ORIGINAL ARTICLE

Satisfaction with care: a study of parents of children with congenital heart disease and parents of children with other diseases

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Satisfaction with care: a study of parents of children with congenital heart disease and parents of children with other diseases

Aim: We compared parents of children with congenital heart disease (PCCHD, n = 1092) with parents of children with other diseases (PCOD, n = 112) regarding satisfaction with their children's care (SCC). We also examined the association between parental/patient characteristics and SCC.
Method: The parents completed a questionnaire about such areas as satisfaction with care, children's health status, and financial situation. The design was cross-sectional and data were gathered over 20 consecutive days.
Results: The univariate and multivariate analyses showed that PCCHD were more satisfied with their children's medical care and waiting period for treatment of their ill children than PCOD, although the difference was only modest. Furthermore, mothers were less satisfied with staff attitudes than fathers, with the lowest satisfaction among mothers of children with CHD. However, the multivariate analysis indicated that less satisfaction with care was more associated with decreasing child age, unemployment, financial burden of disease, social isolation and psychological distress than with children's diseases, their severity and parental gender.
Conclusion: We corroborated some previous findings and may have provided new insights regarding determinants of SCC among parents. Interventions to improve SCC may need to address issues of parental psychological distress, socialization, and financial burden of illness. Possible ways of achieving this are discussed. Finally, research in a longitudinal format is needed to further scrutinize determinants of parental SCC.

Keywords: congenital heart disease, satisfaction with care, parents, psychological distress, social support, financial status.

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Introduction

The prevalence of congenital heart disease (CHD) is estimated at 6–10 children per 1000 born alive (1–3) and diagnoses vary in severity from minor defects to complex ones with fatal outcome (4). Improvements in the management of CHD during the past years have enabled children to survive longer and with better quality of life (3, 5).

Being the parent of a child with CHD has been frequently associated with problems such as sadness, anxiety and anger (6–11). Parents also often worry about obtaining effective treatment for their afflicted children. Although advances in medical services with improved survival rates and quality of life among children with CHD appease parental concerns, other factors such as participation in decision-making about treatment may be important for decreasing parents' apprehensions and for parents' satisfaction with their children's care.

Traditionally, decisions about patient treatment and rehabilitation have been largely confined to healthcare personnel (12). It is only recently that decision-making has gradually moved towards greater consumer autonomy (13–16), despite a consensus that parents of patients and the patients themselves may feel less anxious, and more satisfied and receptive to medical recommendations when there is an understanding between parents/patients and healthcare providers (17–19).

Data on paediatric care indicate that parents want to be involved in their children's treatment and rehabilitation. Studies have suggested that parents highly value such things as information about the illness, participation in treatment, continuity of care and good communication with healthcare personnel (20–28). In addition, parents are

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very concerned about the competence of the carer and staff seniority (23, 29–31).

Cross-cultural/ethnic studies about parental perceptions of their children's healthcare have also provided interesting findings. Shields and King (27) found that parents in developed countries did not differ in their care needs from their counterparts in developing countries. In both developed and developing countries, primary areas of parental concerns were communication with staff and treatment *per se*. Weech-Maldonado et al. (32) found in a study of parental perceptions of paediatric care among White Americans, African Americans, American Indians, Asians and Hispanics, that parents belonging to ethnic minorities were less satisfied with paediatric care than whites, and this was largely due to language barriers. The authors concluded that linguistically appropriate healthcare services are needed to address treatment concerns.

Studies concerning the role of children's illness severity in parental satisfaction with paediatric care have provided conflicting information. Whereas some authors suggest that severity of illness in children may negatively affect parental satisfaction with children's care (SCC) (33, 34), others suggest that this may not be the case (35, 36).

Although parents are gaining more acceptance in the hospital environment, discrepancies still exist about their role in paediatric care. Dardyshire (37) found that parents were not comfortable about participating in care. It was concluded that this discomfort was, among other things, the result of parents feeling judged by staff. Other authors (38, 39) reported that discrepancies existed between what parents thought they could accomplish and what paediatric staff thought parents were capable of.

Many studies in the field have highlighted areas (for example, communication with care personnel) that parents consider important in paediatric care (e.g. 20–31), but few have addressed the question of whether parents are satisfied with the mentioned areas. There is also a shortage of studies about satisfaction with care among parents of children with CHD (PCCHD), and comparisons between PCCHD and parents of children with other illnesses (PCOD). Furthermore, data concerning the influence of such factors as the children's diagnoses and illness severity on parents' SCC are conflicting, implying that further scrutiny may be useful. Moreover, little attention has been paid to predictors of SCC. Controlling for such factors as, for example, parental financial situation, may help to better understand the actual contribution of children's diagnoses and their severity on parental SCC. In addition, there is a shortage of studies examining the effects of, for instance, parents' financial situation and social support on SCC. Such data may be useful for the development of care provision in line with parents' desires and capabilities.

