

# Standards for psychosocial care in pediatric cancer: adapted proposal for Latin American and Caribbean countries

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## ABSTRACT

**Objective.** To highlight the objectives, achievements, challenges, and next steps for the World Health Organization's Global Initiative for Childhood Cancer (GICC) framework, a project designed to improve psychosocial care (PSC) in pediatric cancer centers across Latin America and the Caribbean (LAC).

**Methods.** The project was launched in Peru, the first GICC focal country, in November 2020. The diagnosis phase included a survey and a semistructured interview with health professionals to assess PSC practices in institutions, and a needs assessment survey for caregivers. In the second phase, a strategic plan was developed to address the identified needs, including the adaptation of PSC standards, the establishment of multicenter working groups, the expansion of the proposal, and the development of materials.

**Results.** The study found that PSC was not being adequately provided in accordance with international standards. Six adapted standards were proposed and validated, and more than 50 regional health professionals participated in online activities to support the project. The implementation process is currently ongoing, with the establishment of five multidisciplinary working groups, one regional committee, and the production of 16 technical outputs.

**Conclusion.** This project represents a substantial step forward to improve PSC for pediatric patients with cancer and their families in LAC countries. The establishment of working groups and evidence-based interventions

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strengthen the proposal and its implementation. Development of health policies that include PSC according to standards is needed to achieve sustainable results in the quality of life of children with cancer and their families.

## Keywords

Child health; psycho-oncology; neoplasms; psychiatric rehabilitation; standards of care; Latin America; Caribbean region.

In 2018, the World Health Organization (WHO) announced its Global Initiative for Childhood Cancer (GICC) to achieve at least a 60% survival rate among children with cancer by 2030 (1). The GICC has 2 main objectives: first, to raise awareness about childhood cancer at both the global and national levels to increase its prioritization; and second, to enhance the capabilities of countries in providing optimal childhood cancer care (2). A technical package called *CureAll* is available to guide countries in implementing the initiative.

Annually, in Latin America and the Caribbean (LAC), it is estimated that at least 29 000 children and adolescents (<1 to 19 years old) will be affected by cancer, of whom approximately 10 000 will die from the disease (3). The diagnosis and treatment of pediatric cancer can produce psychosocial repercussions for patients and their families, affecting their adjustment to illness, treatment adherence, and quality of life (4).

Psychosocial care (PSC) is a comprehensive approach to cancer care that includes social, psychological, emotional, spiritual, and functional aspects of the patient journey with the support of an interdisciplinary care team and health service providers (5). Improving the delivery of PSC in childhood cancer treatment centers is relevant to reducing psychosocial risks, promoting coping strategies, and improving well-being in patients and their families (6).

Several proposed standards and guidelines for PSC have been developed at the international level. The Committee of Psychosocial Issues of the International Society of Pediatric Oncology (SIOP), formed in 1991, published a series of documents that included the main recommendations for PSC of children and adolescents with cancer (7). Later, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) developed 15 evidence-based psychosocial standards of care from the evidence, and a consensus was formed through collaboration between a group of pediatric oncology psychosocial professionals and a larger interdisciplinary group of experts and stakeholders (8).

Although some studies have described that PSC provided for children with cancer in high-income countries is consistent with most international standards (9), it is also recognized that financial and institutional challenges hinder implementation, resulting in slow overall uptake (10). In Latin America, a study explored PSC provided in public hospitals in Argentina, and it found only partial compliance with the SIOP recommended standards for PSC (11). However, for low- and middle-income countries (LMICs), there is very limited information regarding PSC delivery models and implementation needs and whether they are consistent with international standards.

We report on a project designed as a formal collaboration between the Pan American Health Organization (PAHO), Childhood Cancer International, and La Roche-Posay Foundation aimed at improving PSC in pediatric cancer centers across LAC through the implementation of standards. This project is

aligned with the *CureAll* objectives, specifically the first pillar which focuses on centers of excellence and care networks to increase access to quality health services (2).

The project was initiated in Peru, the first GICC focal country, and established the multidisciplinary team's scope of PSC practices based on international standards. The objective was to develop a strategic plan to improve PSC, one that would also serve as a model for other LMICs. It included a proposal of adapted standards that were validated by regional experts to ensure their applicability in other countries. Educational materials were developed accordingly.

The project is currently expanding to other countries in LAC, with the primary goal of creating a guide for implementation. This article provides a description of the project's objectives, methodology, accomplishments, challenges, and next steps.

## METHODS

In this article, we report on the survey study and project period from inception in November 2020 through October 2022, noting that the project is currently ongoing. We followed a systematic process (Figure 1) that began with reviewing the relevant literature on pediatric cancer PSC guidelines and international standards (7-11) and conducted a national situational assessment of psychosocial needs and PSC provided in Peru. To address the PSC needs identified, a strategic plan was developed, guided by the project's aims and monitoring and with the involvement of key stakeholders and clinicians.

