

Psychosocial Care for Pediatric Cancer

MODULE 01: Psychosocial assessment



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INTRODUCTION

The aim of the WHO Global Initiative for Childhood Cancer is to offer greater opportunities for cure and a full life for children and adolescents with cancer. This will be achieved to the extent that specific initiatives are carried out and action taken to provide comprehensive care that addresses not only medical care but psychosocial issues as well.

Psychosocial care addresses the social, psychological, spiritual, and functional dimensions of patients during the disease process. This care is not the exclusive purview of mental health workers but part of an interdisciplinary approach aimed at promoting treatment continuity and better psychosocial adjustment of patients and their families.

Evidence-based guidelines (1) and standards (2) have been developed to ensure the quality of that care. Groups of experts from Latin America and the Caribbean recently discussed and revised them to draft a proposal for six standards tailored to the characteristics and needs of the region.

This module presents key information about the psychosocial assessment standard, which emphasizes the importance of identifying psychosocial risk and protective factors in children and adolescents with cancer and their families in terms of their adjustment and treatment continuity. This will make it possible to provide them with timely, comprehensive care consistent with their needs.



1 Maserà G, Spinetta JJ, D'Angio GJ, Green DM, Marky I, Jankovic M, et al. SIOP Working Committee on Psychosocial Issues in Pediatric Oncology. *Med Pediatr Oncol*. 1993;21(9):627–628. Available from: <https://doi.org/10.1002/mpo.2950210903>.

2 Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer*. 2015;62(S5):S419–S424. Available from: <https://doi.org/10.1002/pbc.25675>.

1. WHAT WE KNOW

Advances in childhood cancer treatment have significantly extended patient survival; thus, efforts no longer center only on cure (and hence, reducing mortality), but also on early detection of disease, continuity of treatment, and minimization of toxicity. This has paved the way for a more holistic view of care that, in addition to all of the above, includes other outcomes in the improvement of health, such as adaptation or adjustment to the course of the disease and the subsequent period, the reduction of mental health sequelae, and greater psychological well-being.

These health outcomes derive from psychosocial and economic aspects that operate as risk or protective factors. Early identification of these factors can facilitate an appropriate and timely response, either mitigating the impact of the former or heightening the effect of the latter.

Psychosocial and economic risk and protective factors

Childhood cancer and its treatment are a stressful experience for patients and their families. The lower their stress level, the better they can handle the situation, since moderate stress activates functional coping mechanisms. However, when stress levels are high or accompanied by continuous anxiety and distress, they can jeopardize both the physical and mental health of patients.

Added to the stress caused by the disease and its treatment are other factors that influence access to health services, psychosocial adjustment to the disease, and treatment continuity. These factors can precede the cancer experience or appear or worsen during the course of the disease. Those that positively influence and promote the well-being of patients and their families are called protective factors, while those that negatively influence it are called risk factors.

These factors can be divided into specific spheres ranging from demographic, social, and economic conditions to particular characteristics of patient and caregiver behavior in the personal and family dimensions.

● *Socioeconomic and cultural factors*

Childhood cancer is a costly disease, not only because of the expense involved in its treatment but because household income is often adversely affected, as caregivers must take time off from work or do not have paid leave that allows them to spend time caring for the sick child.

In Latin America and the Caribbean, there are significant gaps in access to health services due to economic factors and because most hospitals (as well as schools and government buildings) are located in the heart of cities. Far from where people with fewer resources live (3), hospitals are not part of people's everyday life and access to them is limited. These factors are associated with poorer childhood cancer outcomes, due to delayed diagnosis, treatment dropout, and the possibility of recurrence. As a result, cancer is the second leading cause of death in children and adolescents up to the age of 19 (4) in Latin America and the Caribbean, with a survival rate of around 55% at best, in contrast to high-income countries, where the figure is over 80% (5).

³ The University of Manchester. *Childhood urban inequalities in Latin America* [undated]. Available from: <https://www.manchester.ac.uk/research/beacons/features/global-inequalities/childhood-inequalities-latin-america/>.

⁴ World Health Organization. *International Agency for Research on Cancer; Global Cancer Observatory*. Geneva: WHO; 2019. Available from: <https://gco.iarc.fr/>.

