

PEDIATRIC ONCOLOGY BEREAVEMENT PROGRAM

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BACKGROUND

Outliving your child is a tragedy for any parent. The sadness, feelings of failure and anguish parents experience are overwhelming, and indeed, health care providers may experience similar emotions.

Often the bereaved parents are young, so their child's death may be the parents' first experience with the death of a close relative.

Caring for children with cancer means that we see children die. The pediatric oncology team develops and cultivates relationships with these children and their families, so providing bereavement care is a natural extension of continuing care.

PURPOSE AND HYPOTHESIS

Our primary objective was to provide ongoing support for families who experienced the death of their child.

Our hypothesis was that continued contact with bereaved families would be beneficial for the families and staff as well.

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WHAT WE DID-TEAM MEMBERS

Our Pediatric Oncology team consisted of two pediatric oncologists, two pediatric oncology nurses, and one Child Life Specialist.

The team conducted regular contact with every bereaved family. The contact consisted of four components.

First, attendance at the memorial or funeral service by at least one team member.

Second, telephone contact at the following times: within the first week of the child's death, at 1,3,6,12, 18 months after the child's death and on the child's birthday.

Third, in November a bereavement letter was mailed to families to let them know that the end of the calendar year can be a difficult time for families who have lost a child.

Fourth, the Child Life Specialist planned a play date with siblings of a child who died about 6 months after their brother or sister's death.

DIAGNOSES

TYPE	N
A.L.L.	6
Brain tumor	4
Germ cell tumor	2
Sarcoma	2
A.M.L.	1
JMML	1
Neuroblastoma	1
Hodgkin's disease	1
Aplastic anemia	1
Sickle cell disease	1
TOTAL	20

CAUSE OF DEATH

Progressive disease	16
Sepsis on therapy	3
Death in remission	1

CONCLUSIONS

Continued involvement of the medical team is welcomed and appreciated by bereaved parents

Although emotionally intense, contact with bereaved parents is feasible and meaningful

WHAT WE FOUND

All 20 families (mother or father) were contacted during a 3 year period according to the 4 components.

No family refused contact ; Every team member participated

Median age at death = 8 years

12 girls/8 boys

Location of death: Home (8) Hospital (12)

Every parent was appreciative that we remember their child, and that simple fact helped in their grieving process

Fifteen families continue to bring gifts of thanks

Fourteen families said they missed us, the health care team

Twelve families said that the impact of surviving siblings is overwhelming

Six families related that they needed a physical location to grieve

Four families mentioned that visiting with the friends of their child was comforting

Parents of school age children found support in their child's teachers

"Normal life" was caring for a ill child, life now seemed "not normal"

Parents report they "See" some of their dead child in their surviving children