

ORIGINAL ARTICLE

## Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer

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### Abstract

**Aim.** Studies of parental reactions to a child's cancer have traditionally been carried out within the framework of psychiatry and psychopathology. We studied the significance of individual resource factors strengthening parents' resilience to long-term cancer-related distress, a focus that has rarely been used. **Participants and methods.** The two-nation Nordic sample included 398 parents; 190 of whom had experienced a child's cancer, and 208 reference parents. We studied the sense of coherence (SOC) using the SOC-13 questionnaire. For assessing distress reactions we used a primarily illness-specific 11-dimensional Parental Psychosocial Distress in Cancer (PPD-C) self-report questionnaire developed for use with parents of childhood cancer patients, and the General Health Questionnaire (GHQ). Resilience was defined as absence of/less severe distress. **Results.** Low SOC was significantly associated with more severe distress in all dimensions of the PPD-C and GHQ. The protective effect of SOC was indicated by it being most negatively related to general psychiatric symptoms, physical and psychological stress symptoms, anxiety and depression. The influence of SOC varied with parents' gender, showing a stronger modifying influence among mothers. Mothers and fathers also differed in their utilisation of professional psychosocial support when confronted with the child's cancer. **Conclusion.** Parental resilience to cancer-related distress varies with identifiable strength factors. A strengths-oriented approach helps in understanding parental adjustment to childhood cancer. In order to counteract psychological vulnerability, addressing resilience instead of pathology helps to identify parents at risk and in need of professional support when faced with a child's cancer.

Although a rare disease, in the industrialised countries childhood cancer is the most common cause of death for children under the age of 20 after accidental death, birth defects, and deliberate harm [1]. The child's illness constitutes a parental stressor, existentially threatening the conception of life as predictable and safe. For most parents, this is followed by the immediate fear of losing their child. The requirements of coping with a suddenly altered life-situation characterised by strain, escalated situational stress and heightened parenting demands [2,3] transforms everyday life.

The existential trauma caused by a child's illness affects the whole family, especially the parents, regardless of individual family members' psychological resources. Nevertheless, as there appears to be more and less adaptive ways of coping with this threat [4,5], individual strengths and resources may

influence the psychological distress reactions [6]. This is supported by previous studies of patients' and families' coping with the threat of illness in general [7], and cancer in particular [4,8].

The strengths-focusing orientation of Antonovsky [9] contributes to an understanding of the part played by an individual's resources in managing situational stressors. This orientation deals with the question: What is it that strengthens some people's ability to manage crises and adapt to stress better than others? The capacity to resist adverse psychological reactions when suffering risk experiences is referred to as resilience [10].

Studies of parental reactions to a child's cancer have rarely adopted a resources-oriented perspective. The focus has been on weaknesses, or formation of psychological or psychiatric symptoms within a framework of psychopathology. However,

regarding other paediatric illnesses or medical conditions, studies of parental strengths and reactions have indicated the potential of SOC to strengthen coping and resilience to distress. Thus, in studying parents of children with learning difficulties, mental retardation and behavioural disorders, Margalit et al. found a positive relationship between low sense of coherence and avoidant non-adaptive behaviour [11]. A more recent study of Icelandic and American parents of paediatric asthma patients showed that sense of coherence modified the effect of family demands on the situational adaptation of parents [12]. Also, SOC has been identified as a significant resource reducing stress among mothers of children with hearing impairment [13], Down's syndrome [14], and developmental disabilities [15]. However, to our knowledge, prior studies have not addressed the relationship between sense of coherence and a variety of symptoms of disease-related distress among the parents of children with life-threatening cancer.

Our aim was to investigate the significance of parental resistance resources, manifested by SOC, in the ability to withstand long-term distress caused by a child's cancer. In our model we examined whether SOC plays a role in parental resilience defined as the absence of, or relatively low levels of distress symptoms. The specific focus was on the relationships between parental SOC and illness-specific and generic distress symptoms. We also wanted to study whether parental (a) *gender*, (b) *level of education*, and (c) *use of professional support* influenced the relationship between sense of coherence and distress. Based on theory and previous adjacent research, we hypothesised that sense of coherence would strengthen resilience.