⁵ Pan American Health Organization. *55% of Children and Adolescents with Cancer Are Cured in Latin America and the Caribbean*. 15 February 2022. Washington, D.C.: PAHO; 2022. Available from: <https://www.paho.org/es/noticias/15-2-2022-55-ninos-adolescentes-con-cancer-se-curan-america-latina-caribe>.

Moreover, disparities based on ethnicity, language, and other cultural factors—such as beliefs and customs surrounding cancer, health, and disease—are known to be associated with access to and use of health services, communication, and treatment adherence (6).

● *Personal and family relationships*

The main caregivers' educational level, as well as their beliefs about diagnosis and treatment, influences how they assimilate medical information, their decision-making about such information, and their communication with others.

Families that have accurate information about the disease process and have regular and transparent communication about it with patients and health personnel achieve better psychosocial adjustment, well-being, and treatment continuity (7).

This adjustment is also influenced by a patient's or family's history of dealing with highly stressful situations. The premorbid psychosocial functioning of patients and their families influences how they cope with the stressful effects of the disease and its treatment (6, 8).

Family dynamics and relationships also play a role in

helping the different members of the family to take responsibility for what the treatment implies and adherence to it.

The degree of cohesiveness and perception of support from family members and the community are associated with better psychosocial functioning and less distress in both pediatric patients and their caregivers during the course of the disease. In contrast, the presence of previous serious conflicts, communication problems, inefficient distribution of responsibilities in the care of the patient and other children or logistics, or an inadequate social support system can pose a substantial risk.

● *Disease and treatment factors*

The psychosocial adjustment of patients can pose specific challenges, depending on the type of diagnosis and treatment. It is known that disease and treatment processes associated with serious neurological, physical, or functional sequelae cause greater stress, anxiety, or health complications (9), as do those involving distorted perceptions and drastic changes in self-image. The length of hospitalization, with separation from parental caregivers and restriction of social and learning opportunities, (10) can also be a stressor.

Related standards and guidance

The importance of identifying psychosocial needs and risks in childhood cancer through assessments or screenings in health centers has been documented by various experts and associations. A group of experts from renowned pediatric oncology institutions and organizations has issued 15 psychosocial standards of care (2). Among them is the need to periodically assess psychosocial and economic aspects for early identification of potential risks that require attention or treatment, as well as protective factors.

2 Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer*. 2015;62(S5):S419-S424. Available from: <https://doi.org/10.1002/pbc.25675>.

6 Kazak AE, Abrams NA, Banks J, Christofferson J, DiDonato S, Grootenhuis MA, et al. Psychosocial assessment as a standard of care in pediatric cancer. *Pediatr Blood Cancer*. 2015;62(S5):S426-S459. Available from: <https://doi.org/10.1002/pbc.25730>.

7 Samudio A, Figueredo D, Torres R, Mattio I, Servin J, Alcaraz E, et al. Estrategias para prevenir el abandono de tratamiento en niños con cáncer en un país en vías de desarrollo. *Pediatría (Asunción)*: Órgano Oficial de la Sociedad Paraguaya de Pediatría; 2013;40(2):119-123. Available from: <https://dialnet.unirioja.es/servlet/articulo?codigo=4485977>.

8 Alderfer MA, Long KA, Lown UT, Marsland AL, Ostrowski NL, Hock JM, et al. Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psychooncology*. 2009;19(8):789-805. Available from: <https://doi.org/10.1002/pon.1638>.

9 Kurtz BP, Abrams NA. Psychiatric aspects of pediatric cancer. *Child Adolesc Psychiatr Clin N Am*. 2010;19(2):401-421. Available from: <https://doi.org/10.1016/j.chc.2010.01.009>.

10 Kazak AE, DiDonato S, Schneider SJ, Pai ALH. Assessing Family Psychosocial Risks in Pediatric Cancer. In: Abrams NOTMAR, Muriel QA, Wiener L (eds.). *Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care*. Springer International Publishing; 2016.

In Peru, a study based on these standards (11) was conducted, gathering quantitative and qualitative information to ascertain the degree of compliance with them and design a proposal for psychosocial standards of care tailored to the national situation and with the potential for expansion to Latin America and the Caribbean. The experts noted

the importance of psychosocial and financial assessments to identify risk and protective factors. However, the results showed that all institutions did not conduct these types of assessments and that in those that did, their frequency and methodology varied widely. The conclusion is that there should be a psychosocial standard of care.

