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PARENTAL REACTIONS IN CHILDHOOD CANCER: DISTRESS, RISK AND RESILIENCE

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ABSTRACT

Parents of children with cancer encounter an exceptionally difficult life experience. Acute and long-lasting distress adds to the initial traumatic experience of being told that a family member suffers from a potentially fatal illness. This thesis investigates the determinants of short and long-term psychological effects in parents in two Nordic sites with different routines for care and follow-up. A general aim was increased knowledge and understanding of parental reactions and psychosocial follow-up needs of families. Study I examined the significance of individual strengths for parental resilience against distress by studying the relationships between Sense of Coherence (SOC) and illness-specific and generic distress symptoms. We also studied whether parental *gender, level of education, and use of professional support* influenced that relationship. Data were collected from 190 parents of 126 childhood cancer (CC) survivors, and 208 parents from the general population. SOC was assessed using the SOC-13 questionnaire. Distress outcomes were measured using the multi-dimensional Parental Psychosocial Distress in Cancer (PPD-C) questionnaire, which covers *uncertainty, loss of control, self-esteem, anxiety, disease-related fear, loneliness, sleep disturbances, depression, and psychological and physical distress*. Non-pathological psychiatric symptoms were screened for using the General Health Questionnaire (GHQ-12).

Study II, included 328 parents of 211 CC patients at one of two sites, either in Sweden or Iceland, and 208 control parents. We studied occurrence of cancer-related parental reactions, and compared distress symptoms in the two national samples. A goal was to identify of nation-, site- and organisation-related determinants of parental experiences. Outcomes were evaluated against non-clinical norm data.

Study I provided support for the hypothesis about a protective influence of SOC, and that SOC is associated with resilience also in this population. Influence of SOC was strongest regarding general psychiatric symptoms, physical and psychological stress symptoms, anxiety and depression, although low SOC was associated with more severe distress general. Influence of SOC was stronger among mothers.

Study II showed that both in the Swedish and the Icelandic groups, distress exceeded the level of a non-clinical norm group. In adjusted analyses comparing parent outcomes Icelandic parents scored significantly higher in distress on 5 of 11 PPD-C subscales. Significant differences, primarily concerning illness-specific distress, and uncertainty due to unmet informational needs, were found between parents at the two sites.

The findings in this thesis indicate that parental resilience to cancer-related distress varies with identifiable strength factors. This suggests that a strengths-oriented approach facilitates understanding of the kind of factors that govern parental adjustment to childhood cancer. Addressing resilience instead of pathology helps identifying parents at risk and in need of intensified psychosocial support.

Distress and needs for illness-related information was more prominent among parents at the smaller Icelandic site. This finding indicates a need for routines to meet parental uncertainty, adapted to conditions prevailing at a low-influx centre with limited resources for specialised psychosocial follow-up. Differences between study groups indicate that compensatory measures in local/national and/or site-related arrangements for care, surveillance and information are possible means by which parental psychosocial services can be improved. Differences in this study in parental outcomes may partly be due to the larger centre having more favourable preconditions for providing a multifaceted caring context, including parental fellowship where informal mutual support and shared information contribute to resilience against illness-related distress.