CLINICAL STUDY

Impact of cleft lip and/or palate in children on family quality of life before and after reconstructive surgery

Macho P, Bohac M, Fedele J Jr, Fekiacova D, Fedele J Sr

Clinic for Plastic, Aesthetic and Reconstructive Surgery Medical Faculty, Comenius University Hospital, Bratislava, Slovakia. machopaloo@yahoo.com

ABSTRACT

BACKGROUND: The aim of the study was to evaluate the impact of cleft lip/palate children together with consequent treatment on quality of family life using standardized questionnaire. Different to previous studies the evaluation of quality of family life by questionnaire was realized twice in the same group of families (before the reconstructive surgery and several months after palatoplasty).

METHODS: The study was conducted in 40 families divided in two groups: 20 families with children with cleft lip (CL), 20 families with children with cleft lip and palate (CLP). The questionnaire of the Impact on Family Scale was used for evaluation of the influence of orofacial clefts on parent’s quality of life. Evaluations were made at the second month of child’s life and at one year of child’s life with reciprocally comparison.

RESULTS: The higher impact of children with CLP on quality of family life was noted at 2 months and 1 year of child’s age as compared to the impact of children with CL. The reduction of impact on quality of life after surgical correction was observed in families of children with CL at one year of child’s age. This decrease of influence on family quality of life was due to significantly lower impact in strain and economic dimensions in families with CL children after operation. However, in the group of families with CLP children no significant changes in the impact on family quality of life were noted when compared to the values before and shortly after the reconstructive surgery.

CONCLUSIONS: This study showed that orofacial clefts in children influence markedly the quality of their family life. The higher impact of children with CLP on quality of family life as compared to children with CL was noted and this impact in CLP group was not influenced shortly after reconstructive surgery. It is suggested that appropriate medical care in Cleft Centre with special psychological support may lead to improvement in quality of life for families with cleft lip and palate children (Tab. 2, Fig. 2, Ref. 14). Text in PDF www.elis.sk.

KEY WORDS: cleft lip, cleft palate, quality of life, the impact in family scale.

Introduction

The increasing attention in medical care is focused on the studies of impact of chronic illness and disability in children on family life (1, 2, 3, 4, 5). Cleft of lip and palate is one of the most common congenital craniofacial malformation that may impose a large burden on the psycho-socio-economic well-being of the affected individuals and their families (6, 7, 8). Newborns with cleft lip or cleft lip with palate have acquired stigmatized face, what leads parents to new challenge, which has to be overcome. Whole after-birth period together with post-operation phase impacts the patient’s quality of life and mainly influences their parents (6, 7, 9, 10). However, the number of clinical studies evaluating the impact of children with cleft lip/palate on the family life is relatively small (6, 7, 9, 10, 11). This was the reason for realization of this study evaluating the quality of life in parents of children registered in our Cleft Centre. The aim of the study was to evaluate the impact of cleft lip/palate children together with consequent treatment on quality of family life using standardized questionnaire. Different from previous studies (9, 10, 11), the evaluation of quality of family life by questionnaire was realized twice in the same groups of families. The first questionnaire was filled out the second month of children’s life (before the operation), the second questionnaire was filled out after reconstructive surgery at the time of the first year of child’s age.

Patients and method

Patients with cleft lip (CL) or with cleft lip and palate (CLP), who were treated in Cleft Centre at the Clinic for Plastic Surgery, Comenius University Hospital, Bratislava and their families were included in this study. Inclusion criteria for entry the prospective 5 years running study were fulfilled by 40 families, and these families were divided in two equal groups. The first group included 20 families with children affected by cleft lip only. The second group included equally 20 families with children with cleft lip and palate. Lip correction was realized in the third month of patient’s life. In case of need (for cleft lip and palate children), the palate
closure was realized at the sixth month of patient’s life. All procedures were performed according to operation protocol valid in our Cleft Centre. The informed consent was obtained from all participating families.

