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Attitudes about dental care among parents whose children suffer from severe congenital heart disease: a case-control study

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Summary. *Objectives.* To examine attitudes and experiences of parents whose children have complex congenital heart disease (CHD) with respect to dental health information and advice, dental care, and service and to compare the results with data from an age- and gender-matched control group without any medical problems.
Setting. Faculty of Medicine (Paediatric Cardiology and Paediatric Dentistry), Umeå University, Umeå, Sweden.
Sample and method. Each group comprised parents of 33 children; the children's mean age was 9·4 years. All the cases and the controls resided in the county of Västerbotten, northern Sweden. Data were collected with a questionnaire with 20 joint questions to both groups and four additional questions to the CHD group.
Results. Of the 20 joint questions, significant differences were displayed in the following areas: the professional group that provided the parents with dental health information and advice ($P < 0{\cdot}01$), attitudes to reception at the dental clinic, and experience of sedation before operative dental treatment ($P < 0{\cdot}05$). Parents to 11 children with CHD who were patients at a specialist clinic for paediatric dentistry scored the reception at the dental clinic as excellent in nine cases and satisfactory in two, compared to excellent (3), satisfactory (11), decent (4), and poor (4) among those who were patients in general dental practice ($P < 0{\cdot}01$). No statistically significant differences in educational level or in parental experience of dental health were noted between the two groups ($P > 0{\cdot}05$).
Conclusion. Children with CHD in northern Sweden mainly receive their dental health information from a physician or a dentist, and healthy children mainly receive information from a dental hygienist indicating that children with CHD are given priority in the dental care system. Parental attitudes to reception in the dental service differed, and parents of healthy children scored the reception at the dental clinic better than parents of children with CHD. It is suggested that children with severe CHD should receive dental care in clinics for paediatric dentistry, particularly at early ages.

Introduction

Congenital heart diseases (CHD), abnormalities in the structural development of the heart, occur in approximately 8 : 1000 live births. Of these, one-third consists of complex anomalies [1]. With improved detection, diagnosis, and progress of surgical and anaesthetical methods, the number of surviving children is increasing [2]. During their first years of life, children with CHD often receive extensive medical and surgical treatment and have shorter or longer stays in hospitals. Early dental health problems are common in children with severe CHD, and there are complicated background factors often associated with nutrition, medication, and the demanding situation of their families [3–7]. Lower frequencies of regular dental care have been displayed in children with CHD than in those without this medical problem [5,8–10]. In a previous study, it was highlighted that in many cases, children with CHD in northern Sweden had been offered more caries intervention than healthy children, but the care had been given when caries were already present [7] in spite of a system where all parents are offered a comprehensive dental care

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for their children from an early age with a strong caries-preventive approach. Common experiences are that many children do not turn up at early dental check-ups because of illness or because they are in hospitals. The increasing survival of children with CHD makes them a significant, proportion of those attending for dental treatment, and it is an essential challenge for dentistry to provide paediatric patients, whose medical health can be hazardous as a result of poor dental health, a dental service that is adjusted to their needs [11]. Therefore, early preventive dental care should be adjusted to the special needs of children with CHD in their first years of life. Knowledge of parental attitudes and experiences of dental care are therefore important. This study examines attitudes and experiences of dental health information and dental care and service of parents with children affected with complex CHD and compares them with results from an age- and gender-matched control group without any medical problems.

The null hypothesis was that there were no differences in attitudes and experiences of dental health information and dental care and service between parents of children with CHD and parents of healthy children.

Materials and methods

The study was performed with a cross-sectional design in 2004. We invited parents of all children with CHD between 3 and 13 years of age ($n = 38$), complexity grading II and III [12], without other chronic diseases or syndromes registered in the Paediatric Cardiology Outpatient Clinic at University Hospital in the city of Umeå. All participants resided in the county of Västerbotten, northern Sweden. For each patient, a healthy child of the same gender and date of birth was selected from the population register for the county of Västerbotten. The parents of these children formed the control group. In the control group, approximately 50% replied to the first questionnaire. Despite reminders, 10 participants in the control group did not reply and they were exchanged with the next child with the same birth date and gender in the population register. In spite of this, there were three nonrespondents. To match the controls, the parents of three children with CHD were excluded. The parents of two children with CHD did not want to participate in the study. The final material thus consisted of parents of 33 children with complex CHD and parents of 33 age- and gender-matched healthy controls. The mean age of the children was 9·4 years, 20 boys and 13 girls.

The dental care system in the area offers all children a comprehensive dental care free of charge between the ages of 3 and 19 years, and all parents are offered dental health information when the child is 1 and 2 years old. Twenty-two participating children with CHD received their dental care in public dental health service clinics, and 11 had been referred for dental care in a specialist clinic for paediatric dentistry organized in the public dental health service. All children whose parents constituted the control group received dental care in the public dental health service clinics.

