Psychosocial Care for Pediatric Cancer

MODULE 03: Mental Health Care
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Cancer poses new and challenging situations for pediatric patients and their families, requiring continuous psychosocial adaptation and adjustment. These situations can cause the expected emotional and behavioral reactions to crisis and uncertainty, as well as psychopathological states that require specialized diagnosis and treatment.

Psychosocial care for pediatric cancer patients should include specialized mental health interventions aimed at promoting well-being, preventing psychological or psychiatric comorbidity, and managing specific situations that arise during adjustment to the disease.

Evidence-based guidelines (1) and standards (2) have been developed to ensure the quality of such 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 mental health care, which involves interventions by mental health specialists for the prevention and management of psychological and psychiatric symptoms in pediatric cancer patients and their families, as well as sequelae specific to the disease and its treatment.

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1. WHAT WE KNOW

Mental health and specialized psychosocial care

A cancer diagnosis has a serious emotional impact that threatens the stability and future prospects of patients and their families. It is therefore a period of crisis for them. Similarly, the disease and treatment process requires constant adjustments, as it disrupts normal life, causes stress, and elicits many emotions that are hard to manage. All this can lead to the emergence or exacerbation of psychological or psychiatric symptoms, undermining quality of life.

Psychological and psychiatric services receive requests for care from patients and their families (parental caregivers, siblings) for mental health issues and specific situations during the course of the disease. They require specialized support and follow-up, such as neuropsychological monitoring or grief counseling for families mourning the death of a child.

- **Mental health of pediatric patients**

Mental health care for children and adolescents involves consideration of cognitive, behavioral, and emotional indicators throughout their development, as well as social skills and adjustments to their environment. Children and adolescents with a cancer diagnosis face many changes that can adversely impact these indicators and pose a risk to their recovery and quality of life.

Pediatric patients can exhibit signs of anxiety, depression, behavioral issues, and other problems. (3, 4). One of the challenges of a mental health diagnosis in this population is distinguishing the symptoms of a particular disorder (e.g., depression) from the physical conditions of the cancer itself and the use of drugs or treatments such as radiation or chemotherapy.

- **Mental health of parents and caregivers**

Having a child diagnosed with cancer can be a disruptive and frightening experience with a profound emotional impact. It also involves significant economic costs, adjustment to a new environment, and balancing the demands of daily living with those of the care of the sick child and other stressors.

Pediatric patients require constant monitoring, and the burden of care often falls on a single person, who becomes the primary caregiver. This is usually the mother, whose role makes her more likely to suffer from greater exposure to depression, anxiety, social isolation, and other symptoms.

The evidence suggests that caregivers typically neglect their own physical and mental health (5), since most of their time and energy is devoted to caring for the sick person. This puts them at constant risk of developing psychopathological symptoms or the intensification of such symptoms.

The division of labor in the family should promote balanced care for the patient, without overburdening any one of its members. Social support is an essential protective factor for caregivers. Paradoxically, however, many parents tend to distance themselves from friends and other family. We also know that many couples find themselves immersed in conflict. They may disagree about the patient’s care or have problems dealing with their own and their spouse’s suffering.
The siblings of children and adolescents with cancer are exposed to considerable stress. Most improve within the first year of the diagnosis but may relapse with the patient’s deteriorating health or death.

The experience is stressful due to several factors: first, the emotional impact of the disease process and, second, the changes to which they must adjust. Siblings must deal with significant disruption in their lives due to the demands of care and household responsibilities, reduced contact with the sick family member, and less attention from parents, as well as challenges maintaining normalcy and participating in normal developmental activities.

The siblings of pediatric cancer patients are at higher risk of emotional and behavioral problems, such as anxiety, depression, post-traumatic stress, lower quality of life, less utilization of medical care, and poor academic and social performance (6). Nonetheless, more evidence is still needed about the mental health of this group.

Pediatric patients whose cancer or treatment affects the central nervous system may develop acute or long-term neuropsychological sequelae. These sequelae are more common at earlier ages, when there is a long interval between the diagnosis and treatment, and when treatment is most intense.

The main sequelae are in the domains of intelligence, attention, memory, language, executive function, neurosensory functioning, perceptual processing, and processing speed (7). If they go undetected and are not treated in a timely manner, these sequelae can significantly affect other aspects of patients’ lives, such as independence, self-esteem, the ability to meet life goals, etc.

