

Clinical Paper  
Craniofacial Anomalies

# Positional cranial deformity— the parents' point of view

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S. Kluba, J. Lypke, W. Kraut, J.P. Peters, B. Calgeer, K. Haas-Lude, M. Krimmel, S. Reinert: Positional cranial deformity—the parents' point of view. *Int. J. Oral Maxillofac. Surg.* 2015; 44: 57–62. © 2014 International Association of Oral and Maxillofacial Surgeons. Published by Elsevier Ltd. All rights reserved.

**Abstract.** The parents' point of view regarding positional cranial deformities and helmet therapy has not been the subject of scientific interest yet. However, carer acceptance is a key factor for therapeutic success. We therefore investigated parental perception. The parents of 218 infants were included in a telephone survey; 122 children had undergone helmet therapy and 96 had not. Satisfaction with the outcome, treatment-associated problems, and parental stress were investigated using a structured questionnaire. The great majority (90.8%) of caregivers were satisfied with the outcome, regardless of whether or not helmet therapy was used. Retrospectively, 76% of the parents of infants who had not undergone helmet therapy would decide against helmet therapy again. Therapy was either temporarily stopped (27.0%) or terminated (4.9%) in 31.9% of infants treated with a helmet. Major problems were sweating (51.1%) and skin lacerations (30.9%). The parents indicated minor (54.9%) or even great (25.4%) personal strain. Conflict with others (38.5%), stress for the child (30.3%), and a financial burden (36.9%) were mentioned most frequently. There appear to be more parental problems than expected associated with helmet therapy. Medical experts should take this into consideration. The indication for a helmet should be evaluated critically and the potential parental burdens should be addressed during counselling.

Key words: positional cranial deformity  
parental perception; helmet therapy.

Accepted for publication 7 October 2014  
Available online 4 November 2014

Positional cranial deformity in early childhood is widespread and parents have become increasingly aware of the problem. Many scientific studies over last two decades have investigated the aetiology, prevalence, risk factors, and different therapeutic approaches, and several systematic literature reviews have been published on the topic.<sup>1–6</sup> There is evident interest in helmet therapy and its effectiveness.<sup>7–13</sup> None of the other existing treatments has been described in such detail from all

medical aspects. A PubMed search using the key words 'helmet therapy plagiocephaly' revealed 122 records alone. However, success is mainly dependent on the consequent application, and therefore ultimately on parental compliance.

Another unresolved point is the differing attitudes towards helmet therapy among medical professionals.<sup>14</sup> Despite the proven effectiveness of the helmet, this therapy remains controversial. The ongoing open debate between specialists,

as well as the question of compliance, has led our scientific interest away from earlier issues.

No matter how specialists discuss this treatment modality, they should incorporate parental perception of the therapy in an overall assessment. Unfortunately scientific data regarding this issue are very limited.

How do carers deal with the problem? After all they are the ones who have to carry the burden of care. As well as the

Table 1. Gender distribution and diagnoses.

	Helmet therapy			
	No		Yes	
	Number	Frequency	Number	Frequency
Plagiocephaly	66	68.8%	80	65.6%
Brachycephaly	13	13.5%	13	10.7%
Plagiocephaly and brachycephaly	17	17.7%	29	23.8%
Female	31	32.3%	35	28.7%
Male	65	67.7%	87	71.3%

childrens' lives, the parents' lives are also significantly, and in different ways, affected by a decision for or against helmet therapy. Therefore we aimed to move our focus away from the professional and medical point of view of the craniofacial specialist and investigated parent perspectives and the burden of care related to helmet therapy.

## Materials and methods

Of 421 children with positional cranial deformities treated in our department, 218 could be included in the study. Criteria for inclusion were the ability to contact the parents and their agreement to participate in the survey. Of the study children, 122 had undergone helmet therapy and 96 had not. The gender distribution and specific diagnoses are presented in Table 1. Unfortunately many of the parents and carers could not be reached due to new and therefore unknown contact data. Of the 203 children who were not included in the study, 117 had been treated with a helmet and 86 had not.

