

# PSYCHOSOCIAL CARE IN PAEDIATRIC ONCOLOGY



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This article explains the need for psychosocial care to be a key part of the treatment process for young people with cancer. Such care should be part of a multidisciplinary approach to cancer management and should involve not just the patient but their families, peers, schools as well as the health-care professionals who treat them. The authors look at how psychosocial care should be applied at each stage of treatment from first diagnosis to treatment plans or palliative care, as well as considering the problems that are particular to specific age groups within the paediatric grouping.

The diagnosis of paediatric cancer is one of the most stressful situations a child or an adolescent and family will face. It presents an overwhelming series of stresses, not the least of which is the possibility of the patient's death. Although the survival rate of childhood cancer has improved significantly, the treatment remains lengthy and intensive, involving fundamental changes in the patient and family's lives. Today, it is well known that a multidisciplinary approach to management should include psychosocial support services from the time of diagnosis to ensure maximum quality of life.

The provision of adequate information and the development of ongoing support will enable patients to grow and develop in preparation for entry into adult life, and to achieve their full potential. Psychosocial support should be an integral part of the total management of all patients.

Management of children and adolescents with cancer requires the participation of a multidisciplinary team – the physician working with other specialists: nursing staff, psychologist/psychiatrist, social workers, teachers, recreation specialists and members of different health-care disciplines as the need arises.

Physicians should incorporate such consultations in the plan of treatment and ideally, the multidisciplinary approach should be introduced in the routine of a patient immediately after the diagnosis is confirmed.

## Communication of diagnosis

As soon as feasible after an initial session at the time of diagnosis, during which the basic aspects of the disease, planned treatments are discussed and concepts of psychosocial care are introduced by the physician, a

professional with expertise in psychosocial issues related to childhood cancer should interview every patient and family. The ill child/adolescent (and siblings whenever possible) should be included in these meetings from the onset, to ensure understanding and to create a model for communication for parents, demonstrating how to discuss difficult health-care issues with their children.

### *Establishing open communication at diagnosis*

- ▶ Questions regarding the type of disease, treatment, prognosis, etc, should be addressed to ensure clarity of communication between the medical care team and the family.
- ▶ Issues related to insurance, financial concerns, social support resources, transportation to the medical centre, etc must also be discussed. Without having a clear understanding of the family's comprehension of their child's illness and the family's resources and needs, the health-care professional cannot determine which psychosocial assistance is needed.
- ▶ During these initial contacts, the identification of patient and parental competencies, strengths and coping skills is critical.
- ▶ Special attention should be placed on the identification of adjustment difficulties that are antecedent to the diagnosis of cancer and may interfere with the patient's care. Areas to be evaluated are marital dysfunction, parental psychopathology, and childhood behavioural/emotional problems. Primary psychosocial professionals (clinical psychologist, social worker, educational specialist and play therapist) should have diagnostic skills to identify both strengths and

weaknesses in these areas.

- Impressions from these family meetings must be reviewed with the oncology treatment team to facilitate the development of a comprehensive care plan.

#### Ongoing contact

- Frequently, in this context, information is not assimilated entirely at the first time. Professionals should repeat the messages at every opportunity, promoting open discussions helping the patient and family members to express their doubts, worries, fantasies, fears, etc.
- Contact and counselling (whenever possible) must be maintained throughout the treatment period to provide continuing guidance and support for the patient and the whole family as they face new problems.

#### Informed consent

- Generally, parents must give signed informed consent to initiate treatment, which may require them to hear details that are extremely difficult to understand. Through informed consent, the professional team should share its knowledge in a sensitive and educational manner that may guide the parents without being coercive.
- Informed consent discussions have specific requirements which include diagnosis, prognosis and procedural information in language understandable to the lay person in order for the family to be informed. Rather than think of informed consent as an unrelated series of permission slips, it may be more beneficial for content and continuity to consider consent as a process that requires a relationship with the caregivers that encourages ongoing dialogue.

### Refusal, non-compliance and abandonment of treatment

Health-care team members must be trained to recognize at the time of diagnosis those predictive psychosocial-economic patterns that predispose patients to these problems so that preventive measures can be instituted.

#### Prevention

- Insufficient and inadequate doctor, family and patient (especially adolescents) dialogue, relationship, trust and mutual information is one of the most important causes of noncompliance.
- Other indicators predictive of a tendency toward noncompliance are signs of family or parental dysfunction, non-comprehension, low socioeconomic

status, and the failure to follow simple instructions and initial appointments.

