

SPECIJALNA EDUKACIJA I REHABILITACIJA

- SPECIAL EDUCATION PROVISION CHALLENGES IN CHINA
- QUALITY OF LIFE OF VISUALLY IMPAIRED
- SOCIJALNO POŽELJNO ODGOVARANJE I STAVOVI
- PODRŠKA RODITELJIMA DECE SA SMETNJAMA U RAZVOJU
- JEZIČKI DEFICITI KOD DECE SA SELEKTIVnim MUTIZMOM



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Special education provision in China – Characteristics and challenges as perceived by stakeholders

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Introduction. China provides special education students with the possibility of indirect enrolment in regular education (inclusion), attendance at special classes and regular education classes (mainstreaming), admission to special education schools (segregation), or admission to home education (exclusion). This promising large system of education has several shortfalls, such as the inadequacy of curriculum, the rivalry between segregation and inclusion trends, teacher preparation, and parents' awareness of their children's needs. *Objectives.* In-depth interviews were conducted to uncover these strengths and shortcomings from the perspective of Chinese stakeholders. *Methods.* Nine in-depth interviews were conducted with special education stakeholders in China. *Results.* Our findings present a detailed analysis that provides a visual summary of the main strengths, weaknesses, and suggestions for improvement, as well as specific features relevant to the Chinese context. *Conclusion.* The results of our study furthered this discussion by revealing our participants' long experience in the field and highlighting some of the current gaps – curriculum, teacher training, the rivalry between special education and inclusive education, and the need to increase parents' awareness of their children's rights in advance of a more inclusive society.

Keywords: special education, China, provision, inclusion, special education teachers

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Introduction

Special Education Development in China

The purpose of this study was to examine the conflict and challenges arising from special and inclusive education in China in relation to inclusion and segregation. Several studies have been conducted on related topics, including whether learning in regular classrooms (LRCs) is inclusion or vice versa. There is considerable uncertainty regarding whether current practices of providing special education, such as inclusion, mainstreaming, segregation, or exclusion, contribute to achieving equality, learning, and a sense of belonging for learners with special educational needs (SENs) or not.

A key objective of China's Medium and Long-Term Education Reform and Development Plan for 2010 to 2020 is to enhance equity and quality for all students and create a society in which learning is a lifelong activity (UNESCO, 2013). The nation strives to attain moderate prosperity by 2020. The study (Deng & Guo, 2007) indicates that since the 1980s, efforts have been made to improve special education services in China through inclusion, in particular LRC. This approach, however, needs periodic improvement. Furthermore, Deng et al. (2001) posited that special education has evolved into a viable project in China. China's special education system has evolved in a number of ways since 1980, among which are economic conditions, Confucian tradition, Western cultural influences, and the social-democratic ideology.

Thus, development in special education remains debatable. Research has demonstrated several shortcomings in the development of special education (e.g., Kritzer, 2011, 2012, 2014; Worrell & Taber, 2009). Conversely, some believe that special education is evolving and becoming a standard model (e.g., Pang, 2010).

Challenges

Researchers have also sought to improve special education in China by identifying areas for improvement. The recommendations made by Ellsworth and Zhang (2007) include the need to develop special education services in China in different areas, ensuring that parents have access to information regarding special education, and providing better teacher training. Yu et al. (2011) analyzed this issue in more detail, noting that teacher quality and the lack of national certification limits national special education services, international collaboration, increased funding, and additional special education undergraduate and graduate programs. These points were also reiterated by McLoughlin et al. (2005), who linked the need for such development to the growth and prosperity of China, making the case that China is at the brink of a new era due to social forces that will have an indelible effect on the country's future.

Further, inconsistent classifications and/or definitions of the special education population between China and international organizations such as the World Health Organization (WHO) have hindered the development of special education in the PRC. Malinen et al. (2013) discussed this in their paper in a comparative manner. China has defined inclusion criteria as visual, hearing, language, intellectual, physical, and mental disabilities as opposed to cognition, mobility, self-care, getting along, life activities, and participation for the WHO.

Further, according to Hu & Szente (2010), the government must address the problem of limited special education services. They report that special education services were confined to certain types of disabilities, such as intellectual disabilities, visual impairment, and hearing impairment, ignoring other disabilities, such as emotional disorders and speech-language impairments. According to Huang et al. (2013), since the late 1970s, special education in the People's Republic of China has experienced substantial reform and rapid development. Education for children with severe developmental disabilities, especially autism spectrum disorders (ASDs), continues to be the greatest challenge in the field.

