



Pediatric Psycho-oncology

Introducing

Preparation for imminent death

By: Maryam Mazloom
PhD in Health Psychology

Long after parents ask *“Will she die?”*
there will be a question about time:

“When will my child die?”

followed by several additional questions, such as

“Will he suffer?”;

“What will it be like?”;

“What does she need?”;

and

“How can we be of help?”

These are all questions about the end of life



Pediatric Psycho-oncology

Care of a Child Dying of Cancer



Care of a Child Dying of Cancer

- In the case of a dying child, the goal of therapy is to maintain the child's comfort and provide support to the child and the family
- The last days, hours and minutes of a child's life will most probably remain engraved forever in the parents' mind.
- Moreover, the way their child dies may play a critical role in the future life of parents and possibly of the other siblings too.
- Therefore, it is difficult to overestimate the importance of a competent, comprehensive and sensitive management during the terminal phase of a child's life.



Care of a Child Dying of Cancer

- Burden of Physical and Psychosocial Distress at the End of Life
- DNR and DNAR Orders
- Palliative Sedation in Pediatric Cancer Patients
- Role of Nutrition and Hydration During the Terminal Phase
- Place of Death



Care of a Child Dying of Cancer

Burden of Physical and Psychosocial Distress at the End of Life

- **Knowing** the most probable **scenario** of approaching death may potentially facilitate better preparation to the optimal management of a child's end-of-life period.
- It is possible and desirable to create a **therapeutic plan before** this period becomes actually evident.
- The **psychological burden** at the end of life is not less significant.
- The management of psychological symptoms is even **more difficult**.
- The **recognition of these symptoms** is not efficient enough, and their successful **management** often can be **more the exception than the rule**.



Care of a Child Dying of Cancer

DNR and DNAR Orders

Reluctant to
discuss the
DNR

Outright
betrayal of
their child

- **The responsibility of the palliative team is** to help parents make a correct **decision** in the best interests of their child.
- It may be prudent to initiate **conversations** with parents about this topic long before a child suffering from progressive cancer approaches imminent death.
- This approach conforms also to the modern concept that promotes **incorporating palliative care into the standard care** of a child sick with cancer from the very initial stages of the child's disease.



Resuscitation Status

- Careful thought should be placed on the exact words used during a discussion about resuscitation status.
- Parents often think that agreeing to *“do not resuscitate”* (DNR) status is choosing death over life for their children.
- It is helpful to explain that it is the uncontrolled cancer that would be the cause of death.
- *More concretely, using the phrase “do not resuscitate” may imply that, when attempted, resuscitation is always successful.*
- However, among children with far advanced cancer, the likelihood of being extubated once on a ventilator and surviving is extremely low.
- Thus, when approaching families about this issue, it is recommended to use the phrase: **“do not attempt resuscitation” (DNAR)**

Care of a Child Dying of Cancer

Palliative Sedation in Pediatric Cancer Patients

- **Alleviating pain** in dying children enhances the **child's quality of life** and eases the distress of their grieving parents
- Difference between **palliative sedation** and **euthanasia**
- Discussion of the issue with the patient's parents
- Not all parents are ready immediately to accept a proposal of this kind at this stage, because of the immense **emotional significance** carried by such a decision.
- Hence, sometimes the performance of other additional medical tests, usually some kind of imaging scan, may be useful in order to help parents understand the real state of affairs and to accept the reality of the situation.
- After their agreement, palliative sedation is commenced.



Care of a Child Dying of Cancer

Role of Nutrition and Hydration During the Terminal Phase



- Very often, parents, and sometimes even the treating medical personnel, find it emotionally too difficult to agree not to give food or fluids to a dying child.
- In certain instances, when there is no consensus between the parents of a dying child and the treating physician, it may be prudent to provide the child with hydration through either a nasogastric tube or a central/peripheral line while forgoing nutritional support.
- Explaining to the parents that the fluids contain a certain amount of glucose necessary for providing energy may facilitate parental agreement to accept the physician's proposal.

Care of a Child Dying of Cancer

Place of Death

- It is generally assumed that most people would prefer to die at home surrounded by close family members and friends. It is logically easy to assume that children do not constitute an exception to this general rule.
- If death at home is not an option, the dying child spends the last days in the hospital. But even in a hospital ward the medical personnel should make everything possible in order to create a sense of “home” for the dying child and the relatives



Psychological Intervention with the Dying Child

Death Awareness in Children

Awareness of death in children has been studied from two complementary perspectives: the **cognitive** one, focusing on children's conceptions of death in general, and the **experiential** one, focusing on children's construction of their state.