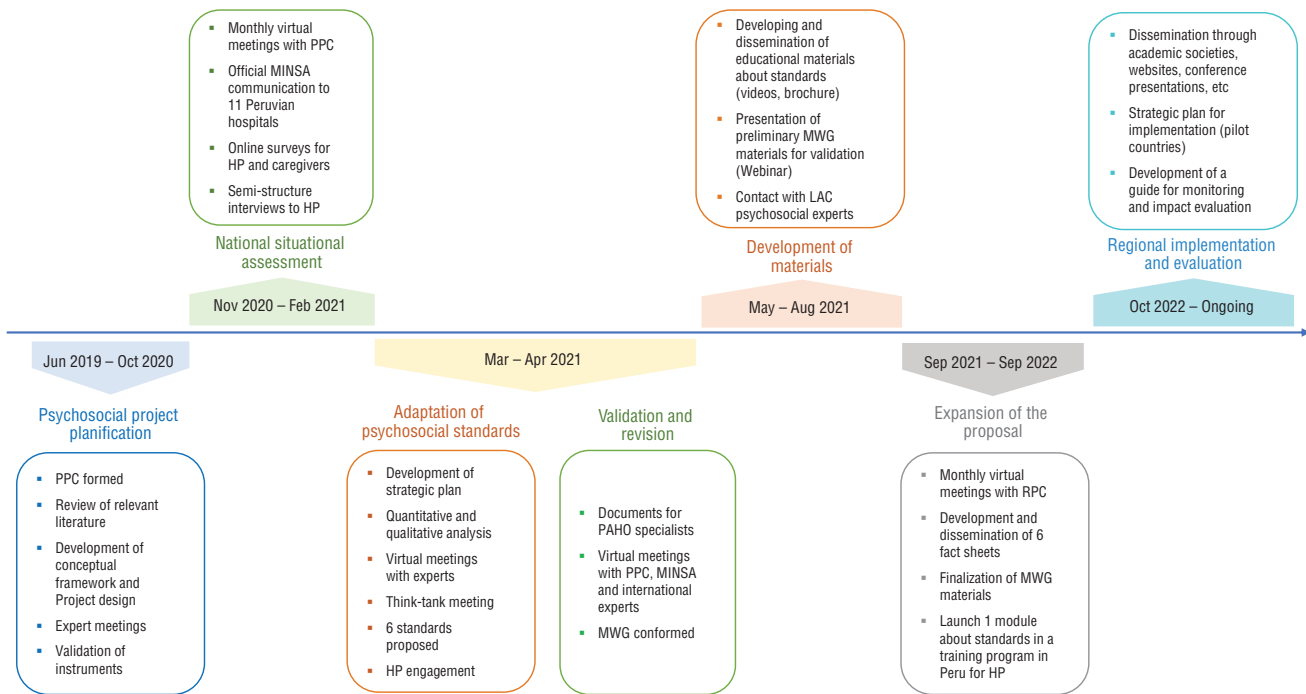
### Assessment of PSC in Peru

**Study sample and participant recruitment.** A national situational assessment was conducted from November 2020 to February 2021 with health professionals and caregivers. The Ministry of Health of Peru (MINSA) sent an official communication to 11 institutions, requesting that two health professionals participate from each center. In addition, a snowball sampling technique was used to complete the sample. Caregivers were contacted via parent organizations and by using a snowball sampling method.

Participation in this study was voluntary and confidential, and both oral and written informed consent were obtained. The study was exempted from ethics committee review given that it did not present any risk to participants and did not require their identification.

**Measurements.** Three methods were used to collect health professional data. First, we administered an online survey consisting of 45 questions divided into three sections: general data, evaluation of PSC standards, and institutional strengths and weaknesses. This survey was adapted from a previously validated English language questionnaire based on international PSC standards (11,12); it was translated into Spanish and

FIGURE 1. Project timeline



HP: Health providers; LAC: Latin American and the Caribbean; MINSA: Peruvian Ministry of Health; MWG: Multicenter working groups; PAHO: Pan American Health Organization; PPC: Psychosocial Peruvian committee; RPC: Regional psychosocial committee

Source: Prepared by the authors from the study findings.

approved by a panel of experts. Second, we conducted semi-structured interviews to validate the survey data and to obtain additional information on health professional motivation, work-related challenges, perception of the multidisciplinary team, and expectations for future training.

Third, to assess caregiver psychosocial needs and perceptions of the PSC, a 24-question online survey was administered. This survey was developed by the authors and included both Likert-type scales and open-ended text responses.

### Statistical analysis

Quantitative data obtained from surveys were analyzed using IBM SPSS Statistics, version 22 (IBM Corp., United States). We assessed the frequency of care provided by the health professionals relative to the Standards of Care (8), and grouped the findings by institution. Descriptive results based on the number and percentage of responses, as well as means, were used to summarize data from caregivers. Qualitative data from open-ended questions and semistructured interviews were transcribed, analyzed thematically, and divided into meaningful units, which were then labeled and coded based on commonalities. This process was used to understand the participants' experiences as a whole (13).

### Strategic plan

A strategic plan was developed; it included the adaptation of PSC standards, the establishment of multicenter working

groups, the expansion of the proposal, and the development of materials.

**Adaptation of PSC standards.** The assessment results were categorized by combining common aspects of both the PSCPC and the SIOF standards (7, 8), along with prioritized objectives and reported needs from health professionals and caregivers. A preliminary proposal of adapted standards was presented to a group of experts for evaluation. We also conducted a virtual think-tank meeting with health professionals from hospitals, associations, and non-governmental organizations nationwide, who care for pediatric patients with cancer.

During the meeting, participants shared the initial survey findings, formed workgroups to validate each primary area as a new adapted standard, and defined implementation goals. Lastly, a general discussion was held.

**Validation and revision.** A final proposal consisting of 6 standards of PSC was created. Each standard was defined, its utility was explained, and its activities for compliance were described. The results of the project were shared with specialists from PAHO and MINSA through several meetings and were reviewed and validated. These contents (the final version of the six standards) were included in the design of educational materials in collaboration with PAHO to be used by the multidisciplinary team. Additionally, multicenter working groups were created to revisit information about each standard and the design activities and tools aimed at implementing them in the country.

