Psychosocial morbidity among parents of children with congenital heart disease: A prospective longitudinal study

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OBJECTIVE: The study objectives were to assess long-term psychosocial morbidity and its determinants among parents of children with congenital heart disease (PCCHD), and to compare mothers with fathers on psychosocial variables.

METHOD: The study design was longitudinal. Data comprising PCCHD (n = 632, 58% were women) were collected on two occasions 1 year apart.

RESULTS: Many PCCHD reported psychosocial problems manifested in depression (18%), anxiety (16%-18%), somatization (31%-38%), and hopelessness (16%) during both measurement points. In addition, 7% to 22% reported psychosocial problems persisting over a 1-year period. Consistently over time, mothers reported more severe symptoms of depression, anxiety, somatization, and hopelessness than fathers. Children's clinical severity did not significantly explain parent's psychosocial morbidity over time. Instead, parental caregiving burden, dissatisfaction with care, social isolation, and financial instability were associated with an increased risk of long-standing psychosocial morbidity.

CONCLUSIONS: An important proportion of PCCHD are at risk of long-standing psychosocial morbidity, suggesting that psychosocial intervention may be beneficial. Feasible interventions are discussed.
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Parenthood is an enterprise usually associated with rewards that go beyond any other human experience. Not all parents, however, have the opportunity to experience the full joy of parenthood. This may be the case if the child is born with congenital heart disease (CHD), the leading cause of death among all congenital malformations. A general view of the research indicates that parents of children with congenital heart disease (PCCHD) report negative cognitive responses (eg, guilt and fear) and psychosocial problems (eg, distress, adaptation problems, dilemmas of social integration, and poor quality of life)[1-10] more so than parents of healthy children[11-15] and parents of children with other diseases.[14,15]

An increased consensus based on the latest findings suggest that the presence of CHD in children and its severity may be less important for parents' psychosocial experiences than other factors such as demographics (eg, gender and ethnicity), socioeconomic stressors, coping strategies, and excessive caregiving burdens.[15-18]

Few studies have addressed the issue of psychosocial morbidity among PCCHD over time. It is suggested that stress levels among PCCHD may vary depending on the stage of treatment,[19] independent of the severity of the defect.[20] Other longitudinal studies have investigated the role of psychosocial resources in the resiliency process, although the findings in this regard are elusive. Although emotional[21] and educative[22] support have been suggested to modify distress and anxiety levels among PCCHD, other resources such as coping and locus of control have not received unequivocal support in the resiliency process.[21,23]

Current reports from longitudinal studies among PCCHD should be interpreted with caution. Most samples represent selected groups of

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parents of children with specific diagnoses[19,23] and age groups,[18,22] and include mothers predominantly.[20,21] We are not aware of longitudinal data representative of all children with CHD, portraying the situation of both mothers and fathers, or accounting for gender differences. The current study is a contribution in addressing these issues. In addition, few of the longitudinal studies have addressed the issue of determinants of the situation of PCCHD across time, with rather inconsistent results regarding the role of psychosocial resources in general.[21-23] Further investigation of this issue is warranted. It is also our intention to determine the role of clinical/care variables in explaining long-standing psychosocial problems among PCCHD.

The aim of the current study is to (1) examine symptoms of depression, anxiety, somatization and hopelessness, satisfaction with care, and social support among PCCHD over time; (2) compare mothers with fathers regarding psychosocial measures over time; and (3) identify and quantify demographic, socioeconomic (eg, financial burdens), and clinical/care variables (eg, severity of CHD and satisfaction with care) that predict psychosocial situation of PCCHD over time. Clinical implications of the findings are discussed.

METHOD

Subjects

Members of the Swedish Heart Child Association who had children born with CHD between 0 and 20 years of age still living at home/or in close contact with the parents were eligible for participation in this study. (The Swedish Heart Child Association is a voluntary association built by parents of CHD children. It provides support for parents and children. It has 6000 members and is represented in all Swedish regions. Further information can be obtained at www.hjartebarn.org.) Of the 1500 PCCHD meeting the inclusion criteria, 1092 participated (response rate of 72.8%) in the first part of this project, and detailed data are reported elsewhere.[15-17,24] There were no significant differences between responders and nonresponders concerning demographics. Data on the nonresponders children's situation were not available (eg, type of heart defect).

For the current study, the same questionnaire was sent 1 year later to the 1092 respondents in the first part; 632 (response rate 58%) responded to the second questionnaire. Thus, the current study comprises repeated measures for the 632 responders. A total of 195 children were represented by both parents (ie, 390 individuals).