2. WHAT WE PROPOSE

We propose that psychosocial assessment be adopted as a psychosocial standard of care for childhood cancer in Latin America and the Caribbean.

Psychosocial assessment standard

“Children and adolescents with cancer and their families should undergo psychosocial assessments that provide the different types of professionals with the information they need to apply a holistic approach focused on well-being, adjustment to the disease process, and treatment adherence.”

Psychosocial assessment is defined as the process of identifying the psychological, social, and economic needs, resources, and risks of patients and their families. This assessment can be done initially, at key points such as the opening of the medical record or the diagnostic period, and, later, systematically, through periodic monitoring of the variables that require it.

Based on the evidence from other countries and on the opportunities for dialogue and consensus with professionals from Latin America and the Caribbean (11, 12), a series of recommendations are proposed for this assessment:

- The assessment must be conducted using a basic instrument or tool. This may be an interview guide or a form or standardized instrument.
- The priority areas should include sociodemographic, educational, and economic aspects; living conditions; access to health services; family dynamics and support; and the psychological adjustment of patients and their families.
- The questions should be correlated with evidence-based psychosocial risk and resilience indicators and prioritized in terms of the outcomes to be influenced (e.g., treatment adherence).
- The questions should be posed in clear and simple language and designed to elicit precise answers that facilitate their entry and systematization in the medical record.
- The response form should enable quick determination of potential courses of action based on specific needs (e.g., referral to specialized support), which should be explained to the family in a timely manner.
- The assessment should be standardized and compulsory, supported by the necessary documentation and institutional action, and resources should be allocated for it.

11 Trigo, V., Vásquez, L., & Villegas, M. (2021). Standards for the psychosocial care of children and adolescents with cancer: A Pilot study in Peru. *SIOP ABSTRACTS. Pediatr Blood Cancer*, 68: e29349. <https://doi.org/10.1002/pbc.29349>

12 Trigo, V., Pascual, C., Vásquez, L., Maradiegue, E., Jimenez, P., Bernedo, H., Sierralta, M., Ruda, L., Salazar, Y., Ugaz, C., Morales, R., Vargas, D., Alvarez, S., Almiron, C., Atausinchi, W., Bernal, C., Castro, C., Campos, A., Galarza, G., Garcia, E., López, M., Madueño, K., Mafaldo, A., Salazar, Y., Plasencia, O., Rosado, S., Villegas, M., Pereda, M., Rios, M., Benites, M., Contreras, D., Velásquez, O., Méndez, T., Perina, E., Rossell, N. (2022). A participative process to adapt and implement psychosocial standards of care in childhood cancer in Peru. *SIOP ABSTRACTS*.

There are different opinions about the degree of specialization required for those who conduct the assessment. Some think that any professional from the multidisciplinary team can do it after receiving training, while others believe that psychologists or social workers should be responsible. This will depend on the criteria and conditions established for the assessment.

It should be emphasized that the object of this standard is not to issue a psychological diagnosis or conduct in-depth assessment of pediatric patients and their families but to obtain key information on psychological, social, and economic variables for guiding and adapting the care they will receive.

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The Global Initiative for Childhood Cancer standard and objectives

The WHO Global Initiative for Childhood Cancer seeks to achieve at least a 60% childhood cancer survival rate globally by 2030. Patients and their families have psychological, social, and economic characteristics that can serve as a resource or a barrier to achieving this, so it is advisable to identify them in a timely manner through psychosocial assessments.

Applying the psychosocial assessment standard in centers for childhood cancer care in Latin America and the Caribbean could yield a series of benefits:

- Health personnel would have useful information to

provide empathetic care tailored to the particular needs of patients and their families.

- Timely referral to specialized support, if necessary, preventing subsequent complications that could threaten patient well-being or treatment continuity.
- General data on families' psychosocial risk and protection indicators would be recorded more broadly in coordination with government entities, so that these data become part of the documentation for the analysis of childhood cancer in each locality, country, or region. This would promote a holistic approach to the problem and could facilitate strategic planning.

