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# THE ROLE OF THE PSYCHOLOGIST AS A MEMBER OF THE CLEFT AND CRANIOFACIAL TEAM IN LOOKING AFTER PATIENTS AND THEIR FAMILIES FROM THE PERSPECTIVE OF THE LITERATURE AND CLINICAL EXPERIENCE

## ROLA PSYCHOLOGA W ZESPOLE OPIEKUJĄCYM SIĘ RODZINAMI Z DZIEĆMI Z ROZSZCZPEM WARGI I PODNIEBIENIA NA PODSTAWIE PIŚMIENNICTWA I WŁASNYCH DOŚWIADCZEŃ

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### **Abstract**

*The aim of the paper is to present the psychological situation of the family of a child with a craniofacial condition, as well as to describe the role of the psychologist in the therapeutic process. The perspective of the paper is based on both the author's clinical experience and a review of the literature.*

*The paper adopted the parents' perspective and is therefore focused on their experiences concerning the diagnosis of the congenital craniofacial malformation. The author made an attempt to define what comprises a problem for parents and identify how their difficulties may influence the child's psychological development. Attention was devoted to challenges stemming from the unknown etiology of the malformation, difficulties in accepting and conducting the multistage treatment, changes in the look of the face, and the broadly considered imperfection. In the review of the literature, particular attention was drawn to identifying the risk factors for psychological development disorders associated with the cleft condition, as well as factors concerning the risk of the disorder influencing the parent-child relationship. It was concluded that the quality of that relationship may be influenced by the psychological state of the parents. Relying upon both the literature and own research results, it was established that the parents' psychological situation can be classified as a trauma. Its significance for the parent-child relationship was identified – especially in reference to parental sensitivity to the child's needs and their ability to support the child. The parent-child relationship may be meaningful for the child's psychological development – especially his or her emotions, self-esteem, and perception of the world.*

*The basic idea was that the parents experience a period of mourning over the imagined "ideal" child, going through which is crucial for them to adapt to their role of parenting a disfigured one. Adjusting to the requirements of the situation, i.e. involvement in treatment, is also among the key challenges. Developing some coping strategies in the parents, as well as introducing certain therapeutic interventions, is of high importance in this process of adjustment. Some fields of psychological work – which are most useful for the parents' sense of competence are also pointed out in the article.*

**Key words:** Poland, craniofacial malformations, psychological trauma, mourning over the ideal child, family's adaptation to the child's disfigurement, parent-child relationship

### **Streszczenie**

**Celem pracy** jest przedstawienie sytuacji psychologicznej rodziny dziecka z wadą wrodzoną twarzoczaszki oraz roli psychologa w procesie terapeutycznym na podstawie doświadczeń własnych i przeglądu literatury

*W pracy przyjęto perspektywę rodziców oraz skupiono się na ich przeżyciach związanych z rozpoznaniem u ich dziecka wady wrodzonej twarzoczaszki. Starano się zdefiniować ważne dla nich problemy oraz zidentyfikować ich znaczenie dla rozwoju psychicznego dziecka. Uwzględniono problemy związane z niejasną etiologią zaburzenia, oraz trudnością w akceptacji długotrwałego, wieloetapowego leczenia, zmian w wyglądzie twarzy oraz szeroko pojętej niedoskonałości dziecka. Na podstawie przeglądu literatury wyodrębniono czynniki ryzyka wystąpienia zaburzeń rozwoju psychicznego dziecka związanych z wadą rozszczepową, a także czynniki dotyczące ryzyka wpływu zaburzeń jego rozwoju na relację rodzice-dziecko, co związane może być z sytuacją psychologiczną rodziców. W oparciu o piśmiennictwo oraz wstępne wyniki badań własnych przyjęto, że sytuację rodziców można określić mianem traumy psychologicznej. Zidentyfikowano jej znaczenie dla kształtowania się relacji rodzic-dziecko – zwłaszcza w zakresie wrażliwości rodzica na różnorodne potrzeby dziecka i umiejętności wspierania dziecka; może to mieć duże znaczenie dla rozwoju psychicznego dziecka – jego emocji, poczucia własnej wartości, jakości postrzegania siebie oraz ludzi i świata. Przyjęto, że dla zaadaptowania się rodzica do sytuacji bycia rodzicem dziecka z wrodzoną wadą, bardzo ważne jest umiejętne przebycie okresu żałoby po nienarodzonym, wyobrażonym „idealnym” dziecku, adaptacja do wymagań określonych sytuacją życiową, m.in. uczestnictwa w procesie terapii dziecka. Strategie i sposoby radzenia sobie uruchamiane przez rodziców, a także określone działania terapeutyczne mają w tym przypadku duże znaczenie. Opisano, w jakich obszarach pomoc psychologa może być dla rodzica i jego kompetencji najbardziej skuteczna.*

