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Family-centred care during midface advancement with a rigid external device: What do families need?

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KEYWORDS

Craniosynostose syndromes;
Midface;
Distraction osteogenesis;
Craniofacial surgery/psychology;
Patient care team/nurse practitioners

Summary Midface advancement with distraction osteogenesis using the rigid external device (RED) is an effective but invasive treatment to correct the hypoplastic midface. This study draws up an inventory of the stressors, needs and coping strategies of families during this treatment, to determine the best conditions for family-centred care.

Data were collected by reviewing the patients' files and administering semi-structured interviews. The data were analysed using the software program Atlas.ti and were re-analysed by an independent researcher. Parents and patients were interviewed separately.

Fourteen families participated. Four patients had an absolute indication for surgery. All families were eager to have the patient's facial appearance improved. Nevertheless, despite psychological counselling, they experienced stress when confronted with the changed facial appearance. Another stressor was weight loss. Six patients were in a state of acute malnutrition and needed supplementary feeding.

We conclude that the best conditions for family-centred care should be aligned to the different phases of treatment. Leading up to surgery it is important to screen families' expectations regarding aesthetic, functional and social outcomes and to assess their capacity to cope with the long treatment and effects of changed facial appearance. Peer contact and psychosocial training to increase self-esteem are tools to enhance co-operation and satisfaction.

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During the distraction and stabilisation phase, we advise the monitoring of nutritional intake and weight. During all phases of treatment easy accessibility to the team is recommended.

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Midface hypoplasia in Apert and Crouzon syndromes can negatively influence a person's physical and emotional performance.¹ A high level of parents' and patients' co-operation and compliance is mandatory for successful completion of midface advancement with the rigid external device (RED) frame and the long aftermath.^{2,3} The RED may give rise to sleeping problems, feeding problems, difficulties in speech and school absenteeism.^{2,3} Family-centred care (FCC) is advised in health care for children with chronic conditions, focussing on decreasing stress, informational support and empowerment.⁴ This study draws up an inventory of the stressors, needs and coping strategies of families during midface advancement with distraction using the RED. The clinical practice study reported here adopted a qualitative research method to determine the best conditions for FCC.

Method

A retrospective qualitative study was performed. A total of 16 families were eligible for this study.

Inclusion criteria were: treatment by the team of the Dutch CranioFacial Centre between 2006 and 2012; sufficient command of the Dutch language and having the cognitive ability to understand and answer the questions. Data were collected by reviewing the patients' files and administering semi-structured interviews by one investigator.

Topics of interest identified through a prior pilot study formed the basis for the semi-structured interviews. Pre- and postsurgical satisfaction with the facial appearance were scored with the Visual Analogue Scale (VAS). Interviewing patients with developmental delay as well as interviewing young children required a special approach, as recommended by Finley et al.⁵ and Blades.⁶ For example, no time-related but event-related questions were asked; short questions and props were used and it was checked how the question was understood; the open-ended questions were asked in a conversational style. Parents and

patients were interviewed separately to avoid mutual influencing. The study was approved by the Erasmus MC medical ethics review board (not subject to the Dutch Medical Research Involving Human Subjects Act).

Data analysis

Interviews were recorded on voice recorders and transcribed. The interview data were compared and complemented with patient file data. This text was discussed with the interviewee and amended if needed. ATLAS.ti[®] software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to analyse the data by categorising in codes and themes. Themes that were identified were reasons for surgery (indication), impact and support (Figure 1). To obtain validity, data were also analysed by an independent researcher. The coded data were compared and adjusted until conformity was obtained. Atlas.ti also provides tools to annotate findings in the primary data material and to visualise complex relations between them. In addition, it provides analytical and visualisation tools designed to open new interpretative views on the material.

Results

Of the 16 eligible families, two could not participate due to personal circumstances. One parental pair did not give permission to include their child; interviewing her would be too confrontational. Thus, a total of 13 families and one parental pair were included. Nine children followed regular school education (Intelligence Quotient (IQ) >85), three required supported education (IQ 70–85) and one needed special education (IQ 50–70).

Indication

Midface surgery should ideally be staged to coincide with facial growth patterns, meaning early surgery between the

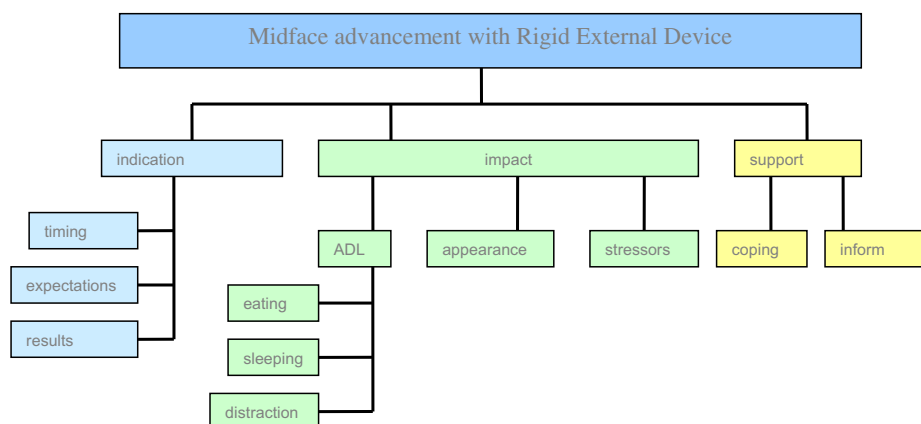


Figure 1 Codes and themes.

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