Personal Practice

Bereavement Management in Pediatric Intensive Care Units

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Introduction

The death or impending death of a child in the pediatric intensive care unit (PICU) affects the dying child, family members, other children and families in PICU as well as the team members. Bereavement support is particularly difficult if the death is sudden and unexpected. During these moments, the PICU team becomes the primary column of support for the family and therefore has significant responsibility and influence over the course of the bereavement process(1). Surveys reveal that only about 6% of doctors working in PICU situations have any training in dealing with a grieving populace. The role of the team following the death of a child in PICU has not been well defined(2). Not surprisingly, the PICU staff often feels overwhelmed in situations of bereavement. An awareness of the sources of stress in grief and a practical approach towards the management is easily acquired with some deliberation and a little practice. We in this article offer helpful suggestions for improving the bereavement support in PICU.

Sources of stress in PICU during bereavement

Sources of stress in PICU have been illustrated in *Table 1*. Some of the stressors are avoidable. Others need to be acknowledged and coping strategies enhanced based on the developmental age and comprehension of events.

Needs of the dying child

Maximize physical comfort

Children experience and form vivid memories of their pain like adults. Their inability to articulate their discomfort and our inability to assess pain in critically ill children leads to inadequate control of pain symptoms. Effective sedation and analgesia needs to be achieved through safe and proven medication regimens(3). Issues in the management of discomfort are presented in *Table II*.

Discuss the child's impending death

Children with deductive reasoning (about nine years) are able to perceive their own impending death and if allowed, will express their feelings verbally or through developmentally appropriate mediums (*e.g.*,drawing, play). Staff and family often erroneously believe that the children need to be protected from the knowledge of their death(4). This leads to the isolation of the child and an increased distress associated with bereavement(5). It thus seems wise to encourage the terminally ill child to discuss issues related to one's death.

Encourage involvement in the end of-life decision-making process

Children are rarely informed that they are dying(6). Traditionally, parents or

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TABLE I–*Sources of Stress in PICU During Bereavement.*

The dying child in PICU	Strange and intimidating PICU environment; separation from familiar caregivers; loss of self control and accustomed routines; inadequate use of analgesia and sedation; lack of play; witnessing the death of fellow patients.
Parents of children in PICU	Loss of parenting role; perceived inefficiency of the PICU team; insecurity of changing family dynamics; blame on the parent for child's condition; limited access to their child; mismanaged bad experiences in the past; uncertainty over outcome; perceived poor social support; inadequate/ conflicting reports on the child's status from team; economic considerations limit treatment options; restricted opportunities for communication with treating team; parents with restricted ability unable to express their emotions; waiting under difficult circumstances; intimidating high-technology environs; sick appearance, behavior and similarities between their child and others with fatal outcome; exposure to grieving relatives or news of other deceased children.
PICU team members	Exhausting physical demands of caring for sick children; conflicts between the team members and the child's family; moral dilemmas due to available technological resources to prolong life; making uncomfortable requests like obtaining consent for a postmortem; breaking bad news to the family; family is perceived as difficult; conflicts within the team; anger at perceived inadequacies.

TABLE II–*Difficulties in Identifying Pain, Discomfort and Advantages of Good Pain Control.*

Difficulties in identifying pain, discomfort	Advantages of good pain control
1. Child's difficulty in articulating symptoms	1. Reduced stress response translates into reduced complications and mortality
2. Staff inability to assess severity of symptoms.	2. Child becomes more cooperative with treatment procedures
3. Child's reluctance to request analgesics for fear of painful injections	3. Calm patients lead to a tranquil healing and working environment
4. Fears about the adverse effects of medication	
5. Difficulties in assessing pain in critically ill, unconscious children	

pediatricians make all treatment decisions on their behalf. Whenever the clinical status allows, the child should be involved in this decision-making process. Prepubertal children may require a proxy decider (usually a parent) to enhance their decision. Adolescents with the decision-making capacity should be given information regarding their illness and available treatment options to arrive at a decision(7).

Validating children's emotions

As the cognitive and emotional development of children influences their understanding of death and fears about dying, they need developmentally appropriate psychological techniques as presented in *Table III*.