**Expansion of the proposal.** A regional committee of representatives from Argentina, Bolivia, Brazil, Chile, El Salvador,

Paraguay, Peru, and Uruguay held four online meetings from June through November 2021 to review the documents and reference materials, to conduct regional discussions relevant to PSC in their countries, and to integrate information into six technical documents, one for each of the six PCS standards. Each technical document provided answers to four questions: (a) What is known?; (b) What is proposed?; (c) What works?; and (d) How is it implemented?

In 2022, these documents were reviewed and validated by experts synchronously (six discussion meetings) and asynchronously (validation questionnaire) to develop six fact sheets and contents for a virtual course. The completed versions of the fact-sheets were forwarded to the PAHO editorial publication team to review, edit, and format. The project is currently expanding to other countries in LAC with the aim of developing implementation and evaluation guidelines.

## RESULTS

### Findings of the PSC assessment in Peru

Twenty-five health professionals (64% physicians, 28% psychologists, and 8% nurses) from nine institutions (five from Lima and four from the provinces) completed the survey. Nineteen providers agreed to be interviewed, however because of scheduling conflicts, only nine providers from eight institutions were interviewed. A total of 104 caregivers participated in the study, including mothers (n = 88), fathers (n = 10), and other relatives (n = 6).

Health professionals and caregivers rated the quality of PSC provided in their centers on a 1 to 5 scale (Table 1). The mean rating given by all health professionals was 2.84. Caregivers ranked each of the services separately; scores ranged from 2.42 to 3.42. The most frequently reported PSC services received by the caregivers was responses to questions regarding diagnosis and treatment, followed by attention to the emotional needs of patients and parents.

The frequency of PSC aligned with international standards was rated from “never” to “always” on a Likert scale. The mean frequencies across the standards ranged from 1.29 to 2.73 on a 1 to 3 scale, and from 1.56 to 3.12 on a 1 to 4 scale. To get closer to the level of compliance achieved for each standard,

the responses of health professionals from the same institution were grouped and categorized into four categories based on the frequency with which activities related to each standard were reported as being provided (Table 2). Results by each institution were also organized into a matrix for better comprehension.

Results of the analyses showed that PSC offered by institutions in Peru was inadequate and not aligned with international standards of care (8). The responses from each institution were mostly classified as “poorly provided” (49.8) and “not provided” (21.9). These deficiencies can be primarily attributed to limited human, material, and financial resources. Although some PSC-related activities were reported to be provided, they were often not included in institutional plans or assigned as tasks to health professionals. Instead, they were undertaken as personal initiatives that frequently demanded more time and resources than were available. Health professionals concurred that incorporating PSC into institutional policies and plans is essential to enhance the quality of care delivered to patients and their families. A strategic plan was designed to improve PSC through the adaptation of standards, the expansion of the proposal, and the production of materials and guides.

### Adaptation of PSC standards

The study findings were organized into five primary areas, with four additional cross-cutting approaches (Table 3). These results were presented for review by 12 health experts in Peru. We also conducted a virtual think-tank meeting with 50 professionals from across the country to validate the primary areas and cross-cutting approaches, establishing six standards for PSC in Peru. Additionally, the relevance of adapting PSC standards was rated 4.95 on a scale of 1 to 5.

### Validation and revision

After consulting with international experts and conducting group discussions, six PSC standards were proposed to define the services that pediatric patients with cancer and their families should be able to access, the competencies and qualifications that the multidisciplinary team must have to contribute to PSC, and the relevant approaches that must be incorporated (Figure 2). Special reports were produced to be reviewed by

**TABLE 1. Health professional and caregiver perceptions of psychosocial care (PSC), November 2020 to February 2021**

Respondent and topic	Total No. <sup>a</sup>	Perception of care, No. (%)					Mean (SD)
		Very bad	Bad	Regular	Good	Very good	
Health professional perception, overall	25	3 (12.0)	6 (24.0)	10 (40.0)	4 (16.0)	2 (8.0)	2.84 (1.11)
Caregiver perception							
Information about diagnosis and treatment	95	10 (10.5)	7 (7.4)	27 (28.4)	35 (6.8)	16 (16.8)	3.42 (1.17)
Parent's emotional needs	84	17 (20.2)	15 (17.9)	25 (29.8)	23 (27.4)	4 (4.8)	2.79 (1.19)
Pediatric patient's emotional needs	87	22 (25.3)	12 (13.8)	22 (25.3)	19 (21.8)	12 (13.8)	2.85 (1.39)
Other family members' emotional needs	55	16 (29.1)	10 (18.2)	17 (30.9)	10 (18.2)	2 (3.6)	2.49 (1.20)
Economic difficulties	66	26 (39.4)	11 (16.7)	9 (13.6)	15 (22.7)	5 (7.6)	2.42 (1.40)
Cultural and/or language differences	36	8 (22.2)	12 (33.3)	9 (25.0)	5 (13.9)	2 (5.6)	2.47 (1.16)
Recovering (re-entry school, survival)	57	12 (21.1)	8 (14.0)	15 (26.3)	18 (31.6)	4 (7.0)	2.89 (1.26)
Bereavement support	24	6 (25.0)	7 (29.2)	5 (20.8)	4 (16.7)	2 (8.3)	2.54 (1.28)

<sup>a</sup>Number of health professionals who rated the quality of PSC provided or number of caregivers who rated the quality of PSC received.

Source: Prepared by the authors from the study findings.



