

Brief communication

Health literacy on quality of life for children with cancer: modules on pediatric palliative care

Ximena García-Quintero,¹ Daniel Bastardo Blanco,² Liliana Vásquez,³ Soad Fuentes-Alabí,³ Sara Benites-Majano,³ Mauricio Maza,³ Cecilia Ugaz,⁴ Roxana Morales,⁴ Justin N Baker,¹ and Michael J. McNeil¹

Suggested citation García-Quintero X, Bastardo Blanco D, Vásquez L, Fuentes-Alabí S, Benites-Majano S, Maza M, et al. Health literacy on quality of life for children with cancer: modules on pediatric palliative care. *Rev Panam Salud Publica*. 2023;47:e134. <https://doi.org/10.26633/RPSP.2023.134>

ABSTRACT

Objective. To describe the development of educational materials for parents and other caregivers of children with cancer, which utilized a culturally sensitive approach to reduce acceptance barriers to palliative care (PC).

Methods. The Pan American Health Organization (PAHO), St. Jude Children's Research Hospital, and partners in Latin America and the Caribbean collaborated in a three-phase project, beginning with a needs assessment survey of caregivers of children with cancer in Peru. Based on this finding, an interdisciplinary team of pediatric PC experts developed educational content that was designed and validated by an international committee of PC and communication experts.

Results. The collaboration resulted in the development of an eight-module series that introduces caregivers to key concepts of pediatric PC, including management of pain, quality of life, and end of life care. The series was designed to reduce caregiver stigma associated with PC through culturally sensitive education that addresses the low levels of health literacy among caregivers in Latin America and the Caribbean. In the 15 months since the launch, these modules have been distributed throughout Latin America and were downloaded 2 825 times.

Conclusions. Educational materials and anticipatory guidance of PC were considered to be a priority for parents and other caregivers of children with cancer throughout Latin America. The materials developed through this project have been widely utilized and are available through the PAHO website and the *Together by St. Jude*TM online resource.

Keywords

Palliative care; quality of life; health literacy; neoplasms; child health; Latin America.

Global childhood cancer survival rates highlight substantial health inequalities throughout the world, with some low- and middle-income countries (LMIC) experiencing a less than 30% 5-year survival rate as compared with greater than 80% in some high-income countries (1). Although improving access to treatment is crucial, a wider focus on the multifaceted challenges that affect high-quality care for children is essential. This includes treatment abandonment, late diagnosis, supportive care, malnutrition, and importantly, palliative care (PC) (1,2).

In response, the World Health Organization (WHO) established the Global Initiative for Childhood Cancer (GICC) in 2018 to improve access to and quality of care for children with cancer worldwide. The GICC strives to achieve a 60% survival rate for children with cancer by 2030 by bringing together stakeholders across sectors and by using the *CureAll* framework as a coordinated operational approach. This initiative recognizes that improving childhood cancer outcomes requires a comprehensive and coordinated approach that addresses the various

¹ Department of Global Pediatric Medicine, St. Jude Children's Research Hospital, Memphis, United States of America. ✉ ximena.garcia@stjude.org

² Department of Strategic Communication, Education and Outreach, St. Jude Children's Research Hospital, Memphis, United States of America.

³ Noncommunicable Diseases Unit, Pan American Health Organization/World Health Organization, Washington, DC, United States.

⁴ Department of Oncology, Instituto Nacional de Enfermedades Neoplásicas, Lima, Peru.

factors affecting survival rates. By focusing on improving access and quality to health care, the GICC aims to improve outcomes and reduce the inequality in childhood cancer survival rates worldwide (3).

The WHO has emphasized the importance of the early integration of PC as a “medical and moral necessity” for children with life-threatening illnesses and their families to enhance their quality of life and address suffering (4). However, despite this recommendation, access and acceptance of PC remains limited worldwide, particularly in LMICs. A study published in January 2023 (5) assessed the perceptions of Latin American physicians regarding the barriers to integrating PC. The study identified several obstacles that impede the integration of PC, including a lack of home-based services (85.8%), limited physician knowledge about the role of PC (83.4%), discomfort among physicians in discussing PC with families (81.3%), restricted access to PC specialists or services (78.7%), and family resistance to the involvement of PC (72.6%). These findings highlight opportunities for integrating PC with childhood cancer care in Latin America and the Caribbean through targeted family education.

