Factors influencing satisfaction and well-being among parents of congenital heart disease children: development of a conceptual model based on the literature review

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Aim and method: The treatment and management of congenital heart disease (CHD) has improved dramatically over the past 25 years, necessitating re-evaluation of satisfaction with care and well-being among CHD children and their parents (PCCHD). The present study reviews the published literature over the past 25 years on parental satisfaction with the paediatric care of CHD and well-being among the parents, with the specific aim of: (a) assessing the extent of psychosocial problems and grade of satisfaction with care and (b) modelling factors associated with satisfaction and well-being among the parents.
Results: There is general agreement in the literature that PCCHD experience psychosocial morbidity to a higher degree than parents of children with other paediatric conditions and parents of healthy children. The research on satisfaction with care among PCCHD is not conclusive, though there is considerable agreement that a substantial proportion of PCCHD may not be receiving adequate information regarding the ill-child's condition, treatment and medical prognosis. Finally, based on the review of factors affecting satisfaction and well-being, a model is generated indicating that interactions between parental perception of CHD, psychosocial resources and social vulnerability may account for differences in well-being among PCCHD, which in turn may explain differences in satisfaction with care among them.
Conclusion: A holistic approach to the care of CHD that acknowledges the role of parents' perception of CHD, need for psychosocial resources and social vulnerability in the adaptation process is recommended to improve parental satisfaction with the care of CHD.

Keywords: congenital heart disease, parents, satisfaction, well-being, psychosocial resources, social vulnerability, family health, review.

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Introduction

Steady technological advancement in the care of children with congenital heart disease (CHD) has rapidly reduced infant, adolescent and teenage mortality attributed to the disease. Only within two and a half decades, survival to adulthood among patients with CHD has increased dramatically from a mere 15% to 85% (1), creating a relatively new and potentially growing patient group, grown-ups with CHD (2). Advances in medical technology notwithstanding, data indicate that CHD children and adults continue to exhibit significant psychosocial morbidity manifested in behavioural, emotional, psychological and social adjustment problems (3–6). One of three children and adults with CHD will meet the criteria for clinical depression (7), which is about three times the ratio observed among peers in the general population (8–11). Parental and specialist psychosocial care of CHD, therefore, is expected to persist despite tremendous achievements in managing the initial physical handicap.

Though medical care of CHD is primarily the responsibility of paediatric personal, the psychosocial care is a responsibility shared by both the main custodian to the child and paediatric personal. With several reforms taking place in health care in the developed countries, for example, staff reductions and increased liberalization of health care in some parts of Europe (12–14), children's professional psychosocial care will increasingly be transferred to the main custodian, the parents in most cases.

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The excessive care burden, coupled by other detrimental factors related with parenting a child with severe chronic illness (e.g. social isolation) is likely to affect familial well-being and quality of life.

The present study reviews the literature on parental satisfaction with paediatric care of CHD and well-being among the parents. The review aims at shedding some light on critical issues with implications for the care of CHD children and their families. More specifically, the study will address the following issues: (a) Are parents satisfied with the care of CHD? (b) Does CHD in children affect their parents' well-being? (c) What are the factors affecting well-being and satisfaction with care among PCCHD? A conceptual model with implications for clinical practice is developed based on the last question.

Method

The research publications/abstracts used in this review were retrieved from medical databases, i.e. Medline, PubMED and CINAHL, a psychological database, i.e. Psychinfo and other general search motors, e.g. Google and findarticles.com. Keywords including Congenital Heart Disease (CHD), Parenting, Wellbeing, Care of CHD, Quality of Life, Social support, Satisfaction with paediatric care, Psychosocial factors and combinations between such terms were used to retrieve relevant material. The material was restricted to the English language and selected with a preference for studies over the past 25 years, owing to the improved prognosis of CHD over the past two and a half decades. About 80 publications/abstracts relevant for this study were retrieved in this manner, with the majority particularly relevant to CHD in general, while others were relevant for introducing and discussing the concepts of primary focus in this study (e.g. satisfaction with care and psychosocial well-being).

The retrieved articles were divided according to the research questions and independently reviewed. Thus, as reflected in the headings of the results, the following four areas were of interest: satisfaction with care, determinants of satisfaction with care, psychosocial well-being and determinants of psychosocial well-being. Based on the overall review, a conceptual model was developed.