FIGURE 2. Adapted standards of psychosocial care in pediatric cancer

## PSYCHOSOCIAL STANDARDS OF CARE FOR PEDIATRIC CANCER: AN ADAPTED PROPOSAL

- The services childhood cancer patients and family should have access to



Source: Prepared by the authors from the study findings.

PAHO specialists, and several review and validation meetings were held with the PSC committee and experts from MINSA and other national and international organizations.

### Establishment of multicenter groups and development of materials

Most participants of the think-tank meeting (98%) expressed their eagerness to contribute to the development of ideas that could improve PSC through the adapted standards. They were willing to join multicenter working groups and to participate in the development of educational and intervention materials.

After validation of the six proposed standards, the information was adapted to seven scripts for audiovisual educational materials—i.e., one about the project and six about each one of the standards. Nine professionals, including psychologists, psychiatrists, clinicians, nurses, and social workers were filmed explaining the principal aspects of each standard. These videos were launched on PAHO TV on YouTube (14) and have been disseminated through national and regional academic societies.

With the support of MINSA, five working groups were established in Peru comprising 32 healthcare providers from 15 institutions. Each group had a coordinator and held bi-weekly, monthly, or bi-monthly meetings for at least one year to develop an activity or materials aligned with one of the first five psychosocial standards and incorporating the cross-cutting approaches for the sixth standard.

For the first standard (psychosocial assessment), a brief questionnaire known as ONPSIPED was tested in three hospitals.

Currently, it is being revised to enhance certain measures, to extend its implementation to more institutions, and to connect its results with protocols and interventions for the multidisciplinary team.

The workgroup for the second standard (psychoeducation and support) has developed an interactive guide for parents. The guide contains medical and psychological questions and answers, and is currently being reviewed by the PAHO team and a group of experts. The guide will be translated into Quechua and designed for usability.

The third standard group (mental health attention) developed a mental health screening tool for parents of children and adolescents with cancer (SNAC). Its first version has been evaluated by expert reviewers, and corrections for the final version are currently in progress.

For the fourth standard (return to daily life), a series of four stories were written for teachers, parents, and the public. Two stories are already published (15) and the other two are being validated.

The workgroup for the fifth standard (health team competencies and self-care) organized a 3-hour national meeting to strengthen PSC competencies. Information about these conferences is currently being incorporated into a document to be shared with professionals. This group is expecting to replicate the experience and establish it as an annual event. For the sixth standard, expert meetings have been scheduled and are currently in progress.

After five months of group work, an online seminar was held to present the progress, challenges, and forthcoming steps

**TABLE 2. Psychosocial standards of care delivered in Peru, by health professional (n=25) and institution (n=9)**

PSS item <sup>a</sup>	Health professional, mean (SD) <sup>b</sup>	Institution, No. (%) <sup>c,d</sup>				
		Frequently provided	Partially provided	Poorly provided	Not provided	Undetermined
PSS1: Assessment of psychosocial healthcare needs	2.38 (0.97)		4 (44.4)	4 (44.4)	1 (11.1)	
PSS2: Monitoring of neurocognitive problems						
During treatment	1.65 (0.65)			3 (33.3)	3 (33.3)	3 (33.3)
After treatment	1.74 (0.62)			5 (55.56)	3 (33.3)	1 (11.1)
PSS3: Screening in long-term survivorship						
Education/vocational	1.62 (0.58)			5 (55.56)	2 (22.2)	2 (22.2)
Relationship difficulties	1.96 (0.46)			7 (77.8)	1 (11.1)	1 (11.1)
Distress, depression, anxiety	2.08 (0.41)			9 (100)		
Risky health behavior	2.04 (0.46)			9 (100)		
PSS4: Psychosocial support and intervention	2.54 (0.72)		1 (1.11)	8 (88.9)		
PSS5: Assessment of financial needs						
At time of diagnosis	2.08 (0.57)	1 (1.11)	1 (1.11)	7 (77.8)		
During treatment	2.04 (0.68)	2 (22.2)		4 (44.4)		3 (33.3)
During survival	1.52 (0.82)			4 (44.4)	4 (44.4)	1 (11.1)
Bereavement	1.29 (0.62)				8 (88.9)	1 (11.1)
PSS6: Assessment of parental mental health needs						
At time of diagnosis	1.88 (0.53)		2 (22.2)	5 (55.56)	1 (11.1)	1 (11.1)
During treatment	2.73 (0.46)	1 (1.11)	2 (22.2)	4 (44.4)	1 (11.1)	1 (11.1)
During survival	1.75 (0.61)		1 (1.11)	5 (55.56)	1 (11.1)	2 (22.2)
Bereavement	1.42 (0.50)			2 (22.2)	4 (44.4)	3 (33.3)
PSS7: Psychoeducation, information, anticipatory guidance						
Diagnosis and treatment	2.44 (0.58)	2 (22.2)	1 (1.11)	6 (66.7)		
Hospitalization	2.68 (0.48)	4 (44.4)		5 (55.6)		
Psychosocial adjustment	2.24 (0.72)	2 (22.2)		6 (66.7)		1 (11.1)
PSS8: Psychosocial interventions for invasive procedures	2.36 (0.70)	4 (44.4)		4 (44.4)	1 (11.1)	
PSS9: Opportunities for social interactions						
During treatment	1.92 (0.76)		1 (1.11)	4 (44.4)	1 (11.1)	3 (33.3)
During survival	1.72 (0.68)			4 (44.4)	2 (22.2)	3 (33.3)
PSS10: Psychosocial support and interventions for siblings	1.56 (0.77)			5 (55.6)	3 (33.3)	1 (11.1)
PSS11: Support for school re-entry						
Hospital school program	2.40 (1.41)	2 (22.2)	1 (1.11)	3 (33.3)	3 (33.3)	
Support for parents	1.44 (0.71)			3 (33.3)	6 (66.7)	
Support for patients	1.56 (0.71)	1 (1.11)		2 (22.2)	6 (66.7)	
Support for teachers/school members	1.16 (0.37)			1 (1.11)	8 (88.9)	
PSS12: Adherence to treatment is assessed and monitored	2.20 (0.82)	2 (22.2)	1 (1.11)	4 (44.4)	2 (22.2)	
PSS13: Palliative care concepts throughout disease process and appropriate end-of-life care						
Palliative care concepts are introduced	2.76 (0.78)	1 (1.11)	2 (22.2)	6 (66.7)		
Developmentally appropriate end-of-life psychosocial care	2.48 (0.96)	1 (1.11)	3 (33.3)	2 (22.2)	2 (22.2)	1 (11.1)
PSS14: Psychosocial care after a child's death						
Contact to assess family needs after child's death	1.76 (0.66)		1 (1.11)	5 (55.56)	2 (22.2)	1 (11.1)
Bereavement support for families	2.12 (0.73)		2 (22.2)	5 (55.56)	1 (11.1)	1 (11.1)
PSS15: Communication, documentation, and training						
Psychologists integrated as integral team members	3.04 (0.84)		2 (22.2)	6 (66.7)		1 (11.1)
Psychiatrists integrated as integral team members	2.46 (1.22)		2 (22.2)	3 (33.3)	2 (22.2)	2 (22.2)
Psychosocial information documented in the medical record	3.12 (1.05)	1 (1.11)	5 (55.56)	2 (22.2)	1 (11.1)	
Total <sup>e</sup>	24 (7.6)	32 (10.2)	157 (49.8)	69 (21.9)	33 (10.4)	

