

Psychological correlates of affect in parents of children with cleft lip and/or palate

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Abstract. – OBJECTIVE: Parents of children with developmental malformations of different kinds are vulnerable to many consequences of the experienced stress and attempts to cope with it. The aim of the study was to determine the psychological correlates of affect for parents of such children.

PATIENTS AND METHODS: The study included 78 respondents: 69 women and 9 men, aged between 20 and 45, all of them parents of children with craniofacial malformations who had their routine check-ups at an orthodontics clinic. The respondents were evaluated using pencil-and-paper questionnaires, the same survey set for all respondents. The following tools were used in the study: the Inventory for Measuring Coping with Stress (Mini-COPE), the Family Resilience Assessment Scale (FRAS), and the Positive and Negative Affect Schedule (PANAS). The guardians' demographic data and the details of the child's medical history were gathered using a questionnaire constructed for the purposes of the study.

RESULTS: The present study confirmed significant correlations between affect and preferred stress coping strategies, as well as between affect and family resilience. Coping strategies and family resilience, treated as a resource, were also significantly correlated in the group of respondents.

CONCLUSIONS: Mental resilience is an important resource contributing to effective stress coping in a situation where a child suffers from malformation.

Key Words:

Affect, Family resilience, Stress coping, Cleft lip and palate.

Introduction

Clefts are among the ten most common congenital malformations. In Poland, the incidence rate of clefts ranges from 1 in 500 to 1 in 1000 new-borns^{1,2}. This includes morphological abnormalities formed during foetal life and present at birth regardless of when they were diagnosed. The etiology of clefts is multifactorial. Studies conducted so far point to the influence of both genetic and environmental factors. The factors include viral infections of the mother during the first trimester of pregnancy, food poisoning, unhealthy eating habits, severe stress, psychological traumas, parents' age, ionizing radiation, chemical agents, taken medication and hypoxia³. Early prevention based on the knowledge of the risk factors mentioned above, elimination of bad habits, availability of prenatal tests, as well as medical care of high-risk patients at a genetics clinic are all important here. The American Academy of Pediatrics suggested that proper folic acid supplementation lowers the risk of cleft occurrence in a foetus⁴. Usually, parents receive a diagnosis already during prenatal testing. The probability of ultrasound prenatal diagnosis depends on foetal age, skills and competence of the sonographer, as well as equipment quality. Cleft should be diagnosed at the latest during an ultrasound examination, mandatory between the 20th and 22nd week of pregnancy. State-of-the-art 3D/4D imaging enables a more precise image analysis and can be used to diagnose even microform clefts. Prenatal

MRI is an imaging method complementary to ultrasound and it enables more accurate imaging of the extent of the cleft^{5,2}. Accurate information allows doctors and parents to gain some additional knowledge about the cleft, plan a treatment and make a prognosis. Mothers can also consult a psychologist and receive some appropriate counselling, to prepare the family emotionally^{6,7}.

The majority of craniofacial clefts occur separately. However, they may also be diagnosed in the course of other genetic diseases or disorders. As many as 600 syndromes in which cleft lip/palate co-occurs have been described. They include the Down syndrome, the Van der Woude syndrome, the Treacher Collins syndrome, the Patau syndrome, the Edwards syndrome, the Pierre Robin sequence or foetal alcohol syndrome². Cleft lip occurs between the 3rd and 7th week of pregnancy, whereas cleft palate – a bit later, between the 5th and 12th week of foetal life^{1,8}. This kind of defect involves both soft and bone tissues and is a result of impaired fusion of the anatomical structures forming the lip and the palate during foetal development. The face becomes deformed to different degrees and feeding, speech or hearing problems occur, which impact the psychosocial development of the child⁹⁻¹¹.