## Participants and methods

### Participants

The study was a Nordic co-project and included parents of children treated at two sites. This resulted in a larger study group than in comparable Nordic studies, which have been national and/or emanated from single centres. The children of participants had been treated at Astrid Lindgren Children's Hospital in Stockholm, Sweden (ALCH, 103 parents of 64 children), or Landspítali-University Hospital in Reykjavik, Iceland (LUHI, 87 parents of 62 children), who were diagnosed with any kind of malignancy or Langerhan's cell histiocytosis (Table I).

Only parents whose child had survived their illness were approached for this study. A known fatal diagnosis, palliative treatment phase, or insufficient knowledge of Swedish or Icelandic to complete questionnaires, were criteria for exclusion. Parents were invited to participate either while attending the in-patient or out-patient unit for treatment or follow-up, or by contacting them by mail if regular routine follow-ups at the hospital had ended. A criterion for inclusion in the study was that a minimum of 36 months had passed from the child's diagnosis in order to comply with the aim of investigating long-term distress and resilience. To limit the group size at the larger Swedish centre, the following procedure was followed: parents of children in treatment were assigned consecutively to the study during the inclusion period. In addition, those with a child off treatment were included by identifying from the hospital records eligible parents who were registered for follow-up visits during two randomly selected months. In Iceland, after identification through the Childhood Cancer Association register, all parents of

Table I. Characteristics of children of parents in clinical group.

Diagnosis	n	%	Age at DX <sup>1</sup> m (SD) <sup>2</sup>	Years from DX to assessment m (SD)	Girls n	Girls %	Boys n	Boys %
Leukaemia	55	47.4	5.9 (4.4)	9.1 (5.5)	21	38.2	34	61.8
Lymphoma	12	10.3	9.7 (5.1)	8.7 (5.2)	3	25.0	9	75.0
CNS-tumour	15	12.9	5.7 (4.8)	6.6 (2.4)	6	40.0	9	60.0
Sympatic nerve system	3	2.6	1.1 (1.6)	9.5 (5.3)	2	66.7	1	33.3
Retinoblastoma	1	0.9	0.3	18.4	1	100.0	0	0
Renal tumour	6	5.2	3.7 (3.5)	7.6 (3.6)	2	33.3	4	66.7
Hepatic tumour	1	0.9	1.9	11.6	0	0	1	100.0
Skeletal tumour	8	6.9	14.8 (3.2)	5.8 (3.0)	1	12.5	7	87.5
Soft tissue sarcoma	4	3.4	12.6 (7.6)	9.2 (3.1)	1	25.0	3	75.0
Germinal cell cancer	4	3.4	8.0 (8.4)	4.4 (1.0)	2	50.0	2	50.0
Other/unspecified	4	3.4	6.5 (6.1)	11.2 (8.0)	1	25.0	3	75.0
LCH <sup>3</sup>	3	2.6	3.5 (0.8)	5.6 (3.0)	2	66.7	1	33.3
Data missing	10	7.9					2	
Total/mean	126		6.9 (5.4)	8.7 (5.4)	42		74	

<sup>1</sup>DX=diagnosis; <sup>2</sup>m=mean, SD=standard deviation; <sup>3</sup>LCH=Langerhan's Cell Histiocytosis.

children in and out of treatment at the time of the study were included.

Although comparison between the clinical group of parents of childhood cancer patients and parents of the general population was not a focus of the study, we also collected normative data regarding SOC. The only reason for collecting these non-clinical reference data was the need to evaluate the feasibility of using SOC as intended; we wanted to examine the degree to which the SOC scale might reflect situational distress in this population [12,16], to ensure a more reliable interpretation of the scores. The non-clinical reference parents were selected from families who a) lived in the catchment area of ALCH, and b) had at least one child corresponding in age to that of the children in the clinical group. They were randomly selected from the population of mothers of children aged 0–16 years. In a letter of invitation, both parents were asked to participate by completing individual questionnaires.

Table II presents descriptive demographic and family data for study and reference groups.