The attrition analysis indicated that responders did not differ from nonresponders regarding demographics (eg, gender and age), children's clinical situation (eg, diagnosis), initial measures (time one, T1 [year 2000]) of financial/employment status, depression, anxiety and somatization symptoms, feelings of hopelessness, social support, and satisfaction with care. Thus, our data are presumably representative of the 1092 respondents to the first questionnaire.

As shown in Table I, the parents provided information on 430 children regarding demographic characteristics and clinical situation. The distribution of different CHD diagnoses among children in our sample was similar to the distribution observed in the population with CHD,[25-27] suggesting that the data are representative of children with CHD.

Measures

Participants completed the same questionnaire on two occasions, time 1 (T1 [year 2000]) and time 2 (T2 [year 2001]), 1 year apart, covering the following variables.

Children's clinical picture. To capture the totality of the child's disability and maximize validity,[28] a number of clinical variables were taken into account. PCCHD were requested to provide information about their child's CHD diagnosis/diagnoses, treatment of CHD (eg, number of operations), and presence of a secondary diagnosis (Table I).

Caregiving time/burden. This variable was assessed with a single open-ended question inquiring how much more time, above the ordinary, the individual parent devotes to caring for the child with CHD daily.

Psychosocial morbidity in this study was defined as any of the symptoms of depression, anxiety, somatization, and hopelessness, and was assessed with the Symptom Check List-Revised (SCL-90-R)[29] and the Hopelessness Scale.[30] Long-standing psychosocial morbidity was defined as having any of the symptoms of depression, anxiety, somatization, and hopelessness persisting over a 1-year period.

The SCL-90-R[29] consists of 90 items divided into nine symptom dimensions assessing the grade of psychopathology. In this study, we used the dimensions of depression (13 items, eg, whether the subject had thoughts of suicide during the past week), anxiety (10 items, eg, whether the subject had experienced feelings of fear during the past week), and somatization (12 items, eg, whether the subject had

Table I
Children's demographic and clinical characteristics

Characteristics	n	%
Age (ys)		
Mean ± SE	8 ± 0.3	
Gender		
Females	186	42
Males	247	58
Disease type*		
PDA	18	4
Coarctation of aorta	17	4
ASD	65	15
VSD	130	30
TOF	48	11
PVS	70	16
AVS	52	12
Transposition of great arteries	35	8
Other heart diseases†	173	40
Number of heart defects		
1	264	61
2	106	24
>3	63	15
Other diseases‡		
Yes	144	33
No	289	67
Surgery		
Yes	351	81
No	82	19

PDA, Patent ductus arteriosus; *ASD,* atrial septal defect; *VSD,* ventricular septal defect; *TOF,* tetralogy of Fallot; *PVS,* pulmonary valve stenosis; *AVS,* aortic valve stenosis; *SE,* standard error.

*Percentages for this variable add up to more than 100% because one child can have several diseases.

†For example, complete arteriovenous canal.

‡Not coronary heart disease (eg, Down syndrome).

gastrointestinal problems during the past week). The items range from 1 to 5 (not at all to very much). High scores indicate high levels of psychopathology. The instrument has been validated,[31] and the internal reliability coefficients (Cronbach's α) for the current sample ranging between .84 and .90 at T1 and T2 demonstrate further its potential utility for the current sample.

The Hopelessness Scale[30] consists of 20 items about one's future. Items are arranged in true/false format. Further, scores can be transformed into norms indicating levels of experienced hopelessness (0-3 = none/minimal; 4-8 = low; 9-14 = moderate; and 15-20 = high). A high score indicates high levels of hopelessness (ie, suicide ideation/risk). The instrument has been validated.[32] Cronbach's α for the current sample ranging between .80 and .84 at T1 and T2 demonstrate further its potential utility for the current sample.

Social support was assessed with the Schedule for Social Interaction,[33] consisting of 12 items involving social attachment in terms of availability of deep emotional relationships (eg, having someone to share deep feelings) and social integration in terms of availability of peripheral social networks (eg, contact with persons who have similar interest as oneself). Items range from 1 to 6 (not available to available), with high scores demonstrating high availability of support. The instrument has been validated,[34] and Cronbach's α for the current sample ranging between .70 and .71 at T1 and T2 demonstrate further its potential utility for the current sample.

Satisfaction with children's care was measured with questions from the Pyramid Patient Questionnaire[35] and the Client Satisfaction Questionnaire.[36] Fifteen relevant questions from the Pyramid Patient Questionnaire and all the eight questions from the Client Satisfaction Questionnaire-8, modified to address parental satisfaction with children's care, were used in this study. Thus, 23 questions were used (eg, satisfaction with children's medical care). In a previous study,[24] a factor analysis of the 23 questions (using varimax rotation) resulted in four distinct factors representing satisfaction with medical care, information, staff attitudes, and duration before treatment. For the purpose of this study (ie, to study satisfaction in general), the average of the four factors was used. Scores ranged from 1 to 4, with high scores demonstrating high satisfaction. Cronbach's α for the current sample was .88 at T1 and T2.

