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Research Paper
Craniofacial Anomalies

Parental perception of treatment and medical care in children with craniosynostosis

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Abstract. Surgery for craniosynostosis implies a relevant strain on the child and the parents. The development of the child's self-perception and self-confidence is mainly influenced by parental attitudes. The outcomes of 46 patients were analysed, taking into consideration parental perceptions. Parents were asked to indicate their satisfaction with the medical care and treatment provided using a questionnaire. Aesthetics were evaluated by the parents and doctors using a score (1 = perfect, 5 = deficient). Major surgical complications (2.2%) were reported only in the case of complex synostosis. Reoperation was necessary in 2.9% of isolated cases and 45.5% of complex cases. In general, parents were satisfied with the medical (1.3) and nursing (1.6) inpatient care. Aesthetic assessments differed between parents and surgeons, although not significantly ($P = 0.27$). The surgeons perceived the results to be better than the parents, especially for complex synostosis (1.3 vs. 2.7). Alopecia and persistent asymmetry led to a worse perception of aesthetics. Persistent bone defects did not influence parental satisfaction. All participating parents would opt for surgery again. Surgery led to satisfactory results with a low risk of severe complications. Nevertheless, the outcomes and limits of the surgical procedure must be communicated effectively to parents, especially in complex cases, to avoid a mismatch in expectations. It would be desirable to implement structured interviews with parents during regular treatment management.

Key words: craniosynostosis; aesthetic outcome; parental satisfaction.

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The reported incidence of craniosynostosis ranges from 1:2000 to 1:2500,[1,2] with an increasing trend in all ethnic groups.[3] It varies greatly in presentation, ranging from single-suture synostosis with a more or less aesthetic problem, up to complex forms or pansynostosis with a disfiguring appearance and severe functional, sometimes life-threatening impairments. In particular, the syndromal forms may not only affect the cranium but also the airways, midface, and other organs, with further disturbances in function, aesthetics, and development. Treatment may be challenging and requires a multidisciplinary and individual approach in order to offer the best options for the normal development of the child in every respect.

Since Tessier introduced craniofacial surgery in 1967, surgical interventions in early childhood have become a major and important part of treatment.[4,5] They improve the cranial shape and create space for the brain, and thereby lay the foundation

Table 1. Syndromes and types of affected sutures.

Metopic	Coronal		Lambdoid		Complex	
$n = 14$ (30.4%)	$n = 14$ (30.4%)		$n = 7$ (15.2%)		$n = 11$ (23.9%)	
	Unilateral	$n = 9$ (64.3%)	Unilateral	$n = 5$ (71.4%)	Pansynostosis	$n = 2$ (18.2%)
	Bilateral	$n = 5$ (35.7%)	Bilateral	$n = 2$ (28.6%)	3 sutures	$n = 3$ (27.3%)
					2 sutures	$n = 6$ (54.5%)
	Saethre–Chotzen	$n = 3$ (21.4%)			Crouzon	$n = 6$ (54.5%)
	Trisomy 21	$n = 1$ (7.1%)			Pfeiffer	$n = 2$ (18.2%)
					Saethre–Chotzen	$n = 1$ (9.1%)

for normal neurological development. The risks and complications are well known.

All interventions are associated with a relevant strain on the child and the parents, not only in a physical sense, but also in a psychological and emotional sense. Continuous assessment of the outcomes of surgical therapy should be performed in order to critically assess the quality and to detect shortcomings. Unfortunately most investigations have focused only on the medical perspective, which, without a doubt, is very important. However, as the child and the parents are the persons who have to carry the main stresses and strains associated with the disorder and its treatment, their opinions should ideally be part of any outcome evaluation. This topic has not been adequately addressed in the medical literature. Therefore, the present study was performed to focus on the parental perception of the quality of the medical service, the communication between medical doctors and parents, and the aesthetic outcomes.