Throughout the course of the disease, the families of pediatric cancer patients experience a series of losses, leaving them in a constant state of mourning. However, the most difficult moment is the one following the death of the patient, which represents another crisis, with intense emotions that are hard to manage and future prospects that are seriously altered.

The reactions that appear during bereavement can resemble psychopathology, and while they are not necessarily that, the family experiences lasting negative effects. If these reactions persist and the loss cannot be assimilated, the family can experience higher rates of depression, anxiety, post traumatic stress, etc. Interventions focused on anticipatory grief management, bereavement support, and the prevention or treatment of pathological grief will be very important in helping the family.

The importance of providing specialized mental health and psychosocial support services to pediatric cancer patients and the members of their family who need them has been documented by various professionals and associations.

In 2015, a group of professionals from Canada, the Netherlands, and the United States of America,

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with support from the Mattie Miracle Foundation, published 15 evidence-based psychosocial standards of care (2) that include standards for the neuropsychological monitoring of patients with a diagnosis of risk; access to psychological or psychiatric interventions for pediatric patients, their parents, and siblings; and support for families in bereavement. The earlier recommendations of the International Society of Pediatric Oncology (SIOP) (1, 8) also included support for patients’ brothers and sisters.

Studies in different countries have explored the link between the services offered in institutions and the aspects mentioned above (9, 10) and have shown that the most common specialized psychosocial interventions target patients and are linked with mental health care.

It is still uncommon in Latin America and the Caribbean to consider mental health part of comprehensive health. This is seen to some extent in the limited human resources in hospitals in the areas of psychology and psychiatry. Part of this deficiency has been remedied in certain centers in Argentina and Peru through the collaboration of organizations outside the hospital.

Support for families in Latin American and the Caribbean, especially siblings, is therefore still limited, as hospitals barely have the resources to cover patient care; families take a back seat. Some foundations and aid organizations offer support services, but follow-through is more difficult in cases requiring specialized mental health care.

Neuropsychological monitoring is very rare, largely because of the shortage of specialized personnel in this field and the prioritization of other services. The majority of sequelae are detected once pediatric patients resume their academic activities and the respective assessments are requested.

Finally, grief counseling following the death of pediatric patients is usually provided initially in the hospital at the time of the event. However, follow-up is rare, due not only to the lack of resources but to the fact that families rarely return to the hospital to receive this support. Some countries have support groups for bereaved parents.
We propose that psychoeducation and support during childhood cancer and its treatment be adopted as psychosocial standard of care for childhood cancer in Latin America and the Caribbean.

Mental health care consists of all interventions by specialists in the field (psychology and psychiatry) and includes subspecialties that address specific needs (e.g., neuropsychology). The main objective of these interventions is to contribute to the well-being of patients and families through the promotion of mental health and the prevention of psychopathology and other psychosocial sequelae.

The interventions can be part of a protocol of regular care for patients or their families, or based on referral of at-risk cases. Patients’ families may require specialized support for particular situations such as bereavement, coping with stress, reassignment of roles, etc.

The WHO Global Initiative for Childhood Cancer (11) aims to ensure that all pediatric and adolescent cancer patients have access to comprehensive quality care that reduces mortality, as well as the sequelae of disease and treatment in different areas of their lives.

Mental health care is part of this comprehensive approach, and adopting it as a psychosocial standard of care will enable children’s cancer centers in Latin America and the Caribbean to lower psychological or psychiatric comorbidity rates among patients and their families by guaranteeing them access to specialized psychosocial interventions. This, in turn, will have an effect on the continuity of treatments and the psychological response to them.

3. WHAT WORKS

In addition to interventions by the various members of the multidisciplinary team to promote mental health and provide mental health care, the available evidence shows that interventions by health personnel and specialized services are very important because they help patients and their families develop functional coping strategies to successfully adjust in the medium and long term.

Psychosocial care is part of comprehensive childhood cancer care. It consists of providing interventions and resources that meet the cognitive, academic, emotional, and spiritual needs of patients and their families.