Parental financial situation was assessed with three questions in "yes/no" format covering concerns about family financial situation, difficulties in raising a reasonable sum of money in a specific period, and difficulties with living expenses (eg, food expenses). In addition, financial burden of disease was assessed on a continuous scale ranging from 1 to 7 with high scores indicating high burden.

Design and procedure

The study design was longitudinal, and data were collected for all parents during 1 month with two reminders being sent on both occasions (T1 and T2).

Data were gathered with the help of the Swedish Heart Child Association (SHCF), which is represented in all Swedish counties. On both occasions, each individual parent was sent a letter informing her/him of the study, about what was expected of her/him and the questionnaire, and was asked to return the completed questionnaire by post. All parents were volunteers. Confidentiality was guaranteed. The regional ethical committee in Stockholm approved the study.

Statistical analyses

Independent-sample *t* test, paired-sample *t* test, and chi-square test were used in the univariate analyses. Block-wise logistic regression analyses were run to identify and quantify predictors of psychosocial morbidity over time. To make casual inference about determinants of psychosocial situation at T2, we controlled for psychosocial situation at T1 in the regression analyses.[37] Candidate determinants in the regression analyses were children's clinical picture, caregiving burden, satisfaction with care, parent's demographic characteristics, unemployment and sick-leave experiences, and changes in financial status and social support between T1 and T2. There was no multicollinearity between the independent variables. Because many parents were couples (n = 390; 195 couples), their scores on psychosocial parameters may be correlated and thus violate a vital condition for regression analysis, that is, independence between observations. Correlation test revealed no significant correlation between dyad's scores, indicating that regression analyses could be applied to the data.

Symptoms of depression, anxiety, somatization, and hopelessness were transformed into dichotomous variables. Parents with scores within or higher than norms from psychiatric outpatients[29] and depressed patients,[30] respectively, formed the risk group of the dichotomy in the logistic regressions. Considering that relatively many univariate tests were performed, there is an increased risk for type-1 error. Therefore, to adjust for this, statistical significance for all univariate analyses was assumed at P less than .01. Significance levels were, however, set at P less than .05 for the regression analyses.

RESULTS

Demographic characteristics of participants

As shown in Table II, mothers were younger than fathers (t [616] = 5.0, $P < .001$) and more likely to be single (Fisher exact test statistic = 16.3, $P < .001$), unemployed, and on sick-leave (χ^2 [4] = 28, $P < .001$). In addition, a higher proportion of mothers than fathers were unemployed both in the short and long term (χ^2 [2] = 13.2, $P < .001$). Similarly, a higher proportion of mothers than fathers reported more than 30 days sick-leave experiences the latest year (χ^2 [2] = 12.3, $P < .01$). Finally, extra time spent caring for the ill child daily decreased significantly on average between T1 and T2 for all participants (t [626] = 2.9, $P < .01$) and fathers in particular (t (240) = 2.6, $P < .01$). The decrease in mothers' caregiving time was not statistically significant.

Financial situation at time 1 and time 2

At T1, more mothers than fathers faced difficulties raising money (χ^2 [1] = 7.4, $P < .01$), as shown in Table III. The same trend was observed at T2 regarding difficulties with living expenses (χ^2 [1] = 7.3, $P < .01$) and difficulties raising money (χ^2 [1] = 7.2, $P < .01$).

Changes in psychosocial variables between time 1 and time 2

As shown in Table IV, levels of somatization increased significantly, on average, between T1 and T2 (t [619] = 3.2, $P < .01$). This increase was attributed to increased levels among mothers (t [380] = 4.4, $P < .001$). There were no significant changes in other psychosocial variables over time.

Differences between mothers and fathers in psychosocial variables at time 1 and time 2

As shown in Table IV, mothers reported on average more symptoms of depression (t [618] = 4.1, $P < .001$) and anxiety (t [618] = 2.7, $P < .01$) than fathers at T1. The same trend was observed at T2 for depression (t [618] = 5.7, $P < .001$) and anxiety (t [618] = 3.9, $P < .001$). In addition, mothers reported more symptoms of somatization (t [618] = 3.6, $P < .001$) than fathers at T2.