Parents and caregivers play the primary role in the care of children with life-threatening conditions. Their active engagement in their child’s care has been associated with improved adherence to treatment and better health outcomes; it is also related to higher health literacy levels (6). Many definitions have been proposed for *health literacy* in the literature, but at its core, the concept refers to an individual’s ability to find, understand, and use information and services to make and take appropriate health-related decisions and actions (6). Thus, patient and family education plays a critical role in increasing a family’s health literacy, which ultimately enables the early integration of PC in the care of children with cancer by addressing caregivers’ PC fears, misunderstandings, and knowledge gaps (7,8).

This article describes the development of educational materials for parents and caregivers through a culturally sensitive approach as a health literacy strategy to decrease acceptance barriers to PC. By directly addressing parents and caregivers’ misconceptions about PC, these materials aim to promote a greater understanding of the fundamental goal of PC—to attend to suffering and improve the quality of life of children with life-threatening conditions.

METHODS

As part of the GICC, the Pan American Health Organization (PAHO), St. Jude Children’s Research Hospital, Latin American regional experts, and international advisors in PC conducted a three-phase approach (Figure 1) to develop health literacy materials for parents and caregivers of children with cancer.

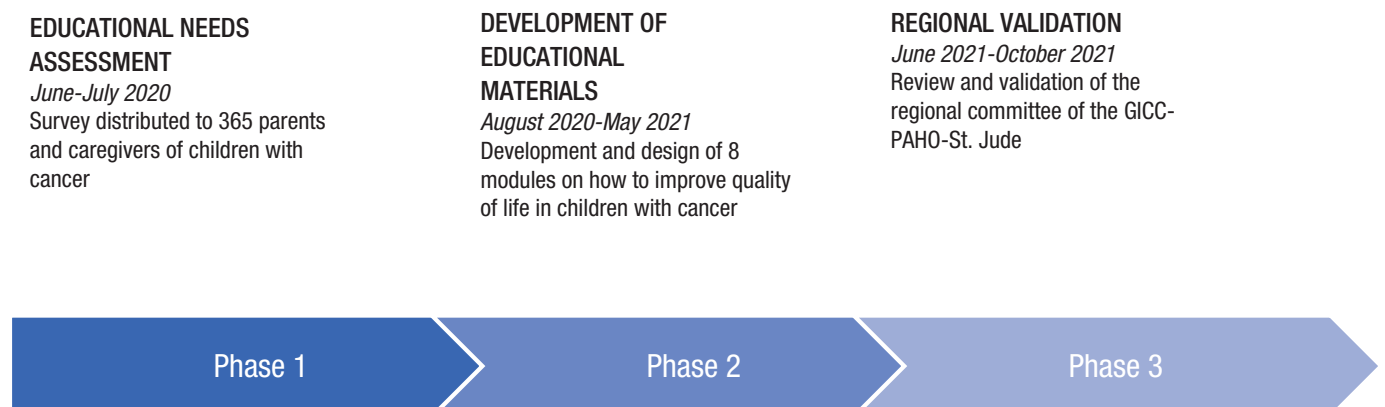
Needs assessment on educational priorities

Peru is the Latin American focus country for the WHO GICC. Eligible parents and caregivers were recruited from 13 hospitals in five cities in Peru: Lima, Arequipa, Cusco, Trujillo, and Chiclayo. Additionally, two non-governmental organizations that support childhood cancer throughout Peru were involved in the recruitment process. The recruitment methods included in-person contacts at hospitals, emails from hospital databases, engagement with social media groups, and personal calls. The survey was designed to be completed by the parent or caregiver either on paper or online. To be eligible for participation, individuals had to be over 18 years of age, able to speak and understand Spanish (or Quechua), and have a child currently undergoing cancer treatment or have had a child in treatment in the past. The results of this needs assessment helped prioritize relevant health literacy topics.

Development of educational modules

An international working group was formed to provide technical assistance in the development of the materials. The team was made up of 42 PC regional leaders from 14 countries in Latin America and the Caribbean. Monthly virtual meetings were held until a consensus was reached on the materials. The team of regional and international experts, along with patient–family representatives from Childhood Cancer International Latam carried out a prioritization activity and defined eight main topics of pediatric PC. These topics included general information on pediatric PC and quality of life, including symptom management, communication with patients and families, and ethical considerations for end of life care.