More specifically, we examined differences between PCCHD and PCOD on SCC, and compared mothers with fathers in this respect. The role of severity of CHD for SCC was also assessed. We also identified and quantified some predictors of SCC among all parents and PCCHD.

Methods

Subjects

Parent's inclusion criteria were: (i) members of the Swedish Heart Child Foundation (SHCF)[1]; (ii) had 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 who met the inclusion criteria, 1092 participated in the study (response rate of 72.8%) and 704 were couples. Responders and non-responders did not differ concerning demographics. Data on the non-responders children's situation were not available (e.g. type of CHD).

A group consisting of 600 parents (random sample of households with children from the general population), served as a comparison condition. Of the 600 parents approached, 405 participated in the study (67.5%). Inclusion criteria were the same as above, with the exception of CHD and SHCF membership. These parents were required to state whether their children were ill and what kind of illness they suffered from. Based on this information, these parents were subsequently divided into two groups, i.e. parents of children with other diseases (PCOD, $n = 112$) and parents of healthy children (PHC, $n = 293$). Of the 112 PCOD and 293 PHC parents, 72 and 208, respectively, were couples. Participants and non-participants did not differ concerning demographics. Information on the non-responders' children's situation were not available (e.g. health). For the purpose of this study, only PCCHD and PCOD were used to evaluate parents' SCC. Thus, the total sample for the current study consisted of 1204 parents.

As shown in Table 1, PCCHD and PCOD provided information on 691 children with CHD and 74 children with other diseases concerning such areas as gender and children's diagnosis. Children with CHD were significantly younger ($t(763) = 4.2$ $p < 0.001$) than children with other diseases. Data on the children's 'time since diagnosis', 'number of hospitalizations' and 'severity of diseases'

[1]The SHCF is a voluntary association built and lead by parents of CHD children. It has various activities such as providing support for parents and children. It has 6000 members and is represented in all regions in Sweden. About 800 children are born annually in Sweden with CHD and many of their parents join the SCHF. However, not all parents are members, and the exact number is unknown. Further information is available at http://www.hjartebarn.org

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

	All children		*CCHD*		*COD*	
Characteristics	*n = 765*	*%*	*n = 691*	*%*	*n = 74*	*%*
Age (years)						
Mean ± SE	8 ± 0.2		7 ± 0.2		11 ± 0.5	
Gender						
Female	331	43	300	43	31	42
Male	434	57	391	57	43	58
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]Pda, patent ductus arteriosus.
[c]C. aorta, coartation of aorta.
[d]Asd, atrial septal defect.
[e]Vsd, ventricular septal defect.
[f]Tof, tetralogy of Fallot.
[g]Pvs, pulmonary valve stenosis.
[h]Avs, aortic valve stenosis.
[i]Transposition of great arteries.
[j]e.g. Complete Av canal.
[k]Concerns only COD (e.g. liver dysfunction).
[l]Concerns only CCHD.
[m]Concerns only CCHD (e.g. Down's syndrome).

(i.e. not CHD) were insufficient to allow a meaningful analysis of these variables. The prevalence of different CHD diagnoses in our data is similar to that observed in the CHD population (3, 4). We may assume therefore that our data are representative of CHD children and thus, their parents.

Measures

Parents completed a questionnaire including various previously validated scales (e.g. SCC). The current questionnaire has not yet been validated. In the univariate analyses, the focus was on the parent's SCC. In the multivariate analyses, the focus was on SCC as the dependent variable and parental demographics, financial situation, global severity index (GSI), hopelessness, social support and children's demographics and health (e.g. severity of the CHD) and care-giving time (i.e. extra time devoted to children's care) as the independent variables.

SCC was measured with questions from the Swedish versions of the Pyramid Patient Questionnaire (PPQ), (40)

and the Client Satisfaction Questionnaire (41). We used 15 relevant questions from the PPQ and all the eight questions from the CSQ-8, which were modified to address parental SCC. Thus, 23 questions were used (e.g. satisfaction with children's medical care). Items ranged from 1 to 4 [strongly disagree (low satisfaction) to strongly agree (high satisfaction)]. High scores correspond to high satisfaction with children's care both on total and sub-scales. A factor analysis (varimax rotation) resulted in four distinct factors representing satisfaction with medical care (e.g. 'I am satisfied with the medical care my child receives/received'), adequacy of information (e.g. 'I am satisfied with the information I receive/received regarding my child's treatment and rehabilitation'), waiting time (e.g. 'I am satisfied with the waiting period before my child received treatment') and staff attitudes/support (e.g. 'I am/was treated with respect by care personnel'). Factor loadings ranged between 0.52 and 0.84. Cronbach α testing for internal consistency ranged between 0.86 and 0.93, indicating good reliability.