Comparison of proportions of parents with patient norms of depression, anxiety, somatization, and hopelessness between time 1 and time 2

As shown in Table V, 13% to 19% reported levels of depression and anxiety at T1 and T2. There was no significant change in proportion between the two periods. The proportion of mothers (χ^2 (1) = 7.2, P

Table II
Demographic characteristics of participants at time 2 (T2)

	All parents (N = 628)		Males (N = 241)		Females (381)	
Characteristics	**n**	**%**	**n**	**%**	**n**	**%**
Age (y)						
Mean ± SE	41 ± .3		43 ± .5		40 ± .3	
Marital status (N)	(618)		(239)		(379)	
Married/cohabited	561	91	228	95	333	88
Single	24	4	1	1	23	6
Divorced	33	5	10	4	23	6
Educational level (N)	(619)		(239)		(380)	
Mandatory	43	7	22	9	21	6
College	299	48	126	53	173	45
University	237	38	76	32	161	42
Other	40	7	15	6	25	7
Foreign background (N)	(610)		(237)		(373)	
Yes	39	6	16	7	23	6
No	571	94	221	93	350	94
Unemployment experience latest year* (N)	(599)		(233)		(366)	
None	458	76	194	83	264	72
< 1 y	77	13	16	7	61	17
>1 y	54	11	23	10	41	11
Sick-leave experiences latest year* (N)	(616)		(238)		(378)	
None	297	48	126	53	171	45
1–30 d	252	41	99	42	153	40
> 30 d	67	11	13	5	54	14
Extra time spent caring for sick child daily (N)	(627)		(241)		(381)	
At T1						
Mean ± SE	1.32 ± .14		1.02 ± .15		1.53 ± .20	
At T2						
Mean ± SE	1.00 ± .10		.70 ± .10		1.06 ± .14	

SE, Standard error.
*Latest year.

< .01) with patient norms of somatization augmented significantly (32%-43%) between T1 and T2. An important proportion of participants reported long-standing symptoms of depression (3%-13%), anxiety (3%-10%), and somatization (16%-27%), with significantly higher proportions among mothers than fathers (Table V) (all gender differences regarding stable distress significant at $P < .001$). Finally, the proportions of parents with hopelessness equivalent to levels observed in depressed patients ranged between 11% and 16% at T1, and between 14% and 16% at T2, with no significant changes in proportions between the two periods. Long-standing hopelessness was reported by 7% with no differences between mothers and fathers.

Child/parental demographic and health determinants of psychosocial morbidity at time 2

Child domains. As shown in Table VI, children's demographic and clinical variables (ie, CHD sever-

Table III
Financial situation at T1 and T2

	All parents				Male				Female			
	T1		T2		T1		T2		T1		T2	
	n	%	n	%	n	%	n	%	n	%	n	%
Concerns about finances (N)	(626)		(618)		(240)		(237)		(381)		(377)	
Yes	230	37	214	35	82	34	71	30	146	38	141	37
No	396	63	404	65	158	66	166	70	235	62	236	63
Difficulties raising money (N)	(626)		(620)		(241)		(238)		(380)		(378)	
Yes	106	17	94	15	28	12	24	10	76	20	68	18
No	520	83	526	85	213	88	214	90	304	80	310	82
Difficulties with living expenses (N)	(627)		(619)		(241)		(238)		(381)		(377)	
Yes	169	27	162	26	53	22	48	20	116	30	113	30
No	458	73	457	74	188	78	190	80	265	70	264	70
Financial burden of CHD*												
Mean ± SE	2.5 ± .06		2.3 ± .06		2.5 ± .11		2.2 ± .11		2.5 ± .09		2.4 ± .11	

CHD, Congenital heart disease; *SE,* Standard error.
*Continuous scale (1–7). High scores indicate high financial burden.

ity, number of CHD diagnoses, concurrent noncardiac disease, and number of operations) did not independently predict parents' distress and hopelessness feelings. On the other hand, caregiving burden and dissatisfaction with children's care predicted distress and hopelessness. Child domains explained 3% to 4% of the variation in psychosocial morbidity among PCCHD over time.

Parent demographics at T2. As shown in Table VI, increasing age was associated with an increased risk of hopelessness. In addition, the risk of depression was higher among mothers than fathers. Together, parental demographic characteristics accounted for 3% to 4% of the variation in psychosocial morbidity among PCCHD over time.

Sick-leave and unemployment between T1 and T2. As shown in Table VI, participants without sick-leave experiences between T1 and T2 were at lower risk of depression, anxiety, and somatization symptoms than participants with more than 30 days sick-leave. In addition, employed parents between T1 and T2 were at lower risk of depression and somatization symptoms at T2 than parents with long-term unemployment at T2. Together, unemployment and sick-leave accounted for 3% to 10% of the variation in psychosocial morbidity among PCCHD over time.