**Słowa kluczowe:** Polska, wady twarzoczaszki, trauma psychologiczna, żałoba po stracie idealnego dziecka, adaptacja rodziny do niepełnosprawności dziecka, relacja rodzic-dziecko

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## INTRODUCTION

Cleft lip and palate is a congenital craniofacial disfigurement<sup>1</sup> that develops in the early stage of pregnancy (from the 4th week). The state has consequences in feeding, chewing, biting, and breathing conditions, as well as odontogenetic, speech, and facial appearance issues (2). According to some “cleft palate foundation” data, up to 85% clefts are non-syndromic (4). Malformation develops as a result of the concurrence of genetic and environmental factors. Cigarette smoking (5), alcohol drinking (6), malnutrition, poor diet (7), and other exogenous factors, such as viral infections and medicines are identified by some authors as environmental factors most likely connected to the cleft condition.

Recent years saw an increase in people’s awareness of the fact that the craniofacial condition in a child is not only a medical issue, but also constitutes a serious psychological problem for the family. As a consequence of the disfigurement parents are facing multiple challenges, e.g. understanding the reason for the condition’s occurrence, coping with certain unpleasant emotions, such as a sense of helplessness, anxiety, guilt – blaming oneself or the spouse (8, 9); insecurity about both the foreseeable and unforeseeable future. Parents are uncertain of what everyday life with the child will be like (e.g. what feeding will look like), and how they themselves and the child will cope with regard to the painful medical procedures – whether they will be able to give the child emotional support and handle their own suffering.

Therefore, researchers worldwide started conducting studies focusing on the psychological aspects of clefts, both from the parents’ and the child’s perspective.

## PSYCHOLOGICAL ASPECTS OF CLEFT LIP AND PALATE – RESEARCH REVIEW CLEFT LIP AND PALATE AND ITS IMPACT ON THE CHILD’S PSYCHOLOGICAL DEVELOPMENT

Research regarding the psychological situation of families with children born with a cleft lip and palate from both the parent’s and child’s perspective concerned: parental experiences (15), the child’s development (16) – their cognitive (19), social, and emotional (20, 21) functioning, as well as parent-child interactions, and the mother-child relationship (17, 18).

The relationship between the cleft condition and specific features of psychological functioning was defined by research in different ways. Authors present diversified views of the risk factors of a psychological development disorder.

In some papers, the facial appearance and social stigmatization which derives from it are identified as the main source of the disorder (22, 23). For years (especially in the 70s and 80s) it was believed that it is the child’s appearance which is to be blamed for possible emotional difficulties. However, more detailed analyses failed to confirm this assumption (e.g. (24)).

<sup>1</sup>In many psychological publications the term „disfigurement” is substituted for term “condition” to avoid negative connotations of the word “disfigurement” and the transient nature of the state; in this paper both terms will be used interchangeably.

## Cleft lip and palate and the parents' psychological state

The influence of the parents' psychological state on both their behavior towards the child and their way of thinking about and perceiving the child was considered (15, 16). The evaluation of the parents' psychological state on learning the diagnosis of the cleft condition led to the conclusion that they were experiencing shock, confusion, despair and a specific narrowing of perceiving information (32). Such observation justifies the conclusion that the parents experience trauma.

The term "trauma", which is widely known in medicine, is defined as "a wound resulting from a sudden, rapid action on the outside that is followed by consequences for the whole organism" (34). In psychology the term is used to describe a wound in the psyche (34). The cause of such a wound is an emotional shock experienced by a person in response to an action. In this situation, the shock is caused by discovering the diagnosis of cleft lip and palate. This is usually unexpected, often unconceivable and undesirable, and for this reason is considered traumatic. Full emotional coping is impossible, as the experience is too difficult, harmful, and unpredictable. The shock, which cannot be overcome, tends to be suppressed, or is persistently present. Coping with the consequences of the shock is beyond one's capacity.