Distress was assessed with the Swedish version of *The Symptom Check List-Revised* (SCL-90-R) (42) consisting of 90 items divided into nine symptom dimensions. In this study, we used the depression (13 items, e.g. thoughts of suicide), anxiety (10 items, e.g. fear) and somatization (12 items, e.g. gastrointestinal complaints) dimensions. The items range from 1 to 5 (from 'not at all' to 'very much'). A GSI was also calculated (the average of individual scores for depression, anxiety and somatization). High score correspond to high levels of psychopathology. Cronbach αs for the PCCHD and PCOD groups were 0.93 and 0.84, respectively.

Parents' negative expectancies about the future were assessed with the Swedish version of *The Hopelessness Scale* (43) consisting of 20 items about one's future arranged in true/false format. Scores can be transformed into norms indicating levels of experienced hopelessness (0–3 = none/minimal; 4–8 = low; 9–14 = moderate; and 15– = high). High scores correspond to high hopelessness levels (i.e. suicide ideation/risk). Cronbach αs for the PCCHD and PCOD groups were 0.82 and 0.77, respectively.

Social support was assessed with the Swedish version of *The Schedule for Social Interaction* (44) consisting of 12 items. Six items involve social attachment in terms of availability of deep emotional relationships (e.g. having someone with whom to share deep feelings). The other six entail social integration in terms of availability of peripheral social networks (e.g. contact with persons who have similar interest as oneself). Items range from 1 to 6 (from 'not available' to 'available'). High scores correspond to high social support both total and component by component. Cronbach αs for the PCCHD and PCOD groups were 0.72 and 0.71, respectively.

We also assessed parental demographics, care-giving time (time spent in caring for ill child) and child demographic/health variables (e.g. CHD severity). Finally, we examined parental financial situation with three questions in 'yes/no' format: (i) parents' concerns about their financial situation; (ii) parents' difficulties in raising a reasonable sum of money in a specific period; and (iii) parents' difficulties with their living expenses (e.g. food expenses).

Design and procedure

The study design was cross-sectional and parental data were collected for all groups during 20 consecutive days with two reminders being sent. Data on the PCCHD were gathered with the help of the SHCF. The PCOD sample was randomly selected from the general population. Each individual parent was sent a letter informing her/him about all aspects of the study and the questionnaire, and was asked to return the completed questionnaire by post. All parent groups participated on a voluntary basis. Confidentiality was guaranteed. The regional ethical committee in Stockholm approved the study.

Statistical analysis

Parental differences in demographics/financial situation were examined with the chi square test. Factor analysis was used to group related items of SCC under a single factor. Reliability was confirmed using Cronbach alpha. Differences between PCCHD and PCOD regarding SCC were examined with t-tests. Pearson's correlation analyses were used to examine associations between SCC and parental social support, distress and hopelessness. Finally, multivariate block-wise linear regression analyses were used to identify and quantify predictors of SCC among parents, while controlling for other possible confounders (e.g. distress). Candidate confounders were entered in the model block by block and the contribution of each block in explaining the dependent variable was expressed in R^2 changes. Associations between confounders and SCC were expressed in standardized betas. Two regressions were performed with the rationale of assessing the contribution of variables (e.g. distress) in explaining variations in SCC separately for all parents and PCCHD.

As many parents were dyads, their satisfaction with care scores may be correlated. This would lead to violation of one of the fundamental assumptions for application of a regression analysis, i.e. independence between observations. We therefore performed Pearson's correlation to assess dependence. As shown by the correlations [PCCHD, $r = 0.25$ ($p < 0.01$); PCOD, $r = 0.26$ (NS)] there was some grade of dependence among PCCHD dyads concerning SCC. To adjust for this, only one of each dyad (half mothers/fathers) and non-dyads were included in the regressions. As shown by the DFs and Ns, single data were

lost for a number of variables. Statistical significance was assumed at $p < 0.05$.

Results

Demographic characteristics of participants

As shown in Table 2, PCCHD were significantly younger than PCOD [$t(1202) = 2.6$, $p < 0.01$). Only 8% were of foreign origin, with an under-representation among PCCHD (6%) compared to PCOD (18%) [χ^2 (1) = 20.4, $p < 0.001$). Mothers of CHD children devoted 2 hours extra time to caring activities for their sick children in contrast to 0.5 hours for fathers [$t(1079) = 3.21$, $p < 0.01$).

SCC (total and sub-scales) among parental groups

As shown in Table 3, PCCHD scored higher than PCOD concerning children's medical care [$t(1162) = 2.44$, $p < 0.05$) and waiting period ($t(1160) = 2.55$, $p < 0.05$), indicating that PCCHD were more satisfied than PCOD. Mothers reported lower satisfaction with staff attitudes than fathers ($t(1157) = 2.39$, $p < 0.05$) when all parents were studied. Similarly, mothers of CHD reported lower satisfaction than fathers of CHD regarding staff attitudes ($t(1078) = 2.5$, $p < 0.05$). There were no significant differences between PCCHD and PCOD concerning total SCC.