Results and discussion

In this section, the results will be presented and consequently discussed to simplify for the readers to follow the arguments for each finding/sets of findings. For the same reason, summaries are presented at relevant parts of this section. Finally, based on the findings and discussion, a model of adaptation is proposed and its implication for intervention discussed.

Satisfaction with children's care

Because the health care professionals' evaluation of the care they offer to patients is supposedly biased towards their own perspective (15), the patient's perception of his/her care has received increased recognition in the evaluation of the quality of health care (16–20). Certain patient groups (e.g. mentally impaired persons and children) may lack the cognitive capacity to identify and evaluate their care needs and outcome, rendering their evaluation unreliable. With regard to ill-children therefore, the views of the main custodian may act as a proxy. Parental satisfaction with their ill-child's care, therefore, qualifies as a marker for the quality of paediatric care.

Several reports on paediatric care signify domains of care that the parents consider important. Among the most important domains identified in the literature are medical care, professional support in terms of communication and information and the parents own role in paediatric care (21–32). Relatively fewer studies, however, have investigated whether parents are satisfied with these domains of care, when in fact it is parental/client satisfaction that will have a bearing on strategies to improve the quality of care.

The findings on PCCHD's satisfaction with children's care seem rather inconsistent (Table 1). A recent study suggested that PCCHD may be more satisfied with paediatric care in general and particularly with medical care and duration before treatment than peers with children suffering from noncardiac illnesses (33). In another recent study (34), it was found that up to 95% of PCCHD who were present during the medical treatment of their CHD child expressed satisfaction with it. In contrast, Young et al. (35) found PCCHD to report low levels of confidence in their ill-child's primary care doctor. This could be reflecting the general practitioners lack of knowledge in this special field 20 years back. Indeed, while the later study was carried out way back in 1994, the former studies have only been recently published.

Despite these controversies, there is considerable agreement in the literature that a substantial proportion of PCCHD (18–36%) may not be receiving adequate information regarding the ill-child's condition, treatment and medical prognosis (31, 36–38; Table 1), yet the significance of such information in moderating distress and increasing satisfaction with care has been demonstrated (39).

Possible determinants of satisfaction with care

While findings regarding whether PCCHD are satisfied or not with paediatric care are inconsistent, there is a consensus in the few studies assessing possible determinants of satisfaction. Some studies have underscored the role of psychosocial resources for parental satisfaction with children's care. In their cross-sectional study, Lawoko and Soares (33; Table 2), found significant association between

Table 1 Research on care of CHD children and psychosocial well-being among parents of CHD children

Authors/country	*Sample*	*Method*	*Outcome studied*	*Results*
Kendall et al. (31)/UK[a]	17 parents of CHD children	Interview study	Rehabilitation services	Parents welcome more support regarding, information about CHD and communication with health team
Silverman et al. (32)[a, b]	Random sample of 102 parents of CHD children	Observational and tape-recorded data	Demand for information on, e.g. treatment	Demand for information increased when active treatment was anticipated, thus more information prior to treatment is recommended
Odegard et al. (34)/ USA	183 parents of CHD aged 0–12 years undergoing surgery	PPI	Overall satisfaction	96.7% of the parents acknowledged PPI as a positive experience for themselves and their children
Kaden et al. (36)[a, b]	285 mothers of CHD children	Mothers description of CHD compared to that of the cardiologist	Understanding of CHD	36% had poor comprehension of the child's CHD
Bulat and Kantoch (37)/USA	65 parents of CHD aged 0–16 years	Survey completed while awaiting ambulatory appointment	Understanding of CHD	89% felt they had adequate information about children's diagnosis, yet only 71% could correctly name the defect with 65% being able to explain in layman language the condition
Beeri et al. (38)/Israel[a]	74 parents of CHD children	A questionnaire study	Description of CHD	18% could not correctly describe their CHD child's malformation
Pinelli (40)[b]	10 mothers of newborn CHD	Interview conducted at admission and 1 month postdischarge	Concerns regarding caretaking task	An overall increase in caretaking concerns of up to 61% was observed during the postdischarge period
Docherty et al. (41)/ USA	78 mothers of medically fragile infants, including CHD	Completion of a questionnaire during child hospitalization	Maternal worry	Mothers worried (in priority order) about medical prognosis, normality of child, duration of hospitalization and whether the child would always be ill
Lee and Chen (42)/ China[a]	10 mothers of CHD children undergoing surgery	Content analysis of narrative verbal recording over time	Stressors	Stressors among the mothers could be categorized as evolving from the ill-child, treatment considerations and the mother herself
Rodrigue et al. (43)/ USA	27 mothers of transplant children (mean age = 8 years), including heart transplantation	Questionnaire completed at pretransplant and at 1 and 6 months post-transplant	Psychosocial symptoms	Increased parenting stress, financial strain, carer burden and family stress reported following transplant and persisting at 6-month follow up
Uzark and Crowley (44)/USA[a]	Parents of 10 heart transplant children	Questionnaire completed following transplant	Family stress	Psychological and social stress related to uncertainty, role strain, social isolation and financial burdens reported following transplantation
Gardner et al. (45)/UK	20 CHD infants and their mothers, 20 infants with no cardiac malformation and their mothers	Mother–infant interaction filmed 2 days prior to and 6 months following cardiac operation in the CHD infants	Affect and engagement	Mothers of CHD exhibited lower levels of positive affect and engagement than mothers of children with no cardiac malformation
Carey et al. (46)/USA	30 mothers of children aged 2–5 years with CHD and 30 mothers of healthy children of matching age	Quantitative self-reports, videotaped mother–child interaction and qualitative parenting response	Mother–infant relationship	Though the quantitative results and the videotape analyses revealed similarities between CHD mothers and the control mothers, the qualitative data suggested that CHD mothers were more vigilant with their children

