ABSTRACT

of the dissertation of doctoral student Imangaliyeva Assel on the topic: "Scientific and substantiated approaches to improving the organization of medical and social assistance to children with congenital malformations of the ear", submitted for the degree of Doctor of Philosophy (PhD) in the specialty "6D110200 - Public Health"

Relevance of the research. Congenital developmental anomalies of the hearing organ are some of the severe pathologies that can lead to conditions ranging from mild hearing loss to total deafness, speech impairment, restriction of social activity and personal disability (Abrol A., Bly R., Sie K. C. Y., Bhrany A.D., 2022).

The aim of the research. Development of a scientifically based model of medical and social assistance to children with congenital ear malformations based on a comprehensive assessment of the health status of children with microtia and atresia of the external auditory canal in the Republic of Kazakhstan.

Objectives of the research:

1. To conduct a study of morbidity of children with congenital ear anomalies in different regions of the Republic of Kazakhstan.
2. To determine the key risk factors contributing to the formation of congenital ear pathologies in children in Kazakhstan.
3. To assess the quality of life of children with congenital ear malformations.
4. To carry out an expert assessment of medical and organizational assistance to children with ear abnormalities in the Republic of Kazakhstan.
5. To develop and implement a model of medical and social care for children with congenital ear malformations.

Materials and methods of the research. 143 sources of domestic and foreign literature were used, method – informational and analytical; data of 153 case histories of children diagnosed with "Microtia and/or atresia of the external auditory canal" were studied, method - analytical; 71 children and their parents diagnosed with "Microtia and/or atresia of the external auditory canal" were interviewed, methods - sociological, statistical; 9 experts were interviewed, method - RAND/UCLA.

Scientific novelty of the research. For the first time in the Republic of Kazakhstan, the primary morbidity of microtia/anotia and atresia of the external auditory canal in the boys/girls section was analyzed and the mapping of periodic prevalence of the studied nosologies in the Republic of Kazakhstan with assessment of the quality of life was carried out, which can be used in planning and resource allocation in the health care system. The obtained data expand the understanding of maternal risk factors in the development of microtia/anotia and atresia of the external auditory canal in children in the Republic of Kazakhstan, are new and have an important applied value for the development of preventive measures. The developed specific tool according to the RAND/UCLA method, based on the expert assessment of a team of specialists gives an opportunity to develop comprehensive medical and organizational care for children with

congenital ear malformations, adapted to the needs and peculiarities of this category of patients.

Practical significance of the research. The developed tool of expert assessment of medical and organizational assistance to children with congenital ear malformations can be used as a justification for a program of targeted measures aimed at providing medical and social assistance to children with congenital ear malformations to determine the optimal approaches to treatment and rehabilitation of patients. The developed model of medical and social assistance to children with congenital malformations of the ear will allow adequate, full and quality diagnosis, comprehensive treatment and rehabilitation, which is of great importance for public health in general and improving the professional training of doctors.

Main points to be defended

1. It was found that for the period from 2015 to 2024 in the Republic of Kazakhstan there was a heterogeneous pattern of dynamics of congenital ear malformations in children (Q16.0, Q16.1 and Q17.2 according to ICD-10), with peak detection in 2017-2018 and subsequent bidirectional change in the indicators (increased incidence of Q16.1 and relative decrease in Q17.2+Q16.0). This reflects the impact of improved diagnosis, organizational changes in the health care system, and external factors (e.g., pandemics), confirming the need for regionally differentiated monitoring.

2. Risk factors associated with maternal health (age 31-40 years, TORCH-infections, gestosis, exposure to chemicals, antibiotics, alcohol and tobacco smoking during pregnancy) were statistically significant and associated with an increased incidence of congenital ear malformations in children. It was found that in the group of children with Q16.1 and Q17.2 boys are significantly more frequent (1.6-2.2 times) compared to girls, which emphasizes the importance of genetic-epidemiological studies and targeted preventive measures.

3. Decreased quality of life indicators in children with ear malformations have been determined. Based on a sociological survey, significantly lower indicators of physical, emotional and social functioning in children with congenital ear malformations (especially in bilateral pathology) were determined. In children aged 5-7 years, the decrease in emotional and role scales is more significant than in 2-4-year-olds, and bilateral lesions and surgical interventions are accompanied by an additional deterioration in subjective quality of life.

