

# Psychosocial Care for Pediatric Cancer

## MODULE 04: *Resources for a Gradual Return to Daily Life*



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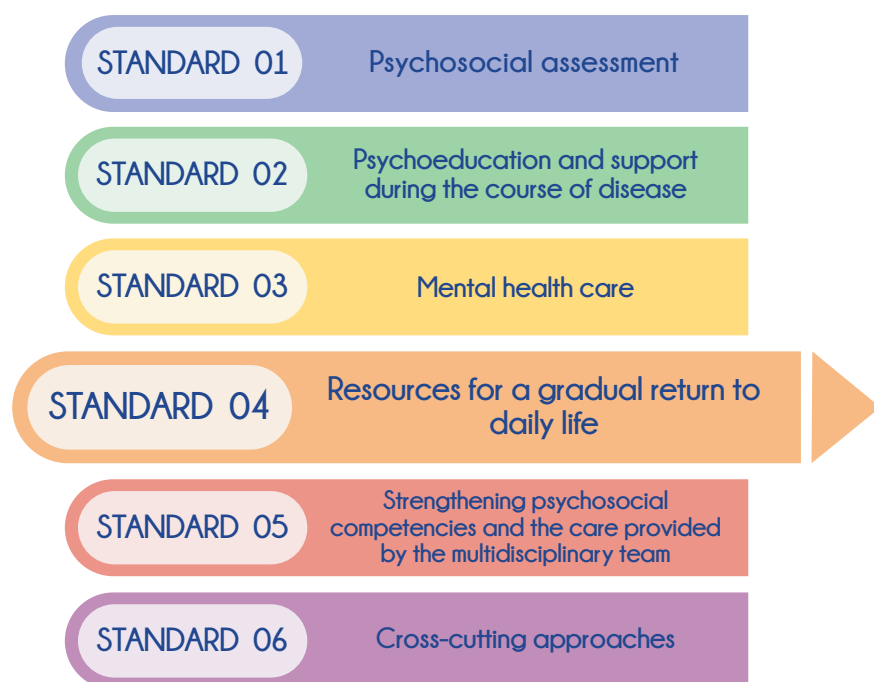
# INTRODUCTION

The diagnosis and treatment of a childhood cancer results in changes that disrupt or alter patients' social relationships and education. Special consideration should be given to this, since childhood cancer survival rates are constantly improving, provided the disease is diagnosed and treated on time. Patients can therefore be expected to gradually resume their everyday activities and continue their path to adulthood. Psychosocial care should be geared to successful treatment, facilitating patients' access to resources that will enable them to continue their development.

A series of evidence-based guidelines (1) and standards (2) has been developed to ensure quality of care. Groups of experts from Latin

America and the Caribbean recently discussed and revised them to develop a proposal for six standards tailored to the characteristics and needs of this subregion.

This module presents key information about the standard for resources aimed at a gradual return to life. The emphasis is on offering patients the opportunity to access a variety of resources (academic, social, etc.) to facilitate a healthy return to their daily lives after cancer treatment, while anticipating potential psychosocial disorders in survivors.



1 Masera 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

More than 80% of children with cancer in high-income countries are cured. This is not the case in many low- and middle-income countries, where the cure rate is around 20% (3). These glaring differences explain why each country prioritizes different objectives and different moments to allocate its resources and measures.

Medicine has clearly established specific interventions for different points in the disease: prevention involves early detection; during the disease, treatment is offered and efforts are made to alleviate symptoms; and afterward, appropriate follow-up focused on preventing sequelae or recurrence. However, in the psychosocial domain, measures are usually limited, focusing on problems that emerge during treatment and often neglecting action to promote post-treatment patient adjustment.

## *Cancer's impact on daily life*

The daily life of children and adolescents consists of opportunities for socialization, play, and learning that are essential for their growth and development. Cancer impacts these dimensions not only during active treatment but also after discharge.

### ● *Constraints on social interaction*

Friendships and other social relationships vary in importance at different times in people's lives. In childhood and adolescence, they play a key role, since they are the first non family ties that are established. Moreover, they influence the way children see themselves and how they feel and behave.

Cancer patients may find their social interactions limited, either because of extended periods of hospitalization or isolation if their defenses are low, or because they have less time to socialize due to the demands of treatment. The length of these periods of social constraint varies but is usually not less than 8 to 12 months, which can cause patients to feel different from their friends and peers, which results in loneliness.