Apart from this, and according to Malinen et al. (2012), the development of special education can also be affected by the attitude of teachers themselves, in particular the tendency to promote inclusive education. To evaluate this, the researchers employed the Teacher Efficacy for Inclusive Practices (TEIP) scale, which considers three variables: efficacy of inclusive education, efficacy in collaboration, and efficacy in managing behavior. The authors suggested that future teacher education programs should emphasize the development of self-efficacy, especially collaboration skills, among teachers.

Suggestions for Development

The formalization of a standard model for special education services in China is merely a matter of time to certain academics. To cite just one example, Trube et al. (2013) concluded their qualitative paper on early childhood special education in China with the statement that education for all and education suited to one's needs and potentials are complemented to Chinese philosophy, and the country has made significant progress in some areas of special education. The Chinese special education system has levels that vary from one province to the next and according to the type of disability. It may be attributed to differences in population density as well as the strategic plans of each province (Holdsworth as cited in UNESCO, 1993). In support of this, Lytle et al. (2005) asserted that governments should begin to develop and implement deaf education programs as soon as possible. Their position was that deaf individuals had limited opportunities for higher education with limited or no support services, teacher preparation for deaf people, and few employment opportunities.

The Present Study

The following three research questions were addressed:

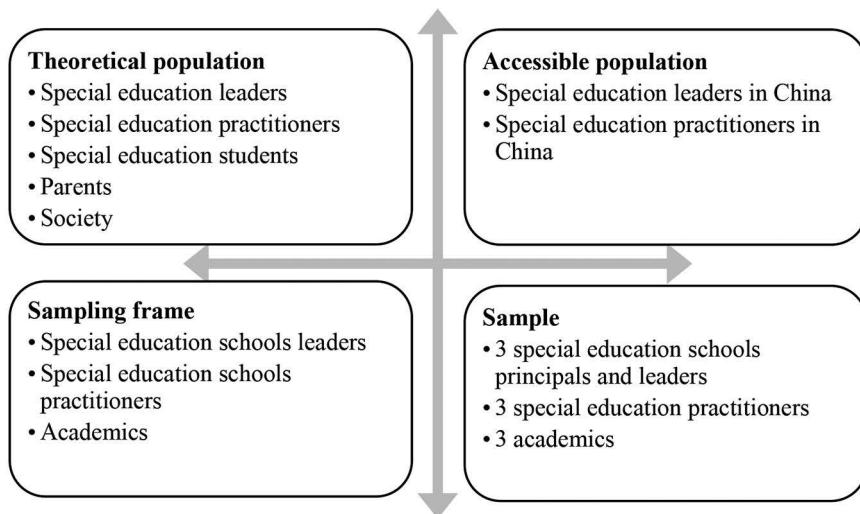
1. In what ways do stakeholders perceive the provision of special education in China?
2. In what ways do stakeholders comprehend the characteristics and challenges of special education in China?
3. What are some of the ways in which special education services are provided to ensure curriculum, teacher training, and parents' awareness are aligned with the needs of learners with special educational needs?

Methods

As a qualitative study from a constructivist perspective, this study contributes to a broader understanding of the current state of special education in China through stakeholders (Järvinen & Mik-Meyer, 2020; Yin, 2016). Qualitative research, including the research discussed in this paper, has the advantage of studying the context, which is the provision of special and inclusive education in China (Tracy, 2020). The remainder of the section outlines the study design, data collection, procedures, trustworthiness, ethical considerations, and a description of the data analysis.

Study Participants

Based on the descriptions found in some studies (Bronfenbrenner 1995; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2007), the examined topic 'special education development' is organized and operated by the interactions and relationships among different factors within the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. This can include leaders and policymakers, special education practitioners, special education students, parents, society, and even the country's economy and policy. As a result of the study's scope, all these factors cannot be considered. Consequently, a non-probability sampling method was utilized, involving heterogeneous sampling of school principals and school practitioners, as well as expert sampling of three special education academics. The following paragraphs describe the sampling framework (Figure 1) and the sociodemographic characteristics of the participants (Table 1).

