

KNOWLEDGE AND ATTITUDES OF SECOND AND FOURTH GRADE SECONDARY SCHOOL STUDENTS ON CHILDREN WITH DOWN SYNDROME

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Abstract: In addition to the wide range of information available today, there are people or persons from different professions but also healthcare professionals who do not have sufficient knowledge of Down Syndrome (DS) and their characteristics, either due to lack of interest, lack of sources of information or an attitude that does not matter to them. They are a vulnerable population that requires increased health support and care compared to a healthy population, with an emphasis not only on the child but also on all family members who are an integral part of their lives and who care for themselves. The research “Knowledge and Attitudes of Second and Fourth Grade High School Students on Children with Down Syndrome” contributes to raising social awareness and awareness of future healthcare professionals and encourages the transition from the medical model to the social model to become more open. The questions used in the survey showed us a very good level of knowledge of second- and fourth-year high school students about the characteristics of persons with Down syndrome and their capabilities or limitations. Most students gained previous knowledge through the media 65.2%. Based on the results obtained, we are faced with a shortcoming in the current education system / practical teaching, where many healthcare professionals graduate from high school and college without ever having encountered this type of work and need to adapt.

Keywords: Down syndrome, quality of life, future medical professionals

DOWN SYNDROME (DS)

Down syndrome (DS) is the most common genetic disorder that results from the excess of one part of the chromosome or part of the chromosome in the nucleus of each cell of the body (Sakač, M, 2018). Also called trisomy. This disorder prevents the normal physical and psychological development of the child, and DS occurs due to misclassification of the chromosomes during cell division of the germ cells, resulting in excess of one or part of the chromosomes in the cell (Hrvatska zajednica za Daun Sindrom, 2016). Pregnant women over 35 years of age have the highest risk of having children with DS, although 70% of children with DS give birth to mothers under the age of 35. The fact that older mothers give birth to children with DS is not because of the age of the woman, but because of the age of the eggs to be fertilized. DS is not dependent on, or influenced by, external factors. Trisomy is not hereditary, but if you have one child born with DS, the chances of having more children with DS are increased. One child with DS is born in 650 newborns. The syndrome affects all racial groups, and it does not matter what family the child is from, what economic status or lifestyle that family lives. There are over 50 characteristics in DS. Their number and intensity vary from person to person. In most cases, DS is diagnosed immediately after birth because of the characteristic appearance of the baby. Some features of DS can also be found in healthy children, so the doctor asks for a blood cell scan for the karyotype that displays the number, size and appearance of chromosomes isolated from a single cell. Excess of all or part of the 21st chromosome confirms the diagnosis of DS (Vuković, D. i saradnici, 2014). DS is characterized by a diversity and severity of abnormalities that include a general developmental delay and a full range of congenital and acquired defects. The organ systems studied in people with DS are more often abnormal than in the general population. More than one

hundred abnormalities have been found in persons with DS, none permanent except two, namely intellectual disabilities and excess chromosomal material (Zergollern-Čupak, L. i saradnici 1998).

We cytogenetically distinguish three types of syndrome:

1. classic type caused by chromosome in separation (95% incidence)
2. mosaic type (frequency 2 - 4%)
3. translocation type (frequency 5%) (Klisović, J., 2016).

The incidence of DS did not change significantly as the life expectancy of people with DS doubled over the last twenty years. Today, 75% of people with DS experience over 50 years (Toler i Freida, 2015). The life expectancy of people with DS is increasing, so that under normal socio-economic conditions, life expectancy is approaching that of the normal population. The most common causes of death for people with DS are heart defects, dementia, hypothyroidism, or leukemia.

People with DS are specific in appearance and can be easily identified. Most show a flat face profile, that is, they develop a specific facial appearance from birth through childhood. The nape of the neck is often flattened and there is excess skin folds in the area. The outer corners of the eye are angled upwards and Brushfield spots are visible which disappear during the first 12 months of life (Bioline International, 2017).

