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Distress and hopelessness among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children

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Abstract

Objective: We examined differences in distress (i.e., depression, anxiety, and somatisation) and hopelessness (e.g., suicide ideation) among parents of congenital heart disease (CHD) children (PCCHD, $n=1092$), parents of children with other diseases (PCOD, $n=112$), and parents of healthy children (PHC, $n=293$). In addition, we determined the proportion of parents in each group whose scores in distress and hopelessness, respectively, exceeded norms for psychiatric outpatients (POPN) and depressed people, and identified determinants of distress and hopelessness among all parents, and the PCCHD. **Method:** The parents completed a questionnaire about such areas as distress and hopelessness. The design was cross-sectional and data were collected during 20 consecutive days. **Results:** PCCHD were generally at higher risk of distress and hopelessness. A significant number of parents, in particular PCCHD, reported levels of distress and hopelessness within/above POPN and depressed people, respectively. Mothers within all parent groups had higher levels of distress and hopelessness than fathers, with the highest levels among mothers of children with CHD compared to mothers in the other groups. Fathers of children with CHD were doing worse than fathers belonging to the other groups. There were no differences between PCOD and PHC. Variables such as employment status and financial situation explained more of the variation in distress and hopelessness among parents than the diseases of their children. **Conclusion:** We corroborated previous findings and provide new insights into the experiences of PCCHD that may be of importance when considering intervention. Further research concerning the parents, in particular PCCHD, at risk of developing psychosocial problems is needed.

Keywords: Congenital heart disease; Distress; Hopelessness; Mothers; Fathers; Parents; Predictors

Introduction

Congenital heart disease (CHD) refers to multiple syndromes ranging in severity from innocent heart murmurs to complex heart conditions that may immediately endanger the child's life (e.g., Ref. [1]). About 1–2% of all children are born annually with CHD and the abnormalities are distributed across the entire population of children independently of social and ethic background (e.g., Refs. [2–6]). The exact aetiology of CHD remains elusive in most cases, but some 10–20% of the defects are due to genetic and environmental factors (e.g., Refs. [7–11]). The diagnosis, medical care, and surgery of CHD have improved markedly during the past years, with a considerable increase in survival rates as one of the main outcomes (e.g., Refs. [6,12]).

The birth of a child is one of the most powerful of the human experiences and it is generally associated with happiness and great expectations among parents (e.g., Refs. [13–16]). The situation may turn into one of dashed joy and feelings of distress if the child has a cardiac defect requiring surgical correction or has so grave deformations that she/he dies. For example, mothers may feel stressed in the presence of the heart disease and more than fathers (e.g., Refs. [17,18]), and may have difficulties in accepting that the child is not healthy or in satisfying the child's hygiene,

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hydration, and nutritional needs (e.g. Refs. [19,20]). Parents of children with CHD (PCCHD) may experience higher stress levels (e.g., Refs. [18,21]) than parents of healthy children (PHC) or parents of children with other diseases (PCOD), and may feel great stress in relation to such things as dilemmas of normality and social integration [22]. Further, PCCHD [23] may experience more feelings of sadness and anger than PHC. The burden of caring for a heartsick child may also be related to worries, concerns, and anxiety, especially among mothers [24–27]. Finally, losing a child may lead to reactions of grief, anger, and guilt in PCCHD (e.g., Ref. [28]).

The literature concerning the parent's psychosocial situation should, however, be taken with caution. For example, in many studies, the findings are based on small samples or a few parents that may not be representative for the population in question or in relation to the children's defects (e.g., type CHD), questionable methods (e.g., unclear reliability of the measures), and little attention is paid to predictors of the parent's psychosocial situation. There are few studies with well-established methods and instruments, large samples of PCCHD, and studies that compare the situation of parents with psychiatric patients. Our intention was to address these and other issues.

Concretely, we examined differences in symptoms of depression, anxiety, and somatisation (i.e., distress) as measured by *The Symptom Check List—Revised* (SCL-90-R) [29] and hopelessness feelings (e.g., pessimism about the future) using the Hopelessness Scale [30,31] between PCCHD and PCOD, and PHC selected from the general population. We also determined the proportion of all parents and PCCHD whose scores in distress were within/exceeded norms of psychiatric outpatients (POPN) [29] and whose levels of hopelessness surpassed those found among depressed patients [30,31]. In addition, we explored the experiences of mothers and fathers in these respects. Finally, we identified and quantified predictors of distress and hopelessness among all parents and PCCHD. Controlling for factors such as unemployment and financial situation may help to better understand the actual contribution of, for example, CHD towards explaining the variation in distress and hopelessness among PCCHD. Such data may be of interest for frequency estimations, and gender, groups, and cross-country comparisons. The data derived may also be useful in designing eventual prevention and intervention programmes to improve the psychosocial situation and quality of life of parents.

Method

Participants

Parent's inclusion criteria in this study were: (i) members of the Swedish Heart Child Foundation (SHCF), (ii) having children born with CHD between 0 and 20 years of age who were alive during the survey, and (iii) the children were living at home, the parents still had the responsibility for their care or had close contacts with them during the survey. Of the 1500 PCCHD meeting the inclusion criteria, 1092 participated in the study (response rate of 72.8%). *T* tests and χ^2 tests showed no significant differences between responders and nonresponders concerning demographic data. Data on the nonresponders children's situation were not available (e.g., type of heart defect).

A group of 600 parents, randomly selected from the general population, served as control group. Of the approached 600 parents, 405 participated in the study (response rate of 67.5%). Inclusion criteria were the same as above, with the exception of CHD and membership in the SHCF. In addition, we required these control parents to state whether their children were ill and what kind of illness they suffered from. Based on this information, the parents were subsequently divided into two groups, i.e., PCOD ($n=112$) and PHC ($n=293$). *T* tests and χ^2 tests showed no differences between participants and nonparticipants concerning demographic data. Data on the nonresponders children's situation were not available (e.g., health). Thus, the total sample consisted of 1497 parents, of which 686 of the PCCHD, 86 of the PCOD, and 166 of the PHC respondents were couples ($n=343$, $n=43$, $n=83$, respectively).

As shown in Table 1, the parents provided information on 691 children with CHD, 74 children with other diseases, and 162 healthy children, with regard to such areas as gender and type of illness. The data gathered on the children's "the time since diagnosis," "number of hospitalisations," and "severity of diseases other than CHD" were insufficient (many parents did not answer these questions) to allow a meaningful analyses of these variables.

