

Lessons Learned following SARS : Caring for Dying Children and their Families during a Pandemic Crisis

Laura Beaune, MSW SickKids Hospital, David Nicholas Ph.D MSW, University of
Calgary, Jodi Hamelin, MSW (c) RA, SickKids Hospital

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Introduction

The severe acute respiratory syndrome (SARS) outbreak in Toronto in 2003 and the resulting infection control practices (e.g., isolation, restricted visitation, masks) made maintaining the practice of family centred pediatric palliative care highly challenging.

Preliminary research and clinical expertise has shown that the impact of SARS on hospitalized patients led to several negative outcomes such as: child isolation and fear, parent and child stress and anxiety, reduced access to and disruption of services, and compromised physical and emotional health (Maunder et al, 2003, Koller et al, 2006, Nicholas et al, 2008).

Caring for inpatient dying children during this time had its own unique challenges: compromised end of life conversations; restricted visitation during baptisms or last rites, missed opportunities to meet, connect with or say goodbye to the dying child.

Understanding the parental experience has helped us develop recommendations that may be used to provide a blue print for future pandemic planning initiatives with respect to the unique needs of dying children and their families.

Methodology

A qualitative research design using semi-structured face to face interviews was implemented.

A subsample of 6 bereaved parents of infants/children (ranging in ages from 8 days to 9 ½ years) who received care at a large academic paediatric hospital in Toronto during the 2003 SARS outbreak were retrospectively interviewed. Diagnosis included prematurity, brain tumour and neonatal complications such as trisomy 13.

Research Questions

- 1) How did hospitalized children in palliative care and their parents experience health care delivery during the SARS outbreak?
- 2) What challenges and barriers were faced and how might these be improved in the future?
- 3) What recommendations do parents provide regarding care in the event of future disease outbreak?

Interview Guide

Domains for Parent Interviews

- ❖ Knowledge of SARS
- ❖ Experiences of Services Received
- ❖ Experiences of Infection Control and Restricted Visitation
- ❖ Perceptions of Care Received
- ❖ Coping Strategies
- ❖ Recommendations

Findings – Parent Quotes

"They were talking about life and death decisions, and I couldn't see these peoples faces, and that was very hard".

"I think that it was very, very difficult for my parents and [husband's] parents and I'm very close to my sisters as I told you earlier. For them to finally meet my baby in a funeral parlor..."

"I think, we weren't worried so much about the disease. We weren't worried about catching it or being exposed to it or passing it on or anything like that."

"They [staff] were so compassionate about it that really, myself, like I never lost it with anybody.... Like they didn't bring SARS into the hospital. They are just trying to deal with it and they are trying to keep our kids who are here right now who are sick, they are trying to prevent them from getting worse".

Findings and Recommendations

Themes

Impact of communication barriers and limited information

Repercussions of visitation restrictions

Conflicted emotions felt by families regarding infection control measures

High quality of care and professionalism of hospital staff appreciated by families

Recommendations:

Ethical framework based on family centred and palliative care principles

Creative communication strategies

❖ Use of videophones and web based interfaces

Family-friendly information sharing

❖ Consistent, truthful and rapid information using various mediums

Adaptive and flexible policies

❖ Exceptions to restricted access & visitation

❖ Creation of additional family rooms

References

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The authors would like to thank the families who participated in this study and acknowledge the support of CIHR who funded the study.