Clefts require a long, holistic, multi-step treatment aimed at restoring the continuity of the affected anatomical structures. Because the cleft impairs the development and anatomy of the middle craniofacial region and results in feeding, swallowing or speech problems, therapeutic intervention of a multidisciplinary team as soon as possible seems relevant. As a rule, such a team should include an orthodontist, an oral and maxillofacial surgeon, a plastic surgeon, a paediatrician, a phoniatriest, a speech therapist, a dentist working with children, a prosthetist, a geneticist, a psychologist, a social worker and a family assistant¹²⁻¹⁴. Most of all, the intervention involves surgical treatment. The first step is a surgical cleft closure. The American Academy of Pediatrics recommends a two-stage method. During the first stage, at between 3 and 6 months old, the cleft lip is surgically closed. Then, between 9 and 18 months, a surgery to close the cleft palate is performed^{15,4}. In Poland, an alternative one-stage surgery of cleft lip and palate is also performed thanks to which both the hard and the soft tissues of the cleft are closed simultaneously. This enables the normal anatomy of nasal and pharyngeal cavity and craniofacial region before a child starts to speak to be reconstructed, which speeds up the process of speech development. The complete closure of the cleft in the first year of

life also improves the possibilities of further correction of the defect¹⁶⁻¹⁷. At further stages of the multidisciplinary care of cleft patients, regular orthodontic check-ups and monitoring tooth growth and replacement is crucial. It enables an appropriate assessment considering further surgeries such as alveolar bone grafting, which should be conducted at the time of frequent tooth replacement (usually between 8 and 10 years for the two-stage cleft correction) as it optimizes the healing of the graft⁴. For the one-stage treatment, grafting is done much earlier, i.e., between 2 and 3 years old¹⁸. Orthodontic treatment is an important element of the therapy used for cleft patients, as it complements the performed surgeries, corrects the co-occurring malocclusion, and as a result contributes to the restoration of normal face anatomy. Apart from the surgical or orthodontic treatment that restores the aesthetics and functions of the tissues affected by the cleft, the psychological support that eliminates the emotional, social and behavioural problems frequently associated with the defect is also vital for the proper development and functioning of a person. A team of psychologists is part of the whole treatment process also to hear the child's voice and obtain their perspective¹⁹.

In the case of chronic disorders, which clefts can be part of, trauma is not just a single event. It is long-lasting and forces the family to adapt to the changing defect-related circumstances. The fact that a child is diagnosed with a cleft, then the course of the disease, as well as long hospitalisation and the necessity to organise one's life with the child's needs in mind, it all poses many new challenges to the guardians of the child. Studies show that fathers often distance themselves from the child and wife, succumb to addictions, devote themselves to work or abandon their family altogether when they find out about the child's malformation²⁰.

Among many different factors involved in the process of coping with a difficult situation, great emphasis has been put on resilience over recent years. Family resilience is its ability to cope with new, possibly destructive, life challenges²¹. According to Walsh, it calls for the initiation of a process that would support positive adaptation to adversities. This ability enables both individuals and whole families to effectively react to difficulties as they occur and cope with them or even grow thanks to them. Walsh enumerates three key processes that, according to her, determine the effective functioning of a family and its resilience. These processes may reduce stress and vulnerability in high-risk situations, foster healing and predispose families to grow because of a

crisis²¹. The three processes include family belief systems (shared vision of reality which strongly influences the perception of the crisis and one's abilities to overcome it), organizational patterns (flexibility and adaptability to existing requirements and conditions) and the communication processes (clear, consistent messages and a high level of trust).

The family resilience theory assumes that thanks to overcoming the adversities, a family can not only return to 'normal' life but also experience growth and transformation of the family as a whole but also of its particular members and relationships between them²².

The research conducted on a group of American families dealing with alcohol addiction revealed that while some of the families suffered very negative consequences of the addiction, which weakened them, there were also many families that could function efficiently and had developed despite the problem. Family resilience was the differentiating factor²³. Byra and Parchomiuk's 2018 study²⁴ conducted on a group of mothers of disabled children showed that resilience is positively correlated with problem-focused coping strategies that imply assigning meaning of the occurring situation, and negatively correlates with emotion-focused and avoidance coping strategies.

The aim of the study was to verify the hypothesis that assumed a correlation between family resilience and parents'/guardians' affect and applied stress coping strategies. The study also aimed to find the psychological correlates of parents'/guardians' affect.

Patients And Methods

The aim of the present study was to determine the correlates of affect experienced by parents of children with clefts and describe how particular coping strategies correlate with parents' affect and how important in this process is a social resource called resilience. The research model is shown in Figure 1.

