

PEDIATRIC PSYCHO-ONCOLOGY

SUPPORTING CHILDREN WITH CANCER

**Soumitra S Datta, Laurie Cardona, Procheta Mahanta,
Sana Younus & Maria Teresa Lax-Pericall**



Soumitra S Datta

Department of Palliative Care and Psycho-oncology, Tata Medical Centre, Kolkata, India & UCL EGA Institute for Women's Health, University College, London

Conflict of interest: none declared

Laurie Cardona

Assistant Professor, Chief of Psychology, Psychology Training Program, Yale Child Study Center, New Haven, CT, USA.

Conflict of interest: none declared

Procheta Mahanta

Department of Palliative Care and Psycho-oncology, Tata Medical Centre, Kolkata, India.

Conflict of interest: none declared

This publication is intended for professionals training or practicing in mental health and not for the general public. The opinions expressed are those of the authors and do not necessarily represent the views of the editors or IACAPAP. This publication seeks to describe the best treatments and practices based on the scientific evidence available at the time of writing as evaluated by the authors and may change as a result of new research. Readers need to apply this knowledge to patients in accordance with the guidelines and laws of their country of practice. Some medications may not be available in some countries and readers should consult the specific drug information since not all dosages and unwanted effects are mentioned. Organizations, publications and websites are cited or linked to illustrate issues or as a source of further information. This does not mean that authors, the Editor or IACAPAP endorse their content or recommendations, which should be critically assessed by the reader. Websites may also change or cease to exist.

©IACAPAP 2019. This is an open-access publication under the [Creative Commons Attribution Non-commercial License](https://creativecommons.org/licenses/by-nc/4.0/). Use, distribution and reproduction in any medium are allowed without prior permission provided the original work is properly cited and the use is non-commercial.

Suggested citation: Datta SS, Cardona L, Mahanta P, Younus S, Lax-Pericall MT. Pediatric psycho-oncology: Supporting children with cancer. In Rey JM, Martin A (eds), *JM Rey's IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva:International Association for Child and Adolescent Psychiatry and Allied Professions 2019.

According to the [World Health Organisation](#) approximately 300,000 children aged 0 to 19 years of age are diagnosed with cancer each year. The common childhood cancers include leukemias, brain cancers, lymphomas, and solid tumours such as neuroblastoma and Wilms tumor. In the past few decades, the outcome of childhood cancer has progressively improved. In high-income countries more than 80% of children with cancer are cured, although in many low- and middle-income countries outcome is less favorable.

Children diagnosed with cancer and their families may be psychologically distressed at the time of diagnosis or later, during the course of treatment. Even with complete recovery, children may have poor self-esteem, hesitate to get back to their usual life, and their families may remain over-protective for many years following cure. Some childhood cancer survivors may not fully explore life due to these worries and fears. Pediatric psycho-oncology is a branch of pediatric liaison psychiatry and health psychology that deals with the emotional and behavioral aspects of children with cancer. This includes identifying and managing the psychiatric comorbidities during cancer care to optimize the medical outcome by influencing maladaptive health behaviors such as non-adherence to health advice, and contributing to the rehabilitation of these children so that they are able to reach their full potential. Assessment and intervention in pediatric psycho-oncology have to be age appropriate, address parental concerns, and be empowering for the primary caregivers. Some of the large oncology centers have mental health professionals dedicated to address the psychological needs of children with cancer but this is not universally available around the world. The present chapter seeks to be a training resource for mental health professionals to understand and learn about the psychiatric and psychological care of children and young people with cancer over and beyond the standard child psychiatry and health psychology interventions.

INTEGRATING PSYCHIATRIC CARE WITH CANCER CARE

Children with cancer as well as their parents are at increased risk for significant psychosocial difficulties during all phases of treatment, including survivorship (Steele, 2015). The Standards for Psychosocial Care for Children with Cancer and Their Families (Wiener, 2015) provides the first evidence-based clinical standards for addressing the psychosocial care of pediatric cancer patients and their families. These standards recommend that:

- Youth with cancer and their families should receive routine and systematic assessment of their psychosocial needs during treatment and survivorship
- High risk patients should be routinely monitored for neuropsychological deficits
- Youth and family should have access to psychosocial interventions, including psychological interventions for invasive medical procedures, and psychiatry as needed
- When necessary, youth and families should receive developmentally appropriate end of life care, including bereavement support.

Patenaude et al (2015) recommend that mental health professionals working in pediatric psycho-oncology be experienced in psychotherapeutic interventions

Sana Younus

Department of Psychiatry,
Aga Khan University, Karachi,
Pakistan.

Conflict of interest: none
declared

Maria Teresa Lax-Pericall

National & Specialist Paediatric
Liaison Services, Kings College
Hospital, South London and
Maudsley NHS Foundation
Trust, Denmark Hill, London.

Conflict of interest: none
declared

Acknowledgements

We are indebted to Mr Sourav Patra of Mandrex Designs, Kolkata, Ms Devi Nandakumar, clinical psychologist, and Dr Arnab Mukherjee, consultant psychiatrist, for helping us prepare the educational videos included in this chapter. The videos were shot at the Tata Medical Centre, Kolkata.

Correspondence: Soumitra Shankar Datta,
ssdatta2000@yahoo.com

In the immediate aftermath of a diagnosis of cancer, many children and parents show high levels of distress. Parents and young people have a need for accurate information delivered in a sensitive and timely manner. [The Childhood Cancer and Leukemia group](#) has resources for parents including information leaflets in various languages. There are also resources for [children in developing countries](#), and guidelines on [how to communicate with children with cancer](#) and their families.

to children with cancer and their families, be trained in grief and bereavement support, and competent in handling the various ethical issues that are unique to pediatric cancer care.