Many ways of coping with stressful and traumatic situations are described in the literature. Lazarus and Folkman defined two of the most common ones: emotion-focused and problem-focused (35). The debate over which of those is more favorable has lasted for years. Nowadays, there is a belief that the choice of one over the other to a great extent depends on the situation. The psychological dispositions of a person, as well as the type of situation, are the main determinants. The case in which one has little or no influence over the situation, and is helpless, demands a different strategy from one where undertaking some activity may help. Therefore, if parents have influence over the situation, problem-focused coping will be useful, and if their influence is negligible, an emotion-focused approach will be preferred (49). However, it is highly likely that the use of only one strategy of coping may often result in particular losses: when it comes to emotion-focusing, such a loss would result in the lack of activity even in these aspects which could be influenced and enhanced. In turn, problem-focusing alone may lead to neglecting both one's own and the child's emotions and psychological needs.

As many authors observe (15, 29, 37, 38), on discovering the diagnosis of disfigurement in their child, next to experiencing shock parents experience sadness and a sense of loss. In this case the "loss" refers to losing the unborn, imagined healthy child (29). In contrast to this imagined child, the one that was born has a flaw, which in the case of cleft lip and palate patients is a visible face disfigurement with feeding difficulties, and in the long run challenged speech development. Moreover, the common lack of knowledge about cleft lip and palate may reinforce parental fantasies on additional pathological conditions that the child may develop over

time. Those factors may lead to an increase in the level of anxiety in the parents, which means that the child is the source of anxiety and insecurity. This may influence the development of a specific parent-child relationship and in turn may have an impact on the psychological state of the child (29).

The natural psychological reaction of a parent following such a loss is bereavement. The basic purpose of the bereavement process is to bury the vision of the imagined child from before the diagnosis, so that the imagination does not overshadow the actual child (29,38). The process of letting go of the imagined child may take time, however not going through with it and not being able to handle the experience of loss could pose a risk to the child's psychological development.

Giving birth to a "defective" child with a disfigurement is, to many parents, evidence of one's own "defectiveness" (15, 28). This may result in an identity crisis, a breakdown of their values and beliefs of the world order. It appears that by attempting to avoid confronting their loss of the imagined healthy child with the flawed child, and experiencing hurtful emotions and bereavement, parents often concentrate only on the disfigurement therapy (42). Such a course of mourning is considered atypical. It is believed to hinder the acceptance of the "imperfect" child on account of certain defense mechanisms leading to distorting reality and perceiving it according to one's desires. As a consequence, the parent's disturbed perception of the child can dominate reality and have an impact on the child's identity (38). The most common defense mechanism in the case of parents of a cleft patient is their belief that on ending the medical treatment (surgical or orthodontic) all the problems the child is facing will magically disappear, the child will change on the spur of that moment – stop being shy and withdrawn and become self-confident. Acknowledging the fact that such an abrupt change is improbable is crucial for the child's psychological development.

## The parents' psychological state and the mental development of the child

What are the consequences of the bereavement of an imagined "perfect" child for the psychological development of the "real" one? This poses an important issue, due to the fact that it is often observed that parents who experienced psychological trauma also endured low mood (or in some cases even subdepressive states), strong uncontrolled emotions or anxiety states next to narrowed perception (38). All of these may affect the parents' interactive competence during their time with the children. Parents who are for any reason immersed in their emotions are said to be emotionally unavailable to their children (29). As some of the cleft research confirmed, the mothers of babies born with cleft lip and palate were less sensitive to the babies' social and emotional signals, and less responsive than mothers of healthy babies. Such an effect was observed both in the case of flaw visibility (cleft lip only and cleft lip and palate) and invisibility (cleft palate only), which seems to invalidate the hypothesis that such mothers' behavior is caused by the unattractiveness of the baby's face (39).

The mother's responsiveness, defined as her sensitivity to signals directed towards her and her ability to react to them, is believed to be one of the basic features of the mother-child relationship, essential to the child's normal psychological development (40, 41).