Research Procedure

In the study, parents and guardians of children under 5 years old and born with a facial cleft were included. Two methods were used, namely the pencil-and-paper method (53%) and an online questionnaire (47%).

The pencil-and-paper evaluation was carried out at the Specialized Dental and Medical Care

Centre of the Poznań University. The respondents were parents and guardians of children who were in the care of the centre. Parents and guardians were asked to fill in a questionnaire during check-ups at the centre. The online questionnaire was disseminated via social media, in group gathering parents of children with clefts. Regardless of the evaluation method, every respondent was informed of the aim of the evaluation and that their participation is voluntary. They were also informed that they can withdraw from the study at any time, without giving a reason. Personal data protection information was also provided. The data were gathered from January 2019 to January 2020. The respondents were asked to fill in a questionnaire consisting of two parts: the first pertaining to the parent's/guardians' demographic data, and the second pertaining to the child's details. The first part included data such as age, sex, guardians' education, place of residence, current employment, family status, number of children in the family and number of chronically ill children in the family. The second part asked about the child's medical history: diagnosis, applied treatment, medical centre responsible for the treatment, concurrent diseases and disorders, concurrent intellectual disability and medical recommendations.

Study Group

The study group consisted of parents of children with cleft lip and/or palate.

The study included a total of 78 participants: 69 women (88%) and 9 men (12%), aged from 20 to 45 years.

As many as 74.5% of the participants were married, 10% were engaged, 10% lived together in an informal relationship and 5% were single.

Among the respondents, 55% received high-

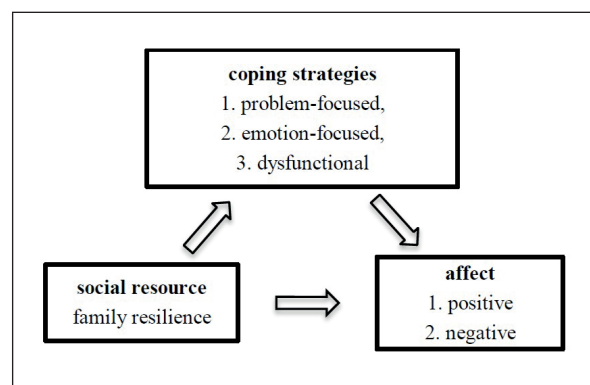


Figure 1. Diagram of the research model.

er education, 13% incomplete higher education, 11.5% secondary vocational education, 7.5% secondary education, 7.5% post-secondary education and 5% vocational education.

As far as the place of residence was concerned, 27% lived in the country, while the rest in a town or a city: 24.5% with over 500 thousand residents, 19% with up to 50 thousand residents, 18% with between 50 and 200 thousand residents and 11.5% in a city between 200 and 500 thousand residents.

As many as 50% of the respondents were employed, 34.5% managed the household, 13% were on parental leave, 1 person was unemployed, and 1 person was a student and an employee at the same time.

Moreover, 15% declared that their children were diagnosed with intellectual disability. For all cases, it was a co-existing Down syndrome.

Research Tools

Inventory for Measuring Coping with Stress (Mini-COPE)

The tool consists of 28 statements describing different behaviours that can occur in response to a stressful situation. For every statement, the respondent has to choose an answer rated on a 4-point scale, where 0 means “I usually don’t do this at all”, 1 – “I rarely do this”, 2 – “I often do this” and 3 – “I almost always do this”. The questionnaire allows the measurement of three kinds of coping with stress (problem-focused, emotion-focused and dysfunctional) described using 14 different stress coping strategies. Based on the questionnaire, 14 scores are obtained for the following strategies respectively: Active Coping, Planning, Positive Reinterpretation, Acceptance, Humour, Turning to Religion, Seeking of Emotional Social Support, Seeking of Instrumental Social Support, Competing Activities, Denial, Venting of Emotions, Psychoactive Substance Use, Restraint Coping, Self-blaming.

Family Resilience Assessment Scale (FRAS)

The FRAS questionnaire is used to measure family resilience and its various aspects included in the following six subscales: Family Communication and Problem Solving, Utilizing Social and Economic Resources, Maintaining a Positive Outlook, Family Connectedness, Family Spirituality and Ability to Make Meaning from Adversity. In the original version, the questionnaire consists of 54 items. Answers are given on a 4-point scale, where 1 means “Strongly agree”, whereas 4 means “Strongly disagree”²⁵.