Medical settings with limited mental health professionals need to utilize other members of the health care team (e.g., nurses, residents) to assist with standardized psychosocial screening of all pediatric patients at diagnosis. Screening of all patients during the immediate time following diagnosis has been supported by research that indicates this is the period of greatest distress for children and their families (Kazak et al, 2015). Universal psychosocial screening has the benefit of identifying children and families with the greatest need of immediate psychological support.

Treatment centers with limited mental health resources also need to provide training to the medical staff in strategies for supporting the emotional health of families and children by teaching the staff how to recognize normative and problematic forms of coping, and principles of child development. Additionally, medical staff should have knowledge about, and access to published and on-line psychoeducational materials that they can share with families including books and videos that provide disease education, procedural preparation, and on-line social support forums (Steele, 2015).

Well-funded, larger pediatric cancer centers may have multiple mental health professionals integrated in the multidisciplinary medical team. In such centers, it is possible for several disciplines (child life specialists, psychologists, psychiatrists, social workers, spiritual leaders) to contribute simultaneously to the emotional well-being of children and their families (Wiener, 2015). The services offered by these providers may include:

- Diagnostic evaluation and assessments of children and family members
- Development and implementation of psychotherapeutic individual and family treatments
- Neuropsychological testing, and
- School-based consultation regarding school re-entry.

Additionally, mental health clinicians provide ongoing consultation on the psychological management of patients to members of the medical team (Wiener et al 2015). The challenge in larger mental health teams is the coordination of communication and intervention efforts, to avoid fragmentation and duplication of services. Therefore, a clear delineation of each mental health professional's role is necessary, and communication of those roles to the families and medical team becomes critical. Multidisciplinary coordination amongst the members of the mental health team can be facilitated through regular psychosocial rounds in which patients' psychosocial care plans are devised collaboratively.

There is an emerging trend in some countries toward the use of telehealth for mental health services for patients with cancer, which aims to reduce barriers to care such as geographical isolation and limited resources (Walsh, 2018). For example, in Australia, there is an on-line parent training program called "Cope, Adapt, Survive: Life After Cancer" which introduces cognitive behavioral interventions to improve the quality of life of families affected by pediatric cancer (Wakefield, 2015).



[Click on the image to view the short video clip: Introduction to Pediatric Psycho-Oncology \(2:33\)](#)

COMMON PSYCHOLOGICAL COMORBIDITIES

Anxiety and Procedural Anxiety

Children with cancer spend prolonged periods of time in hospital and their normal life is invariably disrupted. Understandably, parents are also anxious, and it is not uncommon for children to recognize the increased anxiety of their primary caregivers. Anxiety can manifest at any stage of treatment but is common, often intense, at the beginning, and can at times be expressed as refusal of treatment or procedures. The most common forms exhibited are:

- Procedural anxiety (fear of procedures)
- Generalized anxiety disorder
- Adjustment disorder, and
- Mixed anxiety and depressive disorders.

Procedural anxiety can develop when a newly diagnosed child with cancer has to undergo invasive procedures that are deeply unpleasant (e.g., blood tests, bone marrow biopsy) and must endure frequent admissions to hospital. For a premorbidly anxious child this may lead to extreme fear of hospitals and medical staff. Anticipating painful procedures, children may panic when they travel towards the hospital. It is not uncommon for some children to cry inconsolably or freeze during the procedures. In between procedures they may remain anxious and often talk about the experience of undergoing tests.

Adjustment Disorders

Children and teens with cancer are usually able to comprehend the seriousness of the disease and as a consequence can become quite distressed by the diagnosis. Additionally, they become upset about the loss of contact with peers, disruptions in school attendance and their inability to participate in their usual activities. Patients with adjustment disorder may display transient anxiety, mood symptoms, or conduct problems not severe enough to qualify for a full diagnosis of anxiety or major depression, for example. Irritability or sadness may worsen before each hospital visit, and sleep and appetite may be disrupted for a few days. There may be subjective feelings of an inability to cope and plan ahead. It is assumed that these responses would not have emerged without the stress of cancer.

Depression

Some children undergoing treatment for cancer may present with social withdrawal, low mood, irritability, crying spells, and psycho-motor retardation/agitation suggestive of subsyndromal depression. Some young people may experience depression following mutilating surgery, which may affect their ability to participate in preferred activities or that change their physical appearance. Depression may also emerge due to the loss of contact with peers or the inability to go to school. In the absence of randomized controlled trials on depression in children with cancer, clinicians rely on the existing evidence base. A combination of medication and psychological treatment is possibly the best option as there is no evidence for one treatment over another.

Cognitive behavioral techniques such as relaxation training and cognitive restructuring are particularly effective for children. At times, cognitive behavioral therapy for depression may not be feasible due to the physical and cognitive fatigue



[Click on the image to view a short video clip about depression in children with cancer \(3:11\)](#)

associated with treatment. Alternatively, family therapy may work particularly well as it provides a scaffold around the child and helps to empower the immediate caregivers. The role of medication in treating depression will be discussed later in the chapter.

Agitation and Behavioral Difficulties

Corticosteroids are vital in the treatment of acute lymphoblastic leukemia, which is the commonest malignancy in childhood. Children with leukemia on corticosteroids can present with increased restlessness and agitation. The effectiveness of this group of medications comes with a range of physical and psychological side effects ranging from mild changes in mood and cognition to overt psychotic symptoms (Drozdowicz & Bostwick, 2014). Psychological side effects usually emerge within days of onset of treatment. Like in adults, mood symptoms (e.g., irritability, emotional lability, pressured speech) are the commonest, and are sometimes accompanied by psychotic symptoms (delusions, hallucinations). Chronic treatment with corticosteroids may cause depressive symptoms, while short-term therapy has a greater association with manic symptoms.