### The craniofacial condition and the psychological functioning of the child

The occurrence of the craniofacial condition undoubtedly has an influence on the child's behavior. Before surgical procedure, children born with a cleft palate (concurring with cleft lip or not) were more "problematic" partners of interaction for their parents, for example during feeding. The results of research by Speltz et al. (43) suggest, that the prolonged time of a single feeding, feeding rhythm disturbances caused by choking, regurgitation, as well as the parent's feeling that they should be more direct during feeding (to force-feed the child) weakened the mothers' ability to read the signals sent by the child. What is more, this affected emotional and social signals, as well as feeding-related signals. Children born with cleft lip and palate may be more difficult to understand as partners of social interactions. One of the reasons is the lack of speech clarity.

Even though for a large group of children born with cleft lip and palate psychological development is completely normal, neurocognitive disorders are noticeably more frequent within this group (44, 45, 46). The reason for this is multifactorial. One of these factors may be a more challenged speech development, frequent hospitalizations and the resulting pain and anxiety, frequent ear infections and impaired hearing deriving from it, atypical face appearance, and parent-child relationships (39). It is also believed that the risk of behavior disorders, as well as learning disabilities is higher (44). The children's facial expressions, as well as their speech may be less legible, their reactions to objectively non-threatening situations may be ridden with anxiety and their ability to use or find social and emotional support may be limited. All of these may affect their communication and relationships with peers. It may be influenced by parental difficulties in helping their children develop adaptive social and emotion-regulation strategies.

Recently, as a result of research findings, scientists discontinued focusing on the singular aspects of difficulties, or assuming a one-way influence, and started appreciating the complexity of the intercorrelation between cleft lip palate, child-parent relationships and the child's social function. As a result, research without assuming the influence between the disfigurement and the child's general functioning was launched (18, 25). Assuming that children's psychological development always occurs in a relationship<sup>2</sup> with their parents (26, 27, 28, 29), such a research paradigm deserves special interest. This hypothesis makes it possible to describe the risk factors of psychological development and divides them into two groups: parental experience-related risks (the experience of psychological trauma and bereavement for the unborn

"perfect" child) and experience-related risks suffered by the child.

## METHODOLOGICAL ISSUES

Some of the cited research is exploratory, where authors do not build hypotheses and base their findings on the retrospective accounts of parents (11). There is also research conducted in parallel to the course of medical treatment which concerns both the present and the future, not the past (31). Even though both separately lead to interesting conclusions, it seems that combining those two methodological approaches results in even more intriguing findings and enriches the knowledge and description of the psychological situation of families of children with cleft lip and palate.

A certain serious methodological limitation is mentioned by most of the authors irrespective of their approach to research, namely the difficulty of gathering a representative group of respondents which makes it possible to conduct statistical analyses sufficient for the presentation of final conclusions. Such limitations were also experienced by the author of this paper.

## PSYCHOLOGICAL ASPECTS OF TREATING CLEFT CONDITIONS

Understanding the psychological meaning of medical treatment is undoubtedly one of the greatest challenges for the researcher. It is even more complex given the fact that surgery of the cleft lip and palate has completely different meanings for the parents and the medical team.

From the parents' perspective, their participation in the process of "treating" the child – defined as vying with the cleft condition – starts on the first day the condition is diagnosed. The moment of surgical intervention designates the end of problems in feeding or reading the child's mimics, as well as making certain significant and complicated decisions.

On the other hand, from the medical perspective, it can be assumed that the crucial moment of treatment starts on the day the surgery is conducted. An experienced and well-educated medical team is able to make the flaw less visible, nearly unnoticeable. It seems that from their perspective, it is the priority from the very beginning. However, it should be noticed that invisible does not equate with unnoticeable – some lasting signs remain in the emotional and social functioning of the child, not to even mention the child's quality of pronunciation. Although the distinction between invisible and unnoticeable is natural to doctors, it may not be so to the patients. The doctors should make an effort to make their words addressed to patients honour this distinction.

Doctors should be careful not to transfer their personal comprehension of the meaning of the existence of the cleft condition. It may happen that the doctor, probably trying to comfort the patient, will assure him or her that the flaw

<sup>2</sup>Relationship in psychology is defined as a mental category specifying mutual being in mental space of two people and directing of behaviors toward the other person as well as responding to them mutually (30)

is “slight and unimportant” and “the child can easily be treated”. It should be noted that firstly, the patient or the parents may understand those exact words in a different way from the doctor, and secondly, that it is the patient and the parents who should give meaning to the situation, and decide whether they see the flaw as “slight and unimportant” and whether they perceive the surgical intervention as a relief, or as suffering and difficulty.