All participants were sent written information about the purpose of the study and gave their written consent to participate. A questionnaire was enclosed, with 20 joint questions for both groups of children. Thirteen of the questions concerned the dental health information and dental care and service. Both groups were also asked seven questions that dealt with dental health of the child and his/her parents, the children's and parents' expectations before visits to the dental clinic, and the educational level of the parents. In the questionnaire to the parents of the children with CHD, four specific questions were added, concerning if the child with CHD had siblings, the differences in dental health information compared to healthy siblings, parents' knowledge about antibiotic prophylaxis, and where they had received this information.

The research ethics committee of the Faculty of Medicine at the University of Umeå approved the study.

Statistical analysis

Data were statistically analysed using the Statistical Package for the Social Sciences, SPSS software, version 11·5 (SPSS Inc., Chicago, IL, USA). To test differences in standardized answers between the two groups, Fisher's exact test (two-sided) was used. In the questions 'attitudes to reception in the dental clinic' and 'experience of competence of the dental staff', the CHD group was further subdivided into children who were patients in a specialist clinic for paediatric dentistry or patients in general dental practice. The level of statistical significance was set at 5%.

Results

The results of the questions were subdivided into (a) children and parents, (b) dental health information and advice, and (c) dental care and service.

In subdivision (a), 'children and parents', no statistically significant differences in the parents' view of their child's and the parents' dental health and the child's and parents expectations before visits in the dental clinic or in the educational level of the parents were noted between the two groups ($P > 0{\cdot}05$).

In subdivision (b), 'dental health information and advice' (Table 1), there were no significant differences between the children with CHD and the controls, except for the question, 'where did you get dental health information and advice?' The most common answer among the controls (46%) was that they had received the information from a dental hygienist, whereas 79% of the parents of children with CHD had received their information mainly from a dentist or a physician ($P < 0{\cdot}01$). Fifteen of the parents of children with CHD (45%) and 11 parents of a child in the control group (33%) provided suggestions on how to improve the dental care information.

In subdivision (c), 'dental care and service' (Table 1), none of the parents in the control group and 12% of the parents in the CHD group considered the reception at the dental clinic poor ($P < 0{\cdot}05$). More parents in the control group compared to the CHD group stated that the reception was satisfactory. About one-third of the parents from both groups considered the reception as excellent. Parents to 11 children with CHD (33%) who were patients at a specialist clinic for paediatric dentistry scored the reception at the dental clinic as excellent in 81% and satisfactory in 19%, compared to excellent 14%, satisfactory 50%, decent 18%, and poor 18% among those who were patients in general dental practice ($P < 0{\cdot}01$) (Fig. 1).

In the control group, 84% claimed they were provided with sufficient time at each appointment compared to 61% in the CHD group. Thirty per cent of those in the CHD group stated they were only given part of the time they needed in relation to their needs. The difference did not, however, reach statistical significance ($P > 0{\cdot}05$).

A majority (97%) of the controls had never received sedative treatment before operative dental treatment, whereas 24% of children with CHD had received it at least once. One parent to a child with CHD claimed that he/she had sedative medication before all operative dental treatments. The difference between the two groups was statistically significant ($P < 0{\cdot}05$).

No significant differences could be displayed concerning experience of competence of the dental staff between the two groups ($P > 0{\cdot}05$), whereas 73% of parents of children with CHD who were patients in a specialist clinic for paediatric dentistry scored the competence of the dental staff as excellent compared to only 14% of those who were not ($P < 0{\cdot}01$). Nine parents from the CHD group and two from the controls provided comments regarding dental care and service.

Questions that only were directed to the CHD group are presented in Table 2. All except two children with CHD had siblings; only 10% of the parents of these had the experience that dental health information had been more extensive to the child with CHD compared to the information given to the sibling(s). Thirty-three per cent stated that the information had been adjusted to existing needs. All the parents knew that their child needed antibiotic prophylaxis before invasive dental treatment. A majority (70%) claimed that they first had received this information from a physician. Only 18% stated that a dentist provided them with this information.

Discussion

With knowledge of an unacceptable high caries experience in children with severe CHD in Sweden [7], this study examines attitudes to and experiences of dental health information, dental care, and service between parents of children with CHD and parents of healthy children. The null hypothesis was partly rejected, as there were significant differences between the cases and their controls in from whom dental health information and advice was received, attitudes to reception at the dental clinic and experience of sedation or general anaesthesia.