Children with leukemia rarely exhibit self-injurious behavior but they may become moody and aggressive towards their caregivers. Acute agitation is quite disruptive and often results in a pediatric psycho-oncology referral as nurses and oncologists find it difficult to manage such behaviors. A combination of behavioral interventions and psychotropic medication may be necessary to manage the psychological side effects.

Neurodevelopmental Disabilities

Children with cancer who have a previous diagnosis of autism spectrum disorder or significant developmental delay may be a challenge to manage in the pediatric oncology ward. These children can become distressed by even routine medical procedures, day to day changes in the hospital environment, and their lack of familiarity with the adults attending to them. Children with neurodevelopmental disorders benefit from special accommodations (e.g., single rooms, low stimulation, picture schedules) and often respond better to medical care delivered by a consistent group of nurses and doctors. Often, they struggle with abstract thinking; therefore, medical education needs to be provided in a more concrete way, such as through drawings and photographs. These may help their understanding better than verbal instructions. Most importantly, parents must be actively engaged in the care of children with developmental disorders to lessen their distress.

Substance Misuse

Occasional experimentation with alcohol and substances is common in adolescents. Consequently, teenagers undergoing cancer treatment should be asked routinely about substance use and misuse as that will have serious implications during and following treatment. Once the young persons become cancer survivors, during follow up appointments, they should be specifically asked about high-risk behaviors, including substance misuse. This is particularly important as substance misuse may be associated lack of attendance to appointments and screenings, needed to test for recurrence. Misuse of substances also contributes to an overall

The Life of a 12-year-old

“I want to... I want to walk but I am scared, what if I fall? My parents worry all the time. They usually hold my hands when I walk. Well, I am not like the other kids and I'll never again be like them” muttered Shantanu, a 12-year-old boy diagnosed with medulloblastoma.

Following surgery, he started having difficulties walking, often losing his balance. He had resumed schooling recently. However, he skipped school often, preferring to stay at home. He showed low mood, had lost interest in activities that he enjoyed earlier, had dwindling self-confidence, and low self-esteem.

CBT was initiated to address these issues, having six weekly sessions. Liaison with school helped Shantanu to experience some successes, reinforced by rewards and praise. Over time Shantanu became less preoccupied with his walking difficulties and redirected his spare time into hobbies that required less physical ability, like learning to play chess.

unhealthy life style (Verrill et al, 2000). Substance misuse needs to be addressed during cancer care and at follow-up.

Body Image Problems

Some young people may develop concerns about their body image because of the impact of the disease or its treatment, such as loss of hair or loss of a limb following amputation (Lee et al, 2015). Body image concerns may persist beyond cure and become problematic at the point of their reintegration back to normal life. Psychological treatment is the treatment of choice and may require sessions over many months to restore self-confidence.

CHILDREN WITH BRAIN TUMORS

Brain tumors are the second most common cancers of childhood. The location of primary brain tumors is infratentorial in about 60% of cases (gliomas and medulloblastomas); the remaining are usually midline tumors (e.g., germ cell tumors and craniopharyngiomas). Benign brain tumors are non-cancerous but can be lethal because of their location in the brain, their ability to infiltrate locally, to cause inflammation, or because of the possibility of transforming into malignant. Some tumors can recur after resection. At the time of diagnosis there may be acute or chronically raised intracranial pressure, or infiltration or compression of CNS areas. A presentation with change in behavior may happen but is rare.

Survival for children with brain tumors has improved, but many survivors experience cognitive and psychological or psychiatric consequences, which may be related to the tumor itself, the treatment (surgical, radiotherapy, chemotherapy), or to other factors, like the psychological reaction of the child and family, related and environmental factors. In these cases, mental health clinicians should undertake a thorough assessment of the child's psychological symptoms, they should know the tumor location, staging, therapy, and the physical consequences of the tumor.

Neurocognitive Outcomes

Cognitive consequences typically emerge in the first few years and range from mild to severe. Risk factors for cognitive problems include tumor characteristics, treatment variables (e.g., dose of radiation), and individual variables, such as age at diagnosis (Stavinoha et al 2018; Palmer et al, 2003).

Some aspects of intelligence may be more affected than others (for a review, see Ruiters, 2013). For example, attention, processing speed, and working memory (Reeves et al, 2006) may be affected more than other cognitive constructs and they may have a high impact in the post-treatment adaptation of the child. Importantly, studies have shown that the decline in processing speed and working memory may be related to a failure to make gains over time rather than a true decline in function (Ris & Abbey 2010).

Family and environmental factors are also important but have been less researched. Carlson-Green et al (1995) reported that children from higher socio-economic levels and children whose mothers had better coping strategies had better intellectual outcomes. Arch et al (2012) reported that academic underachievement was related to low levels of support to the family and high levels of conflict; the effects of these two factors continued to be significant after controlling for age

Table I.6.1 Psychosocial assessment of children with brain tumour	
Initial evaluation	Post-treatment evaluation
<ul style="list-style-type: none"> • Premorbid development, psychosocial history and functioning • History of genetic disorders (e.g., neurofibromatosis, nevoid basal cell carcinoma) • Significant life events • Educational attainment and academic strengths and difficulties • Psychological risk factors and resilience • Family functioning, parental psychiatric disorders and their coping with other life events • Availability of social support • Social factors (e.g., poverty, housing) • Type of cancer: nature, location, prognosis, and treatment received so far 	<ul style="list-style-type: none"> • Impact of physical sequelae (e.g., loss of vision, hemiparesis, sensory deficits, epilepsy, neuro-endocrine, speech problems) • Treatment received so far • Educational engagement • Cognitive problems • Psychological symptoms • Family functioning • Changes in parenting style following completion of treatment • Current social circumstances

of the child, radiation, and chemotherapy treatment. The [Children's Oncology Group](#) has developed assessment guidelines for children with brain tumors that can be accessed [here](#).