Their face is flattened and round. Their eyes were slanted (which is why they were called the Mongolism). Brushfield specks are on the iris, and nystagmus and strabismus and infrequently visual impairment are present. The root of their nose is indented and their nostrils are twisted upwards. The ears are usually posteriorly inferior, small, dystrophic, helix folded, and irregular in shape (MDS priručnik, 2019). Their mouths are open, their mouths are lowered, the tongue is large in area and bulging, the lower jaw is small, the palate is wide, and they often have abnormally shaped teeth. Their neck is short and wide due to excess skin. Their shoulders are lowered. The chest is characterized by spaced nipples, and the chest bone is short. The navel is low located (Čulić, V. i Čulić, S., 2008). Their hands are wide and stocky. Their hands are short and wide; their fingers are usually composed of only two phalanges that are short. Fifth-wedge clodactyly is present, which is present in 50% of people with DS, and may have a four-finger furrow (monkey furrow) in the palm of your hand. The feet of people with DS are short and wide. Wide gap between thumb and second toe that occurs in as many as 90% of people with DS. There is also joint hyper elasticity, skeletal malformation and muscular hypotonic (Zergollern-Čupak L., i saradnici 1998).

It is individual which diseases and difficulties occur in a person with DS. People with DS will have various difficulties, most commonly related to cardiovascular disease, respiratory disease, digestive problems, thyroid disease, neurological problems and 5 difficulties, immune and hematological problems, locomotors system problems, dental problems and visual impairment (Sakač, M. 2018).

Congenital heart abnormalities are present in 40-60% of children with DS. The atrioventricular duct defect, ventricular septum defect, Fallot tetralogy, and atrial septum defect are most commonly encountered% (Klisović, J., 2016). Congenital heart defects may include defects in the development of cardiac cavities, cardiac compartments, heart valves, and / or large blood vessels that supply or remove blood from the heart (Vuković, D. i saradnici, 2014). Respiratory pathways are narrow and lined with hyper secretory mucosa, and muscular hypotonic contributes to infections. Hypotonic of the buccal muscles and tongue, narrowing of the interior of the oral cavity and dental malocclusion are often present. Obstructive bronchitis and pneumonia are the most common reasons for hospitalization of children, are complicated, relapsing, and resistant to therapy, cause atelectasis, and are often life-threatening to a child. Oxygen therapy prevents more serious complications (Klisović, J., 2016). Hearing loss may occur in a person with DS, the most common reason being secretory inflammation of the middle ear, and cognitive hearing loss in 40-60%. They are also at increased risk of developing obstructive sleep apnea (OSA) manifested by snoring, lack of sleep,

frequent partial or complete awakening, and mouth breathing (Zergollern, Lj. i saradnici, 1994). Children with DS may have certain conditions that affect the digestive system: anatomical anomalies (eg, duodenal stenosis), functional disorders (GERD, Hirschprung, constipation) and nutritional disorders (celiac disease) (Vuković, D. i saradnici, 2014).

Many children with DS have difficulty feeding and chewing. Constipation is a common problem, the cause of this disorder is insufficient amount of water in the stool. An additional cause of this disorder is hypotonia of bowel musculature and congenital heart defects that do not allow the child to exert additional physical effort when emptying the bowel (Antičević, D., 2008).

DS is affected by the nervous system. The specifics of this syndrome are reflected in cognitive functioning - difficulty in speaking and learning. Children with DS later talk and walk than their healthy peers. The development of cognitive functions is slower, and the aging process is faster. The underlying sign of DS is mental retardation. The occurrence of epilepsy is more common in children with DS than in the healthy population. The two most common periods of epilepsy occur until the second year of life and between 20 and 30 years of age. The first period is characterized the onset of spasmodic spasms, and the second period of tonic-clonic seizures. DS is a neurodevelopmental and neurodegenerative disorder of the brain. The volume of the brain is reduced due to the decrease in the number of neurons and impaired brain development. Neurodegenerative changes in people with DS occur earlier than in healthy individuals. Most people after the age of 35 have changes similar to Alzheimer's (Sakač, M. 2018).