Specialized mental health interventions are provided by psychologists and psychiatrists and professionals from their respective subspecialties in specific areas related to disease, treatment, and psychosocial sequelae. These include psycho-oncology, which is devoted to the prevention, diagnosis, assessment, treatment, rehabilitation, and etiology of cancer and palliative care, improvement of the communication and interpersonal skills of health personnel, and the optimization of resources to promote effective, quality oncology services (12). In the case of psychiatry, the term "oncological psychiatry" is used.

Another specialized field deals with the connection between neurology and mental health, known as "neuropsychology," which studies the relationship between mental processes (e.g., attention, memory, language, perception, executive function, etc.) and behavior and identifies the patient’s level of functioning. Although they be applied to healthy people, interventions in this field usually identify cognitive, behavioral, or emotional changes and potential sequelae due to a specific neurological situation (e.g., side effects of cancer treatment).

Other specialties are based on the age group (e.g., child psychiatry), therapeutic approach (e.g., cognitive-behavioral), or the time or status of treatment (e.g., psychology in palliative care).

Specialized psychosocial interventions provide a clear benefit for pediatric and adolescent cancer patients’ adjustment to the disease process, focusing on mental health promotion, psychopathology prevention, psychodiagnosis, psychotherapy or psychiatric sessions, etc.

Mental health and psychopathology

The most effective interventions for pediatric cancer patients with symptoms of mental health issues (e.g., depression, anxiety, etc.) are those that combine psychology and psychiatry. This combination

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Interventions for the family

As primary caregivers, the patient’s mother and father are profoundly affected and may display symptoms of anxiety, depression, post-traumatic stress, etc.

The most successful specialized mental health services are generally therapies that employ the cognitive behavioral, systemic-family, and problem-solving approach. Support groups moderated by a specialist and couple’s interventions with parental caregivers are also useful, as long as they are tailored to the characteristics and needs of the target population. Psychiatric assessment and pharmacological treatment are useful for parental caregivers whose symptoms are more pronounced and for whom psychological intervention is not enough.

- Neuropsychological sequelae

Some diagnoses or treatments can lead to neurological sequelae by altering certain cognitive and behavioral functions. These changes must be identified early on, and patients must constantly be monitored to facilitate timely treatment.

Monitoring can be done indirectly through interviews with patients or caregivers about academic performance and learning. Direct monitoring can employ standardized self assessment measurements and neuropsychological tests tailored to the pediatric population and the local language and culture. As yet, there is no conclusive evidence regarding when to make these measurements and select interventions. However, experts suggest that they be made periodically after the diagnosis, prioritizing patients at higher risk of neurological sequelae.

The assessment can provide information about the cognitive areas altered and conserved. This will allow for the design of a program tailored for the patient to restore previous cognitive function, foster capacities that were delayed or that failed to develop because of the diagnosis, or compensate for functions that cannot be restored.

- Mental health of parents and caregivers

Patients’ brothers and sisters must also deal with multiple stressors following the diagnosis, which has an emotional impact on the entire family. Increased care demands and changes in roles then emerge that further interrupt or alter different aspects of their daily lives. Siblings are at constant risk of developing a psychopathology or emotional and behavioral issues.

Interventions that promote social support for siblings facilitate healthy adjustment to the experience of the disease, as they serve as a protective factor. This support can be promoted among the family, as well as between the siblings and their peers or friends. Interventions that respond to their information needs and the need to express their emotions about...
the disease are also effective. Individual or group opportunities for psychoeducation or therapy are extremely useful.

- **Family bereavement**

Family support and follow-up interventions after the death of a patient are a feature of good comprehensive care. They can be provided as part of an institutional protocol or through an agreement or link with an outside organization or group to meet the need and guarantee follow-up. At this point, identification of risk factors for pathological grief and other symptoms is key, because timely intervention will prevent future complications for the family.

## 4. HOW TO PROCEED

Mental health care includes a specialized psychosocial approach involving disciplines such as psycho-oncology, psychiatry, and neuropsychology. Pediatric cancer centers in Latin America and the Caribbean have limited resources for this approach. This is largely due to a lack of knowledge about this type of care and the limited importance attributed to it.

To promote application of the standard, it is critical to begin by raising awareness about mental health issues among decisionmakers and the health professionals on the multidisciplinary team regarding the services to be offered. This way, each institution can take part in planning specific activities to meet the standard’s objectives, in the implementation of activities, and in ensuring the necessary conditions for achieving the objectives.