Encourage reminiscence

Validating reminiscences (like positive

TABLE III–*Emotional Needs and Interventions in Dying Children.*

Age	Cognitive development	How they view death/symptoms	Interventions
3 yrs	Pre-operational stage	Temporary separation from parents, view this abandonment / treatment as retribution for bad behaviors, increased nightmares, aggressive play regression to infantile behaviors	Reassurance from staff & parents: that they are loved, have done nothing wrong, are not responsible in any way for their illness, they will not be abandoned
6-11 yrs	Concrete operational stage.	Active fantasy lives, personify death *e.g.*, as a skeleton, imagine themselves changing into the personification of death *e.g*., turning into a skeleton	Address fears associated their "fantasy approach" to death
12-15 yrs	Formal operational stage	Death as a final reality that happens to others but spares them. Death is inevitable, death is final, they can be the victims, experience entire range of emotions, may resist therapy due to concerns specific to this age group, may become withdrawn or openly hostile	Address concerns regarding: loss of bodily control, being imperfect, being different, effects of treatment on body image abandonmen, loss of independence

self-appraisals, social connections, joyful events) and lamenting reminiscences (like negative interpretations of past events, regrets, difficulties) are helpful in bereavement work(8). These evocative techniques are helped by bringing pictures, photo albums, videos and scrap books to these sessions. Conversations with schoolmates, friends and relatives may assist in the expression of a full range of emotions. Pets allowed in the PICU for short visits can ease the child's fears and loneliness(9).

The family of the dying child

Families of dying children are vulnerable and will require help during the acute stages of grief and bereavement support long after the child has died.

Enhancing communication

Communication is vital while working with dying children and their families. Family members who had been accurately informed about expected events around the end of life were often found to experience less anxiety and expend less effort in trying to cope with their loss(10). Frequent, accurate and truthful discussions with parents alleviates the sense of uncertainty and fosters confidence in the team's capability(11). *Table IV* suggests a few strategies to enhance communication between the treating team and the family.

If termination of life support is being planned, prepare the family for the event. More than one formal meeting is required to reach consensus with families about foregoing life support treatment. Families may need to know the approximate length of time the child may survive after life support termination, so that unrealistic expectations may be avoided. In cases where death is anticipated in the ward after withdrawal of the life support, the bereavement support during the transition

TABLE IV–*Strategies to Enhance Communication.*

1. Introduce team members to the family
2. Suggest an appropriate frequency of meetings while allowing for contingency measures in an emergency
3. Communicate a willingness to see them through the entire crisis
4. Indicate members directly involved in the care of their child and and how they may be contacted
5. Avoid scientific jargon and use simple language even with educated individuals
6. Anticipate and encourage questions
7. Frequently stop to check whether the family has kept pace with the rate of delivery of information
8. Explain each procedure/therapy in detail-expectations, possible side effects and other consequences
9. Encourage suggestions from parents *e.g.*, their perception of what the child requires and discuss the appropriateness of each
10. Break bad news tactfully

from PICU to the ward should be planned with the ward team that will receive the child. The grieving family should always be informed in advance of any such transition arrangements(12).

Open visitation

Children represent the dreams and hopes of their parents. Allowing time for goodbyes, visits and rituals permits the opportunity to form some cherished memories(9). Open visitations make the team’s job easier, decrease parental anxiety, and increase the child’s cooperativeness with procedures(13).

Presence of the family while withdrawing life support systems

Frequently families want to be present with the child at the time of death or wish to hold the child in their lap when life support is being terminated. Ask parents if they have such desires. Fears about heightened parental distress during such events are exaggerated. On the contrary, a majority of family members regret not having stayed with their child at the time of death(14).

Spiritual beliefs, rites and rituals

Spiritual beliefs strongly influence the existential issues of life, death and suffering. Parents with strong spiritual beliefs seem to resolve their grief more rapidly and completely after the death of a child(15). Family members find great comfort when they are given an opportunity to perform religious rituals in the PICU(16) and norms need to be established in each PICU that allows the conduct of ceremonies by religious groups within limits decided by hospitals.

Waiting

Waiting for parents of children in PICU is exhausting. The causes for stress and possible strategies to limit these are listed in *Table V*. Although waiting is sometimes unavoidable (like the time taken to perform tests) it can be reduced when possible (like in pain alleviation and delay in conveying medical reports).

Right to privacy

For confidential discussions and personal grieving the family needs privacy when the child is dying. In such situations, the family may be left alone to say goodbye to the child.

TABLE V–*Causes of Stress Associated with Waiting and Strategies to Reduce Them.*

Causes of stress while waiting outside PICU	Strategies to reduce waiting related stress
1. Enforced inactivity	1. Frequent updates of the child's status
2. Inability to leave for fear of missing an important event or report	2. Assisting parents to find a support person (hospital volunteer) to share the waiting with
3. Waiting with uncertainty regarding the outcome	3. Providing a comfortable setting in which to wait
4. Naturally occurring emotions of fear, neglect, anger, loss and fatigue that occur in such circumstances	4. Providing for physical needs (e.g.) ready access to food, lounges for sleeping
	5. Acknowledging the difficulty of waiting during verbal communications with the parents
	6. A arriving at a treatment area long before the procedure begins.

The child's comfort can be monitored by regular visits by staff to the room while still allowing privacy.

Appropriate place of death

If there is a clearly stated wish for spending the last days of life at home, in a "butterfly room" in PICU or a place where the family feels more comfortable instead of in hospital, the family may be encouraged to do so(17). Removal of the life support measures at familiar environment can be offered, if desired, with the medical team in close attendance to ensure the child's physical comfort. It is documented that children die a less stressful death at home than at the hospital. The control and independence the parents have at home facilitates a less traumatic grieving process(18).

