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INTRODUCTION

Childhood cancer is not a single process but a multiplicity of events that occur from a suspected or confirmed diagnosis to the course of the disease itself, depending on the prognosis. At each point, both patients and their caregivers must adjust to changes and deal with considerable stress and anxiety.

Psychosocial care is designed to respond to this situation through interventions that promote an understanding of the diagnosis and treatment, emotional management of the challenges involved, and preparation for procedures.

Evidence-based guidelines (1) and standards (2) have been developed to ensure the quality of this 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 this subregion.

This module presents key information about psychoeducation and support during the course of disease, describing the activities and interventions of the multidisciplinary team during active treatment to facilitate adjustment to the disease and reduce stressors that could lead to treatment dropout.

1. WHAT WE KNOW

When a child or adolescent is diagnosed with cancer, new needs emerge as a result of the disease process and treatment. All of these should be considered in the care provided both to patients and their families in order to promote their psychosocial adjustment.

Childhood cancer: need for psychosocial adjustments

- Receiving information and counseling

Pediatric cancer patients and their primary caregivers stress the need for information and counseling about diagnosis, treatment, and course of the disease (3).

Clear and timely information is essential in order to facilitate their understanding of complicated events and prevent the development of maladaptive beliefs and attitudes that could affect well-being and treatment continuity.

A caregiver’s need for information does not wane with the progression of the disease; quite the contrary, depending on how it progresses, new questions may arise. In their search for answers, caregivers may be inundated with an overwhelming amount of information that is hard to absorb. An external strategy or guide is therefore necessary to help them absorb it little by little and prioritize the most useful content.

The information needs of pediatric patients will vary with their individual characteristics and cognitive and emotional development. However, in all cases, both children and adolescents need to be informed and trust that their caregivers and healthcare providers will be honest with them.

Children and adolescents with cancer who have basic information about their disease and its treatment are better able to cope with the effects, as they have more resources for reducing anxiety and actively participating in their own recovery.

- Moderating the emotional impact

Sadness and fear are among the most common emotions of cancer patients and their caregivers. They are a response to the changes wrought by the disease, the effects of treatment, and the potential losses.

Younger children express emotions through their behavior. As they grow, they can verbalize and channel them in new ways. In contrast, adolescents’ emotional experience is more intense and complicated, fluctuating between inhibition/repression and expression/channelling. As a result, they need opportunities to be heard and validated, and to deal with their emotions. They also need counseling on strategies for understanding and handling what they are feeling – all of which will make it easier for them to cope with stressful situations, help them collaborate in their treatment, and contribute to their well-being.

Caregivers also experience intense emotions but often ignore them because they put the experience of the pediatric patient in their care first and may feel guilty if they do otherwise. They commonly repress these emotions and become isolated, posing a risk to their mental health and psychological adjustment throughout the process.

Managing pain

Pain is a multidimensional experience that affects both physical and emotional aspects and is influenced by subjectivity. In the case of cancer, pain may be the result of medical procedures and treatments rather than the disease itself, which can raise doubts about their effectiveness, creating confusion and causing patients and caregivers to reject them.

For better pain management, patients need psychosocial interventions and support strategies from the health team; similarly, parents and caregivers need support in order to cope with witnessing the pain of pediatric patients and learn how to support them.

Playing an active role in recovery

Pediatric cancer patients and their caregivers rely on health professionals for answers and for the certainty they need in order to make decisions and adjust to the disease. However, if they feel they have little control over what happens to them, they may feel frustrated and helpless, and lose their self-confidence.

Preparing them for future events (e.g., surgery) through adequate information and knowledge about each person’s role (caregivers, professionals, and patients) promotes a sense of control (4), reduces uncertainty, and heightens their sense of agency, promoting treatment continuity.

Having social support

Childhood cancer can affect relationships among family members and between them and other people, even though this is when there is the greatest need for different types of social support (instrumental, emotional, informational, etc.).

Having family or community support cushions the impact of stress and fosters positive emotions. We know that, in addition to support, good communication between adults and pediatric patients about procedures contributes to more coherent memories of the experience (5), reducing the likelihood that patients will relive it as a trauma.