Financial and social determinants of psychosocial morbidity at T2 among PCCHD changes in financial status between T1 and T2. Parents with long-standing financial concerns (ie, concerned about their financial situation during both years) and augmenting concerns between T1 and T2 were at higher risk of psychosocial problems (manifested in depression, somatization, and/or hopelessness) than colleagues without such concerns over the 2-year period. In addition, parents reporting long-standing difficulties with living expenses and those with increasing difficulties with living expenses reported higher risks for psychosocial problems (manifested in depression, somatization, and/or hopelessness). Finally, with increasing financial burden of CHD between T1 and T2, the risk of depression, anxiety, and somatization augmented. Together, changes in

Table IV
Changes in psychologic variables between T1 and T2 and gender differences within T1 and T2

Variable	Time 1 (T1)	Time 2 (T2)	Difference (T2-T1)
SCL-90-R Depression (0–4)			
Male (N)	(239)	(239)	(239)
Mean ± SE	.79 ± .04	.72 ± .04	−.07 ± .04
Female (N)	(381)	(381)	(381)
Mean ± SE	1.06 ± .04	1.11 ± .04	.05 ± .04
Total (N)	(620)	(620)	(620)
Mean ± SE	.96 ± .03	.96 ± .03	.002 ± .03
SCL-90-R Anxiety (0–4)			
Male (N)	(239)	(239)	(239)
Mean ± SE	.55 ± .04	.50 ± .04	−.05 ± .04
Female (N)	(381)	(381)	(381)
Mean ± SE	.72 ± .04	.76 ± .04	.04 ± .04
Total (N)	(620)	(620)	(620)
Mean ± SE	.65 ± .03	.66 ± .03	.01 ± .03
SCL-90-R Somatization (0–4)			
Male (N)	(239)	(239)	(239)
Mean ± SE	.70 ± .04	.70 ± .04	.005 ± .04
Female (N)	(381)	(381)	(381)
Mean ± SE	.79 ± .03	.92 ± .04	.13 ± .03
Total (N)	(620)	(620)	(620)
Mean ± SE	.75 ± .03	.84 ± .03	.09 ± .03
Hopelessness (0–20)			
Male (N)	(241)	(241)	(241)
Mean ± SE	4.54 ± .21	4.72 ± .22	.18 ± .22
Female (N)	(383)	(383)	(383)
Mean ± SE	5.24 ± .18	5.25 ± .19	.01 ± .18
Total (N)	(624)	(624)	(624)
Mean ± SE	4.97 ± .14	5.05 ± .15	.08 ± .14
Social support (6–36)			
Male (N)	(229)	(229)	(229)
Mean ± SE	25 ± .36	25 ± .49	.002 ± .40
Female (N)	(357)	(357)	(357)
Mean ± SE	24 ± .28	24 ± .27	.005 ± .28
Total (N)	(586)	(586)	(586)
Mean ± SE	25 ± .22	24 ± .25	−.1 ± .24
Satisfaction with care (1–4)			
Male (N)	(238)	(238)	(238)
Mean ± SE	2.31 ± .04	2.33 ± .04	.02 ± .04
Female (N)	(378)	(378)	(378)
Mean ± SE	2.31 ± .03	2.32 ± .03	.01 ± .03
Total (N)	(619)	(619)	(619)
Mean ± SE	2.31 ± .02	2.33 ± .02	.02 ± .02

SE, Standard error; *SCL-90-R,* Symptoms Check List - Revised.

Table V
Proportions of parents of children with congenital heart diseases with patient norms of distress (Psychiatric Out-Patient Norms [POPN]) and hopelessness (moderate/high) at T1, T2, and both T1 and T2

Variables	Time 1 (T1)			Time 2 (T2)			Both T1 and T2 (long-standing symptoms)			POPN* (1002)
SCL-90-R										
Anxiety (0–4)	N	n	%	N	n	%	N	n	%	
Females	381	59	16	381	67	18	381	38	10	1.59 ± .04(n = 577)
Males	239	32	13	239	26	11	239	7	3	1.30 ± .04(n = 425)
Total†	620	93	14	620	98	16	620	45	7	1.47 ± .03(n = 1002)
SCL-90-R										
Depression (0–4)	N	n	%	N	n	%	N	n	%	
Females	381	71	19	381	73	19	381	49	13	1.94 ± .04(n = 577)
Males	239	37	15	239	31	13	239	7	3	1.59 ± .04(n = 425)
Total†	620	113	18	620	115	18	620	56	9	1.79 ± .03(n = 1002)
SCL-90-R										
Somatization (0–4)	N	n	%	N	n	%	N	n	%	
Females	381	120	32	381	165	43	381	102	27	.99 ± .03(n = 577)
Males	239	82	34	239	93	39	239	37	16	.71 ± .03(n = 425)
Total†	620	199	31	620	240	38	620	140	22	.87 ± .02(n = 1002)
Hopelessness (0–20)										
Females (N)	(381)			(381)			(381)			
Moderate/high	62		16	62		16	33		9	
Males (N)	(241)			(241)			(241)			
Moderate/high	27		11	32		14	13		5	
Total (N)	(622)			(622)			(622)			
Moderate/high	89		14	94		15	46		7	

SE, Standard error; *SCL-90-R,* Symptoms Check List-Revised; *POPN,* .