3. WHAT WORKS

International scientific data on the efficiency and effectiveness of psychosocial assessments abound, though they are scarce in Latin America and the Caribbean. Documentation from countries that have conducted these assessments and experts agree that a firm theoretical foundation, appropriate instruments and tools, and a committed multidisciplinary team are key for the usefulness of these assessments.

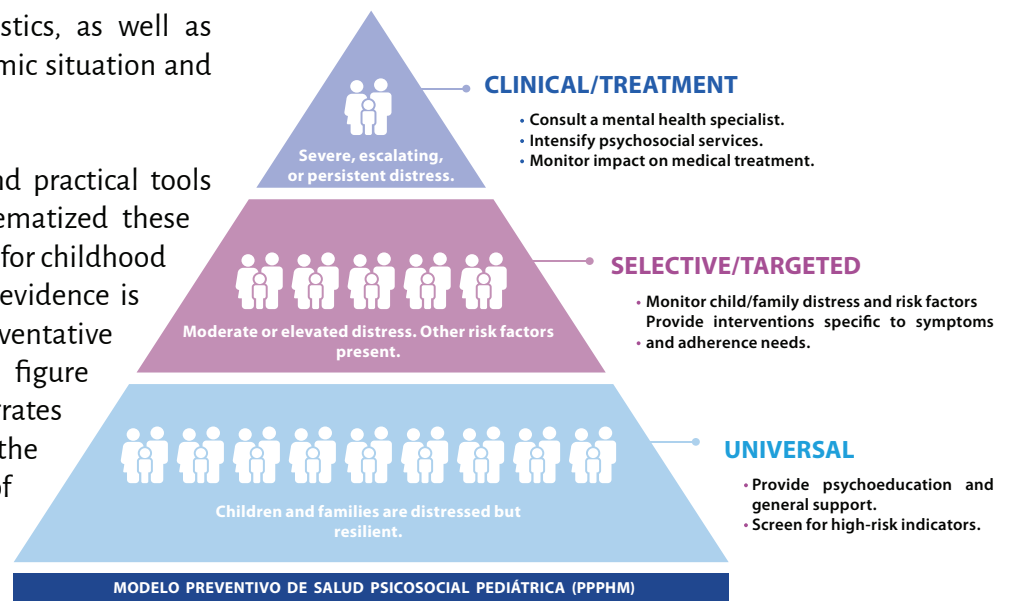
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Having a firm foundation with regard to psychosocial risk and protective factors and models in childhood cancer

Psychosocial care of pediatric cancer patients must start with a socioecological approach that puts them and their families at the center and recognizes their personal and family characteristics, as well as their

social, cultural, and economic situation and dynamics. Psychosocial care of pediatric cancer patients must start with a socioecological approach that puts them and their families at the center and recognizes their

personal and family characteristics, as well as their social, cultural, and economic situation and dynamics.

Different theoretical models and practical tools for specific contexts have systematized these factors. One of the latest models for childhood cancer with a growing body of evidence is the Pediatric Psychosocial Preventative Health Model (PPPHM) (see figure below) (13). This model integrates theoretical aspects and the available evidence on aspects of psychosocial risk in childhood cancer, distinguishing risk levels and connecting each of them with specific types of treatment: universal, selective, and clinical. This model is the theoretical basis for the psychosocial assessment tool (PAT) (14), detailed information on which is provided below.



Furthermore, just as the APGAR test assesses the health of newborns, the Family APGAR (15), developed in the 1970s, is a model that uses the same acronym to represent basic aspects of family functioning:

adaptability, partnership; growth, affection, and resolve.

These aspects are assessed through self-reporting of the satisfaction of family members. This facilitates an initial approach to identifying cases marked by conflict or family dysfunction that requires monitoring and guidance.

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Using instruments and tools tailored to the situation in each region or country

Psychosocial risk assessment in childhood cancer in high- or upper-middle-income countries has been characterized by the use of one or more validated psychological screening instruments (e.g., for depression or anxiety), use of a quick and simple screening instrument, or use of structured clinical interviews with standardized questions.

The most common instruments used for an initial assessment or psychosocial and economic screening include:

- **The distress thermometer (DT)¹.** One of the most common tools used in adult oncology, its use is

being extended to the pediatric context with a version tailored to parents (DT-P). It consists of a graphic representation of a thermometer with a scale ranging from 1 to 10, depending on the degree of stress communicated by the individual. Individuals may also be asked to rate their stress resulting from practical, physical, family, or other problems. The DT form is simple, brief, and focused, making it easier for pediatric patients and their parents to complete.