Assessments

Swedish and Icelandic versions of the Sense of Coherence-Scale (SOC-scale) [17] were used. The instrument covers three components of comprehensibility, manageability and meaningfulness. Sense of

coherence has been recognised as a health promoting resource, which strengthens resilience and develops a positive subjective state of health [18–20]. The SOC assessment scale has been found to be cross-culturally applicable and developed for use in both Sweden and Iceland [21]. In this study a 13-item questionnaire with a 7-point response format scale was used. Part of the items were reverse-scored before analysis, so that a higher total score regularly reflected higher SOC. Summary scores were calculated for parents individually. In prior studies using SOC-13, internal reliability has ranged from 0.74 to 0.91, and the instrument has demonstrated high content, face and construct validity, as well as temporal stability [17,22].

The PPD-C distress measure was originally developed by van Dongen-Melman et al. [23]. It was constructed and used for studying the unique illness-specific conditions for parents of children with cancer [24]. The conceptual framework for the assessment model is based on theory, literature, and in-depth interviews with parents of childhood cancer patients. A detailed account of the rigorous development of the instrument has been presented elsewhere [23,24]. Swedish non-clinical norm data have been published for the parts of the questionnaire that are not illness-specific [25]. The Swedish and Icelandic version of the PPD-C, consists of 11 subscales for *uncertainty*, *loss of control* (regarding personal functioning, parenting

Table II. Clinical and non-clinical group characteristics.

	Clinical group N=190		Non-clinical group N=207	
	Mothers N=114	Fathers N=76	Mothers N=119	Fathers N=88
Site: Swedish (n)	103		208	
Site: Icelandic (n)	87		–	
Number of children/parent, mean	2.9		2.2***	
Ethnicity				
Swedish or Icelandic %	88.9		78.3*	
Immigrant background % <sup>1</sup>	11.1		21.7	
Educational status, n (%)				
Compulsory school <sup>2</sup>	20 (17.5)	15 (19.7)	11 (9.2)	13 (14.9)
Upper secondary	44 (38.6)	22 (28.9)	55 (46.2)	27 (31.0)
College/university	50 (43.9)	39 (51.4)	53 (44.6)	47 (54.0)
Data missing	0 (0.0)	0 (0.0)	0 (0.0)	2 (1.0) <sup>3</sup>
Utilised psychosocial support <sup>3</sup> , n (%)	60 (52.6)	22 (28.9)*	n.a. <sup>4</sup>	n.a.
Number of contacts: 1	9 (15.0)	6 (7.9)	n.a.	n.a.
Number of contacts: 2	7 (11.7)	3 (13.6)	n.a.	n.a.
Number of contacts: 3	6 (10.0)	4 (18.2)	n.a.	n.a.
Number of contacts: 4–10	22 (36.7)	5 (22.7)	n.a.	n.a.
Number of contacts: 11–20	6 (10.0)	2 (9.1)	n.a.	n.a.
Number of contacts: 21 or more	3 (5.0)	0 (0.0)	n.a.	n.a.
Data missing	8 (13.3)	7 (31.9)	n.a.	n.a.

<sup>1</sup>Non-Nordic background; <sup>2</sup>9-year compulsory school; <sup>3</sup>data missing in non-clinical reference group about sex for one and about education for one parent; <sup>4</sup>Not applicable, \* = p < 0.05. \*\* = p < 0.01, \*\*\* = p < 0.001

the patient, the sibling(s)), *self-esteem*, *anxiety*, *disease-related fear*, *loneliness*, *sleep disturbances*, *depression*, and *psychological and physical distress*. The response format of the 125 items asks parents to respond according to 2-, 3-, or 4-point Likert scales (Table III). The in-depth interviews with parents, which were part of the construction of the original questionnaire, ensure construct validity of assessment [24].

A reliable and sensitive short form of the General Health Questionnaire was used, the 12-item version GHQ-12. This is a tool for screening for non-pathological psychiatric symptoms [26], commonly used world-wide, including Sweden and Iceland, in studies of various clinical populations. Items relate to the mastering of daily problems, self-esteem, stress, depression and anxiety. The response format renders Likert-scale scores between 1 and 4, and a summary score provides a global outcome. Cronbach's alpha in the study group was 0.86 (Table III).