*Patient norms (mean ± SE). Concerns only anxiety, depression, and somatization.

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

financial status over time accounted for 5% to 8% of the variation in psychosocial morbidity among PC-CHD over time.

Changes in social support between T1 and T2. Decreasing availability of support between T1 and T2 was associated with an increased risk of depression, anxiety, somatization, and hopelessness symptoms (Table VII). Social support accounted for 2% to 5% of the variation in psychosocial morbidity among PCCHD over time.

The variables in the model explained 16% to 30% of the variation in psychosocial morbidity over time among PCCHD (summing r-square changes in Tables VI and VII).

DISCUSSION

Psychosocial Morbidity over Time

The point prevalence of depression, anxiety, somatization, and hopelessness symptoms among PC-CHD was high both at T1 (14%-31%) and at T2 (15%-38%). The period prevalence of these symptoms (ie, long-standing psychosocial morbidity) was also relatively high (7%-22%). These findings indicate that psychosocial morbidity among PCCHD may be of chronic nature, at least for a significant proportion of them. Although conceptual adaptation models suggest that the stressors associated with parenting chronically ill children may be long-lasting or additive over time,[38] empirical evidence in

Table VI
Logistic regression demonstrating child/parental demographic and health predictors of psychosocial morbidity at T2: Controlling for dependent variable at T1, financial status, and social support

	Relative risk (odds ratio) and R-square changes (in brackets)			
Independent variables	Depression (T2)	Anxiety (T2)	Somatization (T2)	Hopelessness (T2)
Child domains				
Age*	.98	.98	.99	.99
Gender†				
Boys	.94	1.32	.88	.56
CHD severity*	1.10	1.07	1.04	1.10
Presence of other diseases (not CHD)†	1.38	1.40	1.33	1.33
Number of CHD diagnosis*	.84	1.18	1.08	.96
Number of operations*	.89	.94	.90	.91
Caregiving time (T1)	2.03‖	2.00‖	2.02‖	1.99
Satisfaction with care (T1)*	.72‖	.77‖	.83¶	.78‖
R-square change	(.04)	(.03)	(.03)	(.03)
Parent demographics				
Age*	1.06	1.02	.98	1.07‖
Female gender†	2.15‖	1.52	1.06	1.08
Foreign background†	1.40	2.97	1.33	1.03
Education†				
Primary	.42	.29	1.08	.74
Secondary	.42	.30	.98	1.02
University	1.10	.28	.68	1.25
Other‡				
R-square change	(.04)	(.03)	(.03)	(.03)
Sick-leave/unemployment				
Sick-leave days latest year† (T2)				
None	.25¶	.40‖	.27¶	.52
1–30 d	.52	.56	.22#	.61
>30 d‡				
Unemployment during career†(T2)				
None	.33‖	.50	.31‖	.87
<1 y	.87	.86	.86	.87
>= 1 y‡				
R-square change	(.10)	(.03)	(.07)	(.03)

CHD, Congenital heart disease.
§Between T1 and T2.
*Continuous variables.
†Category variables.
‡The comparison categories.
‖$P < .05$.
¶$P < .01$.
#$P < .001$.

Table VII
Logistic regression demonstrating social/financial determinants of psychosocial morbidity at T2 among parents of children with congenital heart disease: Controlling for dependent variable at T1, child health, and child/parental demographics

	Relative risk (odds ratio) and R-square changes (in brackets)			
Independent variables	**Depression (T2)**	**Anxiety (T2)**	**Somatization (T2)**	**Hopelessness (T2)**
Changes in financial status (T1, T2)				
Concerns about financial situation				
Concerned at T1 and T2	3.00‖	1.58	1.14	3.62‖
Decreasing concerns§	.39	1.32	.39	.85
Increasing concerns§	3.01‖	.93	4.95¶	1.76
Not concerned at T1 and T2‡				
Difficulties with living expenses†				
Difficulties at T1 and T2	1.54	1.77	3.18‖	3.59‖
Decreasing difficulties§	1.57	.76	1.27	1.08
Increasing difficulties§	3.72‖	.80	2.29	1.91
No difficulties at T1 and T2‡				
Difficulties in raising money†				
Difficulties at T1 and T2	.81	.97	1.21	2.11
Decreasing difficulties§	1.04	.83	.67	.77
Increasing difficulties§	1.45	1.30	1.35	.79
No difficulties at T1 and T2‡				
Financial burden of CHD* (T2-T1)	1.26‖	1.29‖	1.26‖	1.01
R-square change	(.07)	(.05)	(.08)	(.08)
Changes in social support* (T2-T1)	.86#	.92‖	.91¶	.90¶
R-square change	(.05)	(.02)	(.02)	(.03)

