institutions that develop cancer services and those that participate in twinning partnerships must invest in the nursing workforce. In HICs, death due to toxicity is 0.2% to 7% and abandonment is rare (36). In LMICs, toxicity and abandonment of treatment are the leading causes of death (30). Both require quality nursing care to improve and address the underlying issues. Providing resources and support to improve medical care without comparative interventions for nursing care will produce results that fall short of what is possible and optimal. In some cases, implementation of modern protocols without adequate nursing care can actually cure fewer children due to higher rates of toxic death (37).

While it may be premature to expect that all LMIC nurses in the near future will enjoy the full spectrum of support from improved staffing, educational programmes, essential resources and a safe work environment, this does not mean that achieving the SIOP Baseline Standards should not be the goal. The standards are minimal or baseline and implementation is possible, even in LMICs. For example, implementation of a comprehensive nursing programme at the Unidad Nacional de Oncología Pediátrica in Guatemala City, Guatemala, resulted in improved quality of nursing care as evidenced by a significant increase in the number of quality standards met post-programme implementation and a decrease in the rate of abandonment of treatment. Key to the programme's success was the support of a full-time nurse educator, dedicated solely to staff education and clinical training (28). This model could also be adapted for the implementation of the proposed Baseline Standards.

In many LMICs, nurses achieving the status of a respected member of the interdisciplinary team will require a paradigm shift in hospital culture where nurses are currently expected

to carry out physicians' orders without question, even when the nurses believe there has been an error made. The critical role of autonomous nurses who are able to fully participate in patient care planning and monitoring is often highlighted and should be role modelled by visiting teams from HICs. It is our expectation that over time, the LMIC physicians treating children with cancer who have received training in HICs will also begin to integrate nurses into their daily rounds, patient/parent conferences and treatment decisions.

Although better prevention and treatment of childhood communicable diseases have led to better efforts in cancer care and control in LMICs, there are still some LMICs where communicable diseases remain the leading cause of childhood death. One example is Pakistan, where the cause of death in over 70% of children is communicable diseases (38). Implementing the standards in these countries will be very difficult and could potentially place hospital management in the dilemma of choosing better care to a limited number of children with cancer or providing necessary treatment to a larger number of patients.

Nursing shortages and poor nurse retention rates are a significant challenge in Pakistan, and other LMICs. The nursing pay scales of local hospitals in LMICs compared to HIC institutions are significantly lower and trained oncology nurses are easily employed in HICs. Many nurses therefore, move to other countries for better career opportunities. This problem will continue as long as nurses in LMICs work without adequate support and pay. The cost of adding additional nursing positions and adequate resources will be a challenge. However, this cost must be weighed against the cost of high nurse turnover and an increase in patient complications resulting in longer hospital admissions.

These baseline standards have been welcomed by the international paediatric oncology community. The SIOP PODC Nursing Working Group continues the work of disseminating and advocating for their implementation. Future work will be undertaken to review progress; to understand and address barriers to implementation, and to recognize and celebrate success. To date we are not aware of an LMIC setting that has attempted to implement the standards as a whole. There is interest in the SIOP PODC Nursing Working Group members to bring the standards to their local authorities to advocate for change. Progress towards achieving the standards will be monitored at the annual SIOP meetings.

There are challenges to implementing them, but the fact remains that these basic standards are essential to providing the minimum level of quality nursing care required to improve the survival rate of children with cancer in LMICs. ●

Sara W Day, PhD, RN, FAAN has focused on the development, implementation and evaluation of nursing programmes and models to improve the care of children with cancer and sickle cell disease. Her programmes and models have improved the outcomes of underserved children and have been implemented nationally and internationally in nine countries. She has worked to empower nurses in developing countries to provide quality paediatric oncology nursing care and created programmes to advance the nursing work environment through education and improvement in quality standards. She has 31 publications in peer-reviewed medical and nursing journals and has travelled to 14 countries to present or directly implement her programmes. She was recently inducted as a Fellow of the American Academy of Nursing for her significant contributions to nursing and health care.

Julia Challinor, RN, PhD, MS in Education and MS in Med Anthropology, a former teacher, was the Educational Liaison for children with cancer and those who had survived their disease at the University of California, San Francisco from 1993–2003. From 1994–2006, she also headed A Tomorrow for Children Foundation and worked in partnership with paediatric oncology centres in Latin America. Her current professional focus is mentorship of paediatric oncology nurses in Ethiopia and other developing countries. As an international nursing consultant for oncology with an anthropological perspective, Dr Challinor seeks to strengthen nursing resources and opportunities in countries with limited resources.

Rachel Hollis, FRCN, RGN, RSCN, MHsc is the Lead Nurse for Children's Cancer at the Leeds Teaching Hospitals Trust in the United Kingdom and has spent most of her professional life working in paediatric oncology in the acute hospital setting. She is a member of the SIOP Nurses Steering Committee, and has represented nursing on the SIOP Scientific Committee. She is a former Co-Chair of the SIOP Paediatric Oncology in Developing Countries Nursing Working Group. She has also been an active member of the Paediatric Oncology Nurses Forum of the Royal College of Nursing (RCN) in the United Kingdom. She was awarded a Fellowship of the RCN in recognition of her contribution to children's cancer nursing.

Linda Abramovitz, RN, MSN, BMTCN is currently a practice nurse at the University of California, San Francisco (UCSF). Linda was the Clinical Nurse Specialist for the Pediatric Bone Marrow Transplant Program at UCSF for over 27 years. She received her BSN from the University of Rochester and MSN from the University of Pennsylvania. She is actively involved in paediatric oncology and HSCT nursing as a clinical consultant, educator and researcher at a local, national and international level – professional role development for both staff nurses and advanced practice nurses and the delivery of cultural competent care has been a focus of Linda's work in LMICs and HICs. Currently, Linda is a member of the SIOP Nurses Steering Committee and co-chair of SIOP's Pediatric Oncology Developing Country Nursing Working Group.

Yuliana Hanaratri, RN, BSN, MAN has been a clinical instructor for nursing students in major of pediatric nursing practice from 1997 to 2011 and a lecturer as the St. Carolus School of Nursing Jakarta. She graduated with a Masters degree from the University of the Philippines in 2004. She has focused on paediatric oncology nursing since 2010 and as a nurse educator for the development programme for children with cancer at the Indonesian Anyo Foundation Jakarta since 2012 until the present.

She has published practice guidelines based on the Metro Manila Development Screening Test that is used in training Indonesian nurses in paediatric assessment. These practice guidelines are also included in the paediatric nursing curriculum at the local school of nursing.

Rehana Punjwani, RN, BSN has 14 years of experience in paediatric oncology nursing, working in both direct patient care and administration. She is a founding member and currently Head of the Pediatric Oncology Nursing Education Department at Children's Cancer Hospital in Pakistan, where she has developed and taught paediatric oncology nursing courses. She has worked with Pakistan's Nursing Council to obtain approval for a post-RN diploma in paediatric oncology nursing offered by the Paediatric Oncology Nursing Education Department. This is the only department in Pakistan to offer paediatric oncology nursing education and the only department licensed to offer a post-RN diploma.

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