For the purposes of the study, the questionnaire

was shortened to include 15 items, out of which 14 were taken from the original version and one was added for the Maintaining a Positive Outlook subscale. An additional change was the extension of the answer scale by adding the “I have no opinion” option.

Because of these modifications, the scoring also changed. Scores for particular subscales were not calculated and for further analysis only the overall score of family resilience, calculated as the sum of all answers, was included. Possible scores ranged from 15 to 75 points.

Positive and Negative Affect Schedule (PANAS)

To measure the guardians’ affect, the PANAS scale by Watson and Tellegen was used²⁶. The questionnaire consists of 20 items out of which one half is used to measure the positive affect and the other half – to measure the negative affect. Two separate results are obtained respectively. Each item is a different adjective describing a different mood (e.g., Distressed, Inspired, Proud). The respondents’ task is to identify to what extent they have felt like this over the past month. Answers are given on a 5-point scale, where: 1 means “Very slightly or not at all”, 2 – “A little”, 3 – “Moderately”, 4 – “Quite a bit” and 5 – “Extremely”²⁷.

Results

Statistical Description of Variables

Table I presents the descriptive statistics of variables and normality test results. The variables were not normally distributed, apart from the positive affect scale of the PANAS questionnaire and the overall score for the emotion-focused coping scale measured by the Mini-COPE questionnaire (Table I and II).

Table I presents the results of the correlation between family resilience and other variables. Family resilience was significantly correlated with positive affect (Pearson’s $r = 0.25$, $p < 0.01$) and with negative affect (Pearson’s $r = -0.21$, $p < 0.05$).

Family resilience was significantly correlated with problem-focused coping (Pearson’s $r = 0.34$, $p < 0.01$), as well as with two analysed strategies, namely Active Coping (Pearson’s $r = 0.29$, $p < 0.01$) and Seeking of Instrumental Social Support (Pearson’s $r = 0.21$, $p < 0.05$). Additionally, family resilience was significantly correlated with Positive Reinterpretation (Pearson’s $r =$

0.22, $p < 0.05$) and with Seeking of Emotional Social Support (Pearson's $r = 0.19$, $p < 0.05$), as well as with the overall score for the emotion-focused coping scale (Pearson's $r = 0.17$, $p < 0.05$). The correlation between family resilience and the Turning to Religion subscale was not significant (Pearson's $r = 0.06$, $p > 0.05$). On the other hand, family resilience was significantly correlated with the following subscales of dysfunctional coping: overall score (Pearson's $r = -0.31$, $p < 0.01$), Restraint Coping (Pearson's $r = -0.33$, $p < 0.01$), Psychoactive Substance Use (Pearson's $r = -0.30$, $p < 0.01$), Self-blaming (Pearson's $r = -0.26$, $p < 0.01$), Denial (Pearson's $r = -0.23$, $p < 0.01$).

Table III presents the correlation between the PANAS scale scores and the other variables. All correlations of positive affect with problem-focused coping subscales were significant: overall

score (Pearson's $r = 0.35$, $p < 0.01$), Active Coping (Pearson's $r = 0.26$, $p < 0.05$), Seeking of Emotional Social Support (Pearson's $r = 0.19$, $p < 0.05$).

The results indicate that there are significant positive correlations between the analysed coping strategies and positive affect. As regards the negative affect, no correlations were observed. The highest score was obtained for the correlation between the positive affect and the overall score for problem-focused coping (Pearson's $r = 0.35$, $p < 0.01$). A slightly lower score was observed for the Active Coping strategy (Pearson's $r = 0.26$, $p < 0.05$) and the lowest score was recorded for the Seeking of Instrumental Social Support strategy (Pearson's $r = 0.19$, $p < 0.05$). The correlations of negative affect with the above-mentioned subscales were not significant. With respect to the correlation of positive affect with the emotion-foc-

Table I. Descriptive statistics of variables and normality test results.