CHD, Congenital heart disease.
§Between T1 and T2.
*Continuous variables.
†Category variables.
‡The comparison categories.
‖$P < .05$.
¶$P < .01$.
#$P < .001$.

support of this hypothesis among PCCHD, to the best of our knowledge, has not been advanced. Overall, the relatively high proportion of PCCHD at risk of long-standing psychosocial morbidity motivates the need for psychosocial intervention. Therefore, data on determinants of prolonged psychosocial problems in this group are crucial in determining what form such interventions will take.

Determinants of psychosocial morbidity over time

Children's clinical severity did not significantly predict parent's psychosocial picture over time, which is in line with previous longitudinal data.[20] Several cross-sectional studies have assessed the role of children's illnesses and their severity on parent's concurrent psychosocial health, although

the findings have been contradictory.[15,18,39-41] However, the more recent results, irrespective of study design, seem to support the notion that the severity of children's illnesses may not impact significantly on psychosocial functioning among their parents,[15,18,39-41] contrasting with the relatively older studies suggesting that it may.[41] Discrepancies in the findings thus may be attributable to the time lag between the studies. Technologic advancement in medical care of CHD has radically improved survival statistics for many CHD diagnoses. During the past 2 decades, the proportion of children with CHD surviving to adulthood has increased tremendously from 15% to 85%, suggesting that the gap between severe and mild CHD is rapidly reducing. Thus, the discrepancy in findings regarding the association between children's clinical picture and parental psychosocial functioning may be reflecting improvements in medical care of CHD over time. Indeed, our data suggest that parental satisfaction with children's care was stably high on average during both measurement points.

It is important to distinguish between objective measures of clinical variables as assessed by clinicians (eg, survival statistics of given diagnosis, presence of a secondary diagnosis, number of operations) and subjective measures such as parents' own perceptions of their children's illness and its treatment. We found, for example, that the parents' perception of their ill child's hospital care (manifested in satisfaction with care) and their perceived burden of the caring load were significant determinants of psychosocial morbidity over time, whereas objective measures of clinical severity were not. Thus, research incorporating children's clinical measures/outcomes subjectively assessed by parents is warranted when investigating psychosocial morbidity among the parents. Supporting this argument, data suggest a discrepancy between parent's and clinician's assessment of children's health,[42,43] suggesting that results may differ depending on the assessor.

Consistently over time, mothers were more likely than fathers to report psychosocial symptoms. Moreover, the period prevalence of psychosocial symptoms was significantly higher among mothers (10%-27%) than fathers (3%-16%). A plausible explanation for these gender differences in psychosocial morbidity could be that women often are overrepresented in the lower brackets of the socioeconomic hierarchy,[44] and socioeconomic problems are well-documented determinants of mental illness.[45-48] Our data seem to support both these notions, because significantly more mothers than fathers were on sick-leave, unemployed, and reported prolonged economic difficulties, and these variables turned out to be more important predictors of psychosocial problems than gender per se in the multivariate analyses. Mothers tended to spend more of their extra time with their ill child than fathers consistently over time. Furthermore, although fathers' caregiving burden reduced significantly over time, mothers' burden did not change significantly. Excessive and prolonged caregiving burden among mothers, therefore, may lead to exhaustion and a limitation of distress protective activity such as socialization. Overall, differences in psychosocial morbidity between mothers and fathers may be attributable to underlying confounding between gender and socioeconomic status, as well as roles in caregiving.

The role of psychosocial resources in the resiliency process as modifiers of distress after illness in children has long been emphasized in parental adaptation models,[38,49,50] and the current study seems to provide empirical support for this theory. The regression analyses indicated that parents with a deteriorating financial situation or a pertained poor financial situation between T1 and T2 were at higher risk of psychosocial morbidity manifested in depression, anxiety, somatization, and hopelessness. Accordingly, parents with decreasing financial burdens reported a better psychosocial status (ie, fewer symptoms) over time. Similarly, improvement in the social network over time was associated with an improved psychosocial status among PCCHD. These findings imply that psychosocial support, tangible as well as emotional, is likely to modify psychosocial problems among PCCHD over time, independent of the children's clinical severity. Tangible support could include financial support. Data suggest that the cost of treatment and management of CHD is increasing, with a significant proportion being paid for directly by parents.[51,52] Therefore, interventions such as increasing subvention to the medical care of CHD and/or increasing the sick disability allowance may help in reducing the financial burden, thereby modifying psychosocial problems. Other forms of tangible support could include promoting home care nursing. This may not only reduce the excessive home-care burden of CHD children, a significant determinant of long-standing psychosocial morbidity in our study, but also provide an opportunity for parents, particularly mothers, to unwind or engage in other therapeutic activities such as socialization and exercise. In regard to emotional support, interventions such as cognitive restructuring[53] may be important in changing par-