Such aspects of the intervention as voluntariness are often considered in the literature. The surgery is considered voluntary due to the fact that the treatment is not life-saving (although it undoubtedly influences both the quality of life and the child’s development). On that account, the decision of the parent to allow the intervention is not obvious – at least theoretically. Among the basic motives in favor of such surgery are: basic life functioning (chewing and biting, breathing, hearing, speaking and proper pronouncing), emotional functioning (fear of dissimilarity and standing out, low self-esteem), and social functioning (fear of stigmatization, preventing rejection) (11). Fear of those seems to be particularly important for the parental decision to start treatment.

Whether parents should take part in the process of treatment planning or not is a matter of broader debate in the United Kingdom and the United States (11). One of the arguments being considered is that making the decision to proceed with the treatment might be viewed as an attempt of the parents to cope with the situation – especially with its emotional challenges. Parents might feel that their ability to make the decision is only apparent – and that the bottom line is they can only trust the specialists and base their decisions on medical suggestions (12). Consent to the procedure and making an effort to make their child to look as similar to others as possible and be accepted by others might make the parents feel that they are being good and caring parents and that this is their moral responsibility (11). Such an observation finds confirmation in the interviews with parents conducted by the author. Although the parents’ role in the decision might seem only apparent, the feeling of being engaged in the process of planning the treatment gives them a sense of responsibility and is crucial to the process of saving their child’s quality of life. Moreover, it reduces their sense of helplessness. Much depends on whether doctors allow the parents to join in the process (13). At the same time, making such a decision may give parents the hope (or even an illusion) that they are undistinguishable from others, a “normal” family.

All the psychological aspects of the cleft condition described above were still being overlooked or ignored even at the turn of the millennia. Only 20% of the medical centers which were highly specialized in performing surgical procedures of the cleft lip and palate employed a psychologist at that time (14). As a result of systematic research and observations of the influence of disfigurement on the child’s psychological development, as well as family functioning, the impact of the cleft condition was

noted. As a consequence, psychological support became perceived as necessary help for parents. Psychologists started joining the medical team, and their professional help was directed at both the child, and the family<sup>3</sup> as a whole (14).

According to the knowledge of the author of this paper, there has been no psychological research on this topic conducted in Poland. Due to the intercultural differences and the resulting difficulty in generalizing research results from other countries, researchers from the Institute of Mother and Child decided to conduct their own study.

## THE INITIAL RESULTS OF THE STUDY

### *The objective of the study:*

The study is aimed at exploring the feelings and experiences of parents whose children were born with a cleft lip and palate concerning the diagnosis and the treatment procedure.

### The specific objectives were:

#### *Exploring:*

- the parents’ experience of discovering their child’s diagnosis of cleft lip and palate,
- the parents’ psychological functioning and perception of their children in the process of medical treatment.

## Method

### *Test procedure*

Invitation letters were addressed to parents via the orthodontic clinic. Information concerning: the objective of the study, conditions of the study, as well as offering the possibility of psychological care for the whole family if necessary, were included in the letter. The study constituted of:

- filling out a questionnaire with basic data concerning: demographics, the age of the child, the type of cleft condition, types of specialist care and treatment offered to the child, the type of family, the age of parents;
- A one-hour semi-structured interview with a parent (or both parents).

### *Participants:*

Over the one-and-a-half year period of conducting research, only 7 families decided to take part in the study. The group was heterogeneous with the main differences including: the age of the children (this varied from 3.8 to 14.10, average age= 8.6 SD=4,19) the type of their cleft condition (cleft lip only, cleft lip and palate, complete or incomplete, unilateral or bilateral), the age of the parents, the area of residence (villages, small towns, cities with over 500 000 inhabitants). Even the moment of discovery of the diagnosis varied – only one family found out prenatally.

The common point was the admission by all the parents that they missed psychological support after they discovered the diagnosis. The desire to create a coherent

<sup>3</sup>Such a need was also noticed by the orthodontic clinic of the Institute of Mother and Child. As a consequence, a psychologist became part of the team

system of help for families in which children with the cleft condition are born was their main motive for taking part in the study.