The questionnaire booklet handed out to parents in the study group also addressed illness and treatment-related information, parents' utilisation of professional psychological support, the family structure, educational level, ethnic background, and home language.

### Procedures

All parents received an invitation letter, including written information about the project, and informed consent was obtained from all prior to inclusion. Mothers and fathers were instructed to complete the questionnaires independently, without consulting the other parent. After completion, parents returned questionnaires by mail in a pre-paid return envelope. The study was reviewed and approved by the Swedish regional ethics committee and the Icelandic National Bioethical Committee.

### Data management and analysis

First, parents in the clinical group were compared with parents in the non-clinical group regarding SOC scores using the t-test for independent groups to evaluate the feasibility of SOC for subsequent interpretation and inference. Parents in the clinical and non-clinical groups were compared regarding background variables using the  $\chi^2$  test categorical and ordinal variables, and the t-test for continuous variables.

Analysis related to the primary question regarding the relationship between SOC and distress was carried out by conducting linear regression analyses – adjusted for time passed since diagnosis – for each distress outcome variable separately. In these analyses, single symptom domain scores of the PPD-C, and the summarised GHQ score were inserted as the dependent variable in separate analyses, with the individual SOC-sum score inserted as the independent predictor variable.

With general linear model factorial design two-way ANOVA, and analysis of interaction effects, we also examined whether the relationship between parental SOC and distress was influenced by the following potentially modifying factors: time passed since diagnosis, parent gender, level of education, and utilisation of professional support. Analyses of interaction between these potential modifiers and SOC were conducted in ANOVA's (separate for each modifier), where main -, and interaction effects were simultaneously estimated in the custom model.

In case a significant interaction was found in analyses involving parent gender, these analyses were re-conducted adjusted for the possible dependency caused by both parents of a child at times providing data. The statistical software SPSS<sup>®</sup> 16.0 for Windows (SPSS, Inc., Chicago, Illinois) was used for all descriptive and inferential analyses.

Table III. PPD-C<sup>a</sup> and GHQ<sup>b</sup> distress outcomes of 190 parents in the clinical group.

Variable	No of items	Response format (Likert scale)	Illness-specific or general <sup>c</sup>	Cronbach's alpha	Mean (SD)	N
Uncertainty	21	4-point	IS	0.95	2.80 (0.81)	179
Loss of control – personal functioning	10	2-point	IS	0.83	1.29 (0.28)	184
Loss of control – parenting of patient'	9	2-point	IS	0.79	1.32 (0.28)	184
Loss of control – parenting of sibling(s)	10	2-point	IS	0.89	1.40 (0.32)	167
Self-esteem	4	3-point	G	0.70	1.63 (0.51)	186
Anxiety	17	4-point	G	0.94	2.26 (0.65)	186
Disease-related fear	11	4-point	IS	0.89	2.04 (0.65)	186
Loneliness	8	4-point	IS	0.90	2.04 (0.70)	186
Sleep disturbances	5	2-point	IS	0.77	1.50 (0.34)	183
Depression	10	4-point	G	0.76	1.93 (0.50)	187
Psychological & physical distress	20	4-point	G	0.94	1.70 (0.58)	185
GHQ-12	12	4-point	G	0.88	20.86 (5.95)	187

<sup>a</sup>Parental Psychosocial Distress in Cancer, <sup>b</sup>General Health Questionnaire, <sup>c</sup>IS=illness-specific; G=general.

## Results

Data were collected from 398 parents of children and adolescents, of whom 190 had children that had been diagnosed with cancer (clinical group), while 208 were reference parents of the community (non-clinical group). The clinical group comprised parents of 126 children who were either in treatment or had finished treatment at one of the two sites. Of the 347 parents in the clinical group who received invitations, 197 returned the questionnaires (57%). Due to missing data regarding identification, or incompletely filled out questionnaires, seven respondents were excluded prior to analyses. Data analyses were thus based on the remaining 190 parents. The response rate in the non-clinical group was 56%.

In the clinical group, 128 responders (67.4%) were parents of children where both parents had responded (parents of 64 children), while 62 (32.6%) were parents in families where only one parent responded (parents of 62 children). In the non-clinical group, questionnaires were returned by both parents in 83 families (79.8%), while in 42 families (20.2%) only one of the parents answered.

