

Bridging the chasm between hospital and home: bereaved parents informing a contemporary model of transitional bereavement care

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Background

Parents who have a child who dies from cancer experience a complex layer of losses: that of their child, pre-existing formal and informal relationships in their community, and the loss of their 'hospital family'^{1,2,3}. Following the death of their child, bereaved parents describe feeling isolated and abandoned from the health care team and their community of supporters at the very time they need the care, empathy and support from those they know and trust.

Study aims

1. To explore current hospital-based bereavement follow-up practices in the paediatric oncology setting.
2. To assess the impact of important demographic and medical factors on parents' bereavement experience.
3. To identify the personal, practical and professional resources parents draw on, or would access if available, throughout these various time points.

Method

Participants (parents >6months and <10years bereaved) were recruited through four paediatric oncology sites in Australia. We used a convergent parallel mixed method design:

Self report questionnaire (n=119)
- Demographic characteristics (parent and deceased child)
- Grief: Hogan Grief Reaction Checklist, Hogan et al 2001
- Distress: The Emotion Thermometers Tool© Mitchell et al 2007
- Support service preferences
- Barriers to accessing support

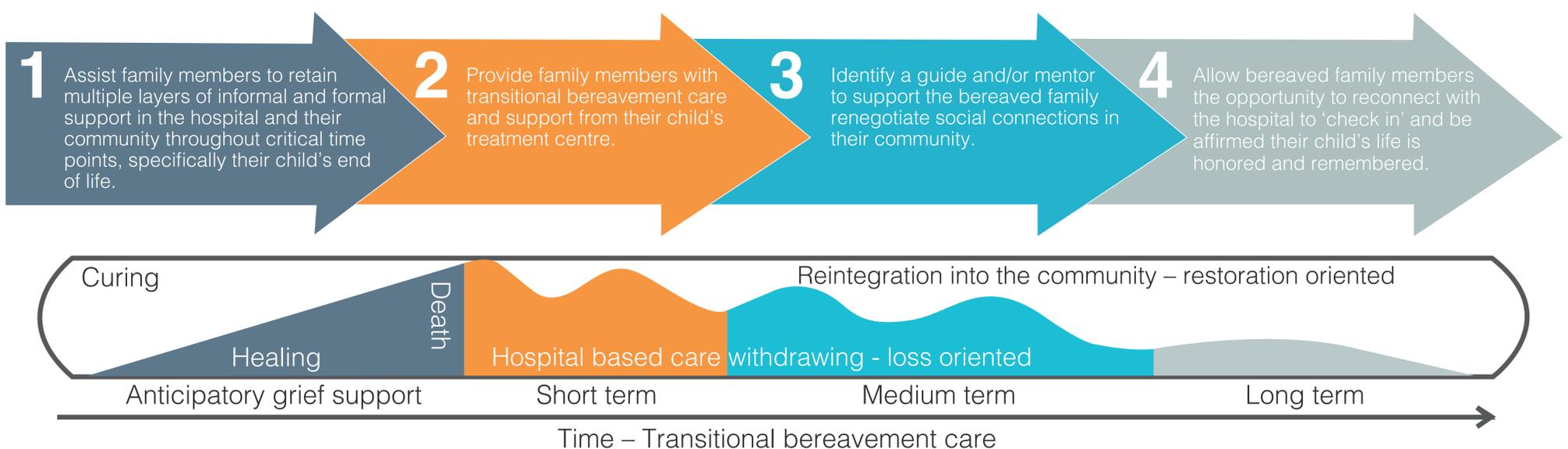
Semi-structured telephone interview (n=41)
Parents' experience of and support accessed at:
- Diagnosis and throughout treatment
- End of life
- Day of their child's death
- After the death of their child

Summary of key findings

1. Parents felt **abandoned and isolated** from the treatment team following the death of their child.
2. Parents indicated the most helpful forms of support as **family, friends and neighbours**, however parents described a decline in the quality of these relationships over time.
3. Parents asked for support and guidance for **their 'whole' community of supporters** including: siblings; grandparents and other extended family members; friends; and other important components of their social network including for example, employers, schools, daycare.
4. **Parents ranked General Practitioners and Cancer Support Organisations** as the most accessed and helpful sources of formal support in the community.
5. Parents valued the **support of bereaved peers** however asked for facilitation of these connections prior to the death of their child or early in their bereavement.
6. **51%** of parents indicated they would have liked more help than they received prior to the death of a child, with **43%** expressing the need for more help than they received in their bereavement.
7. Parents described their greatest barriers to accessing support as **Feeling I need to be strong for everyone else** (78%), **Feeling my concerns are too private to share** (54%) and **Not knowing where to look or who to ask** (51%).

Recommendation: development of a contemporary model of transitional hospital bereavement care

While the hospital may be best placed to provide transitional care in the immediate aftermath of a child's death, this is not sustainable longer term. Reconnecting with formal and informal support in the community has the potential for long-term sustainability. Transitional bereavement care that supports parents to re-engage with support in the community may be a more responsive model. The hospital based team can assist with this transition by over time 'lowering the dose' of what support is offered while simultaneously supporting a family's transition more fully into their community (increasing the community 'dose').



Future directions

Implementation of this new model requires input and formal evaluation from a family, health care professional, and community stakeholder perspective. Future research should seek to understand whether enhancing connections between families and their natural support system at various points through a child's cancer care trajectory and in the family's bereavement does in fact reduce the parents' experience of isolation and abandonment.

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