<sup>a</sup>PSS refers to the 15 standards of care proposed by Wiener and colleagues,<sup>8</sup> and denoted as PSS1: Assessment of psychosocial healthcare needs; PSS2: Monitoring of neurocognitive problems; PSS3: Screening in long-term survivorship; PSS4: Psychosocial support and intervention; PSS5: Assessment of financial needs; PSS6: Assessment of parents mental health needs; PSS7: Psychoeducation, information, anticipatory guidance; PSS8: Psychosocial interventions for invasive procedures; PSS9: Opportunities for social interactions; PSS10: Psychosocial support and interventions for siblings; PSS11: Support for school re-entry; PSS12: Adherence to treatment is assessed and monitored; PSS13: Palliative care concepts throughout disease process and appropriate end-of-life care; PSS14: Psychosocial care after a child's death; PSS15: Communication, documentation and training.

<sup>b</sup>All services/activities were rated by health professionals on 1-4 and 1-3 scales with 1 indicating "never provided" (1-4 scale: PSS1; PSS4; PSS9; PSS10; PSS13; PSS14; PSS15; 1-3 scale: PSS2; PSS3; PSS5; PSS6; PSS7; PSS8; PSS11; PSS12).

<sup>c</sup>Number of institutions that were categorized for each item (service/activity)

<sup>d</sup>Responses of professionals from the same institution were categorized according to frequency of PSS reported (not provided: >75% "never"; poorly provided: >50% "never/occasionally"; partially provided: >50% "when needed/frequently"; undetermined: variety of responses)

<sup>e</sup>Number of times institutions were categorized in each category in all surveys (n=315)