People born with DS have a very weak immune system and are prone to many infections. Their sensitivity threshold is markedly lower than in the general population. Already in the infant's circulation, T-lymphocyte deficiency is observed, and B-lymphocyte count is normal. The reason is that T-lymphocytes have failed to complete their "thymus-dependent" maturation process (Vuković, D. i saradnici, 2014). Due to the markedly reduced resistance of the body to a person with DS, they often suffer from thyroiditis, type 1 diabetes, autoimmune active chronic hepatitis, and systemic lupus. The incidence of leukemia and anemia are more common than in the rest of the population, but fortunately the incidence is very low (Čulić, V. i Čulić, S., 2008).

Orthopedic problems in people with DS are often expressed due to general hypotonia, loose ligaments and consequent instability of the joints. Orthopedic changes in the hip joint are often represented and include hip instability, subluxations and luxation, acetabulum dysplasia. The patello-femoral joint in patients with DS is also more often unstable. On the foot, lowered arches of the feet and adducted front of the foot are most commonly seen. Scoliotic deformity of the spinal column is more common than in the rest of the population and is associated with loose ligaments (Antičević, D., 2008).

Strabismus, myopia, and farsightedness are common in people with DS, but can be easily corrected with aids. It is necessary to practice visual attention, eye contact and visual monitoring of objects with eye movements at an early age. In general, children with DS are much better at visual perception, memory, and data processing and learn more visually. Ophthalmic examinations should be performed periodically to monitor vision (Lauš, M., (2016). Skin changes are already present in early childhood, it is usually soft and velvety skin that becomes dry in late childhood. Dryness is most pronounced in the area of the lower legs and hips (Ivić, N., 2008).

Hearing quality is an important part of the clinical treatment of children with DS. Hearing impairment occurs in 60-70% of cases. During life, children with DS become infected with middle ear inflammatory processes, significant hearing loss. The upper respiratory system and the tear and auditory pathways are small in diameter and are conducive to secretion and infection . (Antičević, D., 2008).

QUALITY OF LIFE FOR PEOPLE WITH DOWN SYNDROME

A significant shift in the rehabilitation of people with disabilities has been made by changing the medical model to a social one. In the medical model, the focus was on the impairment, not the person, and in such a society people with disabilities are seen as a problem. Today, it is generally accepted social model that emphasizes the society's attitude towards persons with disabilities as a basic problem. It places the individual at the center of decision-making when making decisions that relate to him and, most importantly, places the problem outside the person, in society. The basic idea of the model is that the damage that exists objectively should not be negated, but it does not diminish the value of the person as a human being. What excludes people with disabilities from society is the ignorance, prejudice and fears that prevail in that society. Therefore, the social model emphasizes the rights of the individual and seeks to restructure society. With the advent of the social model of disability and the model of human rights, there are significant changes in the attitude of society towards persons with disabilities. The main objective of the policy towards people with intellectual disabilities is no longer to cure and protect, but to fully integrate people with DS into society, while exercising all their rights. Under the influence of these developments is a policy of deinstitutionalization of persons with intellectual disabilities in the context of exercising the right to live in the community. A positive attitude towards people with intellectual disabilities is the basis for activating the necessary factors in society and for achieving all the necessary external conditions, which define the quality of life, without which there is no achievement of the goal of rehabilitation of those persons. Contemporary goals of rehabilitation in the broad sense include the principle of normalization, social integration, individualization, orientation to meeting needs and encouraging independence and autonomy. These objectives are achievable with appropriate formal and substantive conditions. The formal aspect refers to the material conditions of life (spatial, financial, etc.). The content aspect covers the scope and quality of meeting individual needs. Both of these aspects interact and form an indivisible whole, which is ultimately expressed in terms of quality of life. In 1993, the World Health Organization defined quality of life as "an individual perception of one's position in life, in the context of cultural and value systems in which they live and in relation to their own goals, expectations, standards and preoccupations." As Bratkovic and Rozman point out, "it is a complex concept that includes the physical health, psychological state of a person, the degree of independence, social relations, personal beliefs and the relation to the essential features of the environment."