Address parental emotions

Parental emotions correspond to their stage of grief–denial, anger, bargaining, depression and reorganization. Parents when unable to cope with their own emotions may suddenly behave in erratic ways that can easily alienate PICU team members. Bereavement is a time for restoring strained relationships that may otherwise interfere with normal grief resolution(19). If insightful support from the team fails, bereavement counselors may be summoned. Fewer families who receive such timely care need formal counseling at a later date(20). The possible signs that might indicate difficulties in grieving among family members are noted in *Table VI*.

Needs of other children and families in PICU

Superficial similarities between fatalities and critically ill children may engender a sense of panic amongst children or their families. Where possible, within the limits of ethically and legally valid confidentiality considerations, such doubts may be dispelled through empathetic clarification. Parents may be encouraged to form support groups to assist their difficult passage through these trying times.

Needs of the staff

Unresolved bereavement issues amidst PICU staff results in frequent staff turnover, absenteeism, litigation, depression, anxiety and fatigue. This in turn contributes to higher rates of errors in patient management and a compromised quality of care.

Avoiding conflicts

Most conflicts arise as a result of differing opinions between the family and the treating team regarding the child's status or expectations from treatment. Facilitating communication between staff and family members to achieve congruence between the two parties' aims of treatment avoids such conflicts. Identifying capable family members, who can be provided with practical training facilitates a shared responsibility between the staff and family reducing conflicts.

Bereavement support for staff

Debriefing sessions have been used effectively following a particularly harrowing experience to give all staff a chance to ventilate their emotions and reduce grief. A bereavement counselor can adequately assist in the grieving by PICU staff(21).

Improved work pattern, training and family

The work environment has a significant effect on stress levels and various remedies for coping with such stress is presented in

TABLE VI–*Indicators of Families with Grieving Difficulties and Strategies in Bereavement Support.*

Signal indicators of difficulty	Strategies in bereavement support
• Persistent denial of sickness or acknowledgement of severity of illness in the child	• Closure issues: discussing postmortem reports to a certain cause of death
• Anger against the treating team	• A final visit to the ward where child died
• Resistance in compliance with various aspects of therapy.	• Hosting memorial services for the bereaved families
• Emotional, occasionally physical, withdrawal from the child.	• Support issues: staying in touch via letters or phone calls
• Sudden and disproportionate increase in religious fervor	• Access to support groups
• Insistence on seemingly futile therapeutic ventures.	• Referral to professional help in case of pathological grief
	• Techniques to support siblings
	• Recommending specific books or websites the family can access
	• Future issues: family may want to know if surviving/future children are at risk & precautions to be taken

TABLE VII–*Suggestions to Alleviate Work Pressures and Burn-out Among PICU Staff.*

- Providing effective leadership.
- Unambiguous guidelines regarding expectations & work responsibilities
- Avoiding work overload by strictly enforced shift timings, compulsory holidays
- Providing variety of work by rotating staff within PICU or within the pediatric unit.
- Fostering group activities that encourage team spirit
- Providing opportunities for bereavement and stress management training.

Key Messages

- Bereavement in PICU is a pediatric critical care issue.
- Dying or death of a child in PICU is a source of stress to the child, the family, other children and families in the intensive unit as well as to the team.
- Addressing the physical, cognitive, emotional, spiritual needs of the dying child and the family, reducing misinterpretations by others in the PICU, avoiding conflicts between the team and family, bereavement support for staff with improved work pattern and an appropriate follow-up care forms the basis for bereavement management in PICU.

Table VII. Team members living with partners or children are relatively protected from bereavement related stress(22).

Follow-up care

During the follow-up period parents have to tackle a bewildering range of emotions. The critical care team, which was an important ally during the last moments of their child, often withdraws contact following the death of the child. The aim of follow-up care is to address this void by effecting closure for parents who are coping healthily with their grief and identifying those with pathological grief requiring support (*Table VI*).

Most parents are able to cope with and resolve emotional issues associated with bereavement probably because social support from their families is still adequate in India. Also specific to India are culturally sanctioned rituals like wailing and ceremonies around death that help resolution of grief.

The family should be made aware that the end of grief is not severing the bond with the dead child but integrating the child into the family in a different way, than when the child was alive, as a socially shared reality(23).

Conclusion

In conclusion appropriate preparation for death, effective communication, allowing the family increased time with the dying child, privacy, control of acute grief symptoms, an opportunity to go over one's life, a chance to solve unfinished matters, avoiding protracted death, strengthening family ties, addressing parental emotions, tending the needs of other patients and families in the PICU while attending to the well being of the team members as well as follow-up care forms the basic framework for bereavement support in PICU.

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