- **The Psychosocial Assessment Tool (PAT)².** A brief tool for measuring family risk based on the PPPHM model described above, it consists of

13 Kazak, A. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): research, practice and collaboration in pediatric family systems medicine. *Fam Syst Health*, 24(4): 381-395.

14 Smilkstein G. The Family APGAR: a proposal for family function test and its use by physicians. *J Fam Practice*. 1978; 6(6):1231-1239. (ENLACE 1) <https://www.psychosocialassessmenttool.org/>

15 Smilkstein G. The Family APGAR: a proposal for family function test and its use by physicians. *J Fam Practice*. 1978;6(6):1231-1239.

the following seven subscales: family structure or resources, family problems, social support, stress reactions, family beliefs, child problems, and sibling problems. It has strong psychometric properties and has been translated from English into other languages, including Spanish and Portuguese. A study is currently under way in Brazil using this tool that also includes feedback strategies and delivery of the results to the family.

In addition, to identify initial needs, some experts in Latin America and the Caribbean use other tools or activities, such as:

- **Interviews with parental caregivers and direct interaction with pediatric patients** to assess their social support and affect.
- **Self-created checklists** about the main risk factors for treatment continuity.
- **The ONPSIPED form**, a psychosocial assessment tool developed by a group of Peruvian

professionals to support effective application of the psychosocial assessment standard under the Global Initiative for Childhood Cancer. Aimed at identifying the family's main problems and sources of support, it includes a series of questions divided into four areas: sociodemographic data, family dynamics and social support, clinical data, and socioeconomic data. A pilot study was conducted in three institutions, and adjustments are currently being made for the final version.

The evidence and experts subsequently pointed to the importance of creating results-based channels for care and follow-up to meet to identified needs and evaluate their evolution.



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The multidisciplinary team: involved and committed to psychosocial assessment

The majority of indicators in psychosocial assessment are related to psychology or social work. However, to facilitate this assessment and ensure that it benefits patients and their families, the multidisciplinary health team must be involved. For it to get involved and actively participate in the activities involved in the standard, it must first recognize their importance and perceive their benefits. Only then will it be able to commit to them. Some of these benefits on the operational side are the following:

- The assessment will provide professionals with a record summarizing the psychosocial and economic needs of patients and their families, enabling them to make use of this information in the care they provide and facilitate identification of the course to follow in psychosocial care for each family. For example, when health professionals know a family's main stressors, it is easier to dialogue because they are alert to anything that can trigger a crisis or make timely referrals to specialized services if necessary.
- Providing caregivers with the results of

this assessment, including information on psychosocial risk and protective factors, will enable them to better control their situation, allowing them to make decisions that promote the integral well being of pediatric patients and their families, in addition to fostering a partnership with the health team, which is essential for patient adherence to treatment.

- Including psychosocial indicators in institutional, local, or national cancer registries could help inform prevention and intervention policies and programs at various levels.

4. HOW TO PROCEED

Implementation of the standard requires efforts by the various actors involved (patients and families, health professionals, institutions, local and national authorities, etc.). These efforts must be expressed in the planning of specific activities to achieve the standard's objectives, in the implementation of the activities, and in action that guarantees the necessary conditions for accomplishing this.

Institutions can comply with the standard by:

- having systematic assessment tools or protocols that include evidence-based indicators.
- entering psychosocial assessment information in the medical record.
- providing the facilities for professionals to take this assessment into account in their interventions through a biopsychosocial approach, and for timely referral to specialized support, when needed.

Steps for implementation of the standard

• Analysis of needs and resources

To apply the psychosocial assessment standard in a particular institution, locality, or region, it is essential to know basic aspects of their situation, prepare an appropriate design, and determine how the activities will be carried out and evaluated.

Before designing the proposed psychosocial assessment, mapping should be done, including:

1. Identification of the main health outcomes to be impacted (e.g., treatment dropout) and in what timeframe (short, medium, long term).
2. Identification of potential indicators and instruments that address the risk and protective factors associated with these outcomes, and identification of tools for measuring them. These tools may already exist, whether adapted or new, based on the characteristics of the context and objective (e.g., an assessment form).
3. Definition of the conditions necessary for using the tool (environment, human and material resources, available complementary support networks, etc.).