The main dimensions / indicators of quality of life according to Schalock are: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and the enjoyment of rights. Each of these dimensions is viewed in relation to physical, material and social well-being, development and activation, and emotional well-being, and in relation to environmental influences. Thus, physical well-being includes health, mobility and safety. Material well-being includes finance and income, various aspects of living space quality, transportation and security, all aspects that are important to most members of the community. Social well-being encompasses two sub-areas: the quality and extent of interpersonal relationships within the home and household, with family and relatives, friends and acquaintances; and social inclusion, accomplished social activities and level of acceptance or support from the environment. Development and activities are an area related to the acquisition and use of skills (Arandelovac, M., 2016).

In addition to a well-formed rehabilitation plan implemented in hospital settings, it is also necessary to organize the child's leisure well.

Active leisure includes spiritual, mental and physical upgrading as opposed to passive which does

not contribute to personality development, self-realization and emancipation. Passive leisure is bad in itself, if it is really the only way to spend free time.

The way a person spends his or her free time is a very important factor that significantly affects the quality of life of the person. It is also important to emphasize that not only is the way a person spends his or her free time, but also whether he or she has the freedom to choose and make decisions, one of the main skills of self-determination, within that time. Primarily, a person should have acquired self-determination skills (freedom of choice and decision-making). Once these skills have been acquired, it should be possible for a person to apply them in their daily lives without restraint by society. The basic characteristic of leisure is the free development of personality, which indicates the importance of leisure, but also “opens up” the problem of not spending every free time creatively, and instead of promoting personality development, further contributes to its alienation, the sphere of leisure is one of the most important factors of quality of life, an integral part of life that contributes to personal well-being or well-being. It is a thread that leads to complete satisfaction and better quality of life for both the individual and his or her environment – family (Pisaro, M., 2017).

The aim of this research is to examine the level of knowledge of students of second and fourth grades of secondary school of Gemit-Apeiron secondary school about characteristics of persons with DS, their attitudes and behaviors in the presence of persons with this syndrome. I would examine if the sociodemographic characteristics influence the opinions about people with DS, their past experiences and encounters with atypical children or persons, and how they came to current knowledge and information.

MATERIAL AND METHODS

The data was collected from April to July 2019 at the Gemit-Apeiron Secondary School (Medical School). There were 118 participants, second- and fourth-grade students. The survey was conducted through an anonymous survey (instrument) with a rationale for the survey (survey source: “Knowledge and attitudes of future healthcare providers and parents about children with Down syndrome” Klisovic 2016.). The survey questionnaire consisted of twenty-two questions, four of which were personal information questions, twelve questions about knowledge of Down syndrome, and six questions about attitudes and education about Down syndrome. The collected data, in the table below, was categorized and statistically processed by Chi-square tests. The statistical program SPSS version 22 was used for statistical analysis. The data were statistically grouped into tables, presented using absolute numbers and percentages.

RESEARCH SAMPLE

The study involved 118 students, 61 (51.7%) male students and 57 (48.3%) female students (Table 1).

Table 1. Examination of respondents by gender

Gender	Frequency	Percent	Total
Male	61	51.7%	51.7
Female	57	48.3%	48.3
Total	118	100.0%	100.0

At the time of the survey, 50.8% of the students were in the second grade of secondary medical school, and 49.2% of the students were in the fourth grade of secondary medical school at the time of the research (Table 2).

Table 2. Examination of respondents by level of education – grade

Grade	Frequency	Percent	Total
2nd grade	60	50.8%	50.8
4th grade	58	49.2%	49.2
Total	118	100.0%	100.0

According to the place of residence, 103 (87.3%) students responded that they live in the city and 15 (12.7%) students in the countryside (Table 3).