#### *Research techniques and analysis methods*

The research technique of choice was the semi-structured interview. It concerned different aspects of the parents' relationship with the child (*inter alia* how they perceive the child, how they experience their relationship with him or her), parental experience of the diagnosis of the cleft condition and difficulties resulting from it. The questions concerned for example: what according to them was the most stressful and difficult part of the experience, who was the source of support, whether they had contact with a psychologist at any point between discovering the diagnosis and the moment of the interview.

The responses were analysed with the use of qualitative methods, in accordance with the phenomenological approach.

### DISCUSSION AND INTERPRETATION OF INITIAL RESULTS OF OWN RESEARCH

Based on the study interview analysis, as well as on non-directive clinical interviews with the parents of patients of the orthodontic clinic that did not contribute to the research, one may conclude that experiencing the diagnosis, as well as the treatment process strongly influenced both the parents and their relationship with children. It manifested in their attitude to the question of treatment and its impact on the child, and in their responses to questions not directly connected to this subject. There were noticeable difficulties in describing the child in terms of psychological functioning (i.e. describing the child's features or feelings, noticing his or her needs not connected to the cleft condition or treatment. The descriptions were rather full of statements concerning the diagnosis, such as "living a normal life", "coping with life", "being healthy", "being accepted", "being self-confident").

Interviews have shown that the parents of children with cleft lip and palate describe their experience of the diagnosis as one of shock, confusion, and dread, irrespective of the moment of discovery. The question concerning the moment of the diagnosis elicited strong emotional reactions in parents, even years after the diagnosis. In response to it, parents described the feelings of shock, confusion, and despair. They cried at the very thought of that moment, and one person even left the room, leaving the spouse alone to finish the interview. This proves that emotions are strong, even many years after the treatment was finished: "(...) I was absolutely shocked. I couldn't cope with it. Why us? Why our child?(...)" ; "(...) To me, it came as a shock, a tragedy, the end of the world. Everyone said: there are new methods of treatment being developed. And all I had been thinking was: I know all of that, it's easy to say for those who don't have such a problem, who are just witnessing, and we are in the middle of this (...)"

Such a mental state of those parents meets the criteria of psychological trauma. Those criteria are: describing the feeling and emotions of the parents as shock and despair,

as well as a describing their functioning as narrowed understanding of what is happening, as well as narrowed assimilation of information. As previously presented, the experiencing of psychological trauma and bereavement after the unborn healthy child may pose a risk to the actual child's psychological development. Therefore, creating a model of psychological care for families with children born with cleft lip and palate is necessary.

### DISCUSSION AND CONCLUSIONS

Coping with one's emotions caused by the diagnosis of a cleft condition in a child, as well as working on accepting his or her imperfection may have a great impact on the child's mental (29) and cognitive (26, 47, 48) development, according to both the literature and initial research findings. The notion according to which the mother-child relationship is a matrix of the child's mental development (29) is broadly accepted in modern psychology. The impact of the parents' thoughts, perception, and mental representation of the child are of particular interest. It is believed to influence the parents' behavior towards the child, for example during interactions.

Before the aforementioned results are commented, it should be noted that, like many other authors, the author of this paper faced some of the difficulties typical for qualitative research of cleft lip and palate patients and their families – especially, the heterogeneity of the group and the low number of respondents. In addition, the standard questions of who and for what particular reasons takes part in scientific research, and how this affects the group's representativeness of the broader population, still remains. The issue is important for interpreting the results, as well as generalizing them with reference to the whole population. Moreover, the research is still on the course of being conducted.

Research showed that according to the parents' views presented during the interviews, the perception of the child was limited, and that they looked at the child through the lens of the cleft condition and the treatment process. It seems reason enough for psychological intervention, even though the parent may not formulate this as a problem. It remains to be seen whether questioning how the parent perceives the child actually gives accurate information on parental representation. It is still uncertain whether such a procedure is optimal, or whether a different method should also be used.

Assuming that the perception of the child with a cleft condition is limited, such a result suggests that in many respects supporting the parent is the key to the child's mental development. How is the word "supporting" defined? In this case "support" can be both informational (32), as well as emotional – accepting the parents' difficult emotions, allowing them to experience their tragedy and feel their pain, and giving support to the whole family. It seems to be the fundamental task for psychologists and the area within which they can offer help.