Measures

All parents completed a questionnaire covering symptoms of depression, anxiety, and somatisation (i.e., distress) [29] and hopelessness feelings [30]. Data on the parent's demographics (e.g., age), employment status (e.g., sick leave), and financial situation (e.g., difficulties in raising money) were also included. In addition, we collected data on the child's demographics (e.g., gender) and health situation (e.g., diagnosis).

Distress was assessed with SCL-90-R [29], which consists of 90 items divided into nine symptom dimensions. In this study, we used the depression, anxiety, and somatisation dimensions. Depression (13 items) covers such areas as thoughts of suicide and loss of vital energy. Anxiety (10 items) reflects feelings such as nervousness and fear. Somatisation (12 items) covers such areas as cardiovascular and gastrointestinal complaints. The items range from 1 (*not at all*) to 5 (*very much*). High scores correspond to high degrees of psychopathology. A global severity index (GSI) was also calculated based on the average of individual scores for depression, anxiety, and somatisation.

Table 1
Demographic/clinical characteristics of all children, children with CHD (CCHD), children with other diseases (COD), and healthy children (HC)

	All children		CCHD		COD		HC	
Characteristics	$n=927$	%	$n=691$	%	$n=74$	%	$n=162$	%
Age (years)								
Mean ± S.E.	8 ± 0.1		7 ± 0.2		11 ± 0.5		9 ± 0.3	
Gender								
Females	418	45	300	43	31	42	87	54
Males	509	55	391	57	43	58	75	46
Disease type[a]								
Pda[b]			27	4				
C. aorta[c]			25	4				
Asd[d]			169	15				
Vsd[e]			204	29				
Tof[f]			74	11				
Pvs[g]			111	16				
Avs[h]			85	12				
Transposition[i]			50	7				
Other heart diseases[j]			267	38				
Allergy/asthma					55	74		
Ulcer					5	7		
Psychosis					5	7		
Behavioural problems					13	18		
Other diseases[k]					18	24		
Number of heart defects[l]								
1			424	61				
2			167	24				
>3			100	15				
Other diseases[m]								
Yes			235	34				
No			456	66				
Surgery[l]								
Yes			555	80				
No			136	20				

[a] Percentages for this variable add up to more than 100% as one child can have several diseases.
[b] Patent ductus arteriosus.
[c] Coartation of aorta.
[d] Atrial septal defect.
[e] Ventricular septal defect.
[f] Tetralogy of Fallot.
[g] Pulmonary valve stenosis.
[h] Aortic valve stenosis.
[i] Transposition of great arteries.
[j] Complete AV canal.
[k] Concerns only COD (e.g., liver dysfunction).
[l] Concerns only CCHD.
[m] Concerns only CCHD (e.g., Down's syndrome).

Cronbach's α, for the PCCHD, PHC, and PCOD groups, ranged from .84 to .93. The parents were also contrasted, on these dimensions, with norms from a sample of 1002 psychiatric outpatients described in the SCL-90-R manual by Derogatis [29].

Parents' negative expectancies about the future were assessed with *The Hopelessness Scale* [30], which is a 20-item scale containing statements about one's self and one's future. High scores correspond to high degrees of hopelessness. Further, scores can be transformed into norms indicating levels of experienced hopelessness and suicide ideation (i.e., 0–3, *none/minimal*; 4–8, *low*; 9–14, *moderate*; and 15–, *high*). Cronbach's α, for the PCCHD, PHC, and PCOD groups were .82, .70, and .77, respectively. The parents were also compared with values of negative expectations about the future and suicide ideation shown by depressed people described in the articles of Beck et al. [30] and Williams [31].

Design and procedure

We collected data on the PCCHD with the help of the SHCF, which is represented in all the Swedish counties. The parents were sent a letter informing them about the study, about what was expected of them, and the questionnaire. They were also requested to return the completed questionnaire by post. The PCOD and PHC samples were randomly selected from the general population through a company that provides data on the population living in Sweden. We used the same procedure as described above, except for the help of the SHCF. All parent groups were volunteers. Confidentiality was guaranteed. The study design was cross-sectional and data were collected for all groups during 20 consecutive days with two remainders being sent. The study was approved by the ethical committee in Stockholm.

Statistical analyses

The data were examined with ANOVAs, χ^2 tests, *t* tests, and post hoc tests according to Dunn's/Bonferroni method. Blockwise logistic regression analyses were used to identify and quantify determinants of depression, anxiety, and somatisation (i.e., distress) and hopelessness (i.e., negative expectations about the future/suicide ideation) among all parents and PCCHD, while controlling for other possible confounders (e.g., demographic features). In blockwise logistic regression, variables are entered into the regression equation block by block and the contribution of every block in explaining the dependent variable is expressed in r^2 changes. The dependent variable is dichotomous. In our study, the various dimensions of distress were transformed into dichotomous variables. Parents with scores within/higher than POPN [29] were regarded to be at risk for distress and were grouped together. Those with scores lower than POPN were regarded as being at lower risk for distress, and formed the second group of the dichotomy. The same approach was used to transform hopelessness-scores into dichotomous variables, i.e., parents with scores as high as the values shown by depressed people formed the risk group [30,31].

Two regression analyses were performed. The first included all parents, with the rationale of assessing the contribution of the presence of children's diseases in

explaining the parent's distress and hopelessness feelings. The second included only PCCHD, with the intention of assessing the contribution of the children's health situation (e.g., CHD severity) in explaining the parent's distress and hopelessness feelings. Other covariates in both regressions were the parent's demographic characteristics (e.g., gender), financial situation (e.g., problems in raising money), and employment status (e.g., sick leave), and children's demographics (e.g., gender). Significance levels were set at $P < .05$. As shown by the *df* and *n*, single data were lost for a number of variables.