- The health-care team should remain open to discussion when alternative medical treatments are proposed by parents or patients. Careful attention should be paid to the parents' expressed religious or cultural value system. Often an alternative treatment does not significantly interfere with the prescribed treatment and is in itself medically harmless. Physicians should in such cases encourage the parents to supplement conventional therapies with their own cultural and/or religious approaches.

#### Judicial Intervention (when all else fails)

- When parents refuse treatment or completely replace the medical orientation with ineffectual alternative medicine, it may be necessary to resort to legal proceedings to override the parents at once and thus ensure that the best interests of the patient are served.

### Treatment initiation

The most common difficulty for the patient and their parents during the treatment initiation phase of cancer treatment is dealing with their own intense emotions and psychological traumatization.

#### Common difficulties

- Once a course of treatment is specified, the family should be given a "roadmap" outlining the steps in the treatment protocol including a schedule of hospitalizations, medications, outpatient visits and follow-up diagnostic tests.
- Early treatment, side effects and possible complications may suddenly make the patient feel and appear more ill than prior to treatment.
- Family organization is especially challenged during this time. Extremes changes occur in family roles and responsibilities. Family separations and disruptions are seen as the biggest change that occurs from the perspective of healthy siblings.

#### Gaining control

- Once treatment is initiated, the patient and his parents begin to assert some control over the cancer; families increase their reliance on control and rules.

### Ending treatment and survival

Children and families face another transition after cancer treatment.

***Because of the documented difficulties adolescents encounter with emotional problems, greater adverse reactions to chemotherapy and well-substantiated noncompliance, special attention should be given to these patients***

#### *Time of ambivalence*

- As treatment ends, the task becomes living beyond cancer, which is often a time of ambivalence: positive feelings that treatment is over, but concern over the loss of support of the hospital, the medical team and uncertainty over the future.
- The patient (and family) do not always expect physical and emotional recovery to take as much time as it often does, which may be a source of frustration. There is also the fear of possible relapse or recurrence of cancer. This state of apprehension, called “Damocles syndrome” is one of the most unsettling aspects of life after cancer.

#### *Late effects*

- Many paediatric cancer survivors must cope with chronic physical complications of cancer treatment such as organ dysfunction, growth delay or deficiency, infertility and second malignancies.
- Some survivors also have to cope with cognitive late effects of treatment including learning, attention, memory, visual-motor problems, etc.
- It is very important that each centre carefully preserve all the information about survivors through an information system so that these data could be available even after many years.
- The centres should offer (or refer to another centre) programmes that include psychological counseling for young people experiencing adjustment difficulties and physical rehabilitation services for those with significant side effects.

#### *Ethical issues*

- Survivors of childhood cancer and their families could face social and economic discrimination. Constraints have been documented in limited access to social and educational opportunities, employment discrimination and the unavailability (or high cost) of health and life

insurance.

- Comprehensive programmes for survivors must include public education and advocacy that: 1) informs and persuades the general public of the essential normality and productivity of this population; 2) helps create public policies to prevent or confront such discrimination; 3) educates survivors to be advocates for their own social and economic futures.

#### **Treating adolescents**

Because of the documented difficulties adolescents encounter with emotional problems, greater adverse reactions to chemotherapy and well-substantiated noncompliance, special attention should be given to these patients.

#### *Emotional issues*

- Adolescents may display more intense emotional reactions, denial and existential issues as they attempt to cope with cancer stresses. Signs of distress, such as excessive anxiety, moodiness, passivity, changes in behaviour, academic difficulty, etc, should be carefully monitored in adolescent patients. They commonly are more reactive, do not generally show their discomfort to medical staff and can be at greater risk to themselves.
- Adolescents often express difficulties identifying with friends, who are able to be more “carefree”; furthermore, they are more vulnerable to self-image problems because of changes in physical appearance (i.e., hair loss, weight gain or loss) while attempting to adapt to pubertal changes.
- A cancer diagnosis also promotes more dependency on caregivers, which is at odds with the developmental goal of increasing autonomy.
- Fostering connections between adolescent patients can be very beneficial, especially when they have opportunities to participate in non-oncology-related activities such as trips, parties, etc.
- Teen patients may need additional resources when a friend with cancer relapses or dies.

#### *Nausea and vomiting*

- Special care should be made to monitor nausea and vomiting and the adolescent’s experience with chemotherapy.

#### *Compliance*

- Adolescents tend to be less compliant than younger children and need to be involved more fully in the process of information regarding their own treatment. Their

inclusion in the decision-making in every phase of treatment helps set an atmosphere of compliance.

### Counseling

- It is strongly recommended that regular psychosocial services be provided for adolescent patients because of the difficulties they commonly encounter. The earlier the intervention, the better the chance of preventing and reversing them.