Cohn (49)/USA[c]	Parents of infants 0–6 weeks old with CHD and healthy infants	Questionnaire study	Sadness, anger, fear and guilt	Parents of CHD more fearful and are sad and angry to a higher degree than parents of healthy children
Pelchat et al. (51)/ Canada	144 parents of 6 months olds with CHD or downs syndrome or cleft lip/palate and nondisabled children	Self-administered questionnaire completed 6 months after birth of target child	Parenting stress, stress appraisal and psychological distress	Parents of CHD reported greater levels of parenting stress and psychological distress than parents of cleft lip/palate and nondisabled children
Goldberg et al. (52)/Canada	Parents of infants with CHD (n = 52), cystic fibrosis (n = 30) and healthy infants (n = 60)	Questionnaire study	Parenting stress	Parents of ill-children reported greater stress in relation to child stressors. No differences between the groups existed; however, regarding stressors arising life events other than the target child
Lawoko and Soares (61)/Sweden	1092 parents of CHD, 112 parents of children with other diseases and 293 parents of healthy children. All aged 0–20 years	Questionnaire study	Social support	No difference between CHD and controls regarding availability of social support
Sparacino et al. (69)/ USA	8 parents of adolescents/ young adults with CHD	Qualitative pilot study using semistructured interview guide	Parental experiences as children mature	Several themes were identified including dilemmas of uncertainty and social isolation
Ludlow and Levy (70)/USA	28 mothers of 1-year-old infants with CHD (n = 10), hernias (n = 8) and healthy infants (n = 10)	Multidimensional scaling	Social support	Compared to mothers of healthy children, mothers of CHD emphasized the need of medical and spiritual support

[a]Age of children not identifiable from abstract/article.
[b]Country in which study performed not identifiable from abstract/article.
[c]Number of participants not identifiable from abstract.
CHD, congenital heart disease; PPI, parent present induction.

Table 2 Studies demonstrating possible predictors of satisfaction with care and well-being among PCCHD