SCC (total and sub-scales) in relation to parental psychological distress, hopelessness and social support

SCC (total and sub-scales) correlated negatively with GSI, depression, anxiety, somatization, hopelessness and social attachment and positively with social integration. Correlations were significant at $p < 0.01$ with the negative ranging from −0.08 to −0.24 and positive ranging from 0.12 to 0.19. That is with increasing distress, experiences of hopelessness and social isolation, SCC decreased. With increasing availability of social interaction on the other hand, SCC decreased.

Determinants of satisfaction with children's care

All parents. As shown in Table 4, children's illnesses were independently associated with parents' SCC. PCOD were on average less satisfied with their children's medical care and waiting periods than PCCHD. Child variables explained 1% of the variation in SCC.

Parental age independently predicted satisfaction with medical care, i.e. with increasing age, satisfaction with medical care augmented. Parental demographic variables explained 1–2% of the variation in SCC.

Employment status independently predicted SCC among all parents. Compared to unemployed parents, employed parents reported more satisfaction with medical care, staff attitudes and total SCC. In addition, pensioned parents compared with the unemployed reported greater satisfaction with all SCC domains apart from information. Parents with a recent unemployment history tended to report lower satisfaction with all care domains than those without a recent unemployment history. Employment status explained 2–3% of the variation in SCC.

Financial variables did not independently explain variations in SCC among parents. Financial variables explained 1% of the variation in SCC.

Parents with elevated distress (i.e. GSI) were more likely to report lower satisfaction with care. Distress and hopelessness accounted for 1–3% of the variation in SCC.

Parents with high availability of social integration reported greater satisfaction with medical care, staff attitude and total SCC than those with low availability of social integration. Social support variables explained 1–2% of the variation in SCC.

Overall, children and parental characteristics explained 6–12% of the variation in SCC among all parents.

PCCHD. As shown in Table 5, satisfaction with care (all domains) augmented with increasing age of the target child. In addition, the number of CHD diagnosis per child significantly explained variations in satisfaction with staff attitudes among parents, i.e. satisfaction with staff attitudes diminished with increasing number of CHD diagnoses. Child health and demographic characteristics explained 1–5% of the variation in SCC.

Parental demographics did not independently account for discrepancies in SCC. Parental demographics explained 1% of the variation in SCC.

Employed parents were more likely to report satisfaction with all care domains apart from waiting periods than unemployed parents. Furthermore, pensioned parents were more prone to report satisfaction with staff attitudes, waiting periods and total SCC than unemployed parents. In addition, parents with a recent unemployment history were more likely to report lower satisfaction with all care domains, apart from waiting periods, than parents without a recent unemployment history. Employment variables explained 2–4% of the variation in SCC.

The financial burden of CHD independently accounted for variations in SCC (all domains), i.e. with increasing financial burden, satisfaction with care diminished. Financial variables explained 2–5% of the variation in SCC.

Parents with elevated levels of distress were more likely to report lower SCC. Distress and hopelessness explained 1–2% of the variation in SCC.

Parents with high availability of social integration reported higher SCC than those with low availability of social integration. Social support variables explained 1% of the variation in SCC.

Table 2 Demographic/financial characteristics of all parents, parents of children with CHD (PCCHD) and parents of children with other diseases (PCOD)

	All parents		*PCCHD*		*PCOD*	
Characteristics	*n = 1204*	*%*	*n = 1092*	*%*	*n = 112*	*%*
Age (years)						
Mean ± SD	39 ± 7		39 ± 7		41 ± 8	
Gender (N)	(1201)		(1091)		(110)	
Male	468	39	424	39	44	40
Female	733	61	667	61	66	60
Marital status (N)	(1200)		(1090)		(110)	
Single	49	4	44	4	5	4
Married/cohabitant	1097	91	1000	92	97	88
Divorced	49	4	42	3	7	6
Widow/widower	5	1	4	1	1	1
Educational level (N)	(1201)		(1091)		(110)	
Mandatory	133	11	124	11	9	8
Secondary school	551	46	506	46	45	41
University	454	38	406	37	48	44
Other	63	5	55	6	8	7
Foreign-background (N)	(1183)		(1075)		(108)	
Yes	83	7	64	6	19	18
No	1100	93	1011	94	89	82
Occupational status (N)	(1158)		(1049)		(109)	
Blue-collar	449	39	399	38	49	45
White-collar	632	54	575	55	57	53
Own business	48	4	48	5	0	0
Other	29	3	27	2	2	2
Current employment status (N)	(1204)		(1092)		(112)	
Employed	1003	83	913	83	90	81
Employed	34	2	22	2	5	4
Unemployed	43	3	32	3	4	4
Sick-leave	27	2	25	2	2	4
Pension	133	9	100	10	11	9
Other						
Worried about finances (N)	(1201)		(1089)		(112)	
Yes	444	37	400	37	44	42
No	757	63	689	63	68	58
Difficulties with living expenses (N)	(1203)		(1092)		(111)	
Yes	328	27	294	27	34	31
No	875	73	798	73	77	69
Difficulties in raising money (N)	(1200)		(1090)		(110)	
Yes	203	17	177	16	26	25
No	997	83	913	84	84	75
Sick-leave days[a] (N)	(1190)		(1080)		(110)	
Yes	599	50	545	51	54	49
No	591	50	535	49	56	51
Unemployment[a] (N)	(1180)		(1069)		(111)	
Yes	311	26	272	25	39	35
No	869	74	797	75	72	65