4. According to the results of expert analysis (RAND/UCLA), the most effective solution for diagnosis, treatment and rehabilitation of children with ear disorders is the creation of a multidisciplinary team including an otosurgeon, pediatrician, plastic surgeon, psychologist, neurologist, surdologist and sign language therapist. Imaging methods (CT, MRI), implantable bone conduction hearing aids and single-vent surgical and aesthetic correction for unilateral and bilateral ear defects also received high efficiency scores.

5. The developed organizational and functional model of medical and social care for children with congenital ear malformations, based on early detection, diagnosis and treatment by a multidisciplinary team using advanced methods of rehabilitation and surgical treatment, makes it possible to increase the availability

of specialized services and provide a personalized approach depending on the severity and type of pathology. This model has been confirmed by the results of implementation and is focused on improving medical and social care, improving the qualifications of specialists and eliminating existing organizational barriers in the health care system.

The results obtained in the course of our work allowed us to formulate the following conclusions:

1. Epidemiologic analysis of the total incidence of ear abnormalities in the RK for the period from 2015 to 2024 shows a heterogeneous character. The peak of detectability by the studied indicators falls on 2017-2018, after which there is a tendency to a decrease in the total incidence of Q17.2 + Q16.0 and an increase in the total incidence of Q16.1 with stabilization of indicators during the last five years (2020-2024) at an average of 12.24 per 100 thousand, - but which is almost twice as high as the rate for this pathology in 2015 (6.47 per 100,000).

2. Over the ten-year study period (2015-2024), the average overall incidence for Q16.0 + Q17.2 (anotia + microtia) was 3.16 per 100,000 (with 1.6 times more boys than girls); for Q16.1 (congenital absence, atresia and stricture of the external auditory canal (with hearing impairment)) the total incidence was more than 3.6 times higher than for Q16.0 + Q17.2 and amounted to 11.31 per 100 thousand (with boys being 2.2 times more than girls). Leaders on atresia were Aktobe region - 182.14, West-Kazakhstan region - 150.47 and East-Kazakhstan region - 149.01 per 100 thousand of child population. High level of periodic prevalence of microcytosis was observed in Atyrau region - 45,4, North-Kazakhstan region - 37,34 and East-Kazakhstan region - 33,47 per 100 thousand of child population.

3. The results of the maternal risk factors we identified were: maternal age 31-40 years, which amounted to 56.9% in the case group vs. 36.6% in the control group (χ^2=11.062, ρ=0.004), maternal age 40 years and older 13.9% vs. 9.8% (χ^2=11.062, ρ=0.004), TORCH infection in the case group amounted to 45.8% vs. 7.3% in the control group (χ^2=39.868, ρ<0.001), gestosis of pregnant women-36.1% vs. 14.6% (χ^2=23.795, ρ<0.001), exposure to chemical drugs was 18.1% vs. 8.1% (χ^2=4.464, ρ=0.035), taking antibiotics during pregnancy was 36.1% vs. 9.8% (χ^2=20.106, ρ<0.001), alcohol exposure -31.9% vs. 17.1% (χ^2=6.026, ρ=0.014), and exposure to smoking during pregnancy was a potential risk factor 43.7% vs. 30.1% (χ^2=3.647, ρ=0.056).

4. Children with bilateral pathology significantly more often reported low scores on the scales of social and role functioning. Low scores of emotional, social and role functioning were found in the group of 5-7 year olds compared to 2-4 year olds (χ^2=9.004, ρ=0.029). It was found that in general, for both groups, the highest scores were noted on the physical functioning scale. The study showed that physical and emotional functioning scores in the group of children with microtia 2-4 years old were higher than in the category of 5-7 year olds (χ^2=0.995, ρ=0.005) . Children with bilateral ear defects and previously operated children showed low quality of life parameters.

5. The study based on the RAND/UCLA method allowed us to identify priority areas for diagnosis, treatment and rehabilitation of children with congenital

ear malformations. The highest mean values were recorded for ENT doctor (8.55 points for unilateral pathology and 8.66 points for bilateral pathology), otosurgeon (8.44 for unilateral and 9 for bilateral), and surdologist (8.77 and 9, respectively). The most effective methods are: Implantable bone conduction hearing aids in bilateral pathology (7.66) and bone conduction hearing aids on a bandage (7.55). In the case of bilateral microtia, where the need for surgical intervention is more evident, examinations and interventions also receive high scores (e.g. surgical treatment - 5.33). This emphasizes the importance of a combined approach with hearing aids (7.55 and 7.66) and the possibility of surgical correction. No treatment (1.55-2.77) is rated as a highly undesirable approach.