**Source:** Prepared by the authors from the study findings.

**TABLE 3. Prioritized objectives or areas for psychosocial care in Peru after the national assessment**

Areas and/or objectives	Psychosocial needs detected (%)	International standards, PSS <sup>a</sup> and SIOP <sup>b</sup>	Results of interviews/meetings/group discussions with health professionals
<b>Early identification of psychosocial needs and other potential risks for treatment abandonment</b>	Caregivers reported experiencing problems that could be risks for abandonment of treatment and adjustment to the disease and treatment process: <ul style="list-style-type: none"> <li>Economic difficulties (88.5), work leave or resigning (70.2), moving to another city for treatment (57.7), family violence episodes (22.1)</li> <li>Other frequent responses to open-ended questions indicated the prevalence of distress, fear, lack of social support, and coping difficulties</li> </ul>	Assessment psychosocial needs, financial burden, and risk to adherence are contemplated in international standards. <ul style="list-style-type: none"> <li>Psychosocial assessment (PSS1)</li> <li>Assessment of financial needs (PSS5)</li> <li>Assessment and monitoring adherence to treatment (PSS12, SIOP9)</li> </ul>	<ul style="list-style-type: none"> <li>Early identification of psychosocial needs may allow the multidisciplinary team to intervene on time to prevent mental health comorbidity and abandonment of treatment.</li> <li>Information assessed by psychologists and social workers is poorly integrated and considered to benefit families, except for specific agreements with social foundations or organizations.</li> </ul>
<b>Promote psychosocial adjustment during treatment</b>	Caregivers surveyed referred difficulties with their patients throughout the disease process that require orientation and support: <ul style="list-style-type: none"> <li>Manage side effects from their patient treatment (76.0)</li> <li>Communication to patients about their disease and treatment (64.4)</li> </ul>	Multidisciplinary strategies for better adjustment during all disease processes are considered by international standards: <ul style="list-style-type: none"> <li>Communication of diagnosis (SIOP4)</li> <li>Guidance, psychoeducation, and support during treatment and invasive procedures (PSS7, PSS8, SIOP10; SIOP11)</li> <li>Palliative care transition support and promoting its concepts throughout the disease process (PSS13, SIOP6)</li> </ul>	<ul style="list-style-type: none"> <li>Informed patients and families adjust better and contribute to treatment.</li> <li>Substantial additional support interventions are made by motivation from non-mental health professionals (i.e., nurses, palliative care teams).</li> <li>Protocols and guidelines for specific procedures and moments of treatment are required and need to incorporate an interdisciplinary approach.</li> </ul>
<b>Specialized psychosocial support and interventions.</b>	<ul style="list-style-type: none"> <li>Caregivers reported several stressful events and risks for mental health that required specialized interventions including family and parenting problems (66.3 and 65.4, respectively)</li> <li>More than half of caregivers surveyed reported not having received psychological support for them or their patients (54.8 and 58.7, respectively)</li> </ul>	Mental health and other specialized psychosocial interventions are considered by international standards: <ul style="list-style-type: none"> <li>Psychosocial support and access to psychiatry (PSS4)</li> <li>Monitoring of neurocognitive problems (PSS2)</li> <li>Psychosocial care for family members (PSS6; PSS10; SIOP7; PSS14)</li> <li>End-of-life care and bereavement follow-up (SIOP6; PSS14)</li> </ul>	<ul style="list-style-type: none"> <li>Improving coping strategies in patients and their families is necessary to better adjustment and treatment adherence.</li> <li>Protocols that include mental healthcare should be implemented, especially in specific cases such as end-of-life care and bereavement.</li> <li>Lack of psychosocial specialized human resources is mentioned several times.</li> </ul>
<b>Reintegration resources</b>	Caregivers reported a low frequency of recreational and educational activities at their health center. <ul style="list-style-type: none"> <li>School hospital programs (10.6)</li> <li>Peer recreational activities (20.2)</li> </ul>	Services and interventions to promote the development of children and adolescents, despite the impact of the disease and treatment, are included in international standards: <ul style="list-style-type: none"> <li>Academic continuity and school re-entry (PSS11, SIOP2)</li> <li>Opportunities for social interactions (PSS9)</li> <li>Psychosocial support for survivors (PSS3, SIOP3)</li> </ul>	<ul style="list-style-type: none"> <li>Psychosocial support for school re-entry and daily life adaptation, which is not solely focused on the disease, should be provided throughout the disease process, and continue during survivorship.</li> <li>Psychosocial care for survivors should be included as part of their ongoing health follow-up.</li> </ul>
<b>Healthcare competencies and self-care</b>	Caregivers reported experiencing difficulties related to health professionals: <ul style="list-style-type: none"> <li>Communication problems (70.2)</li> <li>Perceived lack of empathy from the professionals towards their patients</li> </ul> Professionals reported: <ul style="list-style-type: none"> <li>Their efforts to improve psychosocial care were hardly supported and compensated at their centers.</li> <li>Experiencing high levels of distress and anxiety, especially when treating difficult cases</li> </ul>	Formation and care of health professionals, and recommendations to improve the alliance they make with families and patients are included in international standards: <ul style="list-style-type: none"> <li>Communication training (PSS15)</li> <li>Recognition, prevention, and remediation of burnout (SIOP8)</li> <li>Therapeutic alliance (SIOP5)</li> </ul>	<ul style="list-style-type: none"> <li>Self-care and mutual care are necessary for health teamwork to prevent burnout and promote well-being.</li> <li>Developing professional competencies aligned with psychosocial care can significantly improve the quality of care provided.</li> </ul>

**Cross-cutting approaches: Life course, rights, gender, and interculturalism**

Factors, such as health rights for minors, and difficulties in providing quality care or access to care due to differences in gender, culture, and life cycle were frequently mentioned in open-ended responses from caregivers and professionals, as well as in interviews and group discussions. These factors are often grouped under the term “cross-cutting approaches” in educational and health fields, and an adaptation for childhood cancer care is required.

<sup>a</sup>PSS refers to the 15 standards of care proposed by Wiener and colleagues,<sup>8</sup> and denoted as PSS1: Assessment of psychosocial healthcare needs; PSS2: Monitoring of neurocognitive problems; PSS3: Screening in long-term survivorship; PSS4: Psychosocial support and intervention; PSS5: Assessment of financial needs; PSS6: Assessment of parents mental health needs; PSS7: Psychoeducation, information, anticipatory guidance; PSS8: Psychosocial interventions for invasive procedures; PSS9: Opportunities for social interactions; PSS10: Psychosocial support and interventions for siblings; PSS11: Support for school re-entry; PSS12: Adherence to treatment is assessed and monitored; PSS13: Palliative care concepts throughout disease process and appropriate end-of-life care; PSS14: Psychosocial care after a child's death; PSS15: Communication, documentation and training.

<sup>b</sup>SIOP refers to the documents of recommendations proposed by the Psychosocial Committee of the International Society of Pediatric Oncology (Masera et al, 2006): SIOP1: Aims and recommendations; SIOP2: School/education; SIOP3: Long-term survivors; SIOP4: Communication of the diagnosis; SIOP5: Therapeutic Alliance; SIOP6: Terminally Ill children; SIOP7: Siblings of Children With Cancer; SIOP8: Recognition, Prevention, and Remediation of Burnout; SIOP9: Refusal, non-compliance and abandonment of treatment; SIOP10: Valid informed consent and participative decision-making; SIOP11: Non-conventional therapies in childhood cancer.