During the disease process, pediatric patients may get to know and interact with other children in a similar situation, which can be a facilitator, since they are in the company of someone experiencing something

similar. However, if the person who they interact with develops complications, it can be a stressor.

### ● *Academic disruption*

School is one of the main opportunities for children and adolescents to socialize and learn. This is where they develop skills and competencies and interact with their friends, peers, and adults who are not their relatives.

When school-age pediatric patients are diagnosed with cancer, they often miss many classes either because of constant medical tests, intensity of treatment, side effects, or complications associated with the process as a whole.

Disruption of school life represents a major loss for children, not only because of its effects on socialization, but because it can limit learning, which jeopardize their development and maturation, and in turn, their sense of security and self-esteem.

3 Pan American Health Organization. Implementación de la Iniciativa Mundial de la OMS contra el Cáncer Infantil en América Latina y el Caribe. Washington, D.C.: PAHO; 2021. Available from: <https://iris.paho.org/handle/10665.2/53921>



Health professionals agree that academic continuity during the disease process (e.g., through hospital classrooms) and school re-entry promote positive patient adjustment. A holistic effort among the actors involved in the three main settings (hospital, home, and school) is therefore important.

### ● *Psychosocial sequelae in survival*

The primary health goal in pediatric oncology is to ensure patient survival while safeguarding quality of life. This implies the hope that patients will not only survive the disease but emerge with the fewest possible medical and psychosocial sequelae.

The evidence suggests that survivors may exhibit sequelae in their growth, development, and sexual maturation, as well as various organic dysfunctions. All this in itself has an emotional impact on childhood cancer patients and requires care for their future life.

At the psychosocial level, the data show cognitive, emotional, behavioral, and social repercussions for some survivors -- for example, a deterioration in their

social relationships, lower educational and vocational achievement, and greater vulnerability to mental health problems (4).

It should be noted that not all survivors are affected in this way or, if they are, the effects are not necessarily serious. Specialists recommend medical and psychosocial monitoring strategies to detect and address any such problems in a timely manner and ensure patients' quality of life.

Another important aspect of the care provided to this population is the language used. Experts from Latin America and the Caribbean note that some pediatric patients who have completed their treatment and are disease-free dislike the term "survivor." Some health professionals are also reluctant to use that term because it can jeopardize the degree of health care and follow-up that these patients pursue and can lead to considerable confusion should the cancer recur. In light of this, some professionals have opted to use the term that best identifies the intervention's target group.

### *Related standards and guidance*

There are international standards for psychosocial care, including those proposed by the International Society of Paediatric Oncology (SIOP) (1, 5) and by a group of professionals from Canada, the Netherlands and the United States of America (2) supported by the Mattie Miracle Foundation. These served as the basis for the proposal described in this module and the rest of the series.

Experts agree on the importance of including interventions that enable pediatric patients to re-enter their daily life; for them to do so, three essential aspects are considered:

- Opportunities for pediatric patients to socialize with their friends and peers.

- Support for academic continuity and school re-entry.
- Psychosocial follow-up for survivors.

Studies have been conducted in several countries to determine whether the services offered by health centers correspond to the proposed international criteria; this was found to be the case in approximately one third of institutions (6). Initiatives in these domains have been documented in Latin America and the Caribbean, but their frequency varies. The greatest contributions have been made through collaboration with external entities and professional initiatives, or because the institutions have provided the facilities for them.

1 Masera 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. (2015) 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>.

4 Annett RD, Patel SK, Phipps S. Monitoring and assessment of neuropsychological outcomes as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(S5):S460-S513.

Available from: <http://doi.org/10.1002/pbc.25749>.

## 2. WHAT WE PROPOSE

*We propose gradual re-entry into daily life as a psychosocial standard of care for childhood cancer in Latin America and the Caribbean.*

### Resources for a gradual return to daily life

*“Throughout treatment, children and adolescents with cancer and their families must have access to resources that allow interaction with their peers, as well as academic continuity. Psychosocial follow-up of child survivors is also necessary.”*

Resources for re-entry consist of services, interventions, and materials that contribute to the continuity of socialization, play, and learning during the treatment of children with cancer and, beyond that, during survival. Although they are primarily patient oriented, they should also include other relevant actors, such as parents and school personnel.

The gradual nature of the standard implies that this type of resource should not be limited to survival but included throughout the disease process, promoting a holistic view of children's recovery and contributing to their quality of life.