An important issue that has to be addressed and solved by the psychologist, is the optimal timing of helping to cope with the parents' emotions. The clinical experience of the author suggests that it is ambiguous, depends on

the individual preferences, abilities, and needs of the parents and may vary to a great extent. Every respondent in the author's study expressed regret that they were not offered psychological care and support on giving birth or discovering the diagnosis. However, whether they would have accepted such help had it been offered to them remains unanswered. Retrospective research results are vitiated by the cognitive error of historical fallacy.

What can doctors do? Firstly, listen to the patient. Secondly, be careful not to impose their own perspective on the cleft condition on parents. Especially the latter is challenging, as the parents' despair may make the doctor feel helpless, and hence they may want to comfort the patient at all costs. This in turn may degenerate into convincing the patient, or imposing one's own perception of the cleft lip and palate and ascribe a certain meaning to it which may all interfere with the mourning and coping processes.

The practical conclusion is that there is a great necessity to conduct an in-depth analysis of the problem, attempting to detach oneself from thinking that the most important issue is the surgical procedure and improvement in appearance. Practice shows that other forms of acting, such as support in the feeding process, or the professional and regular help of a speech therapist help, systematic hearing check-ups, neuropsychological diagnosis and care, and psychological care – both diagnostic and therapeutic – are equally important. The last issue concerns psychoeducation, providing emotional support, *inter alia* during the bereavement process and the process of accepting the “imperfect” child, in the form of verifying the parents' convictions and beliefs. Other forms of help include supporting the interactions and therapeutic work with the child.

When should families be directed to a psychologist? Based on the interviews, it seems that the optimal timing for the first meeting is the moment immediately after discovering the diagnosis. However, this may as well not be true. Firstly, people differ in their preferred coping styles. The first couple of days are considered the time when people should launch their natural ways of reacting. Some may feel the need to concentrate on emotions, talk to others or cry, and not to focus on planning the necessary steps and organizing medical procedures. Others would rather start acting instead of dealing with their emotions. The latter should have the benefits of contacting a psychologist for their own comfort and for the enrichment of their relationship with their child. For the first group, however, informational support should be offered on a par with emotional care.

Soon after the discovery of the diagnosis, parents find themselves in hardship. Interacting with them, as they are buried in pain and suffering is not always simple or pleasant. This soon becomes clear to the people they deal with, which includes members of the medical team. The characteristics of this contact may elicit a sense of helplessness in the medical staff and eventually trigger coping schemes. One such scheme may be to motivate both the parents and the child to focus on dealing with the problem and overcoming it, instead of focusing on their feelings. However advantageous it may be, this

solution is in general very short-sighted. In the long run the process of bereavement and work on accepting the child is unavoidable and necessary.

It is very important to realize that not every parent will be ready to act, no matter what kind of action is undertaken – problem-focused or emotion-focused. This may happen especially in the first stage of the shock. It is likely that accepting support will not be the preferred course of action. Sometimes it takes time before a parent is ready to act. If help is regularly offered to them, such parents may accept and benefit from it when the right time comes.

It also seems that for many reasons it should be the parents who give meaning to what has happened to them when a child with a cleft condition is born, and to how they perceive the condition: as a cosmetic defect, or as a disability? What do they perceive as essential to cope with, so that the bereavement process and accepting reality is dynamic, open to new information and experiences as well as to changes? Even though the doctor might consider the condition as “cosmetic only”, the parent may perceive it differently. Parents have a right to such an attitude – as their way of thinking serves an important purpose in the process of adapting to the situation.

Various actions of doctors, nurses and psychologists, such as offering information concerning the treatment procedure, rehabilitation, and offering emotional support involves accompanying parents and helping them in confronting the challenges of the situation, so that the help offered is as well matched to the individual needs of the family as only possible.

In the United States, conclusions similar to the aforementioned one, motivated the American Cleft Palate – Craniofacial Association to formulate appropriate recommendations for families with children who are born with craniofacial disfigurement as well as to develop a procedure for psychological assessment and treatment:

- Assessment of a child's developmental status
- Neuropsychological testing in older children
- Parental training
- Presurgery anxiety reduction
- Social skills training for children

(cited after Speltz & Richman, 1997). The recommendations include active participation of a psychologist in the process of treatment, as well as after it has finished.

It seems that creating similar recommendations for Poland is crucial. This goal should be set by the medical team.

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