Children's Awareness of Dying

"Mommy, I don't want you to cry when I die, I want to see your smile"

Children's Conceptions of Death

Each of the themes of the death concept is affected differently by major factors, such as age, gender, cognitive ability, and culture

Discussing Palliative Care with Children

Very little is known regarding communication about palliative care with children with advanced cancer; however, knowledge of the developmental understanding of death should help guide this generally unexplored area.

| Age | Overview of children's concepts of death |
|----------------------|---|
| Birth to 2 | Death is perceived as separation or abandonment . Protest and despair from disruption in caretaking No cognitive understanding of death |
| 2 to 6 | Death is reversible or temporary . Death is personified and often seen as punishment. Magical thinking that wishes can come true |
| 6 to 11 | Gradual awareness of irreversibility and finality. Specific death of self or loved one difficult to understand. Concrete reasoning with ability to see cause-and-effect relationships. |
| Older than 11 | Death is irreversible , universal , and inevitable . All people and self must die, although latter is far off. Abstract and philosophical reasoning |

Concerns of the Dying Child

How to Deal with Them Psychologically

- Fear of Abandonment and Separation
- Fears of Leaving the Familiar and of Confronting the Unfamiliar
- Fear of Punishment
- Fear of Pain and Suffering
- Fear of Death
- Being Told the Truth
- Protecting One's Parents
- Guilt in Regard to One's Parents
- Loss of Respect for Authorities
- Loss of Control
- Sadness and Sorrow
- Anger
- Wish Fulfillments
- Hope and Self-comforting
- Search for Meaning



Pediatric Psychological Palliative Care (PPPC)

General Issues in Providing PPPC

The Dying Child and the Family

PPPC and the Treatment Team

Issues of Time and Place



Advance Care Planning (ACP)

Advance care planning (ACP) is an extension of the normal treatment plan, documenting the process of discussing issues and planning ahead with parents and, if possible, the child in anticipation of a future change in condition

Components to be included in pediatric advance care planning (Horridge 2015; Sanderson et al. 2016):

- Advance statements of wishes and preferences
- Statement about discussions with the child and family about appropriate level of intervention
- Statement about resuscitation
- Statement about wishes concerning place of care and death

Nearing Death

- Management of distressing symptoms
- Creating a comfortable environment
- Removing unnecessary equipment, and even reducing light
- Healthcare staff should be available but never intrusive
- Anticipating with the family the physical changes that present near the time of the child's death
- Mouth care and comfort positioning with slightly elevated head can reduce potential discomfort
- Feeling prepared for the child's dying process may help the family to handle the unbearable situation of losing their beloved child

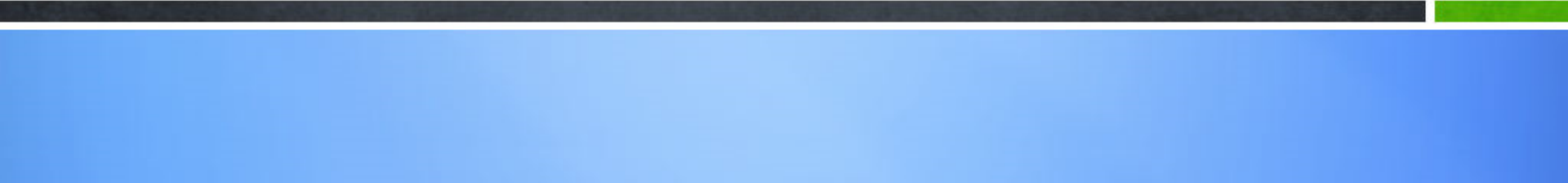
Communication During EOL and Prior to Death

- Talking About Last Wishes
- Anticipation of Grief and Bereavement





Grief & Bereavement



Family Bereavement Care in Pediatric Oncology

The responsibilities and duties of the palliative care providers continue after the child has died, and ideally they would offer family bereavement support

- Hospital-Based Bereavement Care
- Support Groups for Parents
- Interventions for Complicated Grief for Parents
- Bereavement Support for Siblings
- Healthcare Professionals' Views on Bereavement Care

Family Bereavement Care in Pediatric Oncology

Normal Grief vs. Maladaptive Responses to Bereavement



Normal grief:



Feelings

Cognitions

Physical
Sensations

Behaviours



Normal grief

Feelings

- Sadness
- Anger
- Guilt and Self-Reproach
- Anxiety
- Loneliness
- Fatigue
- Helplessness
- Shock
- Yearning
- Emancipation
- Relief
- Numbness

Physical Sensations

- Hollowness in the stomach
- Tightness in the chest
- Tightness in the throat
- Oversensitivity to noise
- A sense of depersonalization
- Breathlessness, feeling short of breath
- Weakness in the muscles
- Lack of energy
- Dry mouth






