

Quality of life of a child with oral and maxillofacial pathology: certain problems in socialization

Viktoria Agaeva^{1*}, Galina Butko¹, and Natalia Bal²

¹Moscow City University, Department of Speech Therapy, Moscow, Russia

²Belarusian State Pedagogical University named after Maxim Tank, Institute of Inclusive Education, Department of Speech Therapy, Minsk, Belarus

Abstract. This article discusses important factors of quality of life of children with oral and maxillofacial pathologies: the issues of socialization and social and psychological adaptation. Cleft lip and cleft palate are common congenital malformations, having impact not only on somatic status but also on socialization, which is determined, in particular, by appearance and speech quality. As a child gets older, the risk of formation of secondary disorders of emotional and personal, behavioral and communicative spheres increases, which negatively affects psychoemotional background of the family. This work is aimed at substantiation of necessity of integrated assistance to families with children with appearance defects as the main subject of their socialization. The research was based on the methods of evaluation of social situation of a child with cleft lip and cleft palate and its influence on successful speech rehabilitation as an important constituent of quality of life. Analysis of the obtained data about opportunities of social adaptation of children with oral and maxillofacial pathologies gives confidence in necessity to maximum involvement of the family of such child into rehabilitation. It is important that all experts of interdisciplinary team understand the most important role of family in rehabilitation success, assist to parents and the child to resolve complicated situations related both with operative intrusion and with subsequent remedial actions. Early terms of integrated assistance allow to eliminate esthetic and functional violations of maxillofacial region, providing opportunities for full socialization of the child. Peculiar attention should be paid to the issue of tolerance of society regarding the persons with maxillofacial abnormalities.

Keywords: cleft lip and cleft palate, quality of life, tolerance, family.

1 Introduction

An important goal of modern socio-economic development of Russia is improvement of quality of population life. The quality of life is determined by a set of properties allowing to satisfy material and spiritual demands of each member of society. Among these are the

* Corresponding author: agaevave@mgpu.ru

quality of education, health care, industrial, trading and engineering infrastructure, social cultural policy, etc. [1].

Socialization of a person with health limitations, including with disabilities, as a provision of appropriate quality of life attracts great attention of modern society. Socialization is included into the strategy of inclusive education, which underlines the importance of solution to these issues already at the childhood stage. In scientific publications, socialization is considered as a complicated and gradual process taking place at three levels: physiological, psychological, and social [2].

Statistic studies of recent decades evidence negative trend of increasing number of children with health limitations and disabilities of various etiology and severity in Russia. The first position (25%) among the reasons causing violation in development is occupied by congenital abnormalities, the second position is occupied by diseases of nervous system, the third position – by infectious and somatic diseases, the fourth position – by psychological disorders. According to the data by World Health Organization, 4–5% of all newborns have this or that pathology, among which oral and maxillofacial disorders equal to 20-30%. Among them, the 3–5 positions are occupied by cleft lip and cleft palate (CLCP), which according to various sources are met once per 1,000 or 460 newborns [3].

Anatomic and physiological changes caused by congenital clefts influence child's health and appearance, and, most importantly, prevent correct speech development. All this results in violation of social adaptation of the child, entails negative changes in the family atmosphere.

Modern opportunities of medical rehabilitation successfully solve the problem of adaptation at physiological level (S.I. Blokhina, G.V. Gonchakov, S.V. Dyakova, Ad.A. Mamedov, V.V. Roginskii, etc.). Psychological and social levels are in the sphere of activity of experts of psychological and pedagogical assistance, their task is to integrate as much as possible the considered persons. Its main condition is participation in the life of healthy peers raised in the spirit of tolerance.

In early age, the main subject of child socialization is family. The members of microsocial surrounding should be ready to creation of such living environment, which would include all constituents of adaptation: medical, psychological and pedagogical, socio-cultural, material and economic, ethical [4-8].

At first, many mothers, upon learning of the birth of a child with an external abnormality, experience shock, horror, up to rejection of their child. A chance of raising a child with abnormality of appearance frightens, especially frightening is the uncertainty about the success of treatment. The parents feel guilt and anxiety, which negatively influence their nervous system. There is a painful reaction to attention to the child's appearance from others. This results in endless search for the reason of occurrence of such defect, leading to mutual accusations, resentments, and sometimes even to family break up [7-9].

Excess of the level of tolerable loads caused by constant stress often leads the parents to various somatic diseases, asthenic and vegetative disorders. A family, raising a child with external abnormalities, almost always closes in on its grief, shutting off from friends, relatives due to subjective settings of the parents.