Psychiatric Outcomes

Children with brain tumors have been found to be more socially isolated, perceived by peers as being sick, easily fatigued, and absent from school more often (Vannatta et al, 1998). Schulte et al (2018) report that half of the survivors of brain tumors experience problems in social relationships and that social deficits may worsen with time. Younger age at diagnosis predicts a poorer social outcome.

Posttraumatic stress symptoms, anxiety, emotional lability, and behavioral problems have been described in patients with brain tumors (Bruce et al, 2011). A review by Zyrianova et al (2016) found that 57% of children with brain tumors had behavioral and psychological symptoms, especially internalizing problems. They report that the location of the lesion is related to the neuropsychiatric outcome. Supratentorial, right-sided cerebellar and vermis lesions having the poorest outcomes. Lesions of the vermis of the cerebellum are associated with dysregulation of affect. Attention problems are common but it is unclear whether full ADHD is more common than in the general population. Various specific syndromes have been described, such as cerebellar mutism, posterior fossa syndrome, and cerebellar cognitive affective syndrome (Schahmann & Sherman, 1998; Levisohn et al, 2000).



TREATMENT REFUSAL

It is not unusual to receive urgent referrals from pediatric oncology teams when young people suddenly refuse treatment (Brown & Slutzky, 2016). This is to be considered as an emergency. Steps for managing this are given in the Table I.6.2. From a medico-legal perspective, in most countries, the medical treatment of children and teens requires consent from one of the parents. However, in reality the young person needs to cooperate in protracted treatments such as those for cancer. It is extremely difficult to undertake a procedure like stem cell transplantation or administer repeated cycles of chemotherapy against the will of the young person even though, legally speaking, parental consent may be adequate and sufficient. Hence, many pediatric oncology teams currently document assent from a young person in addition to parental consent when they treat adolescent patients with cancer.

INDIVIDUAL PSYCHOLOGICAL TREATMENT

Common modalities of psychological therapy are behavioral management and CBT. For very young children, behavioral strategies are often the most feasible. However, for adolescents and school aged children, adapted models of CBT may be used. Some commonly used techniques are:

- Keeping thought diaries
- Teaching progressive muscle relaxation
- Deep breathing
- Guided imagery
- Behavioral activation, and
- Positive self-talk.

Research into interventions for social deficits is limited but one promising study found improvements in self-reported social skills in brain tumor survivors following social skills training, role play, and training in conflict resolution (Barrera

Table I.6.2 Steps to address treatment refusal in young people with cancer

- Establish rapport with the child. This is facilitated if the psycho-oncology team is familiar with all the children seeking treatment for cancer in the hospital, following a shared care model of service delivery
- Discuss neutral, developmentally appropriate topics
- Assess the child's mental state to ascertain if the refusal is related to depression, anxiety, or other problems. If that is the case, start treatment for the psychiatric condition
- Conduct a risk assessment
- Establish the context of treatment refusal. Evaluate if the young person has specific fears associated with the treatment. A common reason is body image concerns associated with chemotherapy. Situational fear or anxiety may require a few days to alleviate
- Work with the pediatric oncology team to explain in a developmentally appropriate language the nature of the treatment and its importance. Convey, without instilling undue fear, that without the treatment the disease is likely to become worse
- Spend time discussing the treatment and addressing the fears

et al, 2018). A review of the management of executive functions' problems in children with posterior fossa tumors found cognitive remediation to be helpful for some aspects, although the evidence is limited (Wolfe et al, 2012). Conklin et al (2015) reported positive effects on cognition with a home delivered computerized program.

LOOKING AFTER THE FAMILIES

Planning a Family Session

Once there is a referral to the pediatric psycho-oncology team, it is useful to plan a family session. If there are siblings who are in school, a session should be arranged on a weekend or after school hours. The main message that needs to be communicated to the family is that *family, the professionals and the young person are all on the same side, trying to deal with the cancer*. Making such a symbolic divide between the "cancer" and "everyone else," often helps the professionals and the family bond as a team. The team should encourage the family to continue being a close-knit unit, especially when the sick child is at home. The family needs to be empowered while myths and irrational fears should be dispelled.

Formal Family Therapy

Some families may benefit from formal family therapy. The systemic and structural schools of family therapy have been used in medical settings. Strategic family therapy techniques are also useful with some of the very anxious families who would prefer to bring the child to hospital for even innocuous reasons. An example of the need to support a family would be when the child's mother spends considerable time trying to feed him, while the child refuses chewing and

swallowing. The clinical team are worried that this may lead to infection and make a referral to pediatric psycho-oncology as they cannot persuade the mother to stop force-feeding the child.

Making Time for Siblings

When the main caregiver within a family is intensely involved in looking after a sick child, this may have an adverse impact on the other children. For example, siblings can feel abandoned and grow angry and resentful. They may feel upset at the loss of consistent contact with both their parent and sick sibling. All children in the family, including those who are physically well, should be made to feel important and loved. Clinicians working with families should encourage siblings to continue with school and remind the caregivers to make time for the healthy siblings. Looking after the emotional needs of the healthy siblings is often overlooked and when done proactively often helps to bind the family together.