Results

Demographic/financial characteristics

As shown in Table 2, the mean age of all parents was 39 ± 7 years. Only 8% were of foreign origin, with fewer among PCCHD (6%) than among PCOD (18%) and PHC (13%) [$\chi^2(2) = 29$, $P < .01$]. PCCHD and PCOD were more worried about their financial situation than PHC [$\chi^2(2) = 10$, $P < .01$]. PCOD were less able to raise a reasonable sum of money within a specific time-period than the other parent

Table 2
Demographic/financial characteristics of all parents, PCCHD, PCOD, and PHC

	All parents		PCCHD		PCOD		PHC	
Characteristics	*n* = 1497	%	*n* = 1092	%	*n* = 112	%	*n* = 293	%
Age (years)								
Mean ± S.E.	39 ± 7		39 ± 7		41 ± 8		39 ± 8	
Gender (*N*)	(1492)		(1091)		(110)		(291)	
Male	591	40	424	39	44	40	123	42
Female	901	60	667	61	66	60	168	58
Marital status (*N*)	(1490)		(1090)		(110)		(290)	
Single	72	5	44	5	5	5	23	8
Married/cohabited	1342	90	1000	92	97	88	245	84
Divorced	69	4	42	4	6	6	20	7
Widow/widower	7	1	4	1	1	1	2	1
Educational level (*N*)	(1491)		(1091)		(110)		(290)	
Primary	167	11	123	12	9	8	34	12
Gymnasium/university	1251	84	912	83	93	84	246	85
Other	73	5	55	5	8	7	9	3
Foreign-background (*N*)	(1473)		(1075)		(108)		(290)	
Yes	121	8	64	6	19	18	38	13
No	1352	92	1011	94	89	82	252	87
Occupational status (*N*)	(1444)		(1049)		(109)		(286)	
Blue-collar	576	40	399	38	49	45	127	44
White-collar	781	54	575	55	58	53	149	52
Own business	53	4	48	4	0	0	5	2
Other	34	2	27	3	2	2	5	2
Current employment status (*N*)	(1494)		(1092)		(112)		(290)	
Employed	1257	84	913	83	90	81	254	88
Unemployed	34	2	22	2	5	4	7	2
Sick leave	43	3	32	3	4	4	7	2
Pension	27	2	25	2	2	2	3	1
Other	133	9	100	10	11	9	19	7
Worried about finances (*N*)	(1477)		(1089)		(112)		(276)	
Yes	521	35	400	37	44	42	77	28
No	156	65	689	63	68	58	199	72
Difficulties with living expenses (*N*)	(1477)		(1092)		(111)		(276)	
Yes	391	27	294	27	34	31	63	23
No	1088	73	798	73	77	69	213	77
Difficulties in raising money (*N*)	(1477)		(1090)		(110)		(276)	
Yes	254	17	177	16	26	25	51	18
No	1223	83	913	84	84	75	225	82
Sick leave days[a] (*N*)	(1478)		(1080)		(110)		(288)	
0	742	50	535	49	56	51	151	52
1–30	598	40	440	41	41	37	117	41
> 30	138	10	105	10	13	12	20	7
Unemployment years[a] (*N*)	(1468)		(1069)		(111)		(288)	
0	1068	72	797	75	72	65	199	69
< 1	203	14	136	13	20	18	47	16
1–5	160	11	109	10	16	14	35	12
> 5	37	3	27	2	3	3	7	3

[a] 12 months prior to the investigation.

groups [$\chi^2(2) = 6.3$, $P < .05$]. Finally, mothers of children with CHD devoted about 2 h extra time to caring for their sick children in contrast to 1/2 h for fathers [$t(1079) = 3.21$, $P < .01$]. There were no other significant differences between parent groups concerning demographic data.

Distress

The univariate analyses showed significant differences among parents concerning scores for distress (i.e., GSI, depression, anxiety, and somatisation) (Table 3). In addition, we found differences in these variables between parent groups and POPN (Table 4).

Comparisons of GSI-scores among parent groups

As shown in Table 3, parent groups differed in GSI-scores [$F(2,1488) = 12.06$, $P < .001$], which was due to higher GSI-scores among PCCHD than among PCOD ($P < .05$) and PHC ($P < .001$). Further, mother groups differed in GSI-scores [$F(2,897) = 7.35$, $P < .005$] and this difference could be ascribed to higher scores among mothers of children with CHD (MCCHD) than among mothers of children with other diseases (MCOD) ($P < .05$) and mothers of healthy children (MHC) ($P < .005$). Fathers also differed in GSI-scores [$F(2,583) = 4.10$, $P < .05$] and the difference was related to higher scores among fathers of children with CHD (FCCHD) than among fathers of healthy children (FHC) ($P < .05$). Finally, mothers had higher GSI-scores than fathers in all groups [PCCHD, $t(1086) = 8.2$, $P < .001$; PCOD, $t(108) = 2.6$, $P < .05$; PHC, $t(286) = 3.3$, $P < .005$].

Comparisons of depression-scores among parent groups

As shown in Table 3, parent groups differed in depression-scores [$F(2,1488) = 13.5$, $P < .001$], which was due to higher scores among PCCHD than among PCOD ($P < .005$) and PHC ($P < .001$). Moreover, mother groups differed in depression-scores [$F(2,897) = 9.6$, $P < .001$]. After testing it was revealed that MCCHD scored higher than MCOD ($P < .05$) and MHC ($P < .001$). Differences were observed between fathers' depression-scores in general [$F(2,583) = 3.2$, $P < .05$], but could not be confirmed by post hoc tests. Mothers reported higher depression-scores than fathers in all groups [PCCHD, $t(1086) = 9.1$, $P < .001$; PCOD, $t(108) = 2.3$, $P < .05$; PHC, $t(286) = 3.7$, $P < .001$].

Comparisons of anxiety-scores among parent groups

As shown in Table 3, parent groups differed in anxiety-scores [$F(2,1488) = 10.8$, $P < .001$], which was due to

Table 3
Means and S.E.s for SCL-90-R (GSI, depression, anxiety, and somatisation) among all parents, PCCHD, PCOD, PHC, and POPN