[a]Twelve months prior to the investigation.

Overall, parental and children characteristics explained 9–17% of the variation in SCC among PCCHD.

Discussion

The univariate analyses showed that PCCHD were more satisfied with their children's medical care and waiting period than PCOD. This was confirmed in the regression analyses in which children's diagnoses (CHD vs. other diseases) were shown to predict parents' SCC, but only marginally (1%). Disease severity among children with CHD, on the other hand, was not associated with parental SCC. Our findings are at odds with studies indicating an association between children's disease severity and

Table 3 Means and SE: satisfaction with children's care (SCC) among all parents, PCCHD and PCOD

Variables	*All parents, n = 1204*	*PCCHD, n = 1092*	*PCOD, n = 112*
Medical care (1–4)			
Male (N)	(453)	(422)	(31)
Mean ± SE	3.51 ± 0.03	3.52 ± 0.03	3.29 ± 0.13
Female (N)	(708)	(660)	(48)
Mean ± SE	3.49 ± 0.02	3.50 ± 0.02	3.28 ± 0.11
Total (N)	(1164)	(1083)	(81)
Mean ± SE	3.50 ± 0.02	3.51 ± 0.02	3.34 ± 0.08
Staff attitudes (1–4)			
Male (N)	(452)	(421)	(31)
Mean ± SE	3.22 ± 0.03	3.22 ± 0.03	3.25 ± 0.13
Female (N)	(707)	(659)	(48)
Mean ± SE	3.12 ± 0.03	3.11 ± 0.03	3.24 ± 0.11
Total (N)	(1162)	(1081)	(81)
Mean ± SE	3.16 ± 0.02	3.15 ± 0.02	3.24 ± 0.08
Waiting periods (1–4)			
Male (N)	(452)	(422)	(30)
Mean ± SE	3.33 ± 0.03	3.35 ± 0.03	3.11 ± 0.16
Female (N)	(707)	(659)	(48)
Mean ± SE	3.30 ± 0.03	3.31 ± 0.03	3.14 ± 0.11
Total (N)	(1162)	(1082)	(80)
Mean ± SE	3.31 ± 0.02	3.33 ± 0.02	3.12 ± 0.09
Information (1–4)			
Male (N)	(453)	(422)	(31)
Mean ± SE	3.27 ± 0.03	3.27 ± 0.03	3.22 ± 0.14
Female (N)	(708)	(660)	(48)
Mean ± SE	3.22 ± 0.03	3.22 ± 0.03	3.38 ± 0.11
Total (N)	(1164)	(1083)	(81)
Mean ± SE	3.24 ± 0.02	3.23 ± 0.02	3.31 ± 0.09
Total SCC (1–4)			
Male (N)	(453)	(422)	(31)
Mean ± SE	3.34 ± 0.03	3.35 ± 0.03	3.23 ± 0.12
Female (N)	(708)	(660)	(48)
Mean ± SE	3.29 ± 0.02	3.29 ± 0.02	3.25 ± 0.10
Total (N)	(1164)	(1083)	(81)
Mean ± SE	3.31 ± 0.02	3.31 ± 0.02	3.25 ± 0.08

parental SCC (33, 34) and in line with data showing no such association (35, 36). Compared with 10–15 years ago, survival rates of children with CHD have increased substantially and their quality of life has improved significantly (e.g. 35, 36), and this may appease parental concerns. It is therefore plausible that disease severity may not impact significantly on parental SCC. All in all, the differences in SCC between PCCHD and PCOD seem not to be related to children's diseases and their severity.