Pharmacological Treatment

Psychotropic medications can be useful in treating anxiety and mood disorders. They can also have a significant role in the management of other conditions like delirium and behavioral disturbances secondary to medication and general medical illnesses. Conklin et al (2010) reported long term positive effects on attention and social skills with carefully titrated doses of methylphenidate in brain tumor survivors.

When using medication for depression, it is important to know about the symptoms of the cancer, side effects of the chemotherapeutic agents, and possible drug-drug interactions. Choice of antidepressant will be based on this information, with the goal to manage depressive symptoms, manage somatic complaints—like pain syndromes or peripheral neuropathy—and reduce, or at least not worsen, the side effects of chemotherapeutic agents. Common antidepressants used include SSRIs, such as fluoxetine and escitalopram.

NEUROPSYCHOLOGICAL ASSESSMENT AND MONITORING OF LATE EFFECTS

Pediatric patients with all types of cancer should have a complete psychosocial assessment covering psychiatric conditions, suicidal ideation, and adjustment, at the time of initial diagnosis, during cancer treatment, and at follow-up. Assessment of parental functioning may be needed as well..

Children treated for central nervous system malignancies and those with acute lymphoblastic leukemia who are treated with CNS directed therapies (e.g., high dose chemotherapy, radiation) are at increased risk for cognitive impairment (Nathan, 2007; Annett, 2015). Indeed, an estimated 50-60% of childhood cancer survivors are at risk for cognitive impairment (Hewitt et al, 2003). Children receiving CNS-directed therapies can suffer acute as well as long term cognitive deficits (Nathan, 2007). Age and intensity of treatment predict later neuropsychological functioning in children treated for acute lymphoblastic leukemia. The areas of cognitive functioning that are most commonly affected include: attention and concentration, memory, language, executive functions, sensory skills, visual-perceptual skills, and processing speed.

The Mother who Wanted her Child to Eat Fruit

An 8-year-old diagnosed with acute lymphocytic leukemia was admitted to the pediatric oncology ward. Nurses noticed that his mouth was often full of food. The staff soon discovered that his mother believed that eating pomegranate would “help to replenish the red blood cells.” The child hated to eat pomegranate, kept the food in his mouth, and avoided swallowing it. The clinicians were soon worried that poor oral hygiene may make him vulnerable to infections. Nursing instructions had not been accepted by the parent and a referral was made to pediatric psycho-oncology.

After a psychosocial assessment, family therapy was offered to the family. It was discovered that the mother emphasized the importance of eating as she had very little control over the other things that were happening to her son. Over time, the patient’s mother became less fixated on the child’s diet and could focus on the bigger picture.

Neurocognitive outcome studies suggest that even when treatment has concluded, children and adolescents are at considerable risk for learning disabilities, reduced educational attainment, compromised employment, and functional impairments in adaptive life-skills, due to enduring neuropsychological deficits. Thus, practice parameters have recommended regular monitoring of neuropsychological functioning through parent and child interviews and standardized assessment protocols (Annett, 2015)

Routine monitoring interviews can be conducted by a range of mental health and health professionals because they are less reliant on training on specific neuropsychological instruments. Monitoring can include patient and parent interviews about school performance, changes in attention, visual-motor coordination, concentration, and memory. This type of monitoring should occur regularly during the acute phase of treatment, with regular follow up inquiries during the remaining treatment phases (Annett, 2015). These interviews can be readily implemented in most clinics, including those that have limited access to psychologists.

Patients identified through clinical interviews as having a decline in functioning should then be referred for more comprehensive neuropsychological and educational evaluation. High risk patients such as those with pediatric brain tumors and children receiving CNS-directed therapies should have a comprehensive neuropsychological assessment after treatment has concluded, followed by reevaluation at 2-3 years after therapy (Annett, 2015). Annual academic testing should be conducted by school personnel so that timely educational and vocational interventions can be implemented. Cancer centers without a neuropsychologist on staff should develop partnerships with psychologists within other hospitals or community practices to facilitate patient access to timely evaluation.

There are very few studies regarding the types of remediation intervention that should be implemented to address the neurocognitive deficits that emerge (Moore, 2013, Annett, 2015). The largest (161 survivors) randomized controlled clinical trial of a cognitive remediation program resulted in modest improvements in metacognitive strategies, improved attention, and academic abilities (Butler, 2008).

APPROACHES TO PEDIATRIC PALLIATIVE CARE

Guidelines developed by the American Academy of Pediatrics (2013) and the Psychosocial Standards of Care for Children with Cancer and Their Families (Weaver, 2015) emphasize the importance of routinely incorporating principles of palliative care in pediatric cancer treatment. The [World Health Organization \(2018\)](#) defines pediatric palliative care as follows:

- It encompasses the active total care of the child's body, mind, and spirit, and giving support to the family
- It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease
- Health care providers must evaluate and alleviate the child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

The essential components of pediatric palliative care identified through published studies, expert opinion, and practice parameters include (Himelstein, 2004; American Academy of Pediatrics, 2013; Weaver, 2015):

- Establishing compassionate and honest communication between the medical team, the child, and family
- Providing ongoing assessment and intervention to lessen physical and psychological suffering
- Addressing the child's and family's spiritual needs
- Engaging the child and family in advance care planning
- Addressing the financial burdens experienced by the family
- Providing support to siblings and
- Providing bereavement support to the family after the death of the child

Given the central importance of supporting children and families in a developmentally informed manner, members of a psycho-oncology team are particularly well prepared to undertake an active role in the delivery of palliative care services (Glazer et al, 2018).

