

Risk and protective factors for parents bereaved from childhood cancer

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Background

Parents bereaved from childhood cancer suffer a concertina of losses prior to and following their child's death. Throughout a child's cancer treatment the interplay between medical, personal and social factors impact significantly on bereavement outcomes.^{1,2,3} Understanding the risk and protective factors for parents throughout this trajectory may help target interventions and resources throughout cancer treatment and the family's transition into bereavement.

Objectives

The objectives of this study were:

1. To identify parent and child demographic factors that impact grief and growth;
2. To identify medical factors of the child diagnosed with cancer that impact grief and growth.

Method

Sample: Participants were recruited through four paediatric oncology sites in Queensland and New South Wales, Australia (>6mths and<10years bereaved; n=119)

Methodology: This study adopted a convergent parallel mixed method design.

Quantitative data: Self report questionnaire: measured parent's demographic characteristics; deceased child's demographic characteristics; grief (Hogan Grief Reaction Checklist – HGRC).

Qualitative data: Semi-structured interview: invited parents to share the story of their experience from diagnosis, the day their child died; and after the death of their child and help they found useful throughout these time points.

Data analysis: We conducted generalised estimating equation analyses to identify predictors of each parent's HGRC subscale score as this approach allowed control of clustering of families where more than one parent from the same family participated. Univariate analyses preceded the multivariate analysis. Variables with a univariate p-value of <0.2 were included in the multivariate models.

Results

Participants included 119 parents representing 99 children (91 mothers, 28 fathers: response rate 22%). Most parents were living in a married/defacto relationship (85%), with a mean age of 47.2 years (SD=8.1 years; range: 31-67 years). Of the deceased children, 56% were male, with a mean age at death of 9.4 years (SD=5.5 years; range 0.17-20 years). The mean time since death was 5.6 years (SD=3.0 years; range 0.56 – 11.01 years). Most (64.7%) were referred for palliative care, and most died in hospital (58.5%).

Factors contributing to despair

You know because my husband had to go back to work, so he was seeing people, he was in contact with people, seeing the outside world that sort of thing. Whereas I had no one you know. I had in-laws galore but they weren't around.
- Mother, 11 years bereaved

Employment: Parents undertaking home duties had significantly higher despair scores than employed parents ($\beta = 4.748$, $p = 0.038$).

Location of death: Parents whose child died in a hospital or hospice had significantly higher despair scores than those whose child died at home ($\beta = 7.249$, $p = 0.050$; $\beta = 2.596$, $p = 0.272$ respectively).

Conclusions

Findings from this study affirm the need to target psycho-social support at critical intervals throughout a child's cancer care trajectory and in parallel assist parents in identifying inter and intra-personal assets which may be enablers in bereavement. Targeting care to parents where there are multiple risk factors prior to the death of a child ensures a preventative model of bereavement care. Future research may inform development of evidence-based transitional bereavement care for families throughout a child's palliative and end-of-life care and their family's bereavement.

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Your support is the gift which will keep giving on.

Factors contributing to disorganisation

It's a big shock to the system. You go from being told what to do every day – come to this appointment and that appointment. Then when it's over, it's just over. That's it. You've got nowhere to go or no one to talk to or ask. Everybody else is working and doing their normal thing, but our normal thing ended.
- Mother, 6 years bereaved

Employment: Parents undertaking home duties or who were unemployed had significantly higher disorganisation scores than employed parents ($\beta = 5.361$, $p = 0.002$; $\beta = 5.384$, $p = .008$ respectively).

Factors contributing to blame/anger

When the radiation started that was horrific. When they made that radiation mask that would cover her face and bolt her to that table. I heard sounds come out of her that I've only heard come out of farm animals. There were times where if I knew now how it was going to end, I would've just scooped her up and brought her home.
- Mother, 2 years bereaved

Relationship status: Partnered parents had significantly higher blame/anger scores than those who were not partnered ($\beta = 7.926$, $p = .001$).

Religion: Participants with no religious affiliation had significantly higher blame/anger scores than those who identified with a religion ($\beta = -6.932$, $p = .048$).

Radiation treatment: Participants whose child received radiation treatment had significantly higher blame/anger scores than those who did not ($\beta = 4.942$, $p = 0.045$).

Palliative care: Participants whose child was not referred to palliative care had significantly higher scores on the blame/anger scale than those whose child was referred ($\beta = -11.815$, $p = .001$).

Location of death: Parents whose child died in a hospital or hospice had significantly higher blame/anger scores than those whose child died at home ($\beta = 11.906$, $p = .001$; $\beta = 13.747$, $p < .0001$).

Factors contributing to growth

I had 9 months to come to terms with the fact that it probably would end that way. [my son's] dad was a lot more optimistic and used to get cranky at me and say "well you have to think positively". I was prepared that it probably wouldn't end well. He probably struggled with the whole process a lot more than I did...
- Mother, 5 years bereaved

Sex: Mothers had significantly higher growth scores than fathers ($\beta = 6.155$, $p = 0.010$).

Education: Parents who had completed high school or university had significantly higher growth scores compared with those who had less than 10 years of schooling ($\beta = 8.459$, $p < 0.001$; $\beta = 5.454$, $p = 0.026$).



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