6. Our proposed method of creating a multidisciplinary team that includes specialized specialists received a high expert evaluation according to the RAND/UCLA method (8.88). Methods of rehabilitation (7.0), availability of auxiliary aids (7.66) and creation of adequate conditions for education of hearing impaired children (6.88-7.33); insufficient funding (6.22) and imperfect regulations (7.22) to protect the rights of children with IDD of the ear remain significant barriers in providing comprehensive medical and social assistance and rehabilitation. The need to improve funding and the regulatory framework is confirmed by high scores related to the organization of training and professional development of specialists (7.88). The main organizational challenges remain the untimeliness of registration and medical examination of children with ear disorders (8.0). Problems of ICD 10 codification (6.22) and insufficient funding (6.22) also indicate barriers to optimal organization of medical and social care.

7. The results of the study allowed us to scientifically substantiate the priority directions of development of medical and social care for children with congenital ear defects based on the identification of risk factors for the development of pathology, assessment of quality of life parameters and expert assessments, the methodology of which was tested in the study. The proposed model of medical and social care for children with congenital ear malformations makes it possible to receive services at an interdisciplinary level with individualized assessment.

Practical recommendation

1. To create a unified system of records (register) of children with congenital ear and hearing pathology, which will unify data, make them comparable with international studies and enable effective planning of medical care.

2. Assesses health-related quality of life parameters in these children. This will enable informed decisions to be made when selecting patients for treatment interventions, including ear reconstruction.

3. Use the method of expert assessments to take into account current scientific evidence and determine the need for medical interventions, which will optimize state budget expenditures.

4. To introduce a model of medical and social care based on the work of a multidisciplinary team that takes into account the full range of diagnostic, therapeutic and rehabilitative measures for patients with microtia and atresia of the external auditory canal.

5. To develop national protocols for the diagnosis and management of patients with congenital ear malformations, using the data of the thesis study as a basis.

6. Consider amending the ICD X revision codification to include data on the degree of hearing loss for more accurate differentiation and treatment tactics.

7. Expand medical and social assistance measures for children with microtia and atresia, including providing them with the necessary technical means of rehabilitation.

8. Review approaches to funding rehabilitation facilities.

Approbation of the work. Materials of the research were presented and discussed at the following forums and conferences: XIII International Multidisciplinary Conference “Innovations and Tendencies of State-of-Art Science”. - Nederland, Rotterdam, 2021; XIX International Multidisciplinary Conference “Prospects and key tendencies of science in contemporary world”. - Spain, Madrid, 2022; International Forum of the ENT. - RK, Aktau, 2022; Republican Forum “Topical issues of the ENT” together with the CASOS. - RK, Almaty, 2023. Conference with international participation “Modern approach to diagnosis and treatment in ENT, head and neck diseases”. - Uzbekistan, Tashkent, 2024.

Publications. On the subject of dissertation work published 7 works, including 3 works - in the editions recommended by the Committee for Quality Assurance in the field of science and higher education of the Ministry of Science and Higher Education of the Republic of Kazakhstan, 1 article in the journal of the international citation base Scopus, 3 publications in the materials of foreign conferences.

Implementation of results. Acts of implementation Children's Center "Aksai" NAO "KazNMU named after S.D. Asfendiyarov, SCP on PCV "Almaty Multidisciplinary Clinical Hospital", Annex D - act No. 0702-04-13/208; No. 01.1.06/1087; Annex D - act No. 0702-04-13/207, No. 01.1.06/1087.

The author’s personal contribution consists in choosing the direction of the research, developing its design and methodology, forming the goal, objectives of the study, organizing and conducting the research, direct participation in all stages of the work, statistical analysis, writing sections of the thesis, interpretation and discussion of the results, formulation of the provisions to be defended, as well as, conclusions and practical recommendations.

Scope and structure of the thesis. The dissertation consists of an introduction, 7 chapters of own research, conclusion, practical recommendations, list of used sources and appendices. The thesis is set out on 208 pages of typewritten text, contains 20 tables and 44 figures. The list of used sources includes 148 titles.