The study showed that children with severe CHD are given priority in the Swedish dental care system, and they mainly receive their dental health information from a physician or a dentist, whereas healthy children mainly receive information from a dental hygienist. Despite this, the guardians in the CHD group were not satisfied with their reception in the same extent as the control group. This may be

Table 1. Joint questions in the subdivisions (b) dental health information and advice and (c) dental care and service. CHD = children with congenital heart disease; C = healthy age and gender matched controls. Figures give percentage in the alternatives.

Questions	Group						*P*-value
(b) Dental health information and advice							
Describe the dental health information and advice		Very poor	Poor	Decent	Satisfactory	Excellent	
	CHD	9	9	24	52	6	0·400
	C	0	6	34	47	13	
The amount of information and advice has been …		Insufficient	Neither sufficient nor insufficient	Sufficient			
	CHD	24	24	52			0·620
	C	16	20	64			
What was the age of your child when you first received dental health information and advice?		< 6 months	6 months–1 year	1–3 years	> 3 years		
	CHD	13	32	42	13		0·556
	C	3	41	41	15		
Where did you get dental health information and advice?		Physician	Dentist	Dental hygienist	Found the information on my own	Other source	
	CHD	36	43	9	6	6	0·000
	C	3	30	46	15	6	
Is it possible to follow the current advice?		Yes, definitely	Yes, partly	Doubtful	No, not at all		
	CHD	41	59	0	0		0·236
	C	24	73	3	0		
Does the current dental health information need to be changed?		Yes, totally	Yes, partly	No	Don't know		
	CHD	12	27	40	21		0·885
	C	9	24	37	30		

Table 1. *continued.*

Questions	Group						*P*-value
(c) Dental care and service							
Describe the reception at the dental clinic		Excellent	Satisfactory	Decent	Poor	Very poor	
	CHD	36	40	12	12	0	0·044
	C	33	64	3	0	0	
Was enough time provided during the appointment at the dental clinic?		Yes, definitely	Yes, partially	Probably not	No, not at all		
	CHD	61	30	6	3		0·088
	C	84	16	0	0		
Have sedatives or general anaesthesia been used for your child?		Never	1–2 occasions	3–4 occasions	> 4 occasions	Always	
	CHD	76	21	0	0	3	0·027
	C	97	3	0	0	0	
What was your experience of sedation or general anaesthesia?		Excellent	Satisfactory	Decent	Poor	Very poor	
	CHD	22	56	11	11		0·500
	C	100	0	0	0		
Was local anaesthesia used when teeth were filled?		Always	Often	Sometimes	Never	Don't know	
	CHD	35	0	13	35	17	0·222
	C	21	8	29	38	4	
What was your experience with respect to the competence of the dental staff?		Very good	Good	Varying	Bad	Very bad	
	CHD	33	33	28	3	3	0·053
	C	9	58	30	3	0	
Do you believe the control intervals were adjusted to meet the needs of your child?		Gaps were too long	Sufficient	Too close	Don't know		
	CHD	18	82	0	0		0·389
	C	30	70	0	0		

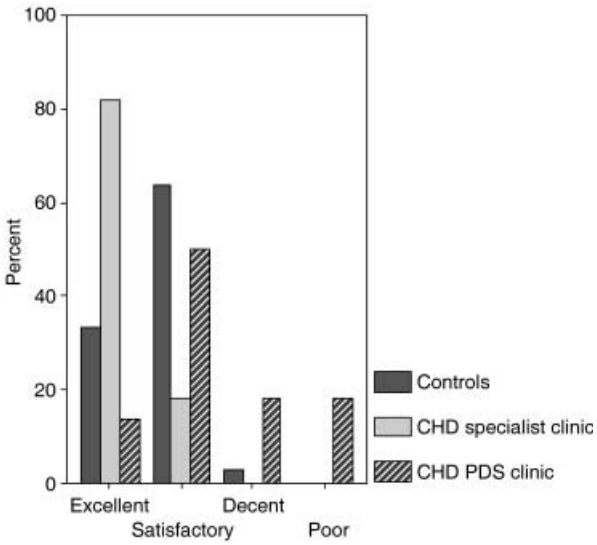

Fig. 1. Attitudes to reception in the dental clinic among parents of children with severe CHD who were patients in PDS clinics (PDS = public dental service) ($N = 22$) or in a specialist clinic for paediatric dentistry ($N = 11$) and in healthy controls ($N = 33$) ($P < 0{\cdot}05$).

the result of the fact that an insignificant higher number of CHD guardians than 'control guardians' had the opinion that they were not provided with enough time at the visit to the dental clinic. The dissatisfaction in the CHD group may depend on the fact that 'CHD parents' have greater demands on dental care because of the illness of their child. There were no significant differences in educational level or the dental health of the father or the mother or in expectations before visits to the dental clinic between the cases and their controls that could help explain the differences in attitudes to reception. Parents of CHD children who were patients in a clinic for paediatric dentistry scored the reception at the clinic and the competence of the dental staff higher than those who were patients in general dental practice. It must be emphasized, however, that the study design only allowed the parents to express their attitude and no comparison between the different types of clinics was performed.