Authors/country	*Sample*	*Design (method)*	*Outcome variable*	*Candidate determinants*	*Results*	*Remarks*
Lawoko and Soares (33)/Sweden	1092 parents of CHD children aged 0–20 years 61% mothers	Cross-sectional (block-wise multivariate linear regression)	Satisfaction with care	CHD severity Child age Parental demographics, employment and financial burden of CHD Parental distress and hopelessness symptoms Social support	Child age, financial burden of CHD, distress and hopelessness significant determinants of satisfaction with care	Distress and hopelessness among parents may impact negatively on satisfaction with care of CHD in children even after controlling for other potential predictors
Chan and Molassiotis (39)/China	50 parents of CHD aged 1–9 years preparing for operative procedure. Predominantly mothers	Longitudinal (repeated measure intervention vs. control group)	Satisfaction with care Anxiety	Anxiety	Decreased anxiety and increased satisfaction for intervention group	A psychoeducation intervention seems effective in reducing anxiety consequently improving satisfaction
Joesch and Smith (47)/ USA	7264 mothers of children with 15 health conditions including CHD	(Cox proportional hazards)	Risk of divorce	Demographics Stage of marriage sample child born Health problems of other family members Birth order of sample child, etc.	Risk of divorce more potent among parents of CHD, parents of cerebral palsy, blind and low birth weight children than among parent of children with other diseases and healthy children	PCCHD may be particularly at risk of marital distress compared with parents of children with other diseases and healthy children
Storhaug (73)/Norway	875 mothers of disabled children aged 0–19 years, 66 with CHD	Cross-sectional (multivariate classification analysis)	Self-reported health	Mothers demographics Child demographics Social insurance Child health (e.g. number of diagnoses	Mother's age, education, spouse's education and profession and child health condition predict maternal health	Child clinical severity predicts maternal health. Observe, however, that the majority in the sample are parent of children with a noncardiac diagnosis
Van Horn et al. (30)/ USA	38 mothers of CHD aged 3–16 years	Longitudinal (repeated measure correlation analysis)	Illness-related concerns	Perception of medical severity Anxiety	Illness-related concerns not necessarily a function of disease severity or emotional state	CHD severity seem not to impact on outcome
Lawoko and Soares (48)/Sweden	1092 parents of CHD, 112 parents of children with other diseases and 293 parents of healthy children. All children aged 0–20 years	Cross-sectional (logistic regressions analyses)	Distress Hopelessness	CHD presence and severity Child demographics Parental demographics, employment and financial situation and burden of disease	Female gender, financial and unemployment problems significant predictors of distress and hopelessness. CHD presence significant	CHD severity seems not to impact on outcome, but its presence seems important for distress and hopelessness

Uzark and Jones (50)/USA	70 mothers and 10 fathers of CHD children aged 2–12 years	Cross-sectional (correlation analysis)	Parenting stress index	Illness severity Time since most recent surgery Child age	Parents of older children report greater stress	CHD severity seem not to impact on outcome
Lawoko and Soares (61)/Sweden	1092 parents of CHD, 112 parents of children with other diseases and 293 parents of healthy children. All children aged 0–20 years	Cross-sectional (block-wise multivariate linear regression)	Quality of life	CHD presence and severity Child demographics Parental demographics, employment and financial situation and burden of disease Parental distress and hopelessness symptoms Social support	Financial burden of disease, distress, hopelessness and lack of social support significant predictors of quality of life. CHD presence significant	CHD severity seem not to impact on outcome
Tak and McCubbin (71)/USA	92 parents of newly diagnosed CHD children under 12 years	Cross-sectional (regression analyses)	Family stress Social support Coping	Child demographic and clinical variables Social support Coping	Social support operated as a resiliency factor between family stress and coping Severity of illness nonsignificant predictor of outcome variables	CHD severity seem not to impact on outcome
Phipps and Drotar (72)/USA	30 mothers of mild CHD, 30 mothers of apnoea children, 30 mothers of healthy children. All children were infants with mean age approximately 5 years	Longitudinal (repeated measure analysis of covariance)	Parenting stress index	Social support Coping Locus of control Information seeking Child illness	Social support important predictor of stress Parents of apnoea higher stress than CHD and healthy group	CHD severity seem not to impact on outcome
Davis et al. (74)/USA	52 mothers of CHD children	Cross-sectional (multiple and hierarchical regression analyses)	Psychological adjustment	Illness severity Maternal education Maternal age Coping Daily stress	Maternal education, stress and coping important predictors of adjustment Illness severity nonsignificant	CHD severity seem not to impact on outcome
Young et al. (35)/USA	170 parents of transplant recipients aged 0–19 years. 92 with CHD, 85% mothers	Cross-sectional (regressions analyses)	Post-traumatic stress disorder symptoms	Child and parent demographics Parental assessment of child health Impact of transplant Attitude towards carer	Controlling for demographics, all other candidate determinants were significant predictors of PTSD	Child health as perceived by parents may be an important factor for parental well-being

