

Navigating New Insight: A Review of Bereavement Practices at the Hospital for Sick Children

Jackie Hubbert, R.N, BScN and Mayola Mathew MSW, RSW

Background

Based on feedback received from families about care at the time of their child's death, a bereavement task force was instituted. This task force decided to perform a review of the bereavement practices at the hospital. Staff were interviewed and to ensure the review included the perspective of the families, we interviewed families who had experienced the death of a child at SickKids.

Method

- Staff were requested to refer appropriate families
- Families were then contacted
- Willing participants were given the choice of being interviewed in person or over telephone
- Families were asked to share their experience
- The interview was then guided by pre-established questions and prompts
- Interviews conducted June – October 2009

Families Interviewed

- 10 families interviewed; majority of referrals from Social Workers
- 6 interviews were conducted in person and 4 over telephone
- All experienced the death of a child between 6 months to 3 years prior to the interview
- Cause of death ranged from unexpected to chronic illnesses
- Age of child at time of death ranged from 3 weeks to 16 years
- 5 out of the 10 children who died were only children
- 6 interviews were with mothers, 1 with father and 3 with both parents
- Families came from diverse backgrounds
- Interpreter requested by one family
- Families received care from 6 different programs

Themes Identified

Families commonly feel:

- "Hurt" and "Isolated" when hospital staff do not follow up with them after their child's death
- Abandoned when transferred from one unit to another or from one service to another
- That they didn't know "what to do next?" and appreciate help with funeral arrangements
- That they would benefit from having an advocate or someone who has been in their shoes
- Concern for families less privileged than themselves and getting support needed.

Other points identified:

- Need to improve relationship with Coroner's Office
- Same level of care is not always provided after hours
- Referrals to community resources would be beneficial
- Individualized care is needed
- Organ donation is a lengthy but valued process
- Families from out of town may need referrals to local resources
- Lactating mothers require immediate support
- Having trust is essential to having a positive death experience

Practice Strengths Identified

- Simple acts of kindness and displays of genuine concern, "labour of love"
- Support and services provided by Palliative and Bereavement Care Service
- Hospital staff attendance at funeral / Shiva
- Honest, frank and compassionate communication
- Recognition of SickKids as a world class institution
- Yearly memorials at the hospital
- Time to grieve

Inconsistent Practices Identified

- Legacy building
- Discussions of cultural practices
- Referrals to Palliative and Bereavement Care Service
- Resources (community and hospital)
- Follow up care

Next Steps For Task Force

- Establish scope of the group and develop working definition for "Bereavement"
- Work towards practice improvements and strategies such as education, policies, system changes and available resources
- Look for opportunities to maximize existing resources to support bereavement care
- Link with available community resources to optimize utilization and look for opportunities to develop new partnerships
- Promote integration with other hospital initiatives such as, New Immigration Support Network, Family Centred Care initiatives, Interprofessional Practice Initiatives etc.



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