### Including brothers and sisters

Members of the health-care team and the parents should:

- involve the siblings from the very beginning;
- keep the siblings informed in an age-related manner – using written, audio/video material – through the different phases of the disease;
- whenever possible emphasize the positive and optimistic side of the treatment;
- explain to them that they were in no way responsible for the cancer;
- siblings should be kept abreast of any late effects of treatment the patients may be experiencing;
- siblings should come to the hospital, especially if they wish to come.

Notable topics exhibited by many siblings:

- feelings of isolation and abandon;
- feelings of guilt for not being sick themselves;
- fears that they too might become sick;
- school problems/school avoidance and other changes in relationship with school and teachers;
- somatic complaints and acting up in order to get attention;
- uncertainty about the future.

### Adaptation of young patients

While many young children have symptoms of depression or anxiety, these are often understandable reactions to their disease and treatment rather than symptoms that meet criteria for a severe diagnosis. Emotional, social and behaviour functioning of children with cancer is associated with the specific developmental phase of the patient.

- Infants, toddlers and preschoolers are sensitive to separations from caregivers and prone to angry outbursts. Babies are often cranky when hospitalized and/or receiving either inpatient or outpatient care.
- Preschoolers often have a difficult time with medical procedures and may demonstrate regressive or aggressive behaviour.

- School-aged children commonly have anticipatory worries about medical procedures, separation anxieties and school re-entry.
- It is recommended that regular psychosocial counselling should be provided for these patients since the diagnosis period.

### Parents/family coping and adjustment

The diagnosis of cancer in a son or daughter is one of the most distressing experiences for families. Monitoring of parental mental health is a necessary component of cancer care for children and adolescents.

- Most parents will report having symptoms of anxiety, depression and feeling overwhelmed. Chronic distressing symptoms such as difficulties making hospital visits, heightened concerns over minor health problems for all of their children or recurrent dreams are commonly experienced by them. Post-traumatic stress symptoms are also common.
- After the first year from diagnosis, parental and family adaptation improves. Careful assessment at diagnosis may reveal risk factors to identify those families who will experience more difficulty adjusting with the demands of treatment.
- Grandparents often play a key role with child care, daily living tasks and care of the patient. Including them in family meetings to provide accurate information about disease, prognosis and treatment plans can be helpful.
- Psychosocial support should focus on coping with stress with special attention to family functioning, parental distress, siblings, grandparents and problems with misinformation from outside sources (many people know about cancer in adults but not in children).
- When symptoms are too severe, a referral for outside assistance from a professional with post-traumatic stress disorder experience is recommended.

### Returning to school

The reintegration of the child with cancer into school is an essential part of the total treatment programme. Only cooperation among the family, care team and educators in addition to a well-structured programme, can help in achieving this goal and preventing serious negative outcomes.

As soon as possible after the initial diagnosis and treatment, within the limits of medical care, children should be encouraged to return to school for the following reasons:

- return to school signals the return to normal routines and provides parents and patient reassurance regarding

improving health;

- ▶ academic issues are important, but even more significant are sustaining adequate peer relationships. Maintaining friendships and routine interactions with peers is essential to normal psychological development;
- ▶ because of the social component of the school experience, attending school even for short periods of time is preferable to homebound education;
- ▶ classmates should be prepared for the patient's return in a manner appropriate for the child's age and school situation.

With permission from the family, school personnel should be contacted as soon as possible to let them know about the patient's disease:

- ▶ in general, school communities associate childhood cancer with immediate death, so they need to be educated about the patient's disease: treatment, side effects, anticipated days of school to be missed, prognosis and special care;
- ▶ a manual for teachers including information about the disease and how to cope with the ill pupil might be useful – teachers should be assured that their role is to teach and the hospital's role is to treat;
- ▶ the psychosocial professional should be involved with the school contact to determine how the patient has done in the past in school and to prepare for future work;
- ▶ if an extended absence from school is inevitable, school personnel should be encouraged to maintain contact with the patient and family via homebound teachers, audio lessons, letters, tapes, etc.

Before the patient returns to school, the psychosocial professional should talk with the patient/family regarding concerns they have about his or her return.

- ▶ Issues that need special attention are any change in the patient's physical appearance and specific ways the patient can talk with peers about his or her illness; special attention should also be placed upon the fact that the

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childhood cancer is not contagious.

Patients with brain tumours or malignancies that compromise central nervous system (CNS) integrity through therapy (e.g., those receiving prophylactic radiation therapy), can have special problems related to returning to school as they commonly experience difficulties with cognitive abilities. These patients are at risk for problems fitting in with peers. They can become socially isolated and experience less social acceptance.