With increasing age among CHD children and their parents, SCC augmented. As suggested previously, developments in the treatment and management of CHD have resulted in children surviving longer with better quality of life. The initial crises that parents face during the first years after diagnosis (e.g. sadness, anxiety and anger) may fade with time as the children's situation improves and results in elevated parental SCC. In addition, as children grow older and their quality of life improves, they may require less help and this may augment parental SCC. It is also plausible that as their children advance in age, parents develop better coping strategies to manage distress and anxiety, which in the current and previous studies (e.g. 45) have been found to associate negatively with SCC. However, as we did not address coping in this study, we are unable to develop this argument further. Finally, one could argue that during the early years after diagnosis, parents may be less knowledgeable about clinical procedures of a complex nature (e.g. heart operations) and therefore less receptive to such medical recommendations for their children. Their judgement of care may thus be negatively affected initially. With increasing knowledge, however, they may be more willing to approve of care procedures. Together, this may explain the positive correlation between increasing age and SCC. However, child age explained only marginally the variation in SCC among PCCHD, which is consistent with findings suggesting that SCC may not be determined by child age and time since diagnosis (e.g. 36).

The univariate analysis showed that mothers of sick children tended to report lower satisfaction with staff attitudes than fathers. However, differences could not be confirmed in a multivariate analysis, which is consistent with data suggesting that parental SCC may not be determined by gender (e.g. 36). In addition, the multivariate analysis showed no difference in SCC between ethnic minorities and native Swedes. This is in line with some studies (e.g. 46) but at odds with others (e.g. 32). These contradictory findings could be a result of differences in methodology and instrumentation. Another explanation could be that SCC may differ depending on the societal context in which participants live. Implementation of medical policies and access to care may differ between countries. According to the Swedish Health and Medical Services Act 1982, the goals of healthcare are good health and the provision of healthcare for the entire population (47). Therefore, factors like gender and ethnicity should not affect the provision of, and satisfaction with, care. Thus, our findings may be a reflection of the success of this programme, at least within paediatric care.

The multivariate analysis revealed that SCC diminished with increasing financial burden of CHD. Furthermore, the analyses indicated that socioeconomic stressors (e.g. unemployment) among all parents, and in particular PCCHD, were associated with lower SCC. Recent developments in the management of CHD have significantly improved survival rates for many CHD diagnoses (e.g. 3). Nevertheless, these developments have lead to life-long follow-ups for a substantial proportion of patients, resulting in increased cost both for parents and society. Indeed, studies suggest that expenditures for CHD treatment and

Table 4 Block-wise multivariate linear regression: predictors of satisfaction with care among all parents (standardized betas and R^2 changes in brackets)

Independent variables	*Medical care*	*Staff attitudes*	*Waiting periods*	*Information*	*Total SCC*
Child variables					
Age[a]	−0.01	−0.01	−0.02	−0.02	−0.02
Child health[b]					
Other disease (not CHD)	−0.09**	−0.06	−0.08**	−0.02	−0.01
CHD[c]					
Gender[b]					
Male	0.05	0.05	0.02	0.04	0.06
Female[c]					
R^2 change	(0.01)	(0.01)	(0.01)	(0.01)	(0.01)
Parental demographics					
Age[a]	0.10**	0.06	0.04	0.03	0.05
Gender[b]					
Male	0.02	0.01	0.02	0.03	0.01
Female[c]					
Foreign Background[b]					
Yes	−0.04	−0.01	−0.006	−0.02	−0.03
No[c]					
Marital status[b]					
Single	−0.08	−0.17	−0.04	−0.11	−0.11
Divorced	−0.12	−0.21	−0.05	−0.16	−0.15
Married/cohabitant	−0.15	−0.25	−0.05	−0.17	−0.17
Widow/widower[c]					
Education[b]					
Mandatory	0.08	0.02	0.04	0.05	0.03
Secondary	0.03	0.06	0.08	0.06	0.04
University	0.05	0.07	0.08	0.04	0.03
Other[c]					
R^2 change	(0.02)	(0.02)	(0.01)	(0.02)	(0.01)
Employment status					
Current employment[b]					
Employed	0.18*	0.21**	0.09	0.11	0.19**
Sick-leave	−0.06	−0.07	−0.004	−0.03	−0.07
Own business	−0.01	−0.01	−0.02	−0.02	−0.02
Pension	0.10*	0.11*	0.11**	0.03	0.12*
Other	−0.08	−0.10	−0.03	−0.04	−0.11
Unemployed[c]					
Unemployment prior to investigation[b]					
Yes	−0.12***	−0.09**	−0.07*	−0.10**	−0.11***
No[c]					
Sick-leave prior to investigation[b]					
Yes	−0.06	−0.07	−0.04	−0.02	−0.04
No[c]					
R^2 change	(0.02)	(0.03)	(0.02)	(0.02)	(0.03)
Financial situation					
Concerns about finances[b]					
Yes	−0.03	−0.03	−0.06	−0.04	−0.05
No[c]					
Difficulties with living expenses[b]					
Yes	−0.05	−0.01	−0.01	−0.04	−0.01
No[c]					
Difficulties raising money [b]					
Yes	−0.005	−0.006	−0.02	−0.01	−0.001
No[c]					
R^2 change	(0.01)	(0.01)	(0.01)	(0.01)	(0.01)