ent's negative appraisals of the future, thereby modifying hopelessness feelings over time. In addition, cognitive behavioral group therapy,[54] with the aim of promoting skills for coping with specific problems, may be beneficial. Group therapy may also introduce a sense of belongingness and thereby strengthen the social network. Finally, psycho-education,[22] which involves among other things teaching parents about their children's illnesses and expected outcome, may help reduce illness-related concerns, thereby decreasing dissatisfaction with children's care, a significant determinant of psychosocial morbidity in this study.

In summary, the current longitudinal study shows that a rather substantial proportion of PCCHD are at risk of long-standing psychosocial morbidity. The study also indicates that mothers more than fathers are at increased risk of chronic psychosocial problems. Finally, the study indicates that variables such as caregiving burden, satisfaction with children's care, financial instability, and social support contribute more in explaining long-standing psychosocial morbidity than children's clinical severity per se. Implications for interventions are discussed, and feasible interventions are suggested.

METHODOLOGIC AND OTHER LIMITATIONS

The strength of the current study lies in its large sample size covering all CHD diagnoses. In addition, the longitudinal design makes it possible to draw causal inference about determinants of PCCHD psychosocial problems over time. These factors notwithstanding, the prospective design could to some degree undermine the validity of the longitudinal study considering that parents of children at varying stages after diagnosis, treatment, and so forth were assessed together. Thus, the time frame in these regards was not uniform. However, considering that most CHD diagnoses are made and treatment is initiated during the first year of birth, the children's age could act as a good proxy for time since diagnosis and duration since initiation of treatment. Because we controlled for children's age in the regression analyses, some grade of validity may have been restored in this regard.

Second, all parents were members of the Swedish Heart Child Association, which is a voluntary membership organization. It is not clear whether voluntary membership will be random or subject to a selection bias because we do not know which parents choose not to join the association. Thus, whether the sample is representative of all PCCHD is difficult to know. However, because the proportions of different CHD diagnoses in our sample are equivalent to those observed in a CHD population, representation with regard to children's CHD can be assumed.

Third, it is important to caution that the instruments assessing psychosocial morbidity (ie, SCL-90-R and Hopelessness Scale) are symptom scales and cannot therefore be used to reflect psychiatric diagnoses, despite the fact that normative comparisons with psychiatric patients exist for these tools. The clinical severity of PCCHD psychosocial problems, therefore, cannot be firmly ascertained in the current study. Complementary inquiries in the survey (eg, whether parents where receiving treatment for psychiatric problems) would have been beneficial to determine the clinical severity of PCCHD psychosocial status.

Fourth, although we attempted to understand demographic, health, and socioeconomic determinants of psychosocial morbidity over time, not all important demographic and familial variables were included in the questionnaire. For example, the number of other children in the family (ill or healthy), birth position of the ill child, and so forth may act as additive stressors increasing vulnerability to psychosocial problems. In addition, personality variables (eg, parental temperament) are likely to affect psychosocial outcome negatively. Future research should incorporate such variables when assessing determinants.

Fifth, the current study used only objective clinical measures when assessing children's clinical severity. Although we included parent's perception of their children's medical care and perceived burden of care in our analyses, future research incorporating parent's appraisals of the illness itself will be paramount in distinguishing the role of illness severity as assessed by different actors (ie, parents vs clinicians) in determining long-standing psychosocial morbidity among PCCHD.

Sixth, the study included children of various ages, with CHD diagnoses of varying severity and perhaps varying care needs. One can therefore question whether the results would vary for parents of children more homogenous in age, diagnosis care needs, and so forth. Research using a stratified analysis is being planned by the authors.

Finally, the applicability of our findings should be limited to societies with comparable financial and health care systems as Sweden. In Sweden, pediatric care is still largely publicly financed. In addition, recent studies among PCCHD in Sweden (indigenous Swedes and ethnic minorities) indicate

a high grade of parental satisfaction with the care of CHD,[24] a factor found in the current study to impact significantly on psychosocial morbidity. Thus, caution should be taken in generalizing our findings to societies with dissimilar financial and health care systems and/or societies characterized by inequalities in access to pediatric care depending on, for example, ethnic affiliation.

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