Mean age of cancer patients at diagnosis was 6.9 years (SD 5.4, range 0–18.0; females mean 5.2, SD 4.9; males mean 7.8, SD 5.5). Seventeen children in the clinical group were diagnosed after their 15th birthday, the oldest being 18 years at diagnosis. Descriptive and summary characteristics for children in the clinical group and for parents in the clinical and non-clinical groups are presented in Tables I and II.

Comparison of non-responding participants (NRP), from whom questionnaires were not returned, with responding participants (RP) showed that the proportion of fathers was higher among NRP (57%) than among RP (40%,  $\chi^2=9.60$ ,  $df=1$ ,  $p=0.002$ ). Diagnostic subgroups categorised as *leukaemia*, *CNS tumour*, and *other* was equally represented among RP and NRP. Groups differed regarding age of child at time of study (RP mean=15.2 years, SD 7.3; NRP mean=18.0 years, SD 7.4,  $t=-3.45$ ,  $df=331$ ,  $p<0.01$ ), and time from diagnosis to time of study (RP mean 8.7 years, SD 5.4 years; NRP mean=11.0 years, SD=6.4 years,  $t=-3.55$   $df=305$ ,  $p<0.01$ ).

Due to the mode of inclusion, the proportion of childhood cancer sub-diagnoses in the final study group did not fully correspond with their proportions in the entire patient population of the Nordic countries [27].

Demographic data for the 190 parents in the clinical group and the 208 parents in the non-clinical reference group are presented in Table II. Educational level was similar in both groups. In the clinical group, the mean number of children per parent was higher ( $t=6.46$ ,  $df=396$ ,  $p<0.001$ ), and the proportion of parents with immigrant backgrounds lower

( $\chi^2=9.08$ ,  $df=2$ ,  $p<0.05$ ). Within the clinical group, 82 parents (43.2%) had utilised professional psychological support, 22 fathers (30.6% of fathers) and 60 mothers (53.1% of mothers,  $\chi^2=9.06$ ,  $df=1$ ,  $p<0.01$ ).

Estimation of reliability of the questionnaires by Cronbach's alpha resulted in 0.88 and 0.86 for the clinical and non-clinical groups respectively regarding the SOC Scale, 0.86 and 0.82 for the clinical and non-clinical groups regarding GHQ, and an alpha ranging from 0.70 to 0.95 for the sub-scales of PPD-C.

In initial comparisons of SOC-outcomes, the clinical and non-clinical groups were similar, although a non-significant tendency for higher SOC was seen for parents in the non-clinical group ( $t=-1.817$ ,  $df=359.5$ ,  $p=0.07$ ).

Distress outcomes for parents in the clinical group are presented in Table III.

### Sense of coherence and distress

An inverse relationship was found between sense of coherence and distress. Negative correlations (beta-coefficients,  $\beta$ ) were found for all the dependent distress variables, with associations varying from moderate ( $r=-0.20$ ) for the PPD-C/*uncertainty* sub-domain to strong ( $r=-0.79$ ) for GHQ (Table IV).

Examination of the effects of independent background variables on the relationship between SOC and distress showed a significant interaction effect between gender and SOC on *self-esteem* ( $p=0.048$ ) and *disease-related fear* ( $p=0.008$ ).

Table IV. Regression derived coefficients and significance level of the effect of sense of coherence on distress factors among parents of childhood cancer survivors.<sup>1</sup>

Distress variable	n	R <sup>2</sup>	$\beta$	F
Uncertainty	178	0.094	-0.197	9.07***
Loss of control – personal functioning	184	0.221	-0.471	25.70****
Loss of control – parenting the patient	184	0.170	-0.413	18.5****
Loss of control – parenting sibling(s)	167	0.170	-0.412	16.8****
Self-esteem (low)	186	0.291	-0.520	37.6****
Anxiety	186	0.418	-0.647	65.8****
Disease-related fear	185	0.202	-0.431	23.0****
Loneliness	185	0.366	-0.608	52.5****
Sleep disturbances	183	0.251	-0.502	30.2****
Depression	187	0.422	-0.653	67.20****
Physical and psychological distress	185	0.422	-0.718	95.7****
GHQ total score	186	0.512	-0.790	164.7****

<sup>1</sup>Univariate linear regression model, adjusted for time elapsed since diagnosis. \*= $p<0.05$ , \*\*= $p<0.01$ , \*\*\*= $p<0.001$ , \*\*\*\*= $p<0.0001$ .