Figure 1*Sampling framework***Table 1***Sociodemographic characteristics of participants †*

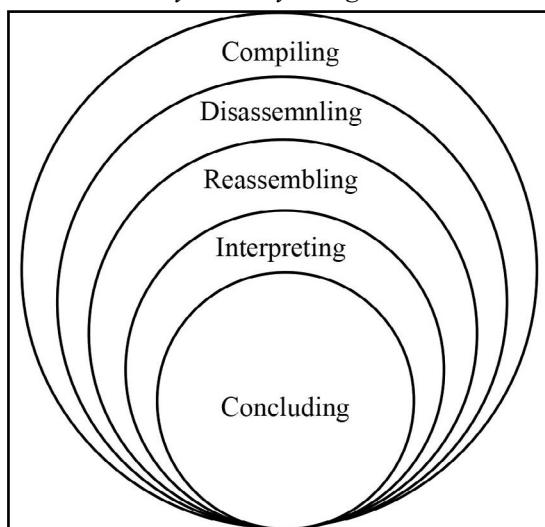
Position	Age	Gender	Experience	Location	Institution	Code
Director and principal	60	Male	39	Beijing	Special education school	SES-1
Principal	52	Female	31	Beijing	Intellectual disability school	IDS-1
Manager	35	Female	14	Beijing	Special education school	SES-2
Practitioner	38	Male	16	Beijing	Intellectual disability school	IDS-2
Practitioner	33	Female	7	Beijing	Special education school	SES-3
Practitioner	30	Female	3	Beijing	Intellectual disability school	IDS-3
Assistant professor	33	Male	11	Wuhan	Public university	PU-1
Postdoctoral fellow	29	Male	7	Beijing	Public university	PU-2
Assistant professor	30	Male	2	Chongqing	Public university	PU-3

Design

As part of the study design, the nine interviews were analyzed in five phases based on a thematic analysis. Based on their views and experiences, principals, practitioners, and academics provided valuable insight into the current state of special education in China. This is illustrated in Figure 2.

Figure 2

Thematic analysis study design



Data collection

Between 1.05.2019 and 30.06.2019, data was collected in Beijing, China. Interviews were conducted at three different locations in Beijing: three at a special and inclusive education school, three at a school for people with intellectual disabilities, two at a university, and one on the internet. Interviews lasted from 50 to 75 minutes. Following the signing of consent forms, the interviews were recorded using mobile phones. Except for the online interview, which was conducted via WeChat, the consent form was verbally signed. The interview was arranged with four academics, but one declined to participate, citing a lack of desire to share his experience on the topic.

In accordance with the supervisor's list of interviewees, the research assistants and the researcher arranged the dates and locations for the interviews. The participants signed consent forms before the interview began. Assisting researchers provided them with the interview questions in Chinese as well.

Procedures

Data collection was undertaken through in-depth interviews with stakeholders in special education, primarily the nine interviews. Yin (2018) described in-depth interviews as “unstructured interviews and intensive interviews” that are “conversational in nature” (p. 351). An in-depth interview was chosen to elicit additional information from the participants and allow them to freely share their experiences and knowledge about inclusion and segregation, as well as special education in general (Yin, 2018). According to Yin (2014), interviewing is a valuable method of validating previously collected data. The primary goal of an interview, he stated, “may be primarily to corroborate some conclusions that you already believe have been established, rather than to explore broader, open-ended topics” (p. 179), although the interview process had the intention of collecting more data than simply validating quantitative findings.

Trustworthiness

We analyzed the nine interviews primarily using content analysis and thematic analysis (Allen, 2017; Trochim, 2006). A thematic analysis involves various phases that ensure trustworthiness (Castleberry & Nolen, 2018; Nowell et al., 2017). For this study, various methods were used to determine trustworthiness. Trustworthiness is defined by four criteria: credibility, transferability, dependability, and confirmability. Each of these criteria was examined using a particular method at each stage of thematic analysis, namely compiling, disassembling, reassembling, interpreting, and concluding. Table 2 shows five phases of establishing trustworthiness and the methods involved.

Table 2

Establishing trustworthiness at the five phases of thematic analysis

Phase	Concepts	Means	Explanation
Compiling	Credibility	Triangulation	Nine interviews were conducted, but the theme and questions for the interviews were controlled to allow the verification of the collected data.
	Transferability	Thick description	The methods section of this study provides a detailed description of data collection.
	Dependability	Detailed documentation	On the procedure section of this study, all the steps for compiling the data are documented and explained in detail.
	Confirmability	Peer checking	A total of three special education researchers and the researcher verified the collected data.