Plagiocephaly was described using the cranial vault asymmetry index (CVAI in %), and brachycephaly with the cranial index (CI in %), as reported by Loveday and de Chalain.<sup>15</sup> CVAI = difference in cranial diagonals/shorter cranial diagonal  $\times$  100; CI = cranial width  $\times$  100/cranial length. The advantage of the indices used is that they allow a comparison independent of the individual childrens' head sizes. CVAI scores  $>$ 3.5% indicate a relevant cranial asymmetry, and normal values for the CI are  $<$ 85%.

Children who underwent helmet therapy had an ultrasound examination prior to treatment in order to exclude a craniostosis. The individual helmets were made by Cranioform (Siegen, Germany). The overall cost of treatment was approximately 1800 Euros, depending on the duration of treatment and the frequency of consultations. For an optimal outcome, parents were instructed to ensure that the helmet was worn for 23 h a day, to check for correct helmet positioning regularly, and to clean the helmet daily.

A structured telephone interview based on a questionnaire was used for data collection. The questionnaire contained single-choice as well as multiple-choice categorical questions. Questions covered satisfaction with the outcome, breaks in treatment, as well as potential treatment-associated problems for the child and also for the parents. We also tried to specify and quantify the reasons for the problems that occurred (Appendix). Parents were questioned after a mean period of 22.48 months (range 0.39–52.08 months).

The statistical analysis was performed using IBM SPSS Statistics for Windows, version 21.0 (IBM Corp., Armonk, NY, USA).

## Results

The initial severity of the cranial deformity differed between the two groups. Children who did not undergo helmet therapy were less affected on average (Table 2). The mean duration of therapy in the helmet

group was 4.52 months (range 1.38–8.39 months).

The survey revealed good subjective overall carer satisfaction (90.8%) with the outcome of therapy, regardless of whether helmet therapy was used or not. However, parents whose child had undergone helmet therapy were more often satisfied (97.5%) than the others (82.3%).

In the conservative management group (positioning, physiotherapy, and/or osteopathy), 65.6% reported a large improvement in cranial shape, whilst a quarter (25.0%) saw only minor and 9.4% no improvement. The reasons why helmet therapy was not initiated are shown in Fig. 1. Seventy-six percent of these parents would decide against the use of a helmet again. Twenty-four percent of parents would retrospectively have preferred therapy with a helmet.

The majority of parents (69.7%) in the helmet group perceived therapy as being unproblematic for the child; 30.3% reported that their child was somehow affected by the helmet. In relation to the number of mentioned complications the percentage of sweating and skin problems was even higher (51.1% and 31.9%) as shown in Fig. 2.

A high number of parents indicated personal strain in connection with the helmet therapy. More than half (54.9%) had minor problems and 25.4% had major problems; a minority (19.7%) reported no problems. A detailed analysis and quantification of the stress that occurred are presented in Fig. 3. As well as the financial burden, social conflicts, disputes, and stress for the child were frequently mentioned.

Another question in the interview specifically addressed the issue of with whom disputes arose (Fig. 4).

A critical aspect in all medical therapy is patient compliance. Interruption to helmet therapy (27.0%) or termination of therapy (4.9%) was reported for 31.9% of patients. However, at 4.9%, the termination rate is quite low. In almost every case where treatment was terminated, the parents justified this by stating that helmet-associated problems were affecting the child. Parental reasons were stated in only one case.

Financial aspects are also important. In the patient cohort of this study, health insurance companies paid for the helmet in 54.9% of cases and some of the insurance companies only partly refunded the complete amount (28.7% of cases); 45.1% of the carers had to cover the costs themselves. Thirty-nine percent perceived the price as being too high and 33.6% as

Table 2. Initial severity of plagiocephaly and brachycephaly.

Severity	Helmet therapy					
	No			Yes		
	Mean	Median	SD	Mean	Median	SD
CI initially (%)	97.88	99.22	4.64	104.50	103.95	4.89
CVAI initially (%)	8.69	8.24	3.13	13.76	13.28	4.10

SD, standard deviation; CI, cranial index; CVAI, cranial vault asymmetry index.

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