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## **The loss of a child to cancer – focusing on siblings**

AKADEMISK AVHANDLING

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## ABSTRACT

**Aims** The overall aim of this thesis was to investigate the long-term psychological health consequences in bereaved families of children who have died from cancer, with a focus on the siblings. Further, we investigated if health-care and family related stressors might affect the long-term psychological health in bereaved siblings. Part of the aim was also to examine bereaved siblings' experiences of participation in a research study about their loss.

**Subjects and Methods** In the initial study, parents who lost a child to cancer four to nine years earlier in Sweden were asked to participate in a nationwide follow-up study, 80% (449/561) participated together with a group of non-bereaved parents from the general population, 69% (457/659). A study-specific, anonymous questionnaire assessing anxiety, depression, quality-of-life and marital status together with a number of other outcomes were distributed to participating parents. In another nationwide follow-up study, we contacted 240 siblings, in Sweden, who had lost a brother or sister to cancer between the years 2000 and 2007; among those, 73% (174) agreed to participate in our study. A control group of non-bereaved siblings, matched for age, gender and place of residence, were also invited, 75% (219/293) participated. A study-specific and anonymous questionnaire assessed the siblings' experiences of participating in the study, their psychological health (anxiety, depression), and their communication with family and others prior to and after the death of their brother or sister, together with other factors.

**Results** Bereaved parents were more likely to be living with the child's other parent, 74% (329/442) compared to non-bereaved parents, 69% (312/452), RR=1.1 (1.0-1.1). None, (0/168), of the bereaved siblings thought that their participation in the study would effect them negatively long-term. Ninety-nine percent of the siblings (171/173) found it valuable to conduct such a study and a vast majority, 84% (142/169) found it to be a positive experience. At follow-up self-assessed low self-esteem ( $p=0.002$ ), difficulties falling asleep ( $p=0.005$ ) and low personal maturity ( $p=0.007$ ) were more prevalent among bereaved siblings. However, anxiety ( $p=0.298$ ) and depression ( $p=0.946$ ) according to the Hospital Anxiety and Depression Scale (HADS) were similarly distributed between bereaved and non-bereaved siblings. Siblings who avoided the health-care professionals, for fear of being in their way during their brother or sisters last month in life, reported an increased risk of anxiety, RR=2.2 (1.1-4.6) as compared with those who did not avoid the health-care professionals. Siblings who talked less about their feelings regarding their brother or sister's illness reported an increased risk of anxiety, RR=2.8 (1.3-6.2) as compared with those who talked more frequently. An increased risk of anxiety was also prevalent among siblings who avoided talking to their parents about their deceased brother or sister, out of respect for their parent's feelings, RR=2.4 (1.1-5.4) as compared with those siblings who reported talking to their parents about the deceased child.

**Conclusions** Parents bereaved due to cancer are not more likely to be separated or divorced from the child's other parent compared with non-bereaved parents. Bereaved siblings are at increased risk of low self-esteem, low personal maturity and sleeping difficulties as compared with non-bereaved peers. Avoiding health-care professionals prior to the brother or sisters death and avoiding talking to their parents following the loss increased the bereaved siblings' risk of long-term (two to nine years following the loss) anxiety. Most siblings reported finding it valuable to participate in this type of research.