Table 3. Survey of respondents by place of residence

Place of residence	Frequency	Percent	Total
City	103	87.3%	87.3
Village	15	12.7%	12.7
Total	118	100.0%	100.0

DISCUSSION AND RESULTS

Table 4. Summary of answers received with statistical values * p

	Number of respondents by observed groups			p*
	2nd grade	4th grade	Total	
1.What is DS				
Heart and blood vessel disease	1	1	2	0,094
Genetic disorder	56	47	103	
Psychic disorder	3	10	13	
2.How many genetic types of syndrome are there				
1	4	7	11	<0,01
2	15	31	46	
3	41	20	61	
3.Can DS be cured				
Yes	2	5	7	0,206
No	58	53	111	
4. Where people with DS need to live				
At the family	51	47	98	0,371
In special institutions	9	11	20	
5. Can people with Down Syndrome be independent (with minimal supervision)?				
Yes	43	38	81	0,380
No	17	20	37	
6. People with Down Syndrome can not learn				
Cook	10	14	24	0,119
To read	15	19	34	
Calculate	35	25	60	
7. Do mothers over 35 have an increased risk of having a baby with DS				
Yes	49	48	97	0,534
No.	11	10	21	

8. How likely is it that a young married couple will have a child with DS again				
Little	32	22	54	
Medium	26	32	58	0,080
Big ones	2	4	6	
9. Can people with Down Syndrome have a job				
Yes	57	48	105	<0,01
No	3	10	13	
10. Do people with DS have higher health needs than the general population?	52	46	98	
They have bigger needs	7	11	18	0,352
They have the same needs as the general population	1	1	2	
They have less need than the general population				
	Number of respondents by observed groups			P*
	2nd grade	4th grade	Total	
11. The main characteristics of people with Down Syndrome are:				
Acts as if she is deaf, avoids eye contact, keeps aside and does not love herself	3	6	9	
cuddle				
Slow growth, irritability, disinterest, arrhythmias	10	11	21	
Aslope eyes, big bulging tongue, wide short fists, curious, communicative	47	41	88	0,251
12. Can people with Down Syndrome start a family?				
They can	31	27	58	
They can not	16	20	36	0,652
They can, but they will get a child with Down Syndrome	13	11	24	
13. If a person with Down Syndrome approached you, what would you do?				
Talked to her like any other person	49	45	94	
They would step down from society	3	7	10	
They would talk to her, but with much pity	8	6	14	0,355
14. Which schools should people with Down Syndrome go to?				
To special schools	15	23	38	
Into ordinary schools, but special program	43	34	77	0,084
Into ordinary schools	2	1	3	
15. Where did you learn about Down Syndrome?				
At school	15	23	38	
Through the media	43	34	77	0,311
Through friends	2	1	3	
16. What would increase the quality of life of children with Down Syndrome and their acceptance?				
Lecture in kindergartens				
Attaching more importance to children with Down Syndrome through the media	14	14	28	0,636
Occasional lectures at a health center or hospital	40	35	75	
	6	9	15	
17. Who is most competent to lead education for people with Down Syndrome?				
Teachers	11	14	25	
Nurses / nursing representatives	27	24	51	0,559
Parents of children with Down Syndrome	22	20	42	

18. Where should education for people with Down Syndrome be conducted?				
In kindergartens	7	12	19	
In schools	43	37	80	0.322
In healthcare facilities	10	9	19	

The study involved 118 students attending Gemit-Apeiron Secondary Medical School, including 60 (50.9%) second-grade students and 58 (49.1%) fourth-grade students, specifically 57 (48.3%) female and 61 (51.7%) male. Of the 118 students, as many as 103 (87.3%) live in urban areas, while 15 (12.7%) live in rural areas.