Table 2 (contd)

Authors/country	Sample	Design (method)	Outcome variable	Candidate determinants	Results	Remarks
Viskonti et al. (75)/ USA	143 and 153 parents of CHD with transposition of the great arteries at age 1 and 4 years respectively	Longitudinal (correlation analysis, linear regression)	Stress	Social support Socioeconomic status	Adjusting for family socioeconomic status, less social support correlated with high stress both at 1 and 4 years	Consistent findings regarding association between social support and stress both at 1 and 4 years
Rona et al. (77)/UK	108 mothers of CHD children <1 year old. In 3 groups: confirmed unconfirmed and undetected CHD during pregnancy	Cross-sectional (logistic regression)	Depression and anxiety	Demographics Social class Religion (i.e. protestant, other and none) Cost of fare to cardiologist	Young mothers and nonprotestants at higher risk of anxiety High fares to cardiologist	Religion seems to have a bearing on parental well-being, i.e. PCCHD belonging to religious minorities at heightened risk of psychological problems

CHD, congenital heart disease.

parental dissatisfaction with care and psychological distress/hopelessness symptoms among the parents. They warned, however, that the direction of causality could not be determined due to the cross-sectional design of the study. Clarifying these results further in a study with a more powerful design (i.e. interventional randomized-control study), Chan and Molassiotis (39; Table 2) demonstrated that the association between parental psychological distress and satisfaction with care was mediated via information dissemination. They indicated that a psycho-education intervention emphasizing, among other things, information about the CHD diagnosis, its treatment and expected outcome would successfully reduce parental anxiety and increase their satisfaction with care. Together, these findings support the utility of psychosocial interventions in promoting parental satisfaction with children's care.

The age of the CHD child has been found to correlate with parental satisfaction, i.e. parents of younger children seem more prone to report dissatisfaction with the care of CHD than peers with older children (33; Table 2). Since most CHD diagnoses are confirmed during the first year of birth, it is highly plausible that age may be reflecting the time since diagnosis of CHD. Thus, time effects, such as gradual acceptance of care, development of coping strategies to counter disease-related distress and information dissemination may account for higher satisfaction among parents to older CHD.

Finally, the economic burden of care experienced by PCCHD has been suggested as a possible eliciting factor of dissatisfaction with care. PCCHD reporting high economic burden of care tend to report lower satisfaction than peers reporting low financial burdens of care, and this independently of the children's clinical severity (33; Table 2).

In summary, the literature on parental satisfaction with the care of CHD seem inconsistent which could be portraying the way paediatric care is organized in different societal context, or differences in methods of assessment. There is, however, a consensus that parental information on CHD may be insufficient, and data suggesting a link between information dissemination and satisfaction with care. The review implies further that psychosocial and socioeconomic support may be beneficial in promoting parental satisfaction with children's care. Finally, there is some implication that the time since diagnosis, reflected in the ill-child's age, may in part account for parental adaptation to and satisfaction with the care of CHD. These factors thus may have implications for interventions to improve the quality of paediatric care of CHD.

Psychosocial well-being of PCCHD

The main body of research on psychosocial well-being has focussed primarily on psychological domains, though few studies on broader psychosocial factors incorporating

psychological, physical and social factors (e.g. quality of life) are beginning to emerge. There is wide consensus in the literature that PCCHD are faced with psychosocial problems (Table 1). PCCHD report concerns about their ill-children's psychosocial adaptation, medical prognosis, financial and caregiving burdens associated with the illness (30, 40–44). When contrasted with other parental groups, PCCHD are more likely to manifest symptoms of negative affectivity and distress (45, 46), including marital distress (47), than parents of healthy children. In addition, they exhibit symptoms of depression, anxiety and hopelessness (48) and are fearful, angry and sad (49–51) to a higher degree than peers with healthy children. The same trend seems to unfold when compared to parents of children with other paediatric conditions. PCCHD report more psychological distress compared to peers having children with cystic fibrosis (52) and children with other noncardiac diseases (48). In addition, they are at higher risk of distress in relation to marital problems than parents of children with asthma, developmental/cognitive/speech disabilities, emotional problems and limb/digit malformation (47).