Related standards and guidance

International psychosocial standards of care were proposed by the International Society of Paediatric Oncology (SIOP) (1, 6) in the 1990s. In 2015, a group of experts from Canada, the United States, and the Netherlands published studies on psychosocial care, with support from the Mattie Miracle Foundation (2). All of these works served as a model for the proposal contained in these modules.

Experts agree that, as part of the care provided by the multidisciplinary team, patients and their caregivers should have resources and interventions that meet the adjustment needs that arise during the course of the disease in terms of information, preparation for invasive treatment and procedures, transition to palliative care, etc. All of

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We propose that psychoeducation and support during the course of childhood cancer and its treatment be adopted as a psychosocial standard of care for childhood cancer in Latin America and the Caribbean.

All members of the multidisciplinary team can play an essential role in psychosocial care as proposed in this standard.

From the moment the diagnosis is conveyed and throughout the disease process, health personnel can help patients and their families understand the situation by offering information and counseling, facilitating their adjustment to the entire process through emotional support.

Based on the evidence from other countries and the conclusions drawn from the opportunities for dialogue with Latin American and Caribbean professionals (9), we propose the following activities aimed at meeting the standard:

- Introduce care protocols that include psychoeducation and support interventions and resources for children with cancer and their caregivers, based on the needs generated by each procedure or stage (e.g., hospitalization, start of chemotherapy, transition to palliative care, etc.).
- Schedule regular activities for patients or family members that offer them support, counseling, and psychoeducation (e.g., workshops, support groups, etc.).
- Provide trustworthy and easily accessible sources of information for pediatric patients and their families.
- Counsel caregivers about strategies they can employ with pediatric patients at critical moments.
- Encourage professionals and family members to engage in open and honest communication about procedures.

References:

The Global Initiative for Childhood Cancer: standard and objectives

The WHO Global Initiative for Childhood Cancer (10) seeks to improve childhood cancer survival rates through early detection, treatment continuity, and better services. This will require the adoption of protocols that facilitate care in the different spheres -- in this case, in the psychosocial sphere.

According to this standard, facilitating access to psychoeducational and support resources for pediatric patients and their caregivers can help meet the initiative's objectives in the following ways:

- Patients and their caregivers will be able to make informed decisions because they will understand the different variables involved in treatment continuity. More information will enable them to play a more active role and increase their sense of security and control, as well as their trust in the health team.
- Patients will be able to prepare themselves adequately for medical procedures, promoting adaptive coping and reducing children's distress. This fosters treatment continuity and lowers the risk of psychological comorbidity.
- Palliative care will be addressed through a holistic approach, with counseling for families. This will reduce the impact of the children's physical and psychological symptoms and promote better long-term outcomes.

3. WHAT WORKS

Ensuring comprehensive well-being in childhood cancer involves the delivery of psychosocial care across the entire package of care provided in health centers. Therefore, in addition to interventions that require mental health specialists, other psychosocial interventions and activities for pediatric patients and their families have been identified that can be handled by the multidisciplinary team.

The most well-known psychosocial care strategies during the course of the disease and treatment are psychoeducation, counseling, and the facilitation of social support. They may be part of the support for coping with the day-to-day challenges of the disease or consist of specific interventions for particular times or situations (e.g., preparation for surgery, transition to palliative care, etc.). It should be noted that specialized mental health interventions (e.g., psychotherapy, neuropsychological assessment, psychiatric consultation, etc.) are not considered, as they are included in the standard for mental health care (see Module 3) (11).

Benefits of psychoeducation and psychosocial support in pediatric oncology

- reduce stress and its associated symptoms.
- promote psychosocial adaptation and adjustment.
- increase the sense of control and degree of self-sufficiency.
- improve quality of life
- increase trust in health personnel and collaboration with treatment.

Psychoeducation and counseling

In the case of psychosocial care for childhood cancer, psychoeducation consists of interventions in which a professional facilitator (a trained health professional) provides information to patients or their families about basic aspects of the diagnosis, treatment, and course of the disease through a two-way process; receives information and clarifies earlier information; and provides counseling for the development of decision-making and psychosocial adjustment skills.