**Source:** Prepared by the authors from the study findings.

necessary to finalize each group's deliverables. Regional specialists were invited to participate in the event and provide their perspectives and feedback.

In 2022, the National School of Public Health of MINSA included a module about PSC standards in its comprehensive pediatric cancer training program. This module covered basic information about PSC in pediatric cancer, a description of the six standards, and strategies for implementation. To date, two editions of the training program have been implemented. More editions are expected to be conducted to incorporate recent evidence about the project and other important information about PSC.

### Expanding the proposal to Latin America and the Caribbean

To extend the proposal, a regional psychosocial committee was established and an operative plan was designed to validate the application of these standards in LAC countries and to promote its implementation and evaluation. In 2021, online meetings were held with professionals from eight LAC countries to share their experiences of PSC activities related to pediatric cancer in their respective countries. Additionally, asynchronous work was carried out that consisted of shared materials, reviewing synthesis of discussions, and preliminary products. In several instances, a lack of documentation to support these experiences was observed. This lack was identified as a substantial barrier that needs to be addressed to strengthen the evidence base for the work that has been done and to demonstrate the relevance and value of PSC.

To address this concern, the information was integrated into a technical document consisting of six modules. The contents were reviewed and validated by regional psycho-oncologists and mental health specialists from PAHO. Validation questionnaires were sent for each document to request quantitative and qualitative feedback on the pertinence, relevance, clarity, and writing style of each section. Additionally, six meetings were held to discuss the implementation section. The final design was disseminated on the PAHO website in English and Spanish (16) and is currently being translated into Portuguese. This information was also adapted for a virtual course for the multidisciplinary team; it consists of eight modules that are currently being revised.

## DISCUSSION

Delivering standardized PSC is necessary to enhance the quality of comprehensive care (17) and to attain improved outcomes in childhood cancer as mandated by the GICC objectives. The PSC standards for pediatric cancer care proposed in this project are the result of a thorough review of international standards (7,8), an assessment of their applicability to institutions in Peru, and validation for other countries in LAC and LMIC around the world.

The proposed standards for pediatric cancer care in this project represent an important step towards improving the quality of care for patients, drawing on both international evidence and local considerations, as well as clinical and academic perspectives. The first four standards include the PSC services and activities that were most common across international standards and were identified as priorities by our experts and local stakeholders. The fifth standard focuses on the psychosocial

training that the multidisciplinary team must have to provide high-quality care, including aspects to ensure their own mental health. Additionally, the sixth standard emphasizes cross-cutting approaches that are tailored to the specific needs of individual patients as well as their families. These approaches include culturally sensitive interventions, age-appropriate activities, and respect for patients' rights and gender equity.

These six standards encourage healthcare providers to consider the characteristics of the patient's life space (18), encompassing both their internal psychological aspects and the external environmental influences when designing interventions and support programs. Additionally, the standards promote the importance of addressing the parent-child bond as an integral part of the care provided during treatment. This approach seeks to promote secure attachments (19), enhancing the sense of security and emotional well-being, especially during times of separation, such as hospitalization. By considering the unique needs of each patient and their family, the healthcare team can provide more personalized and effective care for pediatric patients with cancer.

The adapted version of PCS standards does not aim to replace previous standards; rather it offers a model that can be tailored to the specific needs, prioritized objectives, and available resources of each institution and country. This ensures that interventions consistent with standards are feasible and achievable, with the expectation of reducing problems in implementation as reported by international standards (10). Enhancing PSC in childhood cancer treatment centers with these adapted standards ensures cultural relevance, optimizes resources, and allows for the establishment of short-, medium-, and long-term goals, positively affecting the well-being of pediatric patients with cancer and their families.

This project has achieved several milestones, thanks to the hard work of healthcare professionals in Peru and the wider LAC subregion. The participative approach allowed participants to share their perspectives, values, and reasoning on PSC, and encouraged their engagement with the project and its aims. Collaborative efforts among various institutions and specialties have laid the foundation for larger objectives that could improve childhood cancer health indicators through pediatric care. Sixteen educational materials have been developed about the adapted PSC standards of care for Peru—videos (14), fact sheets (16), virtual courses, brochures—and have been widely disseminated across academic, professional, and caregiver settings. Multicenter working groups used a participatory approach to design additional materials (20) that enhanced the contribution of each professional and empowered them to find solutions together.

This initiative faced some challenges, such as conducting virtual diagnoses due to the COVID-19 emergency, and adapting to changes in usual health services during the pandemic. Virtual meetings allowed greater access to professionals at a national level, and a recommendation is to update the national analysis based on adapted standards with a larger sample and mixed methodologies.

The integration of pediatric care into interdisciplinary work remains weak, partly because of the lack of evidence on its effectiveness and a shortage of psychosocial resources. Policies related to mental health do not usually consider the psychosocial effects of chronic diseases during childhood and adolescence, and policies on oncology only briefly mention



pediatric care. Developing national regulations and policies that promote access to and quality of pediatric care in LAC countries is necessary to improve childhood cancer health indicators and ensure sustainability.

A new strategic plan has been proposed at the regional level that includes the development of an implementation, evaluation, and results framework that considers psychosocial indicators. Validation with experts should be conducted and should involve more stakeholders and specialists from different areas in public health, oncology, hospital administration, and caregiving. A participative approach should be used to continue to provide the opportunity for all participants to be equitably involved and to build the project as a partnership through a co-creative process (20).

## Limitations

Our study has some limitations. The survey phase began during the COVID-19 pandemic; therefore, we had to ensure that the reported data corresponded to the usual operation of each center and not to the emergency period. In this regard, it is necessary to update the information according to the current care provided, including the missing health centers, and adjust the measurement in accordance with the adapted standards.