Table 4 Continued

Independent variables	*Medical care*	*Staff attitudes*	*Waiting periods*	*Information*	*Total SCC*
Distress symptoms and Hopelessness					
GSI[a]	−0.16***	−0.17***	−0.10*	−0.20***	−0.17***
Hopelessness[a]	0.03	0.01	0.01	0.01	0.03
R^2 change	(0.03)	(0.03)	(0.01)	(0.03)	(0.03)
Social support					
Social integration[a]	0.08*	0.12***	0.05	0.05	0.10**
Social attachment[a]	−0.02	−0.04	−0.03	−0.04	−0.03
R^2 change	(0.01)	(0.02)	(0.01)	(0.01)	(0.01)
Total R^2	(0.10)	(0.12)	(0.06)	(0.10)	(0.10)

[a]Continuous variables.
[b]Category variables.
[c]Comparison category.
*p < 0.05; **p < 0.01; ***p < 0.001.

management may be high (e.g. 48) and may exceed those observed for the general population, with a large portion being paid for directly by the parents (49). Unemployed/financially burdened parents may thus be particularly bothered with medical, rehabilitation and other costs for their children, and this may negatively affect SCC.

Our analyses indicate that with increasing psychological distress among parents, SCC diminished, which is consistent with some findings in the field (e.g. 45, 50, 51). Parenting severely ill children may lead to distress and hopelessness (e.g. 52, 53). Distress among parents, and in particular PCCHD, may be a result of, among other things, limited understanding for, and participation in, major decisions about treatments of a complex nature (e.g. heart operations) for their children. Many studies have suggested that parents highly value involvement in their children's care (e.g. 20–28), suggesting that limited involvement may lead to negative effects (e.g. distress). In addition, the financial burden of children's diseases has been suggested to be a source of distress among PCCHD (e.g. 52) and this may negatively affect SCC, as indicated by our study. Together, these arguments may explain the association between distress and lower SCC.

Our analyses suggest that with increasing social integration problems, parental SCC decreased. This may be an indication that parents with social integration difficulties at societal level may also have difficulties in their involvement and communication with care staff, which in turn may affect their SCC. It has been extensively documented that parents highly value involvement and communication with care personnel (20–28). If this is disrupted, satisfaction with staff may be negatively affected. Limited communication between parents and personnel may also contribute to misconceptions about medical care and rehabilitation, affecting parental satisfaction negatively in this regard. This may explain the association between social isolation and less SCC.

Our study may have some implications for interventions to improve parental SCC. In addition to improving children's health situation, interventions may also need to address issues concerning parental distress, financial status and social integration. For example, incorporating adaptive coping measures to manage parental distress, a determinant of SCC, may be useful. This could be accomplished through psycho-education. Indeed, a recent study (45) suggested that educating parents about their children's treatment and expected outcome reduced parental anxiety and consequently SCC. Interventions may also need to be sensitive to socialization issues in order to appease parental concerns about their children's care. For example, providing an opportunity for parents with the same problems (i.e. children's illness) to socialize may help as a buffer against, among other things, distress. Involving parents in their children's care may also ease tension between parents and personnel leading to improved social relations between them, thereby elevating SCC. At the macro level, heavily subsidising paediatric healthcare, especially for CHD, may ease the financial burden of disease and hence elevate parental SCC. Finally, to pave the way for these interventions, increased collaboration and consultation (e.g. exchange of information about parents' situation) between, for example, social workers, parent associations and paediatric care personnel may be necessary. This would enable an effective recognition of parents with problems (e.g. distress and social isolation) so that adequate assistance can be provided at an early stage.

Though the present study confirms some data in the field and may provide new insights, its weaknesses nonetheless need to be acknowledged. First, causality is difficult to ascertain with a cross-sectional design. For example, distress may be a consequence of, rather than a risk factor for, dissatisfaction with children's care. It would require another type of design (e.g. repeated measures) to firmly

Table 5 Block-wise multivariate linear regression: predictors of satisfaction with care among PCCHD (standardised Betas and R-square changes in brackets)