Though other subjective psychosocial variables such as quality of life are receiving increasing acknowledgement as integral indicators of bio-psychosocial outcome (53–58), few studies among PCCHD have addressed these issues. Considering that quality of life encompasses physical, psychological and social functioning, it provides a broader perspective as an assessment instrument of patient outcome than most other measures. Moreover, data suggest that impaired physical and mental functioning may not necessarily imply a poor quality of life in general (59, 60), motivating its potential utility as a measure of health outcome on its own right.

Only one study was identified in the literature among PCCHD that investigated a compound measure of quality of life integrating all its three domains (i.e. physical, psychological and social; 61). The authors compared PCCHD with parents of children with other paediatric illnesses (predominantly chronic) and parents of healthy children on the compound quality of life measure as well as its subdomains. They found PCCHD to report lower quality of life on both the compound measure and specific dimensions than parents of healthy children.

Another aspect of quality of life that has received scant attention in the literature is social support. Social support has often been viewed as an intervening variable mediating or moderating between a potential stressor and bio-psychosocial outcome (62–65). However, some authors have also emphasized that social support/isolation be viewed as an outcome of stressful life events on its own right (66–68). Research viewing social support/isolation as an outcome of psychosocial stressors among PCCHD is scarce and not without contradiction. While some researchers (Table 1) suggest that PCCHD may be faced with social isolation problems in general (69) and more so than peers with healthy children (70), others have not found any significant differences between PCCHD and their peers with healthy children and children with other noncardiac diseases regarding availability of a social network (68). The discrepancy perhaps is a result of differences in the operational definition of social support used in the studies. While the later study focussed on the size of the network, the former studies investigated the perceived meaning of the network. Considering that availability of a large network does not necessarily imply it is supportive, differences may be expected. With regard to the role of social support as a health determinant on the other hand, both large size (68) and meaningful content (71, 72) of a network seem to have positive impact on health outcome among PCCHD.

In summary, most studies on well-being among PCCHD tend to concentrate on psychological domains while other aspects such as quality of life, which covers a wider scope, have only received scant attention in the literature. There is, however, considerable agreement that PCCHD may experience psychosocial morbidity to a higher degree than peers with healthy children and with children suffering from other diseases. The findings regarding social support/isolation as an outcome of stressful life events are contradictory, though methodological issues may account for the differences. Further investigation, particularly with regard to quality of life and social support, however, is warranted among PCCHD.

Possible determinants of psychosocial well-being among PCCHD

Children's clinical situation. While the relatively older research (Table 2) suggests that the children's clinical severity may play an important role for parents well-being (47, 73) the more recent findings seem to entail that it may not (30, 33, 48, 50, 61, 71, 72, 74). The exceptional improvements in treatment and management of CHD over time may account for part of the discrepancy. If clinical severity is being measured using objective measure such as survival statistics of given diagnosis, as is often the case (e.g. 33, 48, 61, 71), then this trend would be expected considering that most children survive to adulthood today (85%) when compared with only two and a half decades ago (15%; 1).

On the other hand, parental subjective assessment of their ill-child's situation, rather than clinical severity, may be responsible for the parents' well-being. If parents perceive the illness as severe, regardless of the diagnosis and illness trajectory, then it is likely to affect their well-being negatively. Indeed, the single study identified in the literature among PCCHD (35; Table 2), in which mothers' perception of the disease was the indicator for illness severity, seems to support this hypothesis. Parental perceptions of their children's disease have often been expressed in terms of the psychological, social and

economic impact of the disease on the family unit (30, 40–46), and studies indicate that these factors, other than clinical severity, may impact significantly on parental satisfaction and well-being (33, 48, 61, 71; Table 2). Thus, the distinction between parental and professional views of children's illness seems paramount when assessing the role of children's illnesses on parental well-being.

The role of psychosocial resources. The role of psychosocial resources for parental adaptation to a potential family stressor has been consistently demonstrated in the literature review of PCCHD (Table 2). Studies have found social support to concurrently correlate with psychosocial outcome, indicating its protective function as a coping facilitator (61, 71, 72, 75). Others have confirmed the role of intervening resources, e.g. social support and coping resources in moderating/mediating between CHD-related distress and bio-psychosocial outcome (71, 74). It has also been suggested that educational interventions may be beneficial in mediating between disease-related distress and parental well-being on the one hand, and satisfaction with care on the other (39, 76).