Because children with CHD have more caries predominantly in the primary dentition [3–7] than healthy children, they also have a greater demand of operative dental treatment particularly at an early age. It has earlier been shown that Swedish children with CHD had a mean dmfs of 5·2 compared to 2·2 in healthy-age and gender-matched controls [7]. This may be a possible reason why the CHD group claimed that they more often received sedative drugs. Earlier studies have described how and why it is important for these children to avoid pain and stress [5], and why the careful use of sedation and local anaesthesia have been recommended [7].

Dentists are advised to provide antibiotic prophylaxis against endocarditis before invasive dental procedures [13] and all the guardians in the CHD group knew that their child needed endocarditis prophylaxis before operative dental treatment. It is difficult to assess this finding in terms of health effects. Earlier studies, however, have displayed

Table 2. Specific questions to parents of children with severe CHD only. Figures give percentage in the alternatives.

Questions					
Does your child have siblings?	Yes	No			
	94	6			
Did you notice differences in dental health information compared to your child's healthy siblings?	Yes, more extensive	Yes, more adjusted to existing needs	No	Don't know	
	10	33	43	14	
Have you been informed that your child needs antibiotic prophylaxis before invasive dental treatment?	Yes	No			
	100	0			
From where did you first receive dental health information about antibiotic prophylaxis?	Physician	Dentist	Dental hygienist	Found information on my own	Other source
	70	18	0	9	3

that the knowledge and compliance with these recommendations have been much lower [3,4,9].

This study investigated 87% of children between 3 and 13 years with CHD complexity grades II and III without other medical problem or syndromes in the county of Västerbotten. Studies based on questionnaires often result in more dropouts than those based on interviews, although it is easier for most people to express opinions if their identity is protected [14]. All parents of children with CHD, except two, replied to our first questionnaire, whereas the number of nonrespondents was higher in the control group. This may be because parents of children with CHD had a higher motivation to participate than parents of healthy children. We do not believe, however, that the exchange of 10 controls who were nonrespondents with the respective subsequent child in the population register with the same birthday and gender may have had any important impact on the results. Of these new controls, seven replied to our questionnaire. Thus, every child with CHD, except three, had an own control with the same birthday and gender. The exclusion of these three children with CHD who lacked controls from the study can not be considered as an important potential for bias.

A British study [8] compared dental attitudes, knowledge, and health practice between a CHD group and a matched control group. In this study, 18% of the children with CHD had not received dental care. In our study, however, all the children with CHD had received dental care. The difference in caries prevalence between Swedish children with CHD and healthy controls is, however, larger than shown in another British study with the similar design as ours [5,7], whereas more untreated caries are shown in British children with CHD than in healthy controls [5]. Parry and Khan [15] investigated the provision of dental care for medically compromised children. The study showed that a dental practitioner had treated patients with CHD in zero to five sessions in the past five years with an average of two patients for each practitioner. Jowett and Cabot noted that many dentists were not confident in treating children with CHD [16]. This lack of experience regarding these children's medical conditions and pharmacological regimes [17,18] is a cause of concern and suggests a need for specialist dental care for these children. According to comments in our questionnaire, there were children from the CHD group who never had visited a specialist clinic for paediatric dentistry. A specialized dental care provider who is trained in the needs of this group may provide parents with more confidence. A systematic integration of medical and specialized dental care should be established for all children with severe CHD before they are 1 year old and the goal should be to maintain oral health. Many parents stressed the importance of early information on how to prevent poor oral health in their comments and suggested that a competent dentist should be included in the team at the cardiology department to overcome difficulties with early dental contacts. A practical way to provide such early contacts could be in conjunction with the outpatient cardiology visit but in the dental clinic.

In conclusion, this study has shown that children with severe CHD in northern Sweden mainly received their dental health information from a physician or a dentist and healthy children mainly received information from a dental hygienist, indicating that children with severe CHD are given priority in the dental care system. Parental attitudes to reception in the dental service differed, and parents of healthy children scored the reception at the dental clinic better than parents of children with CHD. Children with CHD had received sedation before operative dental treatment significantly more often than healthy children. It is suggested that children with severe CHD should receive dental care in clinics for paediatric xdentistry, particularly at early ages.

What this paper adds

- This paper adds information on differences in attitudes to dental care among parents to children with severe congenital heart disease and among parents to healthy children.

Why this paper is important to paediatric dentists

- As there is an increasing number of surviving children with severe congenital heart disease it is important to develop a dental care that is adjusted to these childrens needs.
- The results indicates that these children should receive dental care in clinics for paediatric dentistry, particularly at early ages.

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