Communication Strategies

Direct, honest and timely communication with children, adolescents, and their families about the nature of the illness and prognosis is a cornerstone of pediatric cancer care and palliative care (Weaver, 2015). The Psychosocial Committee for the International Society of Pediatric Oncologists (Masera, 1997) has recommended full disclosure to the child at a pace the child can accommodate, following a sharing conference with the parents. Some parents may have concerns based on cultural, religious grounds or personal experiences with cancer about informing their child about the severity of the illness and poor prognosis. Similarly, family members may fear that providing such information to children will lead to an increase in anxiety or depression. These concerns will need to be addressed directly by offering them psychoeducation about the potential psychological distress that can result when children are given partial and incomplete information. Specifically, children are keen observers of their family and caretakers and often come to astute conclusions about the seriousness of their medical condition even if they have not been informed of the specifics (Walsh, 2018; Glazer, 2018; Johnson, 2017). Occasionally, a child may not want to know, and clearly communicates this to the treating team. In this situation, one needs to explore the reasons for such a preference.

Without direct and honest medical communication, children are likely to develop increased levels of anxiety because of a lack of clear information about their condition. Research has shown that adolescents in particular have a strong desire for honest conversation about their medical condition and prognosis (Weaver, 2015). A member of the mental health team can take the key role of helping parents and the medical team come to an agreement about a staged delivery of information to the child, as well as providing parents with direct guidance regarding communication strategies with their child and the siblings.

ADVANCE CARE PLANNING AND DECISION MAKING

Palliative care discussions should provide families and youth with clear information about options for end of life care, such as the type of treatment

interventions that family and the child may choose to alleviate physical and psychological distress, the utility or futility of life-sustaining interventions such as mechanical ventilation and cardiac resuscitation, and family preferences about location of death. The significance of family centered advanced care planning with children and adolescents has become increasingly recognized as an important aspect of palliative care (Weaver, 2015).

A developmentally informed advance care planning workbook (Voicing My CHOICES) was developed by the National Cancer Institute to assist youth in identifying their preferences for end of life care (Zadeh, 2015). This workbook allows youth to put in writing their wishes regarding the persons they would like to make healthcare decisions for them, the type of life support they would elect to have, the spiritual or religious activities they would like incorporated into their care, the location of death, and the type of funeral service they would prefer (e.g., burial, cremation, organ donation). The psycho-oncology team can play a central role in assisting families, children, and medical providers to have candid and direct conversations about end of life preferences aligned with the family and child's cultural and spiritual values.

Advanced care planning is informing the treating professionals and loved ones of the future medical care one would like to receive if one becomes unable to explain one's wishes. Advanced care planning promotes care that is consistent with a person's goals, values, beliefs and preferences

THE DEATH OF A CHILD IN THE HOSPITAL WARD

Supporting dying children is often a challenge for clinicians due to the intense emotions experienced by everyone involved. However, with advanced planning and a cohesive approach, this clinical challenge can be addressed in an ethical and compassionate manner. The cornerstone is open and frequent communication with the patient and family. It is also important to recognize the impact of the death of a child on the other children in the ward and their families. We recommend that children's cancer centers develop guidelines and

Table I.6.3 Managing end of life care

- Understand the expectations of the patient and family. Primarily, this entails active listening and will need to be done repeatedly during the entire journey
- Help the pediatric oncology team to communicate with family members and the patient. Communication should convey that everything that can be done has been done
- Promote realistic hope. This does not mean about prolongation of life but about expectations that there will be fewer distressing symptoms in the last few days
- Facilitate shared decision making. For example, by empowering the child and family to participate in managing some of the symptoms such as pain, breathlessness etc. This gives the family an opportunity to participate and understand the nature of the situation more fully
- Visit the patient and the family regularly and be present at the time of death, if possible.
- If staff members are distressed with a particular death in the ward, it may be useful to have a session with the staff
- Provide support to family members who request help after the normal bereavement period

Table I.6.4 Death of a child in the hospital

- If death is imminent, allow close family members in the room with the child
- Ensure the room is not visually disturbing for the family members when they visit the patient (e.g., by getting rid of spills, excess medical equipment)
- Bereavement is a private affair and repeated intrusions from professionals should be avoided.
- At least one member of the medical team should be present so that everyone feels the dying child matters as much in death as in life
- Following death, the usual protocols of the hospital should be followed. A doctor attending to the child should break the news to the family at an appropriate time, if they are not already there, in the room.

strategies to deal with such situations while respecting the bereaved family's right to confidentiality. The team should be mindful that even clinicians looking after the child may need emotional support.

Supporting a Child When a Parent Is Dying of Cancer

Occasionally psycho-oncology clinicians are asked to evaluate and support young people whose parent or sibling is the cancer patient. Helping a child come to terms with the imminent death of a close family member is one of the most difficult tasks in psycho-oncology. There are specific child bereavement charities who train professionals working with children going through grief.

Bereavement Support Following the Death of a Child

Bereavement care for parents and siblings for anticipatory grief and after the death of a child has been strongly supported by the American Academy of Pediatrics (2013) and in the Standards for Psychosocial Care (Lichtenthal et al, 2015). Parents and siblings can experience prolonged grief, lasting from months to years, following the death of a child; such bereavement reactions have been known to lead to poor psychological outcomes. Bereaved parents are at increased risk for depression, anxiety, and posttraumatic stress disorder (Lichtenthal et al, 2015). Families can also experience a sense of further loss and abandonment when they no longer have ongoing contact with members of the medical and psychosocial team with whom they have often formed strong relationships.

Importantly, however, families who receive support during the anticipatory grieving process have less complex grief following the death of a child (Donovan et al, 2015), particularly if bereavement support is extended beyond the hospital experience following the death. Studies have established the substantial psychosocial benefits of bereavement services for families (Lichtenthal et al, 2015). A review examining 30 hospital-based bereavement programs found that bereavement services helped family members feel cared for and supported by staff, reduced the sense of isolation, and led to reports of improved coping and personal growth (Donovan et al, 2015).