Psychoeducation can include the following elements:
- Individual or group interventions.
- Material resources for wide dissemination (e.g., guides, stories, etc.).
- Counseling or anticipatory guidance to prepare caregivers and patients for what to expect in the months and years to come.

Finally, these interventions can be part of a medical protocol (e.g., for all patients recently admitted or undergoing certain treatments) or focused on specific needs.

Support during hospitalization

Hospitalization can be a stressful experience for patients and their caregivers as it involves changes in their routine, separation from loved ones and a familiar environment, and constant uncertainty.

The health team should serve as a source of social support for patients and their families, providing both information and education, as noted in the previous section, as well as emotional support through humanized care receptive to the emotional experience.

Health teams that include recreational support activities and strategies for patients enable them to familiarize themselves with the hospital environment and regulate the emotions linked to the entire process, thus contributing both to their adjustment and treatment adherence.

Preparation for procedures

Patients have to undergo medical procedures and treatments that can cause anxiety, pain, and other problems. To prevent this, it is useful to prepare them for the procedures. This consists of support and the use of evidence-based techniques to reduce uncertainty and manage potential anxiety about

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*Socialization with peers and academic continuity activities (e.g., hospital classrooms) are also useful for this purpose. These are detailed in Module 4 on resources for a gradual return to daily life (13).
Palliative care consists of a series of benefits or activities designed to prevent and alleviate suffering throughout the course of the disease and improve the quality of life of patients, families, and caregivers. All this can be accomplished through early detection and proper assessment and treatment of pain and other biopsychosocial problems associated with the disease (12).

There is growing evidence that children with cancer and their families must understand the concept of palliative care early on in the disease in order to facilitate coping with the diagnosis, increase their understanding of complicated treatment plans, manage the symptoms of the disease, and reduce emotional and physical suffering, regardless of the prognosis.

Palliative care is not limited to the context of terminal illness but is part of a holistic approach. If a patient’s prognosis is poor, a family support and grief counseling system should be established. Module 3 on mental health care addresses this point in greater depth (11).

Psychoeducational resources in Latin America and the Caribbean

- **Brazil: Projeto Dodói**

  The objective of this project is to promote the well-being of hospitalized pediatric cancer patients, with emphasis on coping with the stress factors associated with hospitalization and treatment. It consists of a recreational kit with activities that promote psychoeducation, distraction, emotional regulation, and communication with the child.

- **Argentina: Fundación Natali Flexer**

  Since 1995, the foundation has been producing a wealth of psychoeducational material for patients, caregivers, professionals, and others in the form of guides, stories, brochures, and other items that can be downloaded free of charge on registration with the foundation's website (see Useful Links at the end of this module). In addition, the foundation constantly collaborates in training activities and interventions that benefit the pediatric cancer population.

- **Peru: Global Initiative for Childhood Cancer**

  Under the Global Initiative for Childhood Cancer, PAHO has produced several resources that directly or indirectly contribute to meeting the standard's objectives:


  - **Educational sessions for parents**: audiovisual material on topics related to diagnosis, treatment, palliative care, etc. Available on PAHO’s YouTube channel (see Useful Links at the end of this module). [https://www.youtube.com/c/PAHOTV](https://www.youtube.com/c/PAHOTV)

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4. HOW TO PROCEED

Some institutions have services or activities that, while consistent with the standard, are not necessarily systematically or constantly so. Applying the standard requires efforts on the part of the different actors involved (patients and families; health professionals; institutions; local, regional, and national authorities). These efforts must be reflected in the planning of specific activities to meet the standard’s objectives, implementation of the activities, and action that guarantees the necessary conditions for all this to happen.

Institutions can meet the standard by including psychoeducational and support resources and interventions in one or more of the following areas in their multidisciplinary practice:

- Understanding of the diagnosis and treatment
- Preparation for invasive procedures.
- Management of treatment of side effects.
- Adjustment to the hospital setting.
- Transition to palliative care.