Normal grief

Cognitions

- Disbelief
- Confusion
- Preoccupation
- Sense of Presence
- Hallucinations

Behaviors

- Sleep Disturbances
 - Appetite Disturbances
 - Absentminded Behavior
 - Social Withdrawal
 - Dreams of the Deceased
 - Avoiding Reminders of the Deceased
 - Searching and Calling Out
 - Sighing
 - Restless Hyperactivity
 - Crying
 - Visiting Places or Carrying Objects That Remind the Survivor of the Deceased
 - Treasuring Objects That Belonged to the Deceased
- 



Persistent complex bereavement disorder

- ❖ This disorder is characterized by severe and persistent grief and mourning reactions
- ❖ Presence of severe grief reactions that persist at least 12 months (or 6 months in children) after the death of the bereaved
- ❖ It is only when severe levels of grief response persist at least 12 months following the death and interfere with the individual's capacity to function that persistent complex bereavement disorder is diagnosed
- ❖ Prevalence: approximately 2.4%-4.8%

The disorder is more prevalent in females than in males



DSM-5



Abnormal Grief Reactions: Complicated Mourning

- (1) chronic grief reactions
- (2) delayed grief reactions
- (3) exaggerated grief reactions
- (4) masked grief reactions





Grief Counselling

- ❖ **Eight-variable bereavement risk index for identifying the family members in special need of support:**
 - 1. More young children at home**
 - 2. Lower social class**
 - 3. Employment little, if any**
 - 4. Anger high**
 - 5. Pining high**
 - 6. Self-reproach high**
 - 7. Lacking current relationships**
 - 8. Coping assessment by rater requiring help**



Family Bereavement Care in Pediatric Oncology

Factors Impacting on Bereavement Outcomes in Parents

- **Factors Healthcare Cannot Modify or Avoid**

The child's, the parent's gender, previous loss, and economic burden

- **Factors During the Child's Illness and End-of-Life Care**

Family Bereavement Care in Pediatric Oncology

Factors Impacting on Bereavement Outcomes in Parents

- Factors During the Child's Illness and End-of-Life Care Affecting Bereavement Outcome of the Parents
 - ✓ *The child's suffering and medical care during the illness and at end of life*
 - ✓ *psychological and physical symptoms management*
 - ✓ *place of death*
 - ✓ *A good relationship between the healthcare professionals and the parents*
 - ✓ *Understanding the child's prognosis*
 - ✓ *Receiving psychosocial support from the healthcare staff during the last month of the child's life*

Providing Support for Families Experiencing the Death of a Child

Anticipatory Grieving

The process of grieving for family members begins well before the death occurs, often as early as the time the diagnosis is first confirmed or even suspected

Anticipatory grieving allows people the opportunity to start some of the work of grieving before the death has occurred

Parents and other family members may therefore find themselves at times wishing the child would die soon

Understanding that this is a common thought, even among parents who care deeply for their children, may help to alleviate some of the feelings of guilt

Providing Support for Families Experiencing the Death of a Child

Anticipatory Grieving

Individuals do not follow a steady and linear course

The health care providers then find themselves dealing with parents who present conflicting preferences on the course of medical treatment

Health care team also experience anticipatory grieving

Health care team have different levels of acceptance of the eventuality of the child's death

For example, the physician may have accepted that further treatment is unlikely to be curative, while a nurse caring more directly with the child may be questioning unexplored options

Providing Support for Families Experiencing the Death of a Child

Death Notification

contact with
parents/guardians as
soon as possible

private setting

Inform the patient's
primary care provider

including at least one
other professional

Refer to the child who
died by name and/or
relationship to the
survivor

notification of a death
is a process, not an
act

Use clear and simple
language

Don't provide
unnecessary graphic
details

Be conscious of non-
verbal communication
and cues

Remain sensitive to
cultural differences

Do not ignore or
dismiss suicidal or
homicidal statements
or threats

Do not try to "cheer
up" survivors

Feel free to show that
you are upset as well

Take care of yourself

The Needs of Siblings and Other Children

The Value of Being Involved and Supported During Illness

- “See” and acknowledge the healthy siblings.
- Give psychosocial support to siblings during illness, e.g., talk about feelings and the situation but also talk about “normal” things.
- Give suitable information about the illness, the treatment, and the prognosis, together with the parents but also alone with healthcare professionals.
- Involve siblings in the care of the ill brother or sister.
- Give support to the parents as a way of supporting healthy siblings.
- Healthcare professionals should be honest, positive, cheerful, encouraging, strengthen hopes (but not false hopes), empathic, natural, patient, treat everyone warmly, don’t butt in but be nearby, and not do the same things as they have always done.
- Recognize the value of continuity in the care of the brother or sister but also in the contact with the healthy siblings

Interventions Shortly After the Death of the Child

- Treatment of the body with respect and according to the cultural and religious practices of the family and in accordance with local law is of paramount importance.
- The family members are encouraged to stay with their child as long as they wish, unless regional regulations prohibit this.
- Privacy should be respected if the family wishes to be alone with their child.
- Nevertheless it is important to check regularly whether the family has additional needs.