### *The Global Initiative for Childhood Cancer standard and its objectives*

The WHO Global Initiative for Childhood Cancer aims to increase country capacity to provide quality services to pediatric cancer patients. Its efforts are therefore geared not only to increasing survival but to improving children's quality of life.

Adopting the standard will provide resources to facilitate achievement of the following objectives:

- Reduction of the impact of social and academic constraints during the disease process.
- Promotion of healthy development of children that contributes to their growth and maturation.
- Prevention or timely treatment of clinical symptoms or other psychosocial problems.

## 3. WHAT WORKS

The results of interventions for the healthy re-entry of children with cancer into daily life require further investigation. Some longitudinal survivor follow-up studies have been conducted, but they focus on medical, rather than psychosocial aspects. Regarding the latter, there are some cross-sectional studies and achievements from the evaluation of certain interventions. (4, 7, 8).

## Promoting opportunities for play and socialization

### • Play as a health resource

Play is essential for development because it contributes to physical, emotional, cognitive, and social well-being. Play is directly associated with children's health.

During illness, play is also a valuable tool for children's and adolescents' recovery, as seen in the results of recreational programs and interventions in various hospitals (9, 10, 11). Some of these results indicate that play:

- Helps to reduce the fear, frustration, and anxiety associated with hospitalization.
- Increases their sense of control and self-esteem.
- Reduces stress behaviors and improves coping strategies.
- Allows for greater expression of emotional and information needs.
- Facilitates greater participation in and commitment to treatment.

### • Socialization as a health resource

Pediatric cancer patients can socialize with other people their age who are uninvolved in the disease process, such as classmates or cousins. However, they can also forge ties with other patients of a similar age in the hospital. In both cases, socialization enables these patients to develop interpersonal skills. It also amplifies a highly valuable health resource: social support.

The available evidence shows that support groups, camps, online forums, and peer videoconferencing offer positive opportunities for social connection and adjustment. That is why more and more health centers have introduced opportunities to facilitate this type of interaction, such as facilities with areas for group activities or visits (12).

## Facilitating academic continuity

### • Academic continuity outside of school

Children and adolescents have the right to an education. Mechanisms must therefore be introduced during their disease process to guarantee this right. This has led to the emergence of hospital classroom programs, home-based academic follow-up, and home schooling. These activities have proven beneficial for these patients' learning and their rapid adjustment to greater academic demands after their re entry.

In order for academic continuity programs outside the school to yield good results, planning for educational

activities must not be limited to contents and strategies; rather, the curriculum must be adapted and documented for validation by the educational system. It is also advisable to maintain constant contact with the school and continuously update these strategies, adapting them to patients' health status.

### • Promoting a healthy return to school

Attending school allows patients to live normally and distracts them from concerns about their disease. Therefore, it is important that patients return to class as soon as they can, with the necessary precautions.

9 Gonzales R, Benavides G y Montoya I. (2000). Preparación psicológica basada en el juego. In: Ortigosa J, Quiles M, Méndez F. (coords). Manual de psicología de la salud con niños, adolescentes y familia. Madrid: Psicología Pirámide.

10 Wiener L, Battles H, Mamalian C, Zadeh S. ShopTalk: a pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer. *Support Care Cancer*. 2011;19:1049-1054. Available from: <http://doi.org/10.1007/s00520-011-1130-z>.

11 Ullan AM, Beller MH. Integrative pediatrics and child care play as a source of psychological well-being for hospitalized children: Study Review. *Integrative Pediatrics and Child Care*. 2019;2(1):92-98. Available from: <https://doi.org/10.18314/ipcc.v2i1.1613>.

12 Christiansen HL, Bingen K, Hoag JA, Karst JS, Velázquez-Martin B, Barakat LP. Providing children and adolescents opportunities for social interaction as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(S5):S724-S749. Available from: <https://doi.org/doi: 10.1002/pbc.25774>.

School re-entry programs and services that involve the health team, patients, families, and educators have made significant contributions, including:

- Better academic performance and lower levels of

depression in children.

- Less bullying and better social adjustment and learning.
- Positive attitudes among teachers and peers about the patients' return.

### *Sensitizing the environment*

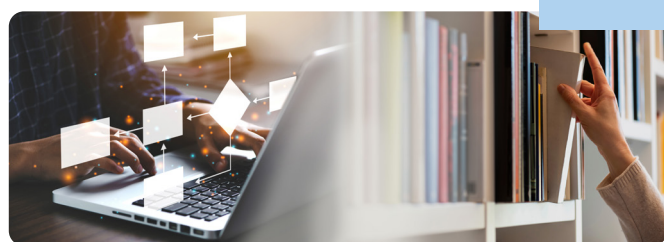
For children or adolescents to continue or resume their normal activities (socialization with other people their age, return to school, etc.), people must make the commitment to receive and welcome them – especially their families, teachers, principals and other school personnel, peers, and other social actors.

