

Journal Watch – Grief and Bereavement – July 2018

Article:

Distrust in the End-of-Life Care Provided to a Parent and Long-Term Negative Outcomes Among Bereaved Adolescents: A Population-Based Survey Study

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Strengths:

- Novel and practical question: identify modifiable risk factor to prevent known harms associated with death of a parent.
- Large sample and high response rate.
- Patient-reported outcomes rather than proxies (participants were adults at time of data collection); anonymous self-reporting prevented interviewer-related bias.
- Analysis adjusted for confounding factors (demographics, family and childhood adversity, or healthcare related factors)
- Long-term consequences (eg. 6 to 9 years post-loss of parent)

Weaknesses:

- Correlation, and not causation: possibility for residual confounding after adjustment, unmeasured confounding variables (eg. use of psychological support), differential attrition, differential misclassification.
- Unknown whether data from non-participants would have changed results (self-selected sample?)
- Specific homogenous sample (teens age 13-16, from originally 2-parent families) - gives results for specific context but limits generalizability
- Although study is published in 2017, data collected in 2009 to 2010 (for a broader study purpose).

Relevance to Palliative Care: First study that associates distrust with negative outcomes in children of deceased parent, even years after the loss. It specifically refers to care provided in their parent's final week of life with cancer – population and timeframe that palliative care providers usually work with. Palliative care providers should consider (assessing appropriateness of each case, and with patient's discretion) involving adolescent children of palliative patients in discussions about their parent's medical condition and addressing their questions and misconceptions. This may play a role in safeguarding the trust in the healthcare provided, and possibly prevent long-term negative outcomes (including bitterness toward healthcare professionals, depression and other psychological symptoms, self-harm, and unhealthy grief).