Variables	All parents ($n = 1497$)	PCCHD ($n = 1092$)	PCOD ($n = 112$)	PHC ($n = 293$)	POPN ($n = 1002$)
GSI (0–4)					
Females (*N*)	(901)	(667)	(66)	(168)	(577)
Mean ± S.E.	0.86 ± 0.02	0.92 ± 0.03	0.73 ± 0.09	70 ± 0.06	1.35 ± 0.03
Males (*N*)	(591)	(424)	(44)	(123)	(425)
Mean ± S.E.	0.54 ± 0.02	0.58 ± 0.03	0.42 ± 0.08	0.44 ± 0.05	1.14 ± 0.03
Total (*N*)	(1492)	(1091)	(110)	(291)	(1002)
Mean ± S.E.	0.74 ± 0.02	0.79 ± 0.02	0.60 ± 0.06	0.59 ± 0.04	1.26 ± 0.02
Depression (0–4)					
Females (*N*)	(901)	(667)	(66)	(168)	(577)
Mean ± S.E.	1.04 ± 0.03	1.11 ± 0.03	0.80 ± 0.10	0.84 ± 0.07	1.59 ± 0.04
Males (*N*)	(591)	(424)	(44)	(123)	(425)
Mean ± S.E.	0.62 ± 0.03	0.66 ± 0.03	0.51 ± 0.10	0.52 ± 0.06	1.94 ± 0.04
Total (*N*)	(1492)	(1091)	(110)	(291)	(1002)
Mean ± S.E.	0.87 ± 0.02	0.94 ± 0.02	0.68 ± 0.08	0.70 ± 0.05	1.79 ± 0.03
Anxiety (0–4)					
Females (*N*)	(901)	(667)	(66)	(168)	(577)
Mean ± S.E.	0.72 ± 0.03	0.77 ± 0.03	0.62 ± 0.10	0.53 ± 0.06	1.59 ± 0.04
Males (*N*)	(591)	(424)	(44)	(123)	(425)
Mean ± S.E.	0.40 ± 0.02	0.45 ± 0.03	0.27 ± 0.08	0.29 ± 0.05	1.30 ± 0.04
Total (*N*)	(1492)	(1091)	(110)	(291)	(1002)
Mean ± S.E.	0.59 ± 0.02	0.65 ± 0.02	0.47 ± 0.07	0.43 ± 0.04	1.47 ± 0.03
Somatisation (0–4)					
Females (*N*)	(901)	(667)	(66)	(168)	(577)
Mean ± S.E.	0.81 ± 0.03	0.86 ± 0.03	0.74 ± 0.09	0.69 ± 0.06	0.99 ± 0.03
Males (*N*)	(591)	(424)	(44)	(123)	(425)
Mean ± S.E.	0.56 ± 0.02	0.59 ± 0.03	0.46 ± 0.08	0.48 ± 0.05	0.71 ± 0.03
Total (*N*)	(1492)	(1091)	(110)	(291)	(1002)
Mean ± S.E.	0.71 ± 0.02	0.75 ± 0.02	0.63 ± 0.07	0.60 ± 0.04	0.87 ± 0.02

Table 4
Number and percentage of all parents, PCCHD, PCOD, and PHC within/above POPN (Means/S.E.s) for SCL-90-R (GSI, depression, anxiety, and somatisation)

	All parents (1497)			PCCHD (1092)			PCOD (112)			PHC (293)			
Variables	*N*	*n*	%	*N*	*n*	%	*N*	*n*	%	*N*	*n*	%	POPN (1002)
GSI (0–4)													
Females	901	197	22	667	158	24	66	11	16	168	28	16	1.35 ± 0.03 (n = 577)
Males	591	71	12	424	61	14	44	2	4	123	8	6	1.14 ± 0.03 (n = 425)
Total[a]	1492	268	18	1091	224	21	110	14	13	291	40	14	1.26 ± 0.02 (n = 1002)
Depression (0–4)													
Females	901	166	18	667	141	21	66	6	9	168	19	11	1.94 ± 0.04 (n = 577)
Males	591	54	9	424	44	10	44	3	7	123	7	6	1.59 ± 0.04 (n = 425)
Total[a]	1492	220	15	1091	185	17	110	11	10	291	29	10	1.79 ± 0.03 (n = 1002)
Anxiety (0–4)													
Females	901	143	16	667	118	18	66	8	12	168	17	10	1.59 ± 0.04 (n = 577)
Males	591	50	8	424	45	11	44	1	2	123	4	3	1.30 ± 0.04 (n = 425)
Total[a]	1492	193	13	1091	161	15	110	10	9	291	21	7	1.47 ± 0.03 (n = 1002)
Somatisation (0–4)													
Females	901	277	31	667	224	34	66	17	26	168	36	21	0.99 ± 0.03 (n = 577)
Males	591	165	28	424	124	29	44	10	23	123	31	25	0.71 ± 0.03 (n = 425)
Total[a]	1492	442	30	1091	344	32	110	27	24	291	60	21	0.87 ± 0.02 (n = 1002)

[a] The totals do not necessarily add to the sum of females and males as participants' norms regardless of gender are compared separately to total norms; N = total number of respondents, n = total number within/above POPN averages, % = n/N.

higher scores among PCCHD than among PHC ($P < .001$). Further, mother groups differed in anxiety-scores [$F(2,897) = 6.1$, $P < .005$] and this difference was due to higher scores among MCCHD than among MHC ($P < .005$). Fathers also showed differences in anxiety-scores [$F(2,583) = 3.2$, $P < .05$]. After testing revealed higher scores among FCCHD than among FHC ($P < .05$). Finally, mothers had higher anxiety-scores than fathers in all groups [PCCHD, $t(1086) = 6.9$, $P < .001$; PCOD, $t(108) = 2.4$, $P < .05$; PHC, $t(286) = 2.8$, $P < .01$].

Comparisons of somatisation-scores among parent groups

As shown in Table 3, parent groups differed in bodily complaints [$F(2,1488) = 6.2$, $P < .005$], which was due to higher scores among PCCHD compared to PHC ($P < .005$). Moreover, mother groups differed in somatisation-scores [$F(2,897) = 3.3$, $P < .05$] and this difference could be attributed to higher scores among MCCHD compared to MHC ($P < .05$). Overall, differences were observed in fathers' somatisation-scores [$F(2,583) = 2.9$, $P < .05$], but could not be confirmed by post hoc tests. Finally, mothers had higher somatisation-scores than fathers in all groups [PCCHD, $t(1086) = 5.8$, $P < .001$; PCOD, $t(108) = 2.3$, $P < .05$; PHC, $t(286) = 2.6$, $P < .05$].

Comparisons of GSI-scores among parent groups vs. psychiatric outpatients

As shown in Table 4, most parents had GSI averages lower than POPN. However, 16% of all parents had scores within/above POPN (PCCHD, 21%; PCOD, 13%; PHC, 14%). χ^2 tests of these differences showed that PCCHD were more likely to have scores within/above POPN than PCOD and PHC [$\chi^2(2) = 8.1$, $P < .05$]. FCCHD (14%) scored more often within/above POPN than fathers of children with other diseases (FCOD) (4%) and FHC (6%) [$\chi^2(2) = 6.1$, $P < .05$].

Comparisons of depression-scores among parent groups vs. psychiatric outpatients

As shown in Table 4, parents' depression-scores were on the average lower than POPN. However, about 13% of all parents exhibited scores within/above POPN (PCCHD, 18%; PCOD, 10%; PHC, 10%). χ^2 tests of these differences revealed that PCCHD had more often depression-scores within/above POPN than PCOD and PHC [$\chi^2(2) = 11.9$, $P < .005$]. MCCHD (21%) also more often reported scores within/above POPN than MCOD (9%) and MHC (11%) [$\chi^2(2) = 12$, $P < .005$].