In Latin America and the Caribbean, different resources are provided to inform these actors about basic aspects of cancer and the school re-entry process. This is primarily accomplished by distributing material and organizing events or activities on specific topics.

The website of the Natalí Dafne Flexer Foundation in Argentina offers a variety of resources and materials to provide caregivers and other adults with information and tools such as a teacher's guide to support the

re-entry process (13). It also publishes articles about survival in childhood cancer patients.

In Peru, under the Global Initiative for Childhood Cancer, a multidisciplinary working group has created a series of stories (14), including two for teachers (15, 16), that are available online; it has also donated some hard copies to the Ministry of Education for distribution and will offer training opportunities in this regard.



### *Follow-up and support*

As mentioned earlier, survivors may experience late medical effects, as well as weakened social relationships and problems in other vital areas of development.

Sustained follow-up programs are rare but have made significant progress in the prevention and timely treatment of clinical symptoms and psychosocial problems in survivors. They also provide evidence on post-treatment psychosocial indicators.

Hospitals have difficulty sustaining psychosocial follow-up programs for survivors because they lack the resources to attend to patients in the chronic phase. Much of this demand has been covered by foundations and organizations that offer interventions and services for survivors. The following are some examples in Latin America and the Caribbean:

- In Colombia, Fundación Sanar Niños con Cáncer has two programs, one focusing on occupational

13 Medín G. La escolaridad del niño con enfermedad oncológica: Guía para docentes. Buenos Aires: Fundación Natalí Dafne Flexer; 2007. Available from: <https://www.fundacionflexer.org/escolaridad-del-nino-enfermo.html>.

14 Trigos V, Pascual C, Vásquez L, Maradiegue E, Jiménez P, Bernedo H, et al. A participative process to adapt and implement psychosocial standards of care in childhood cancer in Peru. 2022; SIOP ABSTRACTS.

15 Pan American Health Organization. Grupo multidisciplinario del Estándar 4. Profesora Gloria ¿Susanita tiene cáncer? Una guía dirigida a docentes. Washington, D.C.: PAHO; 2021. Available from: <https://www.paho.org/es/documentos/profesora-gloria-susanita-tiene-cancer-guia-dirigida-docentes>.

16 Pan American Health Organization. Grupo multidisciplinario del Estándar 4. Después del hospital, Susanita regresa al cole: Una historia dirigida a docentes. Washington, D.C.: PAHO; 2021. Available from: <https://www.paho.org/es/documentos/después-hospital-susanita-regresa-al-cole-historia-dirigida-docentes>.



therapy and the other on improved survival, bringing children together through recreational and informational resources to promote a return to school and a life project.

- In the Plurinational State of Bolivia, four foundations – Fundación Afanic Bo, Fundación Oncofeliz, Fundación Luz de Esperanza, Fundación

Nuestra Esperanza – have implemented projects for return to the classroom and emotional, educational, and other support for young survivors.

- In Argentina, Fundación Natali Dafne Flexer provides follow-up for survivors through emotional support.

## 4. HOW TO PROCEED

Implementation of the standard requires efforts both inside and outside the hospital. Therefore, the activities that will be carried out must be based on interinstitutional partnerships and supported by regulations.

**Institutions can meet the standard by developing activities and protocols for the preparation of resources to facilitate the re-entry of pediatric cancer patients, including:**

- Creating hospital areas for play and social interaction.
- Holding recreational and educational workshops.
- Setting up hospital classroom programs.
- Advising staff at the school that will receive the patient.
- Holding survivor encounter groups.
- Designing a flowchart for regular contact with survivors.

### *Steps for implementation of the standard*

To promote pediatric patients' gradual re-entry into daily life, it is essential to be knowledgeable about basic aspects of the situation of the institution, locality, or specific region where it will be applied, develop an appropriate design, and determine how the activities will be carried out and evaluated.

1

#### *Analysis of needs and resources*

Before the resource proposal for gradual re-entry is designed, mapping should be done that includes:

1. Identifying the current situation in each area addressed by the standard (interaction with peers, academic continuity, and survivor follow-

up) as a potential baseline.