The knowledge and attitudes we have examined through this research have shown that students in both the second and fourth grades have an adequate level of knowledge, but that some facts do not understand or have not encountered them at all. Of the total number of students surveyed, as many as 103 (87.9%) answered that DS was a genetic disorder, indicating that they had already encountered this type of disorder, that is, whether through the media, the Internet, or as part of lectures. Also, students (74.6%) were able to list the characteristics of persons with DS and confirm that they could be recognized if they were met on the street.

When asked “How many genetic types of DS are there?” 61 (51.7%), the student answered correctly the question, that DS has 3 genetic types, but there is a significant difference between the opinion of second- and fourth-grade students as well as the statistical significance of $p < 0.01$. Students (83.05%) believe that people and children with DS should live with their families as this enables them to live a better life. 87 (73.7%) of students think that people with DS can be independent. Since persons with special needs are systematically neglected and as such are considered to be independent of life, there is a need for the establishment of communities, or inclusion, within which persons with disabilities will have better care and a chance for independent life within society. The word inclusion is of Latin origin, meaning inclusion. Living in a community of persons with special needs implies living in an apartment / house, town / village, equal labor rights as social rights, interpersonal relations, freedom of movement, and participation in various cultural and public events within the community (Kelava, I., 2016). This principle of inclusion is also agreed by 77 (65.2%) students who believe that people with DS should go to regular schools with their peers but with a tailored curriculum.

Through specially tailored programs for working with children with DS in schools, the development of appropriate competencies and skills of the children themselves, as well as opportunities for training and a sense of usefulness in society rather than rejection, are fostered. By identifying atypical children for appropriate occupations and focusing on the same, it would change the way in which both society and government view their opportunities and have much greater opportunity to get a job. Positive attitude is expressed by the surveyed students who believe that persons with DS can be employed, as many as 105 students (88.98%), and in this issue there are differences of opinion of second and fourth grades as well as statistical significance where $p < 0.01$.

Developing empathy and accepting people with disabilities enables social integration of atypical children in all spheres of society. Empathy is a trait of quality and professional healthcare professionals. When asked if a person with Down syndrome would approach you, what would you do? 94 students answered to speak to them like any other person, and with this answer showed that they have already developed empathy and that they will become conscientious healthcare staff.

Knowledge of lifestyles and basic information about DS has been learned by the majority of students through the media (65.2%), at school (32.2%) and through friends (2.6%). Through this research we have

come to the realization that little attaches importance during secondary education to educating students on how to handle and health care for children with disabilities. Students complete secondary medical school without ever having the opportunity to meet with such persons during their education and maintenance. By raising the awareness of prospective health care professionals about children with DS or children with any type of learning disability, it helps them understand and accept atypical children, acquire new skills to provide better care, support, focus work on their opportunities and mood-triggering actions rather than anxiety, to apply activities that are aimed at improving the quality of their lives as well as that of the whole family. This approach, attitudes and opinions, along with developing empathy and compassion, are ways to show that a healthcare professional is professional and puts their patients' needs first.

CONCLUSION

Based on this research, students in both the second and fourth grades of secondary medical school showed very good knowledge of the characteristics of children with Down syndrome. There are statistical differences in opinions, attitudes, items that students in second grades knew better than those in fourth grades. According to the results, many of the students surveyed, a dozen of them had one encounter and the rest had no encounter with people with Down syndrome, indicating a lack of experience and an inability to maintain a proper relationship with atypical children. More frequent meetings contribute to better and more efficient care, and increase the value of healthcare professionals in the multidisciplinary chain. For a healthcare provider to collaborate and provide any form of health care to people with DS, they must have contact with DS sometime during medical school practice. Many healthcare professionals today complete high school and higher education without ever meeting people with DS. Adequate changes need to be made, raising awareness among both the population and health professionals about the need or need for additional training in dealing with people with any type of disability. This change alone would improve the quality of life for people with DS, and healthcare professionals would be able to provide quality care without fear of the unknown.

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