Comparisons of anxiety-scores among parent groups vs. psychiatric outpatients

As shown in Table 4, most parents had lower anxiety-scores than POPN. However, about 11% of all parents had anxiety-scores within/above POPN (PCCHD, 15%; PCOD, 9%; PHC, 7%). χ^2 tests of these differences showed that PCCHD more often reported psychiatric outpatient scores of anxiety than PCOD and PHC [$\chi^2(2) = 11.8$, $P < .005$]. Further, FCCHD (10%) more often scored within/above POPN than FCOD (2%) and FHC (3%) [$\chi^2(2) = 7.4$, $P < .05$]. MCCHD (18%) also more often reported scores within/above POPN than MCOD (12%) and MHC (10%) [$\chi^2(2) = 6.9$, $P < .05$].

Table 5
Means/S.E.s of hopelessness among all parents, PCCHD, PCOD, and PHC

Variable	All parents ($n=1497$)	PCCHD ($n=1092$)	PCOD ($n=112$)	PHC ($n=293$)
Hopelessness (0–20)				
Females (*N*)	(897)	(667)	(65)	(165)
Mean ± S.E.	4.9 ± 0.1	5.2 ± 0.01	4.4 ± 0.3	4.1 ± 0.2
Males (*N*)	(586)	(422)	(43)	(125)
Mean ± S.E.	4.1 ± 0.1	4.3 ± 0.01	4.4 ± 0.5	3.4 ± 0.2
Total (*N*)	(1483)	(1089)	(108)	(286)
Mean ± S.E.	4.6 ± 0.08	4.8 ± 0.1	4.4 ± 0.2	3.8 ± 0.1

Comparisons of somatisation-scores among parent groups vs. psychiatric outpatients

As shown in Table 4, average somatisation-scores of parents were lower than POPN. However, about 26% of all parents had scores within/above POPN (PCCHD, 32%; PCOD, 24%; PHC, 21%). χ^2 tests of the differences revealed that PCCHD were more likely to report psychiatric outpatient somatisation-scores than PCOD and PHC [$\chi^2(2)=11$, $P<.005$]. Similar results were found among MCCHD (34%), MCOD (26%), and MHC (21%) [$\chi^2(2)=9.4$, $P<.01$].

Hopelessness

The univariate analyses showed significant differences among parent groups concerning scores for hopelessness (Table 5). In addition, we found differences in hopelessness-scores between parent groups and scores shown by depressed people (Table 6).

Comparisons of hopelessness-scores among parent groups

As shown in Table 5, parent groups differed in hopelessness-scores [$F(2,1481)=10.4$, $P<.001$], which was due to higher scores among PCCHD compared to PHC ($P<.001$). Similar findings were found for mother [$F(2,895)=6.5$, $P<.005$] and father groups [$F(2,584)=4.4$, $P<.05$]. This was due to higher hopelessness-scores among MCCHD and FCCHD compared to MHC and FHC ($P<.005$ and $P<.05$). Finally, MCCHD showed higher hopelessness-scores than FCCHD [$t(1088)=4.2$, $P<.001$].

Comparisons of hopelessness-scores among parent groups vs. scores for depressed persons

As shown in Table 6, about 11% of all parents reported hopelessness-scores similar to depressed persons (nine points), with the highest proportions among PCCHD (13%) and PCOD (13%) and the lowest among PHC (5%). This difference was significant [$\chi^2(2)=14.5$, $P<.005$]. MCCHD (15%) did not differ in hopelessness levels from MCOD (12%), but had higher levels than MHC [$\chi^2(2)=7.6$, $P<.05$]. FCCHD also had greater levels of hopelessness than FHC [$\chi^2(2)=10.6$, $P<.005$].

Determinants of distress and hopelessness

Two separate regressions were run, i.e., one with all parents (Table 7) and the other with only PCCHD (Table 8).

All parents

Block I (children's domains). The children's health status was a determinant of distress and hopelessness. The risk of reporting psychiatric outpatient scores of distress was about twice as much for PCCHD than for PHC. PCCHD also reported five times higher risk of suicide ideation than PHC. The children's domains accounted for 2–3% of the variation in distress and hopelessness.

Table 6
Number and percentages of all parents, PCCHD, PCOD, and PHC for hopelessness levels (minimal/low and moderate/high)

	All parents		PCCHD		PCOD		PHC	
Variable	$n=1497$	%	$n=1092$	%	$n=112$	%	$n=293$	%
Hopelessness (0–20)								
Females (*N*)	(897)		(667)		(65)		(165)	
Minimal/low	775	86	564	85	58	88	153	93
Moderate/high	122	14	103	15	7	11	12	7
Males (*N*)	(586)		(422)		(43)		(125)	
Minimal/low	543	93	387	91	37	86	119	98
Moderate/high	43	7	35	8	6	14	2	2
Total (*N*)	(1483)		(1089)		(108)		(286)	
Minimal/low	1318	89	951	87	95	87	272	95
Moderate/high	165	11	138	13	13	12	14	5

Table 7
Determinants of depression, anxiety, and somatisation (SCL-90-R), and hopelessness among all parents

	Relative risk (odds ratio) and R^2 changes (in brackets)			
Independent variables	Depression	Anxiety	Somatisation	Hopelessness
Child domains (Block I)				
Age[a]	0.9	0.9	1	1
Gender[b]				
Boys	1.1	0.9	1	1.2
Girls[c]				
Health status[b]				
Healthy	0.5*	0.4**	0.5**	0.2***
Other diseases (not CHD)	0.6	0.7	0.8	1
CHD[c]				
R^2 change	(.02)	(.02)	(.02)	(.03)
Parent demographics (Block II)				
Age[a]	1.04*	1	1	1.1***
Gender[b]				
Male	0.4*	0.5**	0.6**	1.1
Female[c]				
Marital status[b]				
Single	0.4	0.5	1.7	2
Married/cohabitant	0.4	0.4	1.7	1.5
Divorced	0.3	0.5	1.2	3
Widow/widower[c]				
Foreign background[b]				
Yes	1.9*	1.4	1.4	1.7
No[c]				
Education[b]				
Primary	0.3	0.8	2	0.4
Secondary	0.4	0.8	2	0.7
University	0.5	1	1.5	0.7
Other[c]				
R^2 change	(.09)	(.08)	(.05)	(.07)