Analyses regarding the effect of gender were also carried out with adjusting for possible dependency between responding parent couples. These subsequent analyses showed that the SOC/gender interaction effect was to some extent reduced to statistically non-significant for self-esteem ( $p=0.077$ ) while marginally strengthened for disease-related fear ( $p=0.005$ ). In both cases, outcomes indicated a stronger negative relationship between SOC and the distress variable in mothers compared to fathers – a tendency that was indicated regarding other distress outcomes as well, although less strong. Also, results showed a significant interaction between education and SOC ( $p=0.021$ ) on the *psychological and physiological distress* variable indicative of a greater protective effect of SOC in parents with a lower, compared to parents with higher education. Time elapsed since diagnosis had no significant influence on the SOC/distress relationship.

## Discussion

In this study, it was found that higher levels of sense of coherence (SOC) were consistently associated with lower levels of distress. This finding supported the hypothesis concerning the role of SOC as a protective psychological resource strengthening resilience to parental distress in reaction to a child's cancer.

Parent's gender and level of education had a partial effect on the resilience-strengthening impact of SOC. Regarding distress outcomes, a more strongly protective effect of SOC was indicated for mothers than for fathers (*disease-related fear*), as well as for parents with lower educational status compared with those with higher (*psychological and physiological distress*).

Findings support the feasibility of the SOC13-scale as a measure of individual strengths facilitating coping, as well as protection against long-term distress in parents of childhood cancer patients.

Studies of parental reactions to a child's cancer have typically dealt with the incidence and severity of distress symptoms, including reactive psychiatric morbidity, while resilience-strengthening characteristics have hardly been investigated at all. These studies indicate that parents run the risk of extraordinary strain, producing a range of psychological symptoms including loss of control, decreased self-esteem, anxiety, depression, and traumatic and post-traumatic stress [25,28,29]. The psychological consequences have been found to persist years after diagnosis and even after successful treatments [24,25]. In studies concerning protective factors and *patient* reactions to illness it has been found that SOC acts as a buffer against stress-related reactions [30,31]. Interestingly enough, our findings indicate that favourable SOC also seems to modify the experience of stress, and

thus improve adjustment in *parents* of children who have survived cancer. This parallels findings from previous studies regarding parents of children suffering from other medical conditions [11–15]. The outcome indicates that identifiable strength factors in individuals do play a role. Parents with a higher sense of coherence may be better prepared to manage stressful situations related to a child's cancer. They come across as less negatively affected and display fewer symptoms of distress. SOC-associated resilience against cancer-related negative reactions was found regarding both general psychiatric symptoms as measured by the GHQ, as well as illness-specific parental distress and fear.

Although the findings indicate support for the hypothesis concerning the resilience-strengthening effect of SOC, questions arise as to the nature of the relationship between sense of coherence and coping with threat. The results showed that the SOC of parents of long-term survivors was similar to those in the non-clinical reference-group. This indicates a relative stability of SOC across situational circumstances. We found a non-significant tendency, however, for lower SOC-scores among parents in the clinical group. Thus, parental strength factors appear to have a possible influence on illness-related distress, while on the other hand, distressing conditions may also reversely influence SOC [9,15]. Antonovsky, for example, points out that situations involving long-lasting extensive stress may be potential modifiers of SOC [9]. Our study group was comprised of parents whose children had already completed up to 2–2.5 years of cancer treatment. For these parents, the first years after diagnosis might have been characterised by this type of persistent and/or cumulative stress [5,24,32]. Our data indicate that the post-treatment period is less apt to affect parental "base-level" vigour.

While both the SOC and GHQ questionnaires are well-established and frequently used in both Sweden and Iceland, the PPD-C questionnaire was used for the first time on an Icelandic group in this study. Sweden and Iceland can be considered to be culturally highly similar. Nevertheless, due to the lack of prior Icelandic experience from use of PPD-C and local norm data, we cannot fully know whether the instrument can be used equally in both countries.