Analysis of families raising children with oral and maxillofacial pathologies demonstrates that more often they are characterized by hyperprotection. Such type of raising promotes personal and social inadequacy of the child. This results in development of aggravating personal aptitudes, such as “nothing can be changed”, which paralyze the child's will and lead to estrangement from ambient world: the state of trained helplessness [10]. In addition, such families are often characterized by authoritarianism, distrust to the child, contradictory raising, and sometimes emotional rejection. All these factors make the family more vulnerable and unable to withstand adversities [11, 12]. The family situation is aggravated by attitude of society to children with facial abnormalities. Researchers define such

phenomenon in attitude of society to persons with corporal defects as “normism”. This notion is determined by historically established and steady stereotype of society regarding human appearance: beautiful, hence, good. A face is a certain signature of a person. Deviations from common standards of facial aesthetics exert significant impact both on everyday communication, and on well-being, self-esteem of persons with peculiar appearance. Various violations in facial structure more often result in negative, rarely compassionate, attitude to such person. E.S. Naboychenko interprets the term “normism” as a variant of discrimination of persons with atypical appearances together with the notions defining other types of discrimination, such as racism, Nazism, sexism, etc. Education of tolerance contrary to “normism” should become the base for successful and painless socialization of people with oral and maxillofacial pathologies [8, 10, 13].

2 Methods

The influence of social situation of development on rehabilitation efficiency of children with CLCP was confirmed by research on the basis of Clinic Center “Maxillofacial, plastic and reconstructive surgery”, Moscow [14]. The authors studied the social situation of development of 104 children being 7–9 years old, living in various regions of Russia and obtaining integrated assistance in the clinic. Among them, 59 children were raised in two-parent family, 30 children – in single-parent family, 8 children – in multichild family, 3 children – in foster family, 4 children – in boarding school.

3 Results

Early surgical treatment (before 3 years old) was performed mainly for children from two-parent families (16 of 59). All children from multichild families and from boarding schools had surgery after the age of three. Favorable speech situation was observed for the children raised in two-parent families: normal speech was observed in 52.5% of cases, rhinolalia – in 13.5% of cases. As for the children from single-parent families, speech was restored in 43.3% of cases, rhinolalia remained in 16.7% of cases. Speech was normalized in three children from multichild families, rhinolalia was observed in three cases, rhinolalia residual effects (RRE) – in two cases. Among three children raised in foster families, normal speech was observed in one child, rhinolalia – in two children. normal speech Not a single child from boarding schools had normalized speech after being surgically treated (Table 1).

Table 1. Analysis of social situation of development of children with CLCP surgery.

Type of family	terms of surgery		speech development		
	before 3 years old	after 3 years old	Norm	rhinolalia	RRE
two-parent (59)	16 (27.1%)	43 (72.9%)	31 (52.5%)	8 (13.5%)	20 (33.9%)
single-parent (30)	4 (13.3%)	26 (86.7%)	13 (43.3%)	5 (16.7%)	12 (40%)
foster (3)	1	2	1	2	-
no family (4)	-	4	-	3	1
multichild (8)	-	8	3	3	2

4 Discussion

Analysis of the obtained data demonstrates that in addition to direct remedial and developing measures aimed at speech normalization and cognitive development of a child with CLCP, an expert of psychological and pedagogical assistance should perform obligatory psychic

correction of violations in personal and interpersonal spheres of all family members [4, 7, 15-17].

While growing, a child gradually gets into new social environment, which should provide social rehabilitation, adaptation and personal development. The child should get used to new environment and new rules of kindergarten, schools, friends and peers. At this stage, stereotypes of interpersonal behavior are intensively manifested in attitude regarding people with physical and psychical abnormalities. It is possible to consider two main aspects: attitude of a human with atypical facial appearance to him (her)self and attitude to him/her by other people.

The studies in the field of child's rehabilitation after maxillofacial surgeries demonstrate that in childhood, a child with atypical appearance experiences greater emotional problems in comparison with normally developing children [12, 18, 19].

Behavioral stereotypes of society regarding children with atypical facial appearance result in their special psychological sufferings. For instance, Steven Richardson revealed certain rating of preferences in communication of normally developing children from 6 to 16 years old. Normal type of development in this rating was at the first position. As for the children with developmental disabilities, the most preferred were children using crutches, followed by children using wheelchairs, and one of the bottom positions was occupied by children with abnormal facial appearance [17, 20].

5 Conclusion

Successful socialization of children with CLCP and improvement of their quality of life will be promoted by solution to the following social and psychological problems by an expert of psychological and pedagogical support: arrangement of education as consecutive solution to personally significant problems; assistance in integration into group of peers by means of creative activity, competitiveness; formation of self-consciousness, self-determination, self-actualization, and self-affirmation; improvement of self-respect, self-estimation and level of ambition.