### Institutions can meet the standard by providing individual or group mental health care that addresses:

- Psychological or psychiatric symptoms in patients.
- Neuropsychological monitoring in at-risk cases.
- Family support during treatment (such as the assignment of roles or care for siblings).
- Managing grief at the end of life.

### Steps for application of the standard

To apply the psychoeducation and support standard in a particular institution, locality, or region, it is important to be knowledgeable about its basic situation, prepare an appropriate design, and determine how the activities will be implemented and evaluated.

### Analysis of needs and resources

Before designing the mental health care proposal, the context for application of the standard should be mapped.

The following steps should be taken:

1. Identify the main specialized mental health care needs of pediatric cancer patients, their caregivers, and their siblings; and the health outcomes to be influenced.
2. Determine which types of services, resources, and interventions are evidence based to meet those needs.
3. Define the prioritized conditions necessary for applying the standard (environment, human and material resources, available complementary support networks, etc.), considering hospital, outpatient, or external implementation, while ensuring alternatives for continuity of care.

2 **Design of the proposal**

After the preliminary analysis, the mental health care proposal is designed in accordance with the standard, including the following:

1. Objectives of the proposal: Indicate the short-, medium-, and long-term objectives and their respective indicators. These must be aligned with the objectives of the mental health service or unit (either responding to or complementing them).

2. Methodology: Describe the type of mental health services, activities, or interventions that should be included, their characteristics (e.g., level of intervention, techniques to be used, duration, etc.), and beneficiaries.

3. Necessary resources: List the necessary resources (human resources, environments, staff training, material resources, etc.).

4. Responsibilities: Assign responsibilities and indicate the tasks in each case.

5. Ethical aspects: Informed consent and verification of the institution’s capacity to meet the identified needs, etc.

6. Strategies for the continuity of mental health care: Describe the strategy that should be implemented to monitor the population served or continue the intervention. This can be done internally or externally (e.g., through a clear referral flowchart).

7. Cross-cutting approaches: The design should include clear guidelines for each cross cutting approach, based on the standard for cross-cutting approaches in psychosocial care for pediatric cancer or other diseases described in Module 6 of this series (16) (life course, rights, interculturalism, and gender).

Once these areas have been defined, the pertinent documentation should be prepared according to the requirements of the respective institution or entity.

3 **Implementation of the standard**

Simultaneously or prior to implementation, efforts should be made to raise awareness among health personnel and the authorities about the importance of mental health care and the demystification of related issues that continue to be stigmatized as a result of ignorance.

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

Application of the standard will be reinforced to the extent that the associated activities are part of the institutional plan and adhere to existing mental health guidelines and orientations. It is also necessary to put in place the means for application of the standard, with a clear timetable and appropriate distribution of roles and resources.

Some activities and resources commonly involve strategic partnerships (e.g., with organizations or foundations that support children with cancer), especially to provide ongoing mental health care outside the hospital. The relevant entities must make an explicit commitment to ensuring that the objectives are met.

4 **Monitoring and evaluation**

Based on the indicators identified previously, a strategy for evaluating mental health care should be prepared as proposed in the standard. This will make it possible to:

- evaluate the process by monitoring achievements, constraints, and the use of resources for the standard’s activities. This will require consideration of the elements described in the design of the proposal.
- assess the impact on the expected outcomes (in the medium and long term), taking into account relevant quantitative and qualitative aspects.
For psychosocial care standards 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, the necessary changes must be made to tailor these mandates to the cancer context.

CONCLUSIONS

- Childhood cancer seriously impacts the lives of patients and their families, who must develop mechanisms to adjust to the situation and reduce cognitive, emotional, and social sequelae.
- The mental health standard of care in childhood cancer states that comprehensive care for pediatric cancer patients should include access to specialized psychosocial care (e.g., psycho-oncology, psychiatry, neuropsychology) for patients, parents, and siblings, as needed.
- Many publications have corroborated the contributions made by specialized psychosocial care to the quality of life and adjustment of pediatric patients and their families; however, documented regional evidence is still scarce.
- Application of the standard should include interventions that address priority psychosocial needs and are sustainable. It should also involve referral and follow up networks to contribute to the well-being of patients and their families, in addition to reducing potential sequelae.
USEFUL LINKS