Parents employment status (Block III)				
Current employment status[b]				
Unemployed[c]				
Employed	0.4*	1.2	0.5	0.1***
Sick leave	0.3	1.2	0.5	0.4
Own business	0.1**	0.8	1	0.05**
Pension	0.3	1	13***	0.2*
Other	0.5	1.2	0.6	0.1**
Sick leave days later year[b]				
None	0.4**	0.4**	0.5*	0.4*
1–30 days	0.4*	0.5*	0.7	0.8
>30 days[c]				
Length of unemployment during career[b]				
None	0.3*	1	0.8	0.5
Less than 1 year	0.5	0.8	1	0.8
1–5 years	0.4	1.2	0.8	0.9
>5 years[c]				
R^2 change	(.08)	(.04)	(.10)	(.06)
Financial status (Block IV)				
Financial concerns[b]				
Yes	3.4***	2.4***	1.9**	1.8
No[c]				
Difficulties with living expenses[b]				
Yes	1.8*	1.3	1.7**	1
No[c]				
Difficulties in raising money[b]				
Yes	1.1	0.9	1.2	0.3***
No[c]				
R^2 change	(.11)	(.07)	(.07)	(.08)
Total R^2	.30	.21	.24	.24

[a] Continuous variables.
[b] Category variables.
[c] The comparison categories.
* $P<.05$.
** $P<.01$.
*** $P<.001$.

Table 8
Determinants of depression, anxiety, and somatisation (SCL-90-R) and hopelessness among PCCHD

	Relative risk (odds ratio) and R^2 changes (in brackets)			
Independent variables	Depression	Anxiety	Somatisation	Hopelessness
Child domains (Block I)				
Age[a]	0.9	0.9	0.9	0.9
Gender[b]				
Boys	1.1	0.9	1.1	1.2
Girls[c]				
CHD severity[a]	1.1*	1.1	1.1	1.1
Other diseases (not CHD)[b]				
No	1	0.8	1	1.1
Yes[c]				
Number of CHD diagnosis[a]	1.2	0.9	1.0	1.3
Number of operations[a]	1.1	1.1	1.0	1.0
Care-giving time	1.1*	1.1*	1.1**	1.1*
R^2 change	(.03)	(.02)	(.02)	(.01)
Parent demographics (Block II)				
Age[a]	1.0	1.0	1.0	1.1***
Gender[b]				
Male	0.2***	0.4***	0.4***	0.4***
Female[c]				
Marital status[b]				
Single	0.9	1	1.2	1.5
Married/cohabitant	1.2	1.7	1.6	3.0
Divorced	0.7	0.7	0.02	0.01
Widow/widower[c]				
Foreign background[b]				
Yes	0.7	0.5	0.9	0.5
No[c]				
Education[b]				
Primary	0.7	1.1	1.9	0.9
Secondary	0.6	1.0	1.7	0.9
University	0.4	0.9	0.9	0.7
Other[c]				
R^2 change	(.10)	(.06)	(.09)	(.06)

Parents employment status (Block III)				
Current employment status				
Employed[c]				
Unemployed	1.7	0.7	1.2	1.7
Sick leave	2.0	0.9	2.4	4.3
Own business	0.8	0.9	1.6	0.2
Pension	0.2	0.3	34.0***	0.1
Other	1.5	1.3	1.2	1.6
Sick leave days latest year[b]				
None	0.4**	0.4***	0.6	1.8
1–30 days	0.4**	0.4**	0.9	1.2
>30 days[c]				
Length of unemployment during career[b]				
None	0.2 *	2.1	1.2	0.4
Less than 1 year	0.6	1.9	1.5	0.4
1–5 years	0.2	2.6	1.3	0.7
>5 years[c]				
R^2 change	(.08)	(.05)	(.08)	(.07)
Financial status (Block IV)				
Financial concerns[b]				
Yes[c]				
No	0.2***	0.3***	0.8	0.4*
Difficulties with living expenses[b]				
Yes[c]				
No	1.0	1.2	0.8	0.9
Difficulties in raising money[b]				
Yes[c]				
No	0.6	0.8	0.6*	1.7
Financial burden of CHD[a]	1.4***	1.4***	1.2***	1.4***
R^2 change	(.10)	(.08)	(.06)	(.09)
Total R^2	(.31)	(.21)	(.25)	(.23)

[a] Continuous variables.
[b] Category variables.
[c] The comparison categories.
* $P<.05$.
** $P<.01$.
*** $P<.001$.

Block II (parents' demographics). Scores of depression and hopelessness augmented with increasing age. Gender was a determinant of distress, but not of hopelessness. The risk of females reporting psychiatric outpatient scores of distress was about twice as high. Foreigners were at a higher risk of reporting outpatient scores of depression than native Swedes. The parents' demographics accounted for 5–9% of the variation in distress and hopelessness.

Block III (parents' employment status). Unemployed parents reported twice and 10 times, respectively, as much risk for developing depression symptoms than employed parents and parents with own business. Parents receiving pension benefits reported 13 times as much risk for somatisation as unemployed parents. Further, the unemployed reported 10 times, 20 times, 5 times, and 10 times, respectively, higher suicide ideation risk than employed parents, parents with their own businesses, parents receiving pension benefits, and with other status (e.g., housewife). Parents reporting more than 30 days on sick leave were at twice as much risk of developing symptoms of depression and anxiety than parents reporting between 0 and 30 days. For somatisation, those reporting more than 30 days on sick leave had twice as high risk of developing symptoms than those without such experiences. The same trend was observed for hopelessness. Parents who had experienced more than 5 years unemployment reported a three times greater risk for developing symptoms of depression than parents without such experiences. The parents' employment status accounted for 4–10% of variation in distress and hopelessness.

Block IV (parents' financial situation). Parents concerned about their finances were at higher risk of reporting psychiatric outpatient levels of distress (two to three times higher risk) than those with no financial concerns. Parents having difficulties with living expenses were at higher risk of developing symptoms of depression and somatisation than those without such difficulties. Further, parents with difficulties in raising money were at three times as much risk regarding suicide ideation than those without such difficulties. The parents' financial situation accounted for 7–11% of the variation in distress and hopelessness. The four blocks accounted for 21–30% of the total variation in distress and hopelessness among all parents.

Parents of children with CHD

Block I (children's domains). Severity of heart defect affected depression, i.e., the more severe the defect the higher the risk of developing depression symptoms. Further, the analyses showed that care-giving time was an important determinant of distress and hopelessness. That is, the more care-giving time, the greater the levels of distress and hopelessness. The children's domains accounted for 1–3% of the variation in distress and hopelessness.