Social disadvantage. The literature review indicates a correlation between social disadvantage and psychosocial well-being (Table 2). PCCHD belonging to ethnic (48) and religious minorities (77) and of female gender (48, 61) have been suggested as being particularly at heightened risk of psychosocial morbidity. In addition, low educated (73, 74), unemployed and financially strained (33, 48, 61) PCCHD tend to report psychosocial problems to a higher degree than their more advantaged peers. These findings indicate that social disadvantage, above those directly related to child illness, are likely to act as an additive stressor increasing parental vulnerability for psychosocial problems.

A conceptual model demonstrating factors influencing satisfaction and well-being among PCCHD

In summary, the findings in Table 2 depict the factors possibly influencing bio-psychosocial outcome among the parents and consequently parental satisfaction with the care of CHD, summarized in the conceptual model in Fig. 1. According to the model, the interaction between parents' perception of CHD in children, intervening variables and external exacerbating variables (i.e. those not directly related to the disease) will prove crucial in determining parents' bio-psychosocial outcome and thereby, satisfaction with care. Parents form a perception of CHD based on, for example, information about the disease (36–38), caregiving and financial burdens of the disease (40, 48, 61). A positive perception of the disease is likely to affect psychosocial outcome positively (following pathway

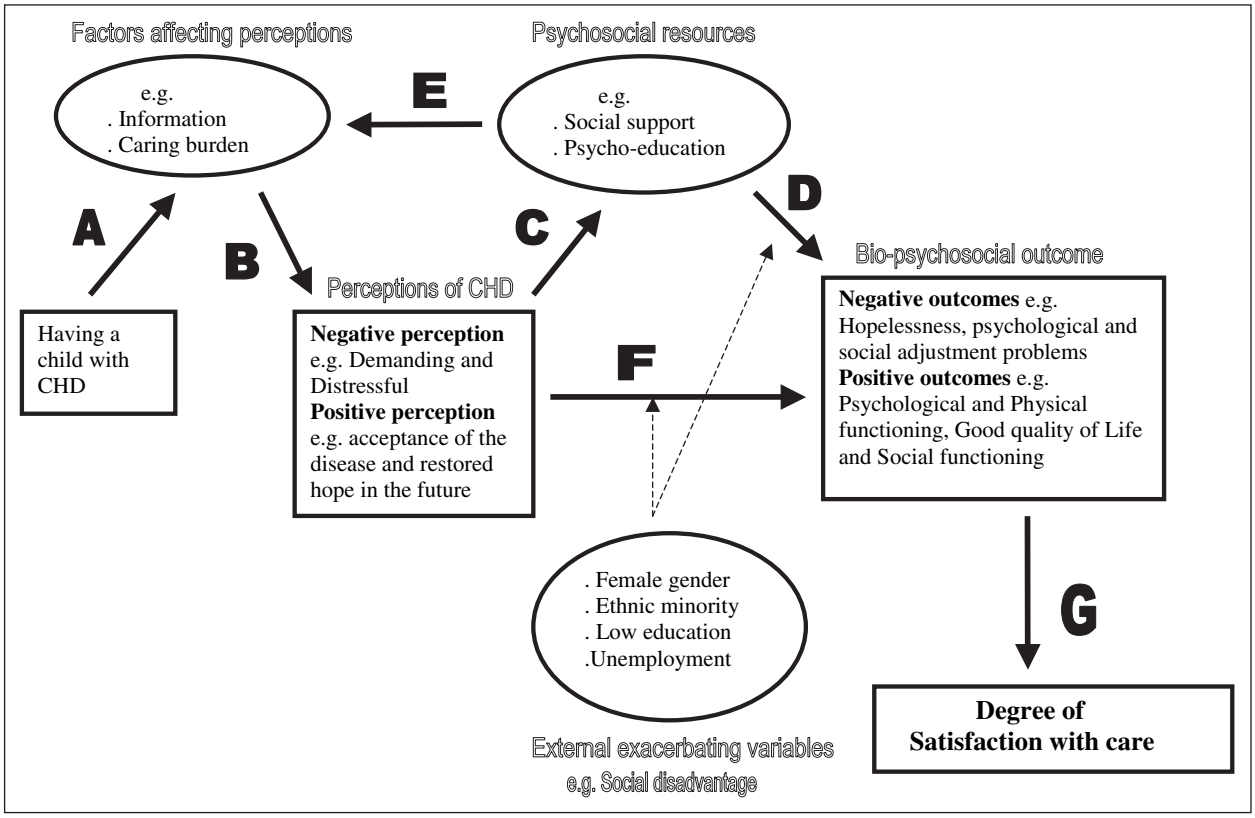

Figure 1 A conceptual model demonstrating factors influencing satisfaction and well-being among PCCHD.