Independent variables	*Medical care*	*Staff attitudes*	*Waiting periods*	*Information*	*Total SCC*
Child variables					
Age[a]	0.11**	0.12**	0.11**	0.12**	0.13**
Gender[b]					
Male	0.02	0.02	0.02	0.01	0.04
Female[c]					
CHD severity[a]	0.06	0.04	0.03	0.05	0.01
Other diseases (not CHD)[b]					
No	−0.05	−0.06	−0.03	−0.02	−0.04
Yes[c]					
Number of CHD diagnosis[a]	−0.04	−0.08*	−0.01	−0.04	−0.07
Number of operations[a]	−0.04	−0.04	−0.03	−0.05	−0.02
Caregiving time	−0.01	−0.02	−0.02	−0.05	−0.04
R^2 change	(0.04)	(0.05)	(0.01)	(0.03)	(0.04)
Parental demographics					
Age[a]	0.01	0.02	0.05	0.01	0.05
Gender[b]					
Male	0.05	0.04	0.04	0.01	0.01
Female[c]					
Foreign Background b[b]					
Yes	−0.02	−0.05	−0.01	−0.03	−0.03
No[c]					
Marital status[b]					
Single	−0.12	−0.14	−0.16	−0.09	−0.11
Divorced	−0.11	−0.16	−0.15	−0.11	−0.15
Married/cohabitant	−0.12	−0.20	−0.15	−0.09	−0.17
Widow/widower[c]					
Education[b]					
Mandatory	−0.09	−0.01	−0.04	−0.05	−0.03
Secondary	−0.14	0.07	−0.08	−0.02	−0.04
University	−0.10	0.01	−0.09	−0.03	−0.03
Other[c]					
R^2 change	(0.01)	(0.01)	(0.01)	(0.01)	(0.01)
Employment status					
Current employment[b]					
Employed	0.12*	0.15**	0.09	0.11*	0.15**
Sick-leave	−0.04	−0.07	−0.06	0.03	−0.07
Own business	−0.04	0.01	−0.02	−0.02	−0.02
Pension	0.10	0.11*	0.11*	0.09	0.12*
Other	−0.07	−0.09	−0.08	−0.06	−0.11
Unemployed[c]					
Unemployment prior to investigation[b]					
Yes	−0.10**	−0.07*	−0.04	−0.09**	−0.09**
No[c]					
Sick-leave prior to investigation[b]					
Yes	−0.04	−0.05	−0.06	−0.06	−0.07
No[c]					
R^2 change	(0.03)	(0.04)	(0.03)	(0.02)	(0.04)
Financial situation					
Concerns about finances[b]					
Yes	−0.07	−0.06	−0.05	−0.01	−0.05
No[c]					
Difficulties with living expenses[b]					
Yes	−0.02	−0.04	−0.01	−0.07	−0.01
No[c]					

Table 5 Continued

Independent variables	*Medical care*	*Staff attitudes*	*Waiting periods*	*Information*	*Total SCC*
Difficulties raising money[b]					
Yes	−0.04	−0.05	−0.01	−0.01	−0.01
No[c]					
Financial burden of CHD[a]	−0.17***	−0.22***	−0.11**	−0.17***	−0.20***
R^2 change	(0.03)	(0.05)	(0.02)	(0.03)	(0.05)
Distress symptoms and hopelessness					
GSI[a]	−0.11*	−0.15**	−0.04	−0.18***	−0.13**
Hopelessness[a]	0.06	0.02	0.05	0.01	0.03
R^2 change	(0.01)	(0.01)	(0.01)	(0.02)	(0.01)
Social support					
Social integration[a]	0.07*	0.13***	0.06	0.04	0.10**
Social attachment[a]	−0.01	−0.04	−0.03	−0.02	−0.03
R^2 change	(0.01)	(0.01)	(0.01)	(0.01)	(0.01)
Total R^2	(0.13)	(0.17)	(0.09)	(0.12)	(0.16)

[a]Continuous variables.
[b]Category variables.
[c]Comparison category.
*p < 0.05; **p < 0.01; ***p < 0.001.

establish causal links. Second, the accuracy of data is solely dependent on the parents' subjective assessment of their own situation and that of their child. Care givers' perception of the care they provide to clients, if incorporated, would give a clearer picture of care provision. Third, we lacked sufficient data on certain variables (e.g. severity of the diseases other than CHD), which precluded an analysis of their influence on parents' perceptions about care. However, as indicated in our results and other findings, children's health variables do not significantly account for discrepancies in parental SCC. Fourthly, our group of PCCHD may not have been representative for all parents of children with CHD, as only members in the Swedish heart child foundation were recruited. However, the prevalence of different CHD diagnosis among the target children in our group was similar to those observed in a CHD population. Therefore, we may assume that our data are representative of CHD children and thus their parents. Finally, the variables used in the current study explained less than 20% of the variation in SCC. A plausible explanation for this low explanatory power could be that parents in general were satisfied with children's care. Thus, independent effects (e.g. differences between groups) may have been small and therefore difficult to capture. Another explanation may be that the instrument was less adequate in addressing parental SCC, since the original version was designed for patient (not parent) satisfaction with care. It is also plausible that our questionnaire did not cover all important determinants of SCC as almost 80% of its variation was unexplained. Despite these limitations, the reliability of the study is confirmed by the fact that some findings are consistent with other research in the field and we may have provided new insights.

The current study has identified parents at risk of reporting less satisfaction with care. The reasons as to why these groups report lower satisfaction however is not explored here. Are they being unrecognized by staff or feeling judged by the staff? These and other questions warrant some exploration in future studies.

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Author contribution

S.L. was responsible for 60% of the manuscript and JJFS contributed to 40% of the manuscript.

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