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Institutionen för Onkologi och Patologi

Teenagers losing a parent to cancer: Experiences, modifiable risk-factors and long-term outcome

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ABSTRACT

Background: We investigated the experiences of cancer-bereaved teenagers. The goal was to identify potentially modifiable risk-factors for long-term psychological consequences and thus be able to guide health-care providers in ways to support bereaved-to-be teenagers.

Subjects and Methods: A study-specific questionnaire was made based on semi-structured interviews with cancer-bereaved youths and tested for face-to-face validity. Through population-based registers, we identified cancer-bereaved children in Sweden who at age 13 to 16 had lost a parent to cancer between 2000 and 2003. Children had to have been living with co-habiting parents, been born in a Nordic country and have an identifiable telephone-number. Out of 851 eligible cancer-bereaved youths, 622 (73%) participated by answering our questionnaire. Registers also provided us with a matched group of non-bereaved youths among which 330 of 421 (78%) participated by answering a less extensive but otherwise identical questionnaire. Data collection went on between February 2009 and March 2010. Participants were between 18 and 25 years of age and parental loss had occurred six to nine years earlier.

Results: Twenty percent of cancer-bereaved youths reported having had a period when they deliberately self-injured, compared with 11% in the non-bereaved group. Adjusting for sex/gender, childhood self-destructive behavior, bullying, physical or sexual abuse, and having had no one with whom to share joys or sorrows, increased the odds ratios from 2.0 to 2.3. Among family- and health-care related and possibly modifiable factors associated with self-injury in univariable analysis, we identified *poor family cohesion before* (RR, 3.4) and *after* the loss (RR, 3.5); *distrust* (RR, 1.7); perceived *poor efforts to prevent suffering* (RR, 1.6); and *poor efforts to cure* (RR, 1.5). Associations with family cohesion were decreased but remained statistically significant after adjustments for multiple variables, including sex/gender, having been subjected to sexual or physical abuse, and depression. For health-care related factors the associations were attenuated.

Eighty-two percent of participants reported moderate to very much trust in the care that was provided to the dying parent. In this group, 11% had moderate to severe depression at time of follow-up, compared with 25% among cancer-bereaved youth reporting distrust (no or little trust) (RR, 2.3). The risk of distrust (no to little trust) was highest among those who never received any end-of-life information (RR, 2.5), those informed only afterwards (RR, 3.2) and those who don't know or remember if end-of-life medical information was given (RR, 1.7). Other important risk-factors for distrust were perception of poor health-care efforts to cure the parent and poor relationship with the well, surviving parent. Ninety-eight percent reported the opinion that teenagers about to lose a parent to cancer should be told when death is imminent. Among 367 (60%) who had been told, 62% were told by parents, 11% by parents together with health-care professionals, and 14% by health-care professionals alone. Mutual pretending and lack of awareness that death was near were prominent reasons for not talking about death in the family. Forty-four percent of the teenagers realized that death was imminent on the last day, half of them only hours before the loss. An additional 19% never realized it.

Conclusions: Self-injury is twice as common in cancer-bereaved youth. Poor family cohesion before and after the loss are important risk-factors for self-injury. The influence of perceptions of poor quality care varies with family cohesion, life-time adversities and depression. One fifth of cancer-bereaved youth reported distrust in the health-care provided in the final week of the dying parent's life. End-of-life information by a physician before the loss lowered the distrust in health-care. Almost all teenagers want to know when a parent's death is imminent but many are never told.