Block II (parents' demographics). Suicide ideation risk augmented with increasing age. Mothers reported approximately two to three times higher risk of developing symptoms of distress than fathers. The parents' demographics accounted for 6–10% of the variation in distress and hopelessness.

Block III (parents' employment status). Parents receiving pension benefits reported about 34 times higher risk of developing symptoms of somatisation than those in employment. Parents who had been on sick leave more than 30 days reported a higher risk for symptoms of depression and anxiety (two to three times higher risk) than those without such experiences. Parents who had been unemployed for more than 5 years were at four times higher risk of reporting symptoms of depression than those without unemployment experiences. The parents' employment status accounted for 5–8% of the variation in distress and hopelessness.

Block IV (parents' financial situation). Parents reporting financial concerns ran about four and three times, respectively, higher risk of developing symptoms of depression and anxiety than those without such concerns. Further, the risk of suicide ideation among parents with these concerns was about twice as high as for their unconcerned counterparts. Parents with difficulties in raising money reported about twice as high risk for developing symptoms of somatisation. The parents' levels of distress and hopelessness augmented with increasing financial burden. The parents' financial situation accounted for 8–10% of the variation in distress and hopelessness. The four blocks accounted for 21–31% of the variation in distress and hopelessness among the PCCHD.

Discussion

PCCHD scored higher on depression than the other parent groups, and reported greater anxiety and somatisation than PHC. Mothers had higher scores than fathers on all distress (i.e., depression, anxiety, and somatisation) dimensions. PCCHD reported greater scores of hopelessness than PHC, even when mothers and fathers were examined separately. Although these group differences tended to be generally small, albeit significant, we found that a rather important number of parents had scores on distress and hopelessness similar/above psychiatric outpatients and depressed people, respectively.

A relatively large number of the parents reported scores of depression ($n = 220$), anxiety ($n = 193$), and somatisation ($n = 432$) within/above POPN [29], with the highest proportion among PCCHD. Of the PCCHD, 18% had scores of depression within/above psychiatric outpatient levels, whereas the figures for the PCOD and the PHC were 10% each. Similar trends were observed in anxiety (PCCHD, 15%; PCOD, 9%; PHC, 7%) and somatisation (PCCHD,

32%; PCOD, 24%; PHC, 21%%). Mothers within all groups reported more often psychiatric outpatient distress levels than fathers. FCCHD had psychiatric outpatient levels of GSI and anxiety more often than FHC.

PCCHD were more pessimistic about the future that the PHC, with mothers as more pessimistic. PCCHD had, on average, hopelessness levels surpassing those found in the general population. Greene [32] reported that in a normal population, the average hopelessness-score was approximately 4.5. The average for the PCCHD was 4.8, whereas PCOD (4.4) and PHC (3.8) had averages below the general population. Moreover, 13% each of the PCCHD and the PCOD, and 5% of the PHC had scores of hopelessness indicating the presence of clinical depression and suicide ideation [30,31].

These data suggest that parents' level of distress (i.e., depression, anxiety, and somatisation), and hopelessness may constitute a threat to their psychological health, at least for a large number of them. Although neither the SCL-90-R [29] nor the Hopelessness Scale [30,31] are diagnostic instruments, they seem able to capture clinical cases of distress (e.g., depression) and suicide risk. Thus, an important proportion of our sample may be considered as being clinically depressed and showing suicide ideation [29–31]. Moreover, a significant percentage of PCCHD reported distress frequencies surpassing those found in the general population (e.g., Refs. [33–36]).

Distress symptoms may be common in most parents before and shortly after the birth of a child. Cohn [23] showed that not less than 50% of PHC reported being, for example, pessimistic, depressed, and worried, which was attributed to major changes in parental roles. Whereas such feelings probably die out over time for PHC, they may intensify for PCCHD upon knowledge that their child is chronically ill or have to undergo heart surgery. The children's illness may also be a source of hopelessness. Positive expectations about the future may be crushed as parents realise that their children are sick. They may also experience feelings of distancing from formal support systems, social isolation, as well feeling exhausted and helpless. Consequently, there may be a real risk for prolonged tension, etc., leading to the development of distress and hopelessness. Thus, the health status of the children may account for the differences in distress and hopelessness between parent groups. The regressions seem to indicate that it may be the case considering the association between the children's health situation and the parents' distress and hopelessness feelings. However, disease accounted merely for 1–3% of the variation in distress and hopelessness among all parents and PCCHD, indicating that its explanatory power was modest. This is in line with data showing that the CHD severity does not predict parental distress (e.g., Ref. [17]) and is contrary to studies suggesting that it may [37–39].

Distress and hopelessness among PCCHD may have also resulted from prolonged parental guilt for not giving birth to a healthy child. Parental guilt may have lead to feelings of worthlessness and helplessness, reduced self-esteem, and self-blame for the child's illness, conducting to the development of symptoms of distress. Parents of severely handicapped children tend to be troubled by guilt (e.g., Refs. [28,40]) and findings indicate that diminished self-esteem may result in intense feelings of anger, fear, and sadness among PCCHD (e.g., Refs. [23,39]). Thus, parental guilt may be involved in the development of psychosocial problems. However, as we did not assess guilt among parents, we are unable to elucidate this question further.

Burden of care may have also lead to distress and hopelessness. The PCCHD's burden of care may be, in many cases, long lasting and the increased time and energy that PCCHD may spend with their children, predominantly mothers, may result in exhaustion. At least, it may reduce distress protective activities such as socialisation and recreation. Parents in Sweden also tend to work full-time [41] and perform various everyday domestic tasks (e.g., feeding the children), with the greatest total workload being left to mothers [42]. Further, we found that PCCHD, mostly mothers, spent extra time caring for their sick children on a daily basis. Thus, the heavy load on PCCHD, particularly on mothers, together with the general workload, may in some measure explain not only the higher levels of distress and hopelessness among PCCHD vs. the other parent groups, but also gender differences. The regressions seem to suggest that it may be the case as mothers were at higher risk of reporting patient levels of distress and hopelessness than fathers, and care-giving time was an important determinant of both distress and hopelessness. As suggested earlier, this may be due to greater involvement of mothers in care-taking tasks and maternal attachment to her infant. Indeed, data on parental caring of chronically ill children including CHD indicate that mothers are highly involved in care-taking tasks and that such involvement may lead to strain (e.g., emotional) (e.g., Refs. [25–27,43–49]). Overall, the findings seem to suggest that burden of care may be related to emotional strain.