FIGURE 1. Development of educational material for parents



Validation and revision

Between June and October 2021, the eight-module series was reviewed, edited, and typeset by the international regional experts working group of the GICC, PAHO, and St. Jude Children’s Research Hospital. This guide includes a range of topics related to PC and quality of life (Figure 2), such as symptom management, communication with patients and families, and ethical considerations at end of life care. The content was developed and designed for parents and caregivers through a literature review and the incorporation of health literacy best practices in content development and design. The content was written in plain language and organized into small sections to ensure understandability. Additionally, the design incorporated white space, illustrations, and sub-headers to improve readability. The final version was reviewed and copyedited by the PAHO editorial publications team. The materials were then circulated among the collaborators for approval and subsequent publication and distribution through official communication channels, including on the PAHO and the *Together by St. Jude*™ websites and communication channels.

RESULTS

The educational needs assessment was distributed to 365 parents and caregivers in Peru in 2020. The participants were 71% mothers, 17% fathers, and 12% other caregivers who were not parents and their average age was 37.9 years across the group. The assessment showed that PC was among the three most common educational priorities (67%) for respondents, along with general information about cancer and adverse effects (85%) and nutrition (75%).

Eight modules on pediatric palliative care

The *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care* (in Spanish and Portuguese) developed by PAHO, St. Jude Global Palliative Care Program, *Together by St. Jude*™ program, and the international PC working group is a comprehensive guide for families of children receiving treatment for cancer. The guide focuses on delivery of PC and consists of eight modules that cover a range of topics related to PC and quality of life (Figure 2). A brief description of the content of each module follows.

FIGURE 2. Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care



Module 1: Pediatric Palliative Care Overview defines pediatric palliative care and answers frequently asked questions from parents, including whether palliative care is reserved for the end of life and how it benefits children in their treatment.

Module 2: Home Care addresses the general recommendations for the child at home after being discharged from the hospital. It provides general guidance for the use of home care medical devices, such as oxygen, secretion aspirator, gastrostomy, and tracheostomy.

Module 3: Quality of Life in the Hospital introduces strategies to improve the quality of life of children in the hospital by making the best of the situation, such as creating family moments, strengthening sources of support, allowing the child to continue attending classes, and reducing stress.

Module 4: Symptom Management provides general recommendations for the initial management of care at home for the most common symptoms in children in palliative care (fever, pain, respiratory distress, and constipation, among others), emphasizing timely consultation with the health care team of the patient.

Module 5: Caring for the Caregiver shares self-care strategies to promote well-being in parents and caregivers because caring for a child with a life-threatening condition is challenging. Care of the caregiver improves the care and quality of life of children at home.

Module 6: Communication informs on the rights of children and families to receive medical information, and offers guidelines for strategies to better communicate with children about cancer.

Module 7: Spirituality discusses the concept of spirituality in children, and offers recommendations to develop and practice spirituality, in general, while respecting the patient's and family's religious beliefs.

Module 8: End-of-Life Care makes recommendations for end of life care and offers a support system to better cope with this stage of the disease while acknowledging that the death of a child is an indescribable loss, with pain and suffering for the whole family.

Dissemination of the modules

By incorporating health literacy best practices into the content development and design, this resource is an easy-to-use and digest guide written for parents and caregivers. Since its publication in November 2021, the series has been distributed to Latin American Ministries of Health and regional networks of PC professionals via official PAHO communications, and it has been made available to the public via the *Together by St. Jude*TM online resource (together.stjude.org) and social media. By February 2023, these materials had been downloaded at least 2 825 times, indicating a substantial interest in and demand for this type of educational resource among parents and caregivers of children with cancer in Latin America and the Caribbean.

DISCUSSION

The goal of pediatric PC is to improve quality of life for children and adolescents with life-threatening conditions and for their families (7). However, misconceptions and negative perceptions remain obstacles to accessing and acceptance of PC, especially in LMICs, where low-level health literacy is a

substantial challenge (8-10). The *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care* provides foundational knowledge to parents and caregivers of children and adolescents with cancer so that they can feel empowered to contribute to the care and betterment of their child's quality of life. The development of this first-of-its-kind educational booklet series can serve as a model to produce culturally sensitive resources on health topics with limited public knowledge.

Our study findings reveal that the development of educational materials and anticipatory guidance on PC is a priority for parents and caregivers of children with cancer in Latin America and the Caribbean. The *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care* plays a vital role in breaking the stigma associated with PC through culturally sensitive patient and family education. This is particularly important in LMICs where most of the children who need PC reside. In addition, it addresses the low-level of health literacy among Latin American parents and caregivers regarding pain relief, handling of distressing symptoms, care at home, communication, quality of life, and care at the end of life. Since its launch, the modules in the series have been downloaded widely and are being distributed throughout Latin America during conferences, workshops, and virtual events.