ABF). On the other hand, negative perceptions (e.g. distressful, demanding, etc.) may affect health outcome negatively (35, 40, 48, 61). Psychosocial resources, however, may act as intervening variables aimed at maintaining psychosocial balance. This could happen in two ways. **(1)** Resources such as social support may facilitate coping with negative perceptions/effects of the disease (61, 71, 72, 75) thereby maintaining psychosocial balance (following pathway ABCD).
(2) Resources such as psychoeducation (e.g. providing sufficient information on the disease) are likely to modify negative perceptions of the disease (39, 76) leading to psychosocial adaptation (following pathway ABCEBF).

However, social disadvantage may act as an exacerbating factor increasing vulnerability for ill-health (48, 73, 74, 77), independently of perceptions of disease and psychosocial resources to counter disease-related distress (33, 61, 68). This variable thus is likely to hinder adaptation at points F and D.

The bio-psychosocial outcome among PCCHD is likely to affect the degree of satisfaction with the care of CHD (link G in Fig. 1). Parents' experience of hopelessness/anxiety and social dysfunction (33, 39), for example, are likely to lead to dissatisfaction with care. However, interventions (e.g. psychoeducation) have been demonstrated to reduce psychological symptoms (e.g. 39) and thereby successfully increasing satisfaction with care.

The model generated here is in some regards similar to that reported earlier by Hill (78), emphasizing the significance of psychosocial and coping resources for parental adaptation, and later modified by McCubbin and Petterson (64) to incorporate the role of additional stressor, over time, related to child illness (e.g. financial burden of illness) in the adaptation process. However, exacerbating factors beyond those related to the disease (i.e. social disadvantage) have, to the best of my knowledge, not previously been integrated in parental conceptual adaptation models on their own right. Yet, they have a bearing on clinical practice to alleviate suffering and promote well-being and satisfaction among PCCHD. In addition, the association between well-being and satisfaction with care has previously been excluded in adaptation models, a link consistently demonstrated in the review.

Conclusion and implications for paediatric care

In conclusion, PCCHD face psychosocial problems to a higher extent than parents of children with other diseases and parents of healthy children. The review on the level of satisfaction with care among PCCHD in general did not yield conclusive results, though a consensus is reached indicating that a considerable proportion of the parents may not be receiving sufficient information on the disease. With regard to determinants of satisfaction and well-being the findings were more consistent and it can be concluded that the interaction between parents' perception of CHD, psychosocial resources and social vulnerability are paramount for parental adaptation to CHD in their child, which in turn may influence satisfaction with the care of CHD.

The review implies a holistic approach in the paediatric care of CHD children and their families, where the interactions suggested herein are taken into consideration. The challenge therefore is for care professionals to acknowledge these aspects in their recent work to improve the quality of paediatric care. The model generated here could be helpful in initiating this effort.

Limitations

The reviewed material revealed some gaps apparent in the literature. All studies identified with regard to satisfaction and well-being (Table 1), are based on data from high-/middle-income countries, particularly from North America and Europe. The cultural validity of the findings and the model may thus be put at jeopardy. Because the benefits of technological advancement in the treatment and management of CHD is not yet being enjoyed in low-income countries, it is likely that the picture portrayed in this study may not be relevant for these countries. Efforts to study this hypothesis, however, have been futile owing to the lack of research in the field in low-income countries. Finally, most findings with regard to determinants are based on studies with a cross-sectional design, making it difficult to draw inference on cause and effect. For example, the association between well-being and psychosocial resources may be reciprocal. While resources may act as protective agents against ill-health, it is also plausible that ill-health may affect parental ability to acquire and meaningfully utilize psychosocial resources. More studies with longitudinal design are necessary to confirm causal links. Owing to these limitations, the model generated here should be seen as a first step in the development of a conceptual model of satisfaction with care and well-being among PCCHD.

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