Additionally, there is insufficient documented information about psychosocial interventions in LAC. Therefore, we believe it is necessary to involve more psychosocial professionals from additional LAC countries to supplement the information of this study, strengthen the proposal, and facilitate its implementation.

## CONCLUSIONS

The findings of this project highlight the need for adapting and improving international standards for pediatric care in LMICs, such as Peru. Given that collaborative efforts and the development of educational materials have brought progress, challenges such as integrating pediatric care into interdisciplinary work and promoting policies for access and quality of care, must be addressed. To address these challenges, the proposed plan includes the development of an implementation, evaluation, and results framework that considers psychosocial

indicators. By implementing these measures, we can anticipate improvements in childhood cancer health indicators, thereby ensuring sustainable pediatric care in LAC. By addressing these challenges and implementing the proposed plan, improvement of childhood cancer health indicators can be expected, ensuring sustainable pediatric care in LAC. Overall, the findings of this study underscore the importance of tailoring global standards to local contexts and engaging local stakeholders in the process of adaptation to ensure effective and equitable healthcare delivery for all.

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## Normas para la atención psicosocial en el cáncer pediátrico: una propuesta adaptada para los países de América Latina y el Caribe

### RESUMEN

**Objetivo.** Resaltar los objetivos, logros, desafíos y próximos pasos a seguir en el marco de la Iniciativa Mundial contra el Cáncer Infantil de la Organización Mundial de la Salud (GICC, por su sigla en inglés), un proyecto diseñado para mejorar la atención psicosocial (APSS) en los centros de atención oncológica pediátrica de América Latina y el Caribe.

**Métodos.** El proyecto se inició en Perú, el primer país que puso en marcha esta iniciativa mundial, en noviembre del 2020. La fase de diagnóstico incluyó una encuesta y una entrevista semiestructurada con profesionales de la salud para evaluar las prácticas en materia de APSS en las instituciones, junto con una encuesta de evaluación de necesidades para las personas cuidadoras. En la segunda fase se elaboró un plan estratégico para abordar las necesidades reconocidas, el cual comprendió la adaptación de las normas en materia de APSS, la creación de grupos de trabajo multicéntricos, la ampliación de la propuesta y la elaboración de materiales.

**Resultados.** En el estudio se descubrió que no se proporcionaba una APSS adecuada y conforme a las normas internacionales. Se propusieron y convalidaron 6 normas adaptadas, y más de 50 profesionales de la salud de la región participaron en las actividades en línea dirigidas a apoyar el proyecto. En estos momentos está en marcha el proceso de implementación, que incluye la creación de 5 grupos de trabajo multidisciplinarios, un comité regional y la elaboración de 16 productos técnicos.

**Conclusión.** Este proyecto supone un gran avance para la mejora de la APSS de los pacientes pediátricos con cáncer y sus familias en los países de América Latina y el Caribe. La creación de grupos de trabajo y las intervenciones basadas en la evidencia permiten consolidar la propuesta y su implementación. Es necesario formular políticas de salud que comprendan una APSS basada en normas para lograr resultados sostenibles desde el punto de vista de la calidad de vida de los pacientes pediátricos con cáncer y sus familias.

### Palabras clave

Salud infantil; psicooncología; neoplasias; rehabilitación psiquiátrica; nivel de atención; América Latina; Región del Caribe.

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## Padrões de atendimento psicossocial em câncer pediátrico: proposta adaptada para países da América Latina e do Caribe

### RESUMO

**Objetivo.** Destacar os objetivos, as conquistas, os desafios e as próximas etapas da Iniciativa Global para o Câncer Infantil (GICC), um projeto criado pela Organização Mundial da Saúde para melhorar a atenção psicossocial em centros de câncer pediátrico na América Latina e no Caribe.

**Métodos.** O projeto foi lançado no Peru, o primeiro país focal da GICC, em novembro de 2020. A fase de diagnóstico incluiu uma pesquisa e uma entrevista semiestruturada com profissionais de saúde para avaliar as práticas de atenção psicossocial nas instituições, bem como uma pesquisa para avaliar as necessidades dos cuidadores. Na segunda fase, foi desenvolvido um plano estratégico para atender às necessidades identificadas, incluindo uma adaptação de padrões de atenção psicossocial, o estabelecimento de grupos de trabalho multicêntricos, a expansão da proposta e o desenvolvimento de materiais.

**Resultados.** O estudo constatou que, de acordo com padrões internacionais, a atenção psicossocial não estava sendo adequadamente oferecida. Seis padrões adaptados foram propostos e validados, e mais de 50 profissionais de saúde da região participaram de atividades on-line para apoiar o projeto. O processo de implementação está em andamento, com a formação de cinco grupos de trabalho multidisciplinares e um comitê regional e a produção de 16 relatórios técnicos.

**Conclusão.** Este projeto representa um avanço substancial para melhorar a atenção psicossocial para pacientes pediátricos com câncer e suas famílias nos países da América Latina e do Caribe. A criação de grupos de trabalho e intervenções baseadas em evidências fortalecem a proposta e sua implementação. É preciso desenvolver políticas de saúde que incluam atenção psicossocial segundo padrões estabelecidos para alcançar resultados sustentáveis na qualidade de vida das crianças com câncer e de suas famílias.

**Palavras-chave** Saúde da criança; psico-oncologia; neoplasias; reabilitação psiquiátrica; padrão de cuidado; Região do Caribe.

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