

The Palliative and Bereavement Care Service Evaluation of After Hours On Call Services

Ashley Teschner, MSW, SickKids Hospital, Christine Newman, MD FRCP(C), SickKids Hospital, Jodi Hamelin, MSW, McMaster Children's Hospital, Laura Beaune, MSW, SickKids Hospital, Maria Rugg, CNS/NP, Office of the Chief Coroner, Rose Steele, RN, PhD, York University

SickKids
THE HOSPITAL FOR
SICK CHILDREN

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Team for Research in Adolescent and
Childhood Palliation and Grief



Background

Recently, the after hours on call program for the Palliative and Bereavement Care Service (PBCS) at SickKids has changed. As of August 2008, families involved with the program will no longer receive 24/7 care from the team. This change differs from many Canadian and American Associations' pediatric palliative care standards, policies, reports, guiding principles and norms of practice. These Associations support and advise a "gold standard" of pediatric palliative care being available to children and families 24 hours a day, 7 days a week by a specialized palliative care team. As well, pediatric palliative care literature emphasizes how much coordination and continuity in the delivery of their child's palliative care reduces families' frustration and confusion. Parents have identified the importance of health care providers being familiar with their children as individuals (Darnill, 2006; Heller, 2005; Meyer, Ritholz, Burns, & Truog, 2006).

Since this change seems counter-intuitive to pediatric palliative care best practices, the PBCS decided to conduct a quality management/program evaluation project of the after hours on call services provided to children and their families in the hospital comparing the services from before and after these 2008 changes. Interestingly, thus far, no department within SickKids has done a formal evaluation of the after hours on call services provided to patients and families.

Focus

The evaluation surveys aimed to answer the question:
What impact, if any, will this change in service delivery have on palliative children and their families?

Methodology

- In phase 1, two standardized surveys were distributed to two groups of stakeholders:
 - 1) Bereaved parents who received care according to the previous standard- access to the service 24/7 and
 - 2) Families actively involved with the PBCS before and/or after the change has taken place in the service delivery of palliative care.
- Evaluation is both retrospective and prospective.
- Surveys asked parents of their thoughts on how a pediatric palliative care service should run, and asked them to assess their experiences with the PBCS at SickKids.
- Phase 2 will re-evaluate experiences of the families who have now seen the changes in after hours on call services.
- New surveys will also be sent to families who have joined the PBCS after August 2008.
- The evaluation is comparative, as it seeks to understand the experiences of the individuals who received 24/7 service from the PBCS compared to those who have not received this service.

Findings

- Surveys were sent to 27 families.
- 15/27 are families actively involved with the PBCS, 12/27 were bereaved families.
- There was a 41% response rate.
- 8/11 of the respondents found it absolutely important that the after hours on call team be someone they are familiar with, and who was familiar with their child's medical history.
- 100% of the respondent families also found it important that the health care provider answering the after hours call would be able to relieve emotional distress of the child/family.
- 9/11 parents were extremely satisfied with the quality of care provided by the PBCS at SickKids (6B/3A).

Emerging Themes

- Families found the PBCS team to be extremely supportive, helpful and truly cared about the child/family.
- Several families mentioned that they grew close with the PBCS team.
- When asked for suggestions for the after hours on call service, several families said that no changes were necessary, and were saddened to hear that the service had changed.



"adding life to a child's time"