Phase	Concepts	Means	Explanation
Disassembling	Credibility	Triangulation	In-depth interviews led to the collection of too much data. Transcription of the first interview took too long, resulting in dense data. Therefore, a decision was made to transcribe data selectively.
	Transferability	Thick description	The procedure and data analysis section provides a detailed coding and analysis description.
	Dependability	Detailed documentation	Each step, process, and procedure of data disassembly is documented in detail.
	Confirmability	Peer checking	Three researchers participated in the interviewing, transcription, and translation into English, and one researcher also checked the coding of themes and analysis steps.
Reassembling	Credibility	The emic or folk perspectives of the participants	Research assistants who assisted the researcher in data collection were instructed to refrain from changing the questions or attempting to direct the interview toward a specific conclusion.
	Transferability	Thick description	A detailed description of the final themes is presented on the data analysis page.
	Dependability	Detailed documentation	Each of the steps, processes, and procedures involved in reassembling data are documented in detail.
	Confirmability	Peer checking	To ensure the final data was not beyond the scope of the study, the generated and emerging themes were compared to the objectives of the study. This was verified by a colleague with a similar background.
Interpreting	Credibility	Progressive subjectivity checks	From time to time, the researcher assessed how the analyzed data is supporting or opposing some of the proposed theories. This issue has been left as part of the discussion of the study, limitations, and future research.
	Transferability	Thick description	Interpretation procedures are detailed in the section on procedures and data analysis.
	Dependability	Detailed documentation	We have carefully documented each step, process, and procedure of data interpretation.
	Confirmability	Repeated checking	Continual checks are conducted to ensure accuracy.

Phase	Concepts	Means	Explanation
Concluding	Credibility	Peer debriefing	Peers have suggested that the conclusion should be focused on the relevance and contribution to the field, society, and country.
	Transferability	Thick description	Results are described, analyzed, and explained, while results and conclusions are discussed and derived.
	Dependability	Detailed documentation	A detailed description of all steps, processes and procedures is provided.
	Confirmability	Peer checking	The conclusions are peer-reviewed and reflect the results of the findings while answering the study's questions.

Ethical Concerns

Because most interviewees do not speak English well enough to conduct interviews in English, the supervisor arranged the interview consent at the beginning. Prior to the interview, each interviewee signed the consent form. In the ninth interview, the consent form was verbally approved.

Furthermore, the use of ethics is ensured during interviewing, during which the visited schools request that the names of the schools and universities be kept confidential. The names and affiliations of interviewees were also coded upon request.

Data Analysis

It was decided to proceed with the analysis of the interviews in five phases: compilation, disassembly, reassembly, interpretation, and conclusion. Following compilation, disassembly, and reassembling of the data, the analysis was arranged in accordance with the views and experiences of leaders, practitioners, and academics. Accordingly, the remainder of the analysis is guided by the themes that appeared on the interview form (See Figures 3 and 4). As well as summarizing and paraphrasing, selected excerpts were chosen for their relevance to the themes. Throughout the results, discussion, and analysis of the study, we referred to the interviewees by their titles (director, principal, manager, special education practitioner, and special education academic/expert). Therefore, we have replaced the names of the schools and universities associated with the interviewees (special education school, intellectual disability school, university in Beijing, university in Wuhan, university in southwest China).

Figure 3
Sample data extraction screenshot for provision, strengths, weaknesses & unique features.
Status of special education I

Interviewee	Better provision	Main strengths	Main weaknesses	Subtheme	Unique features
Director and principal	Shortage of educational resources; More people should study special education, and there should also be relevant courses of special education in the pre-service training of ordinary teachers	The advantage of the administrative system, the Chinese government stipulated what tasks to achieve, the school must do	Teachers expect more experts to do some training, so that there will be more students and more lectures	The administrative system is unique. The government can force schools to integrate all students into the education system	The administrative system is unique. The government can force schools to integrate all students into the education system
Principal	We need to improve integrated education to create an integrated environment for kids. Secondly, we should improve the development of Special Education, especially on teachers' training. Then we can have enough people for this cause	Large population