The development of this resource is aligned with the WHO recommendation that recognizes PC as a critical part of caring for children living with life-threatening or life-limiting illnesses (4) and the *CureAll* framework of the GICC, which emphasizes centers of excellence (pillar C), universal health coverage (pillar U), and advocacy (pillar A) (3). Additionally, this project shows how international collaborations and multidisciplinary efforts can catalyze the development of high-quality and cost-effective patient education resources (3).

Limitations

Despite the positive effects of the *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care*, there are some limitations to consider. First, it is currently available only in Portuguese and Spanish, limiting its reach in Latin America and the Caribbean; for example, among indigenous populations. However, efforts are underway to translate the modules into additional languages to expand their access and reach in LMICs with populations that do not speak Portuguese or Spanish. Additionally, the series focuses specifically on children with cancer, not children with other life-threatening or life-limiting illnesses. To address this potential gap, similar resources specifically tailored to other life-limiting conditions need to be developed through similar collaborations among health care professionals, patient advocacy groups, and organizations specializing in the care of these children. Finally, although the series is a valuable resource for improving access and acceptance of PC in LMICs, it may not address all the complex cultural and social barriers that exist in each area of Latin America and the Caribbean, and further research is needed to measure its effects on PC access and acceptance across countries.

Conclusions

The *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care* represents an important step forward in the development of high-quality, cost-effective resources

for parents and caregivers of pediatric patients with cancer in Latin America and the Caribbean. By providing essential information on pediatric PC, the series has the potential to improve access and acceptance of PC among families of children with cancer and to positively affect the overall quality of life for this vulnerable population. International collaborations and multidisciplinary efforts are essential for developing patient and family education materials and anticipatory guidance in PC as a strategy to improve health literacy and, therefore, the early integration of PC into childhood cancer care. The freely available resources developed through this project can serve as a model for the development of similar resources on other health topics to improve health literacy, especially in LMICs.

Author contributions. X.G.Q., L.V., D.B.B., S.F., C.U., R.M., and M.M. conceived the original idea; L.V., C.U., and R.M. collected the data; X.G.Q., D.B.B., L.V., S.F.A., J.B., and M.M. analyzed the data/contributed data or analysis tools/interpreted the results;

X.G.Q., L.V., and D.B.B. wrote the paper; S.F., J.B., and M.M. reviewed the paper. All authors reviewed and approved the final version.

Acknowledgements. The authors would like to acknowledge the palliative care working group of the Global Initiative for Childhood Cancer. Additionally, our deepest gratitude to the parents and caregivers in Peru who completed the survey so that we might better address their needs for health literacy in palliative care.

Conflicts of interest. None declared.

Disclaimer. Authors hold sole responsibility for the views expressed in the manuscript, which may not necessarily reflect the opinion or policy of the *RPSP/PAJPH* and/or the Pan American Health Organization (PAHO).

REFERENCES

1. Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Girardi F, Atun R. Global childhood cancer survival estimates and priority-setting: a simulation-based analysis. *Lancet Oncol.* 2019;20(7): 972-83.
2. Lam CG, Howard SC, Bouffet E, Pritchard-Jones K. Science and health for all children with cancer. *Science.* 2019;363(6432):1182-6.
3. World Health Organization. CureAll framework: WHO global initiative for childhood cancer: increasing access, advancing quality, saving lives. WHO; 2021. [Accessed 8 August 2023]. Available from: <https://apps.who.int/iris/handle/10665/347370>
4. World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers and managers. WHO; 2018. [Accessed 8 August 2023]. Available from: <https://apps.who.int/iris/handle/10665/274561>
5. McNeil MJ, Ehrlich B, Wang H, Bustamante M, Dussel V, Friedrich P, et al. Assessing Doctors' Attitudes on Palliative Treatment (ADAPT) Latin America study group. Ideal vs actual timing of palliative care integration for children with cancer in Latin America. *JAMA Netw Open.* 2023;6(1):e2251496.
6. Papadakos JK, Hasen SM, Barnsley J, Berta W, Fazelzad R, Papadakos CJ, et al. Health literacy and cancer self-management behaviors: A scoping review. *Cancer.* 2018;124:4202-10.
7. World Health Organization. Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice. Geneva: WHO; 2021. [Accessed 8 August 2023]. Available from: <https://apps.who.int/iris/handle/10665/345674>
8. Christensen, Deborah Lynn. The impact of health literacy on palliative care outcomes. *J Hosp Palliat Nurs.* 2016;18: 544-9.
9. Batterham RW, Hawkins M, Collins PA, Buchbinder R, Osborne RH. Health literacy: Applying current concepts to improve health services and reduce health inequalities. *Public Health.* 2016;132:3-12. [Accessed 8 August 2023]. Available from: <http://dx.doi.org/10.1016/j.puhe.2016.01.001>
10. Morrison AK, Glick A, Shonna Yin H. Health literacy: implications for child health. *Pediatr Rev.* 2019;40(6): 263-77. [Accessed 8 August 2023]. Available from: <https://doi.org/10.1542/pir.2018-0027>

Manuscript submitted 4 April 2023. Revised version accepted for publication on 31 July 2023.