The impact on family scale questionnaire (12) was used for evaluating the impact of cleft lip/palate and following operative treatment on the quality of parent’s life. The questionnaire was filled first time at the second month of child’s age (before the operation), than the second questionnaire with the same questions at the age of one year of affected child with correlative comparison. The questionnaire involves 27 questions with one of four possible answers in points (high impact 4 points – low impact 1 point) and the degree of impact on family was quantified by reached points. Four dimensions in the questionnaire were marked as the most important and analyzed: economic (changes in the family’s economic status, 6 items), social (the quality and quantity of interaction with other persons outside the family, 4 items), familial (quality of interaction within the family unit, 7 items) and strain (subjective burden experienced by the primary caretaker, 10 items). The data were analyzed using statistical t-test method and SPSS software version 10.0.

Results

The comparison of averages of total points in the group of families of children with cleft lip only to the group of patients with cleft lip and palate showed higher impact of combined cleft lip and palate on family life (Tab. 1). The differences were significant at 2 months and also at 1 year of children age. The significant decrease of the average of total points (11.5 %) (p < 0.05) was noted in the families of children with CL after reconstructive surgery at the age of one year (Tab. 1). However no significant changes in impact on family life were noted in the group of children with CLP after the operation.

The average scores of impact on family life in economic and social dimensions in the questionnaire were lower in comparison to familial and strain dimensions in both CL (Fig. 1) and CLP groups (Fig. 2) at 2 months and also at 1 year of child’s age. Significant decrease in average of score points in strain dimension (anxiety feelings) on quality of life was observed in families with CL children after operations (Fig. 1, 15.9 % decrease, p < 0.001). However, the score in other dimensions (social, familial) decreased only slightly and improvement of the quality of life was not significant. There were no significant differences in average values of the score of points in economic, social, familial and strain dimensions before and after the surgery in families with children with cleft lip and palate (Fig. 2).

The average of number of points in response to individual items of questionnaire in the four dimensions showed that there are differences in the impact of dimensions on quality of life in

<table>
<thead>
<tr>
<th>Group</th>
<th>CL 2 months</th>
<th>CL 1 year</th>
<th>CLP 2 months</th>
<th>CLP 1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of values</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>MEAN±SE</td>
<td>56.9±2.93</td>
<td>50.9±2.83*</td>
<td>64.9±2.81†</td>
<td>62.0±3.06‡</td>
</tr>
<tr>
<td>Median</td>
<td>55.5</td>
<td>47.0</td>
<td>62.0</td>
<td>60.5</td>
</tr>
<tr>
<td>25% percentil</td>
<td>48.0</td>
<td>44.0</td>
<td>57.0</td>
<td>48.0</td>
</tr>
<tr>
<td>75% percentil</td>
<td>64.8</td>
<td>53.8</td>
<td>70.0</td>
<td>72.0</td>
</tr>
</tbody>
</table>

CL – families with children with cleft lip, CLP – families with children with cleft lip and palate 2 months, 1 year – the age of children at the collection of questionnaire. Statistical significance of differences: *CL 2 months: CL 1 year p ≤ 0.05, † CL group: CLP group p ≤ 0.05

<table>
<thead>
<tr>
<th>Group</th>
<th>CL 2 months</th>
<th>CL 1 year</th>
<th>CLP 2 months</th>
<th>CLP 1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimension items</td>
<td>6</td>
<td>1.55±0.09</td>
<td>1.35±0.07*</td>
<td>2.07±0.11†§§</td>
</tr>
<tr>
<td>Economic</td>
<td>4</td>
<td>1.45±0.05</td>
<td>1.26±0.06</td>
<td>1.93±0.12§</td>
</tr>
<tr>
<td>Social</td>
<td>7</td>
<td>2.91±0.11</td>
<td>2.81±0.11</td>
<td>3.08±0.10</td>
</tr>
<tr>
<td>Familial</td>
<td>10</td>
<td>2.13±0.08</td>
<td>1.80±0.06**</td>
<td>2.31±0.08</td>
</tr>
</tbody>
</table>