Variable	M	SD	Kolmogorov-Smirnov Z-Test	
			Z	p
PANAS				
Positive Affect	33.78	6.25	0.72	0.200
Negative Affect	22.37	6.89	0.14	0.01*
FRAS				
Family Resilience	59.42	13.05	0.19	<0.001*
Mini-COPE				
Problem-focused Coping				
Overall Score	14.32	2.63	0.16	<0.001*
Active Coping	5.07	1.03	0.28	<0.001*
Planning	4.97	1.09	0.25	<0.001*
Seeking of Instrumental Social Support	4.27	1.36	0.17	<0.001*
Emotion-focused Coping				
Overall Score	17.17	3.78	0.09	0.200
Acceptance	4.66	1.11	0.20	<0.001*
Humour	1.59	1.35	0.19	<0.001*
Turning to Religion	2.50	1.98	0.17	<0.001*
Seeking of Emotional Social Support	4.44	1.21	0.18	<0.001*
Positive Reinterpretation	3.99	1.37	0.21	<0.001*
Dysfunctional Coping				
Overall Score	12.55	6.35	0.12	0.004*
Competing Activities	3.10	1.49	0.18	<0.001*
Denial	1.65	1.49	0.22	<0.001*
Venting of Emotions	2.86	1.29	0.16	<0.001*
Psychoactive Substance Use	0.83	1.52	0.43	<0.001*
Restraint Coping	1.50	1.72	0.22	<0.001*
Self-blaming	2.60	1.76	0.13	0.003*

*The variables distribution significantly differed from the normal distribution.

cused coping subscales, only the correlation with the Positive Reinterpretation strategy was significant (Pearson's $r = 0.35, p < 0.01$). With respect to the correlation of positive affect with the emotion-focused coping subscales, none of the correlations were significant.

On the other hand, positive affect was significantly correlated with all the subscales of dysfunctional coping: overall score (Pearson's $r = -0.43, p < 0.01$), Psychoactive Substance Use (Pearson's $r = -0.34, p < 0.01$), Denial (Pearson's $r = -0.33, p < 0.01$), Self-blaming (Pearson's $r = -0.32, p < 0.01$), Restraint Coping (Pearson's $r = -0.31, p < 0.01$). Also, for the correlation of negative affect with dysfunctional coping subscales, all correlations were significant: overall score (Pearson's $r = 0.41, p < 0.01$), Self-blaming (Pearson's $r = 0.38, p < 0.01$), Psychoactive Substance Use (Pearson's $r = 0.30, p < 0.01$), Denial (Pearson's $r = 0.28, p < 0.05$), Restraint Coping (Pearson's $r = 0.27, p < 0.05$).

Discussion

The most important outcome of the study was the significant correlation between family resilience understood as a resource and parents'/guardians' affect. The greater the resilience, the higher the score of the affect scale despite the child's chronic condition. High resilience is also connected with more frequent use of problem-focused and emotion-focused coping strategies and a lower preference for dysfunctional strategies. The analysis of the correlation between the affect and chosen coping strate-

Table II. Correlation between the FRAS scale scores and the PANAS and Mini-COPE scales scores.

Variable	Family Resilience
PANAS	
Positive Affect	0.25**
Negative Affect	-0.21*
Mini-Cope	
Problem-focused Coping	
Overall Score	0.34**
Active Coping	0.29**
Seeking of Instrumental Social Support	0.21*
Emotion-focused Coping	
Overall Score	0.17*
Turning to Religion	0.06
Seeking of Emotional Social Support	0.19*
Positive Reinterpretation	0.22*
Dysfunctional Coping	
Overall Score	-0.31**
Denial	-0.23**
Psychoactive Substance Use	-0.30**
Restraint Coping	-0.33**
Self-blaming	-0.26**

* $p < 0.05$, ** $p < 0.01$.

gies when faced with an adversity revealed that a high positive affect increases the tendency to apply problem-focused strategies. No correlation between affect and emotion-focused coping was observed, apart from a significant correlation with the Positive Reinterpretation strategy. An analysis of affect and dysfunctional strategies revealed strong correlations. The results show that a positive affect reduces the frequency of using dysfunctional strategies, whereas a negative affect increases it.

Table III. Correlations between the PANAS scale scores and the Mini-Cope scale scores.