Alfabetización en salud sobre calidad de vida en pacientes pediátricos con cáncer: módulos sobre cuidados paliativos pediátricos

RESUMEN

Objetivo. Describir la elaboración de material educativo para progenitores y otras personas que cuidan de pacientes pediátricos con cáncer mediante un enfoque sensible a las especificidades culturales, a fin de reducir los obstáculos a la aceptación de los cuidados paliativos (CP).

Métodos. La Organización Panamericana de la Salud (OPS), el St. Jude Children's Research Hospital y asociados de América Latina y el Caribe colaboraron en un proyecto de tres fases, que se inició con una encuesta de evaluación de las necesidades de las personas que cuidan de pacientes pediátricos con cáncer en Perú. A partir de estos resultados, un equipo interdisciplinario de expertos en CP pediátricos elaboró un material educativo diseñado y validado por un comité internacional de expertos en CP y comunicación.

Resultados. Esta colaboración permitió diseñar una serie de ocho módulos en los que se presentan conceptos clave de los CP pediátricos, como el tratamiento del dolor, la calidad de vida y los cuidados terminales. Estos módulos se diseñaron para reducir la estigmatización asociada a los CP por parte de las personas encargadas de los cuidados, mediante una educación que tiene en cuenta sus especificidades culturales y aborda el bajo nivel de conocimientos básicos de salud de estas personas en América Latina y el Caribe. En los 15 meses transcurridos desde su publicación, se han distribuido por toda América Latina y su contenido se ha descargado 2 825 veces.

Conclusiones. Se consideró que los materiales educativos y la orientación preparatoria sobre los CP constituyen una prioridad para los progenitores y otras personas encargadas del cuidado de pacientes pediátricos con cáncer en toda América Latina. Los materiales elaborados mediante este proyecto han sido ampliamente utilizados y están disponibles en el sitio web de la OPS y en el recurso en línea *Together by St. Jude™*.

Palabras clave Cuidados paliativos; calidad de vida; alfabetización en salud; neoplasias salud infantil; América Latina.

Alfabetização em saúde sobre qualidade de vida para crianças com câncer: módulos sobre cuidados paliativos pediátricos

RESUMO

Objetivo. Descrever o desenvolvimento de materiais educativos para pais e outros cuidadores de crianças com câncer por meio de uma abordagem sensível à cultura para reduzir as barreiras de aceitação dos cuidados paliativos (CP).

Métodos. A Organização Pan-Americana da Saúde (OPAS), o St. Jude Children's Research Hospital e parceiros da América Latina e do Caribe colaboraram em um projeto de três fases, que iniciou com uma pesquisa de avaliação das necessidades dos cuidadores de crianças com câncer no Peru. Com base nos achados dessa pesquisa, uma equipe interdisciplinar de especialistas em CP pediátricos desenvolveu um conteúdo educacional que foi concebido e validado por um comité internacional de especialistas em CP e comunicação.

Resultados. A colaboração resultou no desenvolvimento de uma série de oito módulos que apresenta os principais conceitos dos CP pediátricos aos cuidadores, incluindo controle da dor, qualidade de vida e cuidados de final de vida. A série foi concebida para reduzir o estigma dos cuidadores em relação aos CP por meio de educação sensível à cultura, abordando os baixos níveis de letramento em saúde entre os cuidadores da América Latina e do Caribe. Nos 15 meses desde seu lançamento, os módulos foram distribuídos em toda a América Latina, tendo sido baixados 2 825 vezes.

Conclusões. Os materiais educativos e a orientação prévia sobre CP foram considerados uma prioridade para os pais e outros cuidadores de crianças com câncer em toda a América Latina. Os materiais desenvolvidos por meio desse projeto foram amplamente utilizados e estão disponíveis no site da OPAS e no recurso on-line *Together by St. Jude™*.

Palavras-chave Cuidados paliativos; qualidade de vida; letramento em saúde; neoplasias saúde da criança; América Latina.