Steps for application of the standard

Application of the psychoeducation and support standard in a particular institution, locality, or region requires knowledge of basic aspects of its situation, the preparation of an appropriate design, and the determination of how the activities will be carried out and evaluated.

1. Analysis of needs and resources

Before designing the psychoeducation and support proposal, mapping should be done that includes:

1. Identification of the main health outcomes to be impacted (e.g., psychological adjustment to the disease) and the time frame (short, medium, or long term).
2. Identification of the times when the need for specific interventions to achieve these outcomes arises (e.g., diagnostic information, pre-surgery preparation, support in the transition to palliative care, etc.).
3. Determination of which activities, resources, or interventions will respond to these needs (e.g., workshops, production of materials, etc.).
4. Determination of the prioritized conditions necessary for implementation (environment, human and material resources, complementary support networks, etc.); verification of how many are met and which should be included (e.g., some interventions may already have been carried out and need only to be improved or included in a protocol).
5. Review of past experiences and resources external to the institution, especially those that are evidence-based, to respond to these needs or situations.
Design of the proposal

Based on the information from the mapping, specific objectives are established and a proposal is designed for psychoeducational and support activities for application of the standard. For this design, the following should be indicated:

1. Timing of the intervention: e.g., first hospital admission.
2. Objectives: state the objectives with their respective short-, medium- and long-term indicators, based on the specific situation.
3. Methodology: describe the type of activity, intervention, or resource (e.g., psychoeducational program).
4. Necessary resources: list the human resources, settings, training, or materials needed.
5. Responsibilities: describe the potential services and the members of the multidisciplinary team that might carry out the activities, as well as the tasks in each case.
6. Ethical aspects: informed consent and verification of the institution’s capacity to meet the needs identified, etc.
7. 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 childhood cancer or other illnesses (life course, rights, interculturalism, and gender perspective).

Once these areas have been determined, the pertinent documentation should be prepared, based on the requirements of the respective institution or entity.

Action for implementation

Simultaneously or prior to implementation, efforts should be made to inform health personnel and the authorities about the role of health professional role in psychosocial adjustment and, specifically, the activities that should be undertaken to meet the standard.

The proposal design document should include the above-mentioned points in an operational plan with clear and specific indicators, so that achievements and the potential for improvement can be assessed.

Implementation of the standard will improve to the extent that its activities are part of the institutional plan and the necessary means for this to happen are guaranteed, with a clear timetable and appropriate division of roles and resources.

Some activities or the use of some resources are commonly implemented through strategic partnerships (e.g., with organizations or foundations that support children with cancer). Arrangements for this should be made in advance, with a clear definition of roles and responsibilities in each case. The relevant entities must therefore make an explicit commitment to ensuring that the objectives are met.

Monitoring and evaluation

Based on the predetermined indicators, a strategy should be developed to assess the psychoeducation and support provided in order to:

• Evaluate the process by monitoring achievements, constraints, and use of resources for the activities to meet the standard. To do so, the elements described in the design of the implementation proposal should be considered.
• Assess the impact on the expected outcomes (in the medium and long term), taking relevant quantitative and qualitative aspects into account.

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

- Childhood cancer creates a series of needs in patients and their caregivers that must be promptly addressed. These needs may be related to information, emotional or social support, pain management, etc.
- The psychoeducation and support standard for childhood cancer is designed to ensure that children with cancer and their families receive psychoeducation and support to facilitate their adjustment to the changes wrought by the disease and prepare them for procedures, offering a holistic view of palliative care as a measure to reduce suffering. The standard’s objectives are related to the goals of the WHO Global Initiative for Childhood Cancer.
- Important initiatives are under way in Latin America and the Caribbean for the launch of activities and the development of psychoeducational materials, some of which are freely available on the Internet (see Useful Links at the end of this module).
- Application of the standard in each institution or locality must meet priority needs and must be tailored to the specific characteristics and resources. We therefore suggest starting out with a needs and resource assessment.
- We recommend that the members of the multidisciplinary team and the respective entities be familiar with the proposal and be able to commit to its implementation.
USEFUL LINKS