Medical settings vary considerably in their capacity and resources to provide bereavement services. Some have sufficient resources to have multidisciplinary teams providing a broad range of services, such as attending funerals, sending cards



[Click on the image above to view a short video clip about managing grief in children \(4:08\)](#)

or emails, follow-up phone calls, connecting parents to other families who have lost a child, establishing group support programs, conduct home visits or hospital-based family meetings during the first year following the loss, and establishing an annual day of remembrance for all families to attend. Some oncology programs conduct formal clinical assessments of parents' and siblings' coping in order to make referrals for follow-up mental health support if needed. Yet, others have very limited resources to offer even minimal follow-up inquiries with families.

Practice guidelines (American Academy of Pediatrics, 2013; Lichtenthal et al, 2015) strongly recommend that bereavement care be provided for anticipatory grief and continue after the death of the child. A member of the health care team should contact the family at least once following the death of a child, to let the family know that their child and them are not forgotten, as well as to assess the family's emotional, psychological, spiritual, and practical needs. Additionally, a member of the psychosocial team should work to identify families that are at risk of poor psychological outcomes and refer them to social or mental health services. Importantly, each family has a unique manner of grieving, therefore, bereavement programs should be flexible to individualize the type of support offered (Donovan, 2015).

Child mental health professionals can assume a leadership role in pediatric palliative care teams by promoting interdisciplinary methods of evaluating child and family coping along the continuum of care, including the bereavement period. Mental health providers can also assist in creating a network of community-based resources to which families can be referred for ongoing support.

Importantly, the American Academy of Pediatrics (2013) has recommended that members of the health care team receive ongoing psychological, ethical, and spiritual support to assist them with the stress of caring for children with life-limiting diseases. Within the hospital setting, support for all staff can be provided through peer support groups, group debriefing, psychological and spiritual counseling, and educational programs tailored for the health care team. Mental health professionals can develop psychoeducational programs and a culture of support for the hospital staff who experience the psychological challenges of caring for seriously ill children.

Ongoing Mental Health Interventions Following the Death of a Child

Some families request ongoing mental health support for siblings experiencing bereavement because they are at a loss as to how to support the surviving children. It is important to inform them that most children are resilient; this helps them overcome adversity and loss if supported by friends and family, without professional help. Parents often benefit from reassurance that the symptoms exhibited by their children are part of the normal grieving process and will likely resolve gradually. If there are symptoms of pathological grief (e.g., absence of grief or very severe and prolonged grief) then professional help may be advisable. Mental health intervention may be necessary when there is parental psychopathology or psychosocial adversity that affects the adults' ability to support surviving children.

CONCLUSION

Pediatric psycho-oncology is a challenging yet rewarding field. Mental health clinicians entrusted with working with children and young people with cancer need to be well versed with the unique strategies and methods of working with children and have a clear understanding of the nuances of working with children with specific types of cancer. With increased survival, pediatric psycho-oncology is likely to become increasingly important in the overall planning of cancer care in children.

REFERENCES

- American Academy of Pediatrics (2013). Pediatric palliative care and hospice care commitments, guidelines and recommendations. *Pediatrics* 132:966-972.
- Annett R, Patel S, Phipps S (2015). Monitoring and assessment of neuropsychological outcomes as a standard of care in pediatric oncology. *Pediatric Blood Cancer* 62:S460-S513.
- Arch E, Gerhardt C, Barrera M et al (2012). Family factors associated with academic achievement deficits in pediatric brain tumor survivors. *Psycho-Oncology* 22:1731-1737
- Barrera M, Atenafu E, Sung L et al (2018). A randomized control intervention trial to improve social skills and quality of life in pediatric brain tumor Survivors. *Psycho-Oncology* 27:91-98.
- Brown AEC, Slutzky AR, (2017). Refusal of treatment of childhood cancer: a systematic review, *Pediatrics* 140:e20171951.
- Bruce M, Gumley D, Isham L et al (2011). Post-traumatic stress symptoms in childhood brain tumour survivors and their parents. *Child: Care, Health and Development* 37:244-251.
- Butler R, Copeland D, Fairclough D et al (2008). A multicenter, randomized clinical trial of a cognitive remediation program for childhood survivors of a pediatric malignancy. *Journal of Consulting and Clinical Psychology* 76:367-378.
- Carlson-Green B, Morris RD, Krawiecki N (1995) Family and illness predictors of outcome in pediatric brain tumors. *Journal of Pediatric Psychology* 20:769-784.
- Conklin HM, Ogg RJ, Ashford JM et al (2015). Computerized cognitive training for amelioration of cognitive late effects among childhood cancer survivors: a randomized controlled trial. *Journal of Clinical Oncology* 33:3894-3902.
- Conklin HM, Reddick WE, Ashford J et al (2010). Long-term efficacy of methylphenidate in enhancing attention regulation, social skills, and academic abilities of childhood cancer survivors. *Journal of Clinical Oncology* 28: 4465-4472.
- Donovan L, Wakefield C, Russell V et al (2015). Hospital-based bereavement services following the death of a child: a mixed study review. *Palliative Medicine* 29:193-210.
- Drozdowicz L, Bostwick J (2014). Psychiatric adverse effects of pediatric corticosteroid use. *Mayo Clinic Proceedings* 89:817-834.
- Fiorini J. J. & Mullen J. A. (2006). Understanding Grief and Loss in Children, VISTAS: Compelling Perspectives on Counseling, 7:31-34.
- Glazer J, Pao M, Schonfeld D (2018). Life-threatening illness, palliative care and bereavement. In A Martin, M Block, F Volkmar, (eds) *Lewis' Child and Adolescent Psychiatry* 5th edition. Philadelphia: Wolters Kluwer, 946-956.