CL – families with cleft lip children, CLP – families with children with cleft lip and palate 2 months, 1 year – the age of children. Statistical significance of differences between groups: 2 months: 1 year * p ≤ 0.05, ** p ≤ 0.01, CL – CLP § p ≤ 0.05 §§ p ≤ 0.01
families of children with CL or CLP. Higher impacts of familial
and strain dimensions were noted in all groups as compared to
economic (financial) and social dimensions (Tab. 2). In fami-
lies having children with CLP higher impact of economic and
social dimensions in comparison to CL was observed at the age
of children of 2 months and also 1 year (Tab. 2). The significant
difference between CL and CLP groups was also noted in strain
dimensions in children 1 year of age, mainly due to decrease of
impact on quality of life in CL group after reconstructive surgery
in children (Tab. 2).

Discussion

The detailed knowledge of impacts influencing the quality of
life in families having children with cleft lips or cleft lip and palate
might support affected families in coping with the particular situ-
ation and providing adequate care for the patients (6). Most of the
previous studies on the effects of oral clefts in children on quality
of life of families have been conducted at different ages with dif-
ferent groups of children and at various periods after palatoplasty
(9, 10, 11, 13, 14). There were no observations on the impact of
orofacial defects in children on the quality of family life before
the operation, thus it was not possible to evaluate the effects of
reconstructive operations. Results of our five years long running
prospective study show evaluation of the impact of cleft lip/palate
in children on parent’s quality of life during the first two months
of child’s life (before the operation) and also at the end of first
year (after reconstructive surgery). This made it possible to com-
pare the immediate effects of reconstructive surgery of clefts on
quality of family life. In the contrary to our expectation the results
revealed low impact of orofacial cleft of children on social inter-
actions and economic burden of family, but very high influence
on family interactions and strain.

The results of our observations during the early period of life
of children with oral clefts showed differences in the impact of
various dimensions of life in families with CL or CLP on quality
of family life. The economic impact was represented by increased
costs for frequent visits for out-patient examinations, (the need for
operative correction at three months and subsequent controls), the
stop in work due to care for a child, causing financial problems
for family. The impact of economic dimension on quality of life
in our study was not so high as compared to familial and strain
dimensions. This is due to the fact that in Slovakia the maternity
leave takes three years, so the feeling of losing the work for the
need of taking care of children has only a low impact.

Social interactions with other people for parents with affected
child represent a low impact on quality of life. The mean values of
points in social dimension showed the higher impact in CLP group
as compared to CL. These results are in agreement with observa-
tions of Kramer et al (9), who described that families with older
children with CL had smaller reduction in family functioning than
families with children with CLP or CP.

The most impacted dimensions influenced by the child’s dis-
ease were interactions inside the family (represented by the feeling
of tightening of the relationship in the family, the need for com-
munication with partner, the feeling of having not enough time
for other members in the family, making the effort for treating the
child as a healthy one). The score of impact in this familial dimen-
sion was not influenced by reconstructive surgery of the defects
after this short period after operation.

The strain (subjective feeling of burden, fatigue for carry for
the child, a worry what happens to the child in the future, interfer-
ence with relatives) is a dimension also with high influence on the
quality of parent’s life. Many times strain is presented as feelings
not being understood by other people, worries about future, feel-
ing of instability in life in crisis when the child is ill, carelessness
when things go allright. However, in this dimension a significant
improvement was noted after one year in CL group as compared
to the impact of cleft in child before the operation. In families with
children with CLP no significant changes in the impact on quality
of family life of this dimension were noted at short period after
CLP reconstruction. It seems reasonable that longer period after
operation in CLP children is necessary to observe also a decrease
of impact on quality of life in strain dimension.

In conclusions our prospective study showed, that clefts in
children influence markedly the quality of their family life. The
higher impact of combined cleft lip and palate of children on
quality of family life was noted as compared to the influence of
children only with cleft lip. A significant decrease of impact in
strain and economic dimensions after reconstructive operation
appeared in families of children with cleft lip. However, no changes
in impact on family life after operation were noted in families
of children with cleft and palate. It is suggested that appropriate
medical care in Cleft Centre with special psychological support
may lead to improvement in quality of life for families with cleft
lip and palate children.

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