Materials and methods

Patients with different forms of craniosynostosis who underwent remodelling of the cranium in the form of a fronto-orbital or occipital advancement from 2000 to 2012 were included in this study. Isolated metopic, coronal, lambdoid, and all complex synostoses were investigated. Sagittal sutures were excluded, as they were treated with a craniectomy. The distribution of the patients by type of craniosynostosis is shown in Table 1.

As craniosynostosis is a rare disease, only 46 patients – 26 male and 20 female – fulfilled the criteria for study inclusion.

One single craniomaxillofacial surgeon and one single neurosurgeon jointly operated on the children. Surgery was performed with an open approach for both fronto-orbital and occipital advancement. The tongue-in-groove technique was used for the fronto-orbital advancement and the occipital advancement was performed according to Zöller.[6] Resorbable plates and sutures were used for fixation.

The medical data were collected by retrospective review of the medical charts. The following parameters were considered of interest: age at the time of first consultation and surgery, incidence of surgical complications, duration of inpatient treatment, necessity of further surgery, undesired results such as bony bumps (probably due to resorbable osteosynthesis plates), persistent asymmetry, scarring, alopecia, and bony defects.

The aesthetic outcome, always a subjective and soft criterion, was evaluated in terms of a harmonious and satisfying head shape and look. It was rated by the attending surgeons during follow-up, as well as by the parents, using a questionnaire with a scoring system (1 = perfect, 5 = deficient). Additionally, the evaluations were assessed against the registered medical data regarding the presence of undesired surgical results. This was of interest particularly for cases with scores <2 in order to identify possible reasons for the inferior rating.

The questionnaire also contained questions on the perceived quality of (1) the communication (preoperative consultation, postoperative information, and discharge interview, rated as 'perfect', 'largely appropriate', 'could be improved', or 'missing'), and (2) the medical and nursing inpatient service and attendance in the craniofacial outpatient clinic (rated as 1 = perfect to 5 = deficient). Parents were further asked (1) whether they would opt for the procedure again (rated as 'same way again', 'surgery again but not in the same clinic', or 'no surgery'), (2) how they perceived a distributed list of telephone numbers of other affected families who had undergone the same procedure (rated as 'not received', 'very helpful', 'helpful', 'not very helpful', 'unsettling', or 'not used'), and (3) how they perceived the duration of the hospital stay (rated as 'too short', 'appropriate', or 'too long'). The response rate to the questionnaire was 52%.

All data were transferred to JMP 10 statistical program (SAS institute Inc., Cary, NC, USA). Most data were analysed descriptively. For the statistical comparison of aesthetic outcomes as perceived by the parents and doctors, the significance level was set at 0.05.

Results

Analysis of medical and perioperative data

The first consultation at the special craniofacial outpatient clinic, as well as the surgery, took place much earlier for children with single-suture synostoses compared to those with complex forms. One child in this group, who had come from abroad, presented for the first time at the age of 4 years (Fig. 1).

The data from the chart review for the medical and surgery-associated parameters are presented in Table 2. The surgical complication rate for the surgical techniques applied for fronto-orbital and occipital advancement was found to be 15.2%. There was only one severe complication (2.2%), with an iatrogenic injury of the sinus followed by temporary disturbance

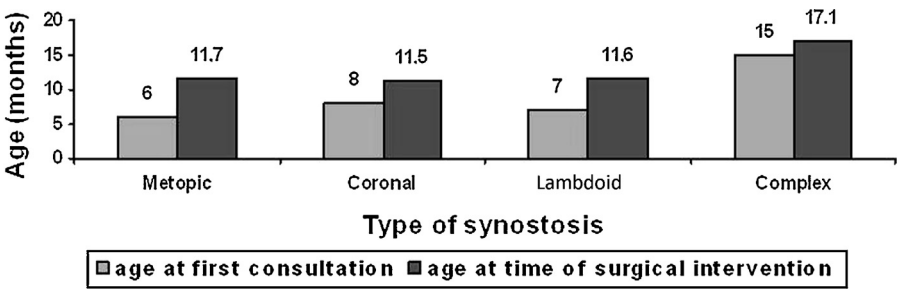

Fig. 1. Age distribution of the patients.