Interventions Shortly After the Death of the Child

- Religious and cultural needs and wishes should be fulfilled whenever possible.
- Depending on religion and culture, some of the families desire to perform specific rituals with or without their spiritual leader.
- In some cultures, washing or bathing of the body is an act of spiritual cleaning and should therefore be done in agreement with the family.
- some families may appreciate taking home their dead child from the hospital, particularly when the child and family had strongly wished to be at home during EOL.

Clinical Implications

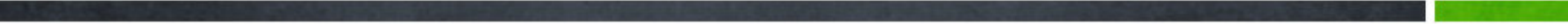
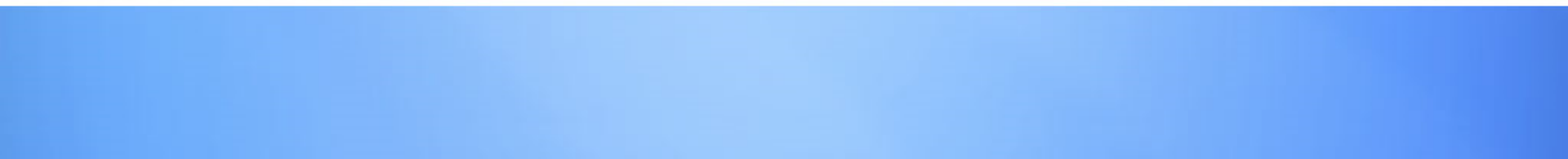
- Important goals in pediatric palliative care to facilitate the families' bereavement outcome should include minimizing the ill child's suffering, especially pain and anxiety.
- Healthcare professionals play a key role in supporting the parents to talk to their children (the ill child and healthy siblings) about the impending death if parents want to, in order to prevent regrets later on.
- It is important for healthcare professionals to understand that the many varied grief reactions are normal and that there are no distinct stages of grief

Clinical Implications

- It is important to remember that most individuals will adjust to life without their child/ brother/sister and without the need of therapeutic interventions.
- A death of a child to cancer is not always predictable, but in cases where death is unavoidable, it is important to prepare the whole family for the impending death.
- Lack of communication about what to expect when death occurs can result in anxiety many years after the loss among siblings.
- Create time and space for siblings to spend time with the ill child on their own in order to create important memories together.



Clinical Implications

- Help the grief reactions. family to identify an extended family member or friend who is in a position to help the siblings during the illness and after bereavement.
 - The existence of open communication and sharing of thoughts and feelings can be an important part of a positive relationship between parents and healthy siblings.
 - Families should have access to the care team after the loss of the child.
 - Screening efforts need to be improved for families at risk of prolonged or complicated
- 
- 

Conclusion

For a parent, witnessing the death of their child is a tragic event, one that cannot be compared in its severity and intensity to anything else. The physician is often unable to prevent this death but is responsible for making it as peaceful and free of suffering as possible. The ultimate gratification of the physician in his work as a palliative care specialist is rendering it possible for the bereaved parents to find meaning and solace in the death of their child. This is achieved by vigorous control of all physical symptoms in a dying child and by close attention to all existential, emotional and social demands of both the child and his or her relatives.



References

- ❖ **American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (DSM-5®). American Psychiatric Pub.**
- ❖ **Barnett, L. (Ed.). (2008). When death enters the therapeutic space: Existential perspectives in psychotherapy and counselling. Routledge.**
- ❖ **Kreitler, S., Ben-Arush, M. W., & Martin, A. (Eds.). (2012). Pediatric psycho-oncology: Psychosocial aspects and clinical interventions. John Wiley & Sons.**
- ❖ **Wolfe, J., Jones, B. L., Kreicbergs, U., & Jankovic, M. (Eds.). (2018). Palliative care in pediatric oncology. Midtown Manhattan, NY, USA: Springer International Publishing.**
- ❖ **Worden, J. W. (2018). Grief counselling and grief therapy: A handbook for the mental health practitioner. Springer Publishing Company.**
- ❖ **Yalom, I. D. (2008). Staring at the sun: Overcoming the terror of death. The Humanistic Psychologist, 36(3-4), 283-297.**





جهان بیمار و رنجور است
دو روزی را که بر بالین این بیمار باید زیست
اگر دردی ز جانش بر ندارم نابخوانمردی است
«زنده یاد فریدون مشیری»