4. Identification of conditions that can be met in advance, those that can be sought, and those that are not currently possible, in order to perform the assessment and adequately respond to its results.

• Design of the proposal

Para elaborar la propuesta de evaluación psicosocial como estándar a implementar, se debe tener en claro lo siguiente:

1. **Characteristics of the assessment:** tool, forms, and application period, personnel in charge, times when it will be performed, etc.
2. **Necessary resources:** settings, staff training, material resources, etc.
3. **Internal management of the results:** entry of the information in the medical record, dissemination of the information among the professionals involved, referral flow chart, if applicable, etc.
4. **Communication with and feedback to the family:** objective, format to be followed, responsibilities, referral route or general recommendations, etc.

5. **Ethical aspects:** informed consent and verification of the institution's capacity to respond to identified needs, etc.
6. **Cross-cutting approaches:** clear guidelines and orientations for each cross-cutting approach, as indicated in the standard for cross-cutting approaches in psychosocial care for childhood cancer (life course, rights, interculturalism, and gender) or other illnesses that should be considered.

The design of the proposed assessment must be reflected in a document that meets the requirements of the respective institution or entity.

- **Resources for application of the standard**

Simultaneously or prior to application, efforts should be made to inform health workers and the authorities about the importance of psychosocial assessment and its benefits.

The proposal should include the aforementioned points in an operational plan with clear and specific indicators, in order to evaluate achievements and the potential for improvement.

Application of the standard will improve to the extent that its activities are part of the institutional plan and

the necessary means for them are guaranteed, with a clear timetable and appropriate division of roles and resources.

The commitment of the respective entities must be explicit, and roles and tasks must be assigned to ensure compliance.

- **Monitoring and evaluation**

Based on the previously identified indicators, an assessment strategy must be developed to:

- Evaluate the process by monitoring achievements, constraints, and the use of resources for the standard's activities. To do so, the aspects described in the design of the psychosocial assessment must be considered qualitatively (e.g., Is the assessment being conducted in the planned time frame? Are the results being managed properly?) and quantitatively (e.g., the percentage of new patients assessed in a given time period).
- Evaluate the impact in terms of the expected outcomes (in the medium and long term), taking relevant quantitative and qualitative aspects into account (e.g., number of referrals to the specialized mental health service).

CONCLUSIONS

- Psychosocial assessment is the first psychosocial standard of care for childhood cancer. It focuses on identifying the psychosocial resources and risks of patients and their families to offer a holistic approach.
- Assessment of risk and protective factors for the psychosocial adjustment of children with cancer and their families allows their needs to be addressed in a timely manner and mitigates the impact on health outcomes.
- Most of the evidence on the usefulness of psychosocial assessments has been obtained from upper-middle- and high-income countries; however, there are some emerging initiatives in Latin America and the Caribbean.
- Application of the psychosocial assessment standard involves a series of steps that are detailed in this module. Implementing each of them requires the support and commitment of the respective entities.

USEFUL LINKS

- Pan American Health Organization. Cancer in childhood and adolescence. Washington, D.C.: PAHO; [undated]. Available from: <https://www.paho.org/es/temas/cancer-ninez-adolescencia>
- Pan American Health Organization. World Initiative against Childhood Cancer in Peru: Psychosocial Committee. Washington, D.C.: PAHO; [undated]. Available from: <https://www.paho.org/es/iniciativa-mundial-contra-cancer-infantil-peru/iniciativa-mundial-contra-cancer-infantil-peru-11>
- Pan American Health Organization. PAHO TV: Estándares de cuidado psicosocial en childhood cancer. Washington, D.C.: PAHO; [undated]. Available from: <https://youtu.be/6kNCUboenlw>
- Pan American Health Organization. PAHO TV: Estándar 1: Evaluación psicosocial. Washington, D.C.: PAHO; [undated]. Available from: <https://youtu.be/VVqGOuNhaPo>
- Psychosocial Assessment Tool (PAT). Available from: <https://www.psychosocialassessmenttool.org/>