The response rate in the clinical group was 57% which is acceptable, although low enough to exercise caution in generalising the findings for the entire population of parents of childhood cancer patients. Analyses of differences between responders and non-responders in the clinical group indicate that findings might not be fully applicable for parents of older children (diagnosed earlier in time), nor to fathers. Furthermore, our study focused on parents

of children who survived a cancer that was diagnosed a relatively long period of time previously (mean time since diagnosis of 8.7 years) and who had all completed up to 2–2.5 years of treatment. Findings may therefore not apply to parents of newly diagnosed children. Another limitation concerns the simultaneous assessments of SOC and distress. Although the main findings provide interesting targets for follow-up studies, we cannot make definite conclusions about inferred causal relationships, since SOC was not assessed in parents prior to the child's cancer.

Forthcoming studies would benefit from investigating additional resilience-related determinants at an early stage. Repeated assessments over time in a longitudinal approach would add to our understanding of how strengths and distress are causally related, and whether parents with identifiable resources recover faster or more completely. A prospective approach initiated closer in time to child's diagnosis could address the question of how individual strengths are related to parental reactions to acute, chronic or ongoing stress.

Interpreted in the light of similar studies [19], the clinical implications of the findings are that screening for strengths can be useful in predicting the severity of stress-reactions in parents of children with cancer. The SOC scale integrates essential parts of a well-established stress-coping model, and the 13-item version is short and easy to use. It provides an opportunity for identifying parents in need of intensified psychosocial follow-up. The integration of a resources perspective in psychosocial care would promote parents' resilience when dealing with childhood cancer.

## Acknowledgements

This study was supported by grants from The Swedish Childhood Cancer Foundation, Swedish Cancer and Traffic Injury Fund, and the Iceland Kristin Fund. We thank Jeremy H. Becker for helpful comments during preparation of the manuscript. Among those who contributed to make this study possible, our greatest appreciation also goes to all mothers and fathers who participated. The authors declare no conflict of interest.

## References

- [1] Centers-for-Disease-Control-and-Prevention-(CDC). Trends in childhood cancer mortality – United States, 1990–2004. *MMWR Morb Mortal Wkly Rep* 2007;56:1257–61.
- [2] James K, Keegan-Wells D, Hinds PS, Kelly KP, Bond D, Hall B, et al. The care of my child with cancer: Parents' perceptions of caregiving demands. *J Pediatr Oncol Nurs* 2002;19:218–28.
- [3] Allen R, Newman S, Souhami R. Anxiety and depression in adolescent cancer: Findings in patients and parents at the time of diagnosis. *Eur J Cancer* 1997;33:1250–5.