- ▶ Neuropsychological testing before the patient returns to school is recommended to facilitate appropriate classroom placements and to develop appropriate education programmes.
- ▶ Results must be carefully reviewed with parents and school professionals to ensure their understanding of the patient's cognitive abilities.
- ▶ In addition to an initial screening before the patient returns to school, for all patients with brain tumour follow-up neuropsychological assessment within six months and one to two years after diagnosis is recommended.
- ▶ School progress needs to be monitored after treatment for these patients to appreciate fully the extent and nature of late effects.

### **Death and dying**

Today 30% to 40% of childhood cancer patients will die. In developing countries rates of survival can be poorer.

Continuity of care and the opportunity to work with known staff members is particularly helpful in the terminal phase of the disease.

- ▶ Health-care teams should facilitate communication between family and patient regarding death and dying since they need more assistance to talk about these issues. Particular attention should be paid to siblings and grandparents to ensure that they have an opportunity to discuss their feelings, ask questions, say goodbye and understand the situation.
- ▶ Families should be able to share concerns about death and affirm their relationships with one another to say goodbye to the patient. Children with cancer often reach an understanding of what death means at a much younger age than their healthy peers.
- ▶ Silence can result in unnecessary suffering. While parents may want to "protect" their son or daughter from the knowledge that the illness is terminal, feelings of isolation and abandonment can occur at a time when the need for support and communication is the greatest.

- An open environment where the patient feels free to express concerns and worries is essential.
- The oncology team (and local health-care professional) should sustain contact during and after the terminal phases of treatment.

Essential recommendations for assisting terminally ill patients and their families include:

- each centre should develop a uniform philosophy on key issues (e.g., communication, support, pain control) regarding the final phases of care for the dying patient, producing local recommendations regarding treatment and care based on group discussion;
- avoid a “ruthless obstinacy” approach; know when to move from cure-oriented therapy to palliative care;
- listen to the patient, keep in touch with the family and try to develop and retain a good relationship with everyone involved;
- include in the final decision-making process the parents, the siblings and the child (depending on their ages and level of development) and the local family physician;
- control both physical and psychological pain as well as other disturbing symptoms;
- enable the patient to die at home when possible and if desirable by him or her and the family;
- deal with issues of bereavement among the members of the health-care team;
- encourage post death follow-up visits for parents and siblings, reflecting on the medical history of the patient and acknowledging the ongoing needs of parents, siblings and extended family.

After a patient dies, the individual patient’s history should be evaluated. This evaluation should be made by the health-care team as a group. It is very important to reflect on all events in order to help the staff come to terms with their own concerns (e.g., frustration, failure, helplessness, loss, grief).

### Impact on health professionals

Burnout in health-care professionals treating patients with cancer often manifests itself as a multistep process progressing slowly over time.

The impact of burnout can be profound on the individual, on the team and therefore on the patients and families for whom health care is provided. Common reactions are:

- mental and physical exhaustion (becoming emotionally exhausted from constant confrontation with death, loss, distress and pain associated with physical symptoms of exhaustion, poor sleep, poor concentration and

depression;

- indifference (feeling unmotivated and disinterested manifesting irritability, ill-temper and lack of participation);
- sense of failure as a professional (developing an increasing sense of professional failure: the professional believes that he/she is no longer as capable, caring or competent as before);
- sense of failure as person leading to a despairing self-hatred and isolation, a sense of hopelessness: the individual performs his responsibilities without involvement, commitment or enthusiasm.

In addition to a level of burnout that can be caused by the nature of the work itself, the causes of burnout in health-care professionals can be both institutional (the work environment) and personal.

- The nature of the work itself: being in frequent contact with patients having difficult treatment/recovery trajectories, seeing many patients die, etc.
- The work environment: setting with too many demands and not enough time, excessively authoritarian and an atmosphere of hostility and tension among fellow staff members.
- The characteristics of the individual: becoming too deeply involved with particular patients, difficulty in sharing work-related feelings and issues, high demands on him- or herself, difficulty in asking for counselling when needed, etc.

Suggestions to prevent and remediate burnout (professionals should select those modes that would best apply to their centres, each with its own needs, resources and circumstances):

- a good team leader can help prevent burnout through setting up a general atmosphere of calm, support and lack of tension, finding in-hospital mechanisms to control work stressors, encouraging open discussion of problems as departmental policies, interpersonal difficulties or other potential and actual points of conflict, etc;
- a periodic, regularly scheduled staff meeting with the team leader present and a psychologist or trained social worker presiding can be of considerable help;
- a careful modification of individual factors: learn to set personal limits both for time and for energy; avoid over-involvement; let needs be known both to work peers and to supervisors; keep communication lines open with colleagues, attend workshops and training sessions on burnout. ●

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