- Hewitt M, Weiner S, Simone J (2003). *Childhood Cancer Survivorship: Improving Care and Quality of Life*. Washington, DC: National Academies Press.
- Himelstein B, Hilden J, Boldt A et al (2004). Pediatric palliative care. *New England Journal of Medicine* 350:1752-1762.
- Johnson LM, Torres C, Sykes A et al (2017). The bereavement experience of adolescents and early young adults with cancer: Peer and parental loss due to death is associated with increased risk of adverse psychological outcomes. *PLoS ONE* 12(8):e0181024.
- Kazak A, Abrams A, Banks J et al (2015). Psychosocial assessment as a standard of care in pediatric cancer. *Pediatric Blood Cancer*, 62: S426-S459.
- Lee M, Mu P, Tsay S et al (2012). Body image of children and adolescents with cancer: A metasynthesis on qualitative research findings. *Nursing and Health Sciences*, 14:381-390
- Levisohn L, Cronin-Golomb A, Schmahmann J (2000). Neuropsychological consequences of cerebellar tumour resection in children: Cerebellar cognitive affective syndrome in a paediatric population. *Brain* 123:1041-1050
- Lichtenthal W, Sweeney C, Roberts K et al (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric Blood Cancer* 62:S834-S869.
- Masera G, Chesler M, Jankovic M et al (1997). SIOP working committee on psychosocial issues in pediatric oncology: guidelines for communication of the diagnosis. *Medical Pediatric Oncology* 28:382-385.
- Moore I, Hockenberry M, Krull K (2013). Cancer-related cognitive changes in children, adolescents and adult survivors of childhood cancers. *Seminars in Oncology Nursing* 29:248-259.
- Nathan P, Patel S, Dille K et al (2007). Guidelines for identification of, advocacy for, and intervention in neurocognitive problems in survivors of childhood cancer. *Archives of Pediatric & Adolescent Medicine* 161:798-806.
- Palmer S, Gajjar A, Reddick W et al (2003) Predicting intellectual outcome among children treated with 35-40 Gy craniospinal irradiation for medulloblastoma. *Neuropsychology* 17: 548-555
- Patenaude A, Pelletier W, Bingen K (2015). Communication, documentation, and training standards in pediatric psychosocial oncology. *Pediatric Blood Cancer* 62:S870-S895.
- Reeves C, Palmer S, Reddick W et al. (2006). Attention and memory functioning among pediatric patients with medulloblastoma. *Journal of Pediatric Psychology* 31:272-280.
- Ris MD, Abbey R. (2010) Paediatric brain tumors. In Yeates KO, Ris MD, Taylor HG, Pennington BF (eds) *Pediatric Neuropsychology. Research Theory and Practice*. The Guildford Press, New York.
- Ruiter M, van Mourik R, Schouten-van Meeteren AY et al (2013). Neurocognitive consequences of a paediatric brain tumour and its treatment: a meta-analysis. *Developmental Medicine and Child Neurology* 55:408-417.
- Schmahmann J, Sherman J (1998). The cerebellar cognitive affective syndrome. *Brain* 121:561-579.
- Schulte F, Brinkman T, Li C et al (2018). Social adjustment in adolescent survivors of pediatric central nervous system tumors: A report from the Childhood Cancer Survivor Study. *Cancer* 124:3596-3608.
- Stavinoha P, Askins M, Powell S et al (2018). Neurocognitive and Psychosocial Outcomes in Pediatric Brain Tumor Survivors. *Bioengineering* 5:73.
- Steele A, Mullins L, Mullins A et al (2015). Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. *Pediatric Blood Cancer* 62:S585-S618.
- Vannatta K, Gartstein M, Short A et al (1998). A controlled study of peer relationships of children surviving brain tumors: Teacher, peer and self ratings. *Journal of Pediatric Psychology* 23:279-287.
- Verrill J, Noll R (2000). Aggression, antisocial behavior, and substance abuse in survivors of pediatric cancer: possible protective effects of cancer and its treatment. *Journal of Pediatric Psychology*, 25: 493-502.
- Wakefield C, Sansom-Daly U, McGill B, et al (2015). Online parent-targeted cognitive-behavioural therapy intervention to improve quality of life in families of young cancer survivors: a study protocol for a randomized controlled trial. *Trials* 16:153.
- Walsh C, Zebrack B (2018). Cancer. In Martin A, Block M, Volkmar F (eds) *Lewis' Child and Adolescent Psychiatry* 5th edition. Philadelphia: Wolters Kluwer, 912-918.
- Weaver M, Heinze K, Kelly K et al (2015). Palliative care as a standard of care in pediatric oncology. *Pediatric Blood Cancer* 62:S829-S833.
- Wiener L, Kazak A, Noll R et al (2015). Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatric Blood Cancer* 62: S419-S424.
- Wolfe K, Madan-Swain A, Kana R (2012). Executive dysfunction in pediatric posterior fossa tumor survivors: a systematic literature review of neurocognitive deficits and interventions. *Developmental Neuropsychology* 37:153-75.
- [World Health Organization \(2018\). Definition of Palliative Care for Children.](#)
- Zadeh S, Pao M, Wiener L (2015). Opening end-of-life discussions: how to introduce Voicing My Choices, an advance care planning guide for adolescents and young adults. *Palliative Support Care* 13:591-599.
- Zyrianova Y, Alexander L, Faruqui R (2016). [Neuropsychiatric presentations and outcomes in children and adolescents with primary brain tumours: Systematic review.](#) *Brain Injury* 30:1-9.