The issue of tolerant attitude of society to people with atypical appearance refers mainly to working with healthy peers, their parents, teachers of educational establishments. Various forms of working can exist: reading and discussion of books and films about disabled people; conversations; explanation of problems of disabled people and their rights; simulation of behavior situations; socially colored play situations [15]. Of great importance is personal example of adults, their understanding of situation, readiness to support such person. Very frequently children with atypical appearance receive unfavorable signals from peers in the course of routine communication and feel like outcasts and inferior people. In such cases, adults should, first of all, demonstrate tolerant attitude to a "special" child.

Therefore, oral and maxillofacial pathologies form a set of anatomical and physiological, psychological, and communicative violations. Their consequences are personality disorders leading to social disadaptation and requiring for implementation of consistent program of medical and social, and psychological and pedagogical assistance. Successful socialization of children with CLCP, hence, improvement of quality of their life, are promoted by provision of motivation competence of family members and tolerant attitude of society to people with atypical appearance. Another important factor is availability of high-quality medical care, staff potential and competence of experts of psychological and pedagogical assistance, which are characteristic, in particular, for convenience of urban environment.

References

1. A.A. Starikov, *Akademicheskij vestnik uralniiproekt raasn*, **3(34)**, 46–49 (2017)
2. A.V. Mudrik, *Bulletin of Orthodox St. Tikhon Humanitarian University. Series 4: Pedagogy. Psychology*, **51**, 56–64 (2018). <https://doi.org/10.15382/sturIV201851.56-64>
3. N.A. Kasimovskaya, Ye.A. Shatova, *Voprosy sovremennoy pediatrii*, **19(2)**, 142–145 (2020). <https://doi.org/10.15690/vsp.v19i2.2107>
4. V.V. Tkacheva, *Modern problems of science and education*, **4**, 155 (2016)
5. I.Yu. Levchenko, V.Ye. Agaeva, *Detskaya i podrostkovaya rehabilitatsiya*, **2(34)**, 31–35 (2018)
6. O.V. Yugova, *The role of the family in the formation of the child's speech and correction of its violations*, in the Collection of scientific articles based on the materials of the International Scientific and Practical Conference: Speech therapy assistance in the context of special and inclusive education: traditions and innovations, Moscow City University, Institute of Special Education and Comprehensive Rehabilitation, 21–22 March 2019, Moscow, Russia, 324–329 (2019)
7. G.P. Priyono, I. Rafiyah, I. Nurhidayah, *Journal of Nursing Care*, **1(2)**, 164–171 (2018). <https://doi.org/10.24198/jnc.v1i2.17129>
8. D. Chattopadhyay, A. Das, R. Deol, V. Thakur, *Journal of Cleft Lip Palate and Craniofacial Anomalies*, **7(1)**, 50-53 (2020). https://doi.org/10.4103/jclpca.jclpca_13_19
9. L.V. Akulenko, *Childrens' dentistry (GEOTAR-Media, Moscow, 2017)*
10. Ye.S. Naboychenko, *Pedagogical education in Russia*, **9**, 65–71 (2017)
11. T.N. Brazgun, V.V. Tkacheva, *Sistemnaya psikhologiya i sotsiologiya*, **3(27)**, 84–98, (2018)
12. M. Delgerbaigal, B. Bulgan, G. Ayanga, et al., *Innovation*, **12(4)**, 33–39 (2018).
13. K. Bettens, C. Alighieri, L. Bruneel, L.D. Meulemeester, K.V. Lierde, *Journal of Communication Disorders*, **85**, 105991 (2020). <https://doi.org/10.1016/j.jcomdis.2020.105991>
14. I.Yu. Levchenko, V.Ye. Agaeva, *Pediatrica. Journal named after G.N. Speransky*, **96(5)**, 217–221 (2017). <https://doi.org/10.24110/0031-403X-2017-96-5-217-221>
15. O.G. Prikhodko, O.V. Yugova, *Vospitaniye i obucheniye detey s narusheniyami razvitiya*, **1**, 49–56 (2019)
16. G.A. Butko, S.P. Oltu, *Problems of modern pedagogical education*, **66(3)**, 30–34 (2020)
17. M.R. Dias, A.C. Neves, I. Santos, R. Ferreira, *International Journal of Recent Scientific Research*, **7(8)**, 13178–13185 (2016)
18. V.A. Zelenskiy, *Pediatric oral and maxillofacial surgery: treatment and rehabilitation (Yurayt, Moscow, 2019)*
19. Yu.S. Rogozhina, N.V. Obukhova, S.I. Blokhina, T.Ya. Tkachenko, *System integration in health care*, **3(40)**, 26–39 (2018)
20. S.A. Richardson, *Rehabilitation Psychology*, **28**, 131–140 (1983)