Variable	Positive Affect	Negative Affect
Mini-COPE		
Problem-focused Coping		
Overall Score	0.35**	-0.002
Active Coping	0.26*	-0.02
Seeking of Instrumental Social Support	0.19*	-0.09
Emotion-focused Coping		
Overall Score	0.17	0.08
Turning to Religion	-0.12	0.15
Seeking of Emotional Social Support	0.07	0.12
Positive Reinterpretation	0.35**	-0.12
Dysfunctional Coping		
Overall Score	-0.43**	0.41**
Denial	-0.33**	0.28*
Psychoactive Substance Use	-0.34**	0.30**
Restraint Coping	-0.31**	0.27*
Self-blaming	-0.32**	0.38**

* $p < 0.05$, ** $p < 0.01$.

Among the respondents, only 11.5% were men. Such a great disproportion made the analysis of sex differences impossible. The disproportion may be explained by the fact that women are more likely to take parental leaves and give up their professional lives to take care of their children.

The results indicate that family resilience is a resource that can be beneficial to parents/guardians when a child becomes seriously ill. High resilience was correlated with adaptation strategies such as problem-focused or emotion-focused coping strategies. Additionally, it co-existed with higher levels of positive affect. It all points to the idea that when organizing support for families with chronically ill children, developing the family resilience aspects, such as mutual respect, cooperation, open communication and emotional expression within a family should be considered.

In their 2015 study, Antoun et al²⁸ conducted the Oral Health-Related Quality of Life (OHRQoL) evaluation of orthodontic patients to measure, among other things, the psychological and social impact of the received treatment. The authors emphasized the unexpected results in a group of patients with cleft lip and/or palate which did not reveal any substantial differences at various stages of the treatment. The results obtained post-treatment were scarcely or moderately different when compared with the initial results. For the other two groups, i.e., general and post-operative patients, the differences in the obtained results were considered to be high and the patients reported significant OHRQoL improvement after they received orthodontic treatment. One of the reasons why cleft patients failed to notice any significant benefits from the orthodontic treatment, also in the sense of their psychological comfort, is the long and multi-step treatment that lasts from early childhood to adulthood. On the contrary, in post-operative patients the results indicated a significant OHRQoL improvement because they had their defect corrected and could experience improved face aesthetics within a relatively short period of time.

Early, prenatal diagnosis of the cleft can greatly affect the way the parents cope emotionally with the situation. In their 2018 review, Sreejith et al⁷ focused on the importance of prenatal diagnosis of clefts with respect to the psychological consequences of coping with the diagnosis. Such a diagnosis results in a high level of emotional stress. As a rule, parents strongly support prenatal clefts diagnosis methods because it gives them a chance to come to terms with the situation, get some support and counselling and prepare themselves within the scope of matters such as feeding or therapeutic pos-

sibilities for correcting defects. Thanks to 3D imaging, parents can also become aware of what the child is going to look like at birth²⁸⁻³⁰. Poehlmann et al³¹ observed specific patterns of adaptation in mothers, associated with the etiology of the child's disability and the amount of information available to the parents about the condition. It has been observed that because of an early diagnosis and availability of information on the Down syndrome, parents of children with the Down syndrome receive more professional and social support, compared to parents of children with the fragile X syndrome, and thus have a better chance for positive adaptation. There is no specific data on how family resilience affects adaptation for children with the Down syndrome and with or without cleft lip/palate. However, studies on parents of children with the fragile X syndrome suggest that additional diagnoses associated with the fragile X syndrome might affect the adaptation process, lowering the parents' well-being. This suggests the need for further research on how parents of children affected by cleft lip/palate and genetic disorders (such as the Down syndrome) adapt and what kind of resources they need for developing resilience, ultimately resulting in the well-being of the whole family system.

Conclusions

Family resilience is an important factor contributing to the well-being of parents bringing up children with cleft palate/lip and the functioning of the family system. Higher family resilience is positively associated with affect, despite a child's chronic condition. High resilience is also associated with the use of positive coping strategies (problem-focused and emotion-focused).

Prenatal diagnosis provides an opportunity to prepare for the challenges posed for the family system and to develop different aspects of family resilience.

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