- [4] Forinder U. Bone marrow transplantation from a parental perspective. *J Child Health Care* 2004;8:134–48.
- [5] Lindahl Norberg A, Lindblad F, Boman KK. Coping strategies in parents of children with cancer. *Soc Sci Med* 2005; 60:965–75.
- [6] McSherry WC, Holm JE. Sense of coherence: its effects on psychological and physiological processes prior to, during, and after a stressful situation. *J Clin Psychol* 1994;50:476–87.
- [7] Schnyder U, Buchi S, Morgeli H, Sensky T, Klaghofer R. Sense of coherence – a mediator between disability and handicap? *Psychother Psychosom* 1999;68:102–10.
- [8] Mullen PM, Smith RM, Hill EW. Sense of coherence as a mediator of stress for cancer patients and spouses. *J Psychosoc Oncol* 1993;11:23–46.
- [9] Antonovsky A. *Unrevealing the mystery of health: how people manage stress and stay well*. San Francisco: Jossey Bass; 1987.
- [10] Rutter M. Implications of resilience concepts for scientific understanding. *Ann NY Acad Sci* 2006;1094:1–12.
- [11] Margalit M, Raviv A, Ankonina DB. Coping and coherence among parents with disabled children. *J Clin Child Psychol* 1992;21:202–9.
- [12] Svavarsdottir EK, Rayens MK, McCubbin M. Predictors of adaptation in Icelandic and American families of young children with chronic asthma. *Fam Community Health* 2005;28:338–50.
- [13] Hintermair M. Sense of coherence: A relevant resource in the coping process of mothers of deaf and hard-of-hearing children? *J Deaf Stud Deaf Educ* 2004;9:15–26.
- [14] Hedov G, Anneren G, Wikblad K. Swedish parents of children with Down's syndrome. *Scand J Caring Sci* 2002;16:424–30.
- [15] Olsson M, Hwang C. Sense of coherence in parents of children with different developmental disabilities. *J Intellect Disabil Res* 2002;46:548–59.
- [16] Wolff AC, Ratner PA. Stress, social support, and sense of coherence. *West J Nurs Res* 1999;21:182–97.
- [17] Antonovsky A. The structure and properties of the sense of coherence scale. *Soc Sci Med* 1993;36:725–33.
- [18] Eriksson M, Lindstrom B. Antonovsky's sense of coherence scale and the relation with health: A systematic review. *J Epidemiol Community Health* 2006;60:376–81.
- [19] Surtees PG, Wainwright NW, Khaw KT. Resilience, misfortune, and mortality: Evidence that sense of coherence is a marker of social stress adaptive capacity. *J Psychosom Res* 2006;61:221–7.
- [20] Hart KE, Wilson TL, Hittner JB. A psychosocial resilience model to account for medical well-being in relation to sense of coherence. *J Health Psychol* 2006;11:857–62.
- [21] Eriksson M, Lindstrom B. Validity of Antonovsky's sense of coherence scale: A systematic review. *J Epidemiol Community Health* 2005;Sect. 460–6.
- [22] Feldt T, Lintula H, Suominen S, Koskenvuo M, Vahtera J, Kivimaki M. Structural validity and temporal stability of the 13-item sense of coherence scale: Prospective evidence from the population-based HeSSup study. *Qual Life Res* 2007; 16:483–93.
- [23] Van Dongen-Melman JE, Pruyn JFA, De Groot A, Koot HM, Verhulst FC. Psychometric properties of an instrument measuring psychosocial functioning of parents of children who survived cancer. In: *On surviving childhood cancer: Late psychosocial consequences for patients, parents, and siblings* (Dissertation). Rotterdam, The Netherlands: Erasmus Universiteit 1995;101–20.
- [24] Van Dongen-Melman JE, Pruyn JF, A. DG, Koot HM, Hahlen K, Verhulst FC. Late psychosocial consequences for parents of children who survived cancer. *J Pediatr Psychol* 1995;20:567–86.

- [25] Boman K, Viksten J, Kogner P, Samuelsson U. Serious illness in childhood: The different threats of cancer and diabetes from a parent perspective. *J Pediatr* 2004;145:373–9.
- [26] Goldberg D, Williams P. *A user's guide to the General Health Questionnaire*. Windsor: NFER-Nelson; 1991.
- [27] NOPHO. *Childhood cancer in the Nordic countries. Report on epidemiologic and therapeutic results from registries and working groups*. NOPHO annual meeting, Reykjavik, Iceland. Reykjavik: Nordic Society of Pediatric Haematology and Oncology; 2007.
- [28] Kazak AE, Alderfer M, Rourke MT, Simms S, Streisand R, Grossman JR. Posttraumatic stress disorder (PTSD) and post-traumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *J Pediatr Psychol* 2004;29:211–9.
- [29] Lindahl Norberg A, Boman KK. Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress, depression and anxiety. *Acta Oncol* 2008;47:267–74.
- [30] Dantas RA, Motzer SA, Ciol MA. The relationship between quality of life, sense of coherence and self-esteem in persons after coronary artery bypass graft surgery. *Int J Nurs Stud* 2002;39:745–55.
- [31] Soderman AC, Bagger-Sjoberg D, Bergenius J, Langius A. Factors influencing quality of life in patients with Meniere's disease, identified by a multidimensional approach. *Otol Neurotol* 2002;23:941–8.
- [32] Lesko LM. Surviving hematological malignancies: Stress responses and predicting psychological adjustment. *Prog Clin Biol Res* 1990;352:423–37.