Financial strain/instability may have also accounted for discrepancies in distress and hopelessness levels between parent groups. The financial and welfare situation in Sweden has deteriorated during recent years (e.g., significant cuts in health care services). The negative impact of the crisis has been hard on families with children, especially on families with chronically ill children, with noticeable decreases in their standard of living (e.g., Ref. [41]). We also found that PCCHD had greater financial problems than PHC. Thus, the general financial instability among families with children, together with the additional financial problems to which PCCHD are subjected, may explain the higher levels of distress among PCCHD. The regressions on the parent's financial situation indicate that it may be the case as unemployment, sick leave, and financial difficulties augmented levels of distress and suicide ideation risk among parents in general, and PCCHD in particular. These findings, together with the general decrease of living standard

among parents and other data showing that PCCHD have more expenses/costs than PHC (e.g., Refs. [50,51]), suggest that financial strain/instability may be important in the development of ill-health. Indeed, financial strain/instability (e.g., unemployment) explained more of the variation in distress and hopelessness than the children's disease. Other sets of data that show an association between financial strain/instability and health problems (e.g., Refs. [52–55]) seem to further support our views.

Age was a determinant of distress and hopelessness levels. However, there were no significant differences in age between PCCHD, PCOD, and PHC. This finding suggests that parents, like the general population, are likely to show more depression symptoms as they advance in age, and that it may have little to do with the children's health situation. Data on the association between increased age and a higher risk for depression (e.g., Refs. [33,56]) seem to support this view. However, we found no correlation between increased age and depression among PCCHD, only a correlation between age and hopelessness. These results are difficult to reconcile considering the association between depression and hopelessness. One explanation would be that the Hopelessness Scale [30,31] is more sensitive to age effects than the SCL-90-R [29].

The regressions of all parents showed that foreigners reported more often psychiatric outpatient levels of depression than native Swedes. However, when analysing the PCCHD separately, ethnic background did not account for differences in depression. This may be due to a larger number of foreigners in the PCOD and PHC groups than in the PCCHD, an additive or random effect. On the other hand, data from various sources in Sweden (e.g., Refs. [57–60]) indicate that "foreign-born" per se is an independent risk factor for increased ill-health. Thus, the differences between foreigners and native Swedes may not be related with the children's health situation.

In summary, PCCHD tended to experience higher distress and hopelessness levels than other parent groups, with the highest proportions among mothers, which confirms previous data (e.g., Refs. [18,21]). Although these group differences were generally small, albeit significant, our data suggest that the risk for developing psychological symptoms as well as being at suicide ideation risk is not all together negligible among all parents, but seems considerably higher among PCCHD, with the highest risk among mothers. Indeed, we found an important number of parents with scores in distress within/above norms from psychiatric outpatients [29] and surpassing frequencies found in the general population (e.g., Refs. [33–36]), and hopelessness levels above those shown by depressed people [30,31]. Further, FCCHD showed higher GSI and anxiety levels than FHC, which seems to contradict previous findings (e.g., Ref. [61]). Finally, variables such as unemployment and financial difficulties may have a greater explanatory power concerning the differences in distress/hopelessness between the parent groups than the children's health situation as suggested by some authors (e.g., Refs. [37–39]).

Though the current study corroborates previous findings on the situation of PCCHD and may provide new insights in the field, its weaknesses need to be acknowledged. Firstly, causality is difficult to ascertain with a cross-sectional study. It would require another type of design (e.g., repeated measures) to firmly establish causal links. Secondly, the accuracy of data was solely dependent on the parents' subjective assessment of their own situation and that of their child. Thirdly, the group of children with other diseases consisted of children with disorders that varied in typology, nature, and severity. This makes the group rather less homogenous compared to heart-diseased and healthy children. Fourthly, we lacked sufficient data on certain variables (e.g., severity of the diseases other than CHD), which precluded an analysis of their influence on the parent's distress and hopelessness feelings. However, as indicated in our results and other findings described in the discussion, health variables were only modestly related to parental difficulties. Fifthly, our group of PCCHD may not have been representative for all parents of children with CHD. Sixthly, one may question the clinical importance of our findings as differences between parent groups were small, albeit significant. On the other hand, we found that a relatively great number of parents, in particular PCCHD, had levels of distress and hopelessness similar/above values found in psychiatric outpatients and depressed persons, respectively. Finally, the normative data used for comparisons were based mainly on non-Swedish samples. Nonetheless, reliability estimates with respect to distress and hopelessness from our sample do not differ from those of the normative samples. Despite these limitations, the reliability of the study is confirmed by the fact that most findings are consistent with other research in the field and we may have provided new insights.

Concluding, despite the contributions by health personnel in improving the psychosocial situation of PCCHD, it appears that more needs to be done to reduce among other things levels of emotional strain. Interventions aimed at improving the situation of PCCHD may require a widening of the issues to be addressed and cooperation between different disciplines. Our data indicate that disease is of little weight when explaining the parents' feelings of distress, hopelessness, and suicide ideation. Other variables such as household finances and employment status may be more vital. Thus, what may so far seem to be solely the responsibility of medical practitioners in reducing distress levels, may be also tackled at an aggregate level by the state with interventions such as subventions to medical care for chronically sick children. Our results indicate also that improvements of well-being among PCCHD may require particular attention to be paid to the mothers' situation as they seem more burdened than fathers. Interventions need to address parental roles, be highly sensitive to women's problems, and focus more on such issues as socialisation

and recreation as a buffer against distress than upon the children's diseases and their severity. It is possible that young and old parents have different styles/capacities to cope with everyday problems, care-taking, etc., implying that such issues must also be addressed. Further, our results indicate that a relatively large number of parents of sick children, in particular PCCHD, might be, for example, clinically depressed. It is therefore of great importance that interventions identify these persons rather quickly, be sensitive to their problems, and help them adequately. Finally, the experiences and needs of foreign parents ought also to be addressed in interventions. Among other things, foreigners in Sweden tend to live in greater isolation, have difficulties in their contacts with the care system, and are often discriminated. Paying particular attention to their problems may have a therapeutic effect.

The association between distress, hopelessness, and illness is a complex one as we suggest in our study. Although we pointed to some important determinants of distress and hopelessness, much of its variation remains to be explained. It follows that further research is necessary, not the least concerning the identification of characteristics of parents that may be at risk of developing psychosocial problems.

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