2. Based on this, set the priority re-entry objectives for the short, medium and long term in the areas addressed by the standard.
3. Indicate the types of services, resources, or interventions required to meet the objectives; bear in mind that they must be evidence-based and tailored to the characteristics of the

population and the point at which they are provided.

4. State the necessary conditions for application of the standard, based on the priorities (setting, human and material resources, partnerships with other institutions or entities, etc.).
5. Explore previous resources for similar objectives (e.g., previous programs at the center). Assess the relevance and feasibility of their use or adaptation.

## 2

### *Design of the proposal*

Following the preliminary analysis, the proposal for implementation of the standard must be designed. This will require the following:

1. Describe the types of activities or interventions needed to meet each priority objective (e.g., a hospital classroom program) and describe the characteristics of each.
2. Necessary resources: Specify the necessary resources (human resources, physical spaces, staff training, material resources, etc.) and the strategic partnerships that should be forged.
3. Responsibilities: Assign responsibilities and indicate the tasks involved in each case.
4. Ethical aspects: Informed consent and verification of the institution's capacity to meet the identified needs, etc.
5. Cross-cutting approaches: Clear guidelines and orientations for each cross cutting approach that should be considered in the design, as indicated in the standard for cross-cutting approaches in psychosocial care for pediatric cancer or other diseases, described in Module 6 of this series (18) (life course, rights, interculturalism, and gender).

Once these elements have been determined, the pertinent documentation should be prepared in keeping with the requirements of the respective institution or entity.

## 3

### *Implementation of the standard*

Simultaneously or prior to implementation, efforts should be made to inform health personnel and the authorities about the importance of pediatric patient

re-entry. Re-entry should be a strategy throughout the process, not only for survivors.

The design of the proposal should include the aforementioned points in an operational plan with clear and specific indicators, so that achievements and potential improvements can be assessed.

Application of the standard will improve to the extent that its activities are part of the institutional plan and comply with existing mental health guidelines and orientations. Similarly, the means for its application must be guaranteed.

For some activities or the use of some resources, strategic partnerships must be created (e.g., with the school of origin, ministry of health, childhood cancer organizations or foundations, etc.). The commitment of the respective entities must be explicit in order to ensure that the objectives are met.

## 4

### *Monitoring and evaluation*

Based on the previously identified indicators, a strategy must be developed to evaluate achievements with respect to pediatric patients' re-entry into daily life, as proposed by the standard. To this end, as in other modules, two types of evaluation are proposed:

- Evaluation of the process by monitoring achievements, constraints, and the use of resources for the standard's activities, considering the aspects described in the design of proposal and how much corresponds to intra- or extra-hospital variables.
- Assessment of the impact on the expected outcomes (in the medium and long term), considering relevant quantitative and qualitative aspects.

For activities under the psychosocial care standard to be sustainable, they must follow the current regulations governing cancer and mental health care, the rights of children and adolescents, and the management of social vulnerabilities. Otherwise, changes must be made to tailor these mandates to the cancer context.

# CONCLUSIONS

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- Comprehensive care for pediatric cancer patients should promote not only their physical recovery but also their emotional and social recovery, so that they can gradually participate in activities consistent with their needs beyond the disease phase and re-enter daily life.
- The resources for the re-entry of pediatric cancer patients are all interventions, services, and materials that promote the continuity of socialization, play, and learning processes during treatment and then during survival.
- The standard calls for the provision of such resources to childhood cancer patients.
- Much of the effort in these areas is carried out by foundations and organizations, either independently or in partnership with health and educational centers.
- To apply the standard, it is important to identify the priority needs in each domain (social, academic, survival, etc.), propose objectives to meet them, and determine the methodology and partnerships necessary to carry out the activities.

The activities will be sustainable insofar as they comply with current regulations governing education, health, and the rights of children and adolescents.

# USEFUL LINKS

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- Fundación Natalí Dafne Flexer. Buenos Aires. Available from: <https://www.fundacionflexer.org/>.
- Fundación Sanar niños con cáncer (Colombia). Available from: <https://sanarcancer.org/>.
- 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: Estándar 4: Recursos para la reincorporación progresiva a la vida cotidiana. Washington, DC: PAHO; [undated]. Available from: [https://youtu.be/GU\\_M1XuTdqY](https://youtu.be/GU_M1XuTdqY).
- Pan American Health Organization. PAHO TV: Estándares de cuidado psicosocial en childhood cancer. Washington, DC: PAHO; [undated]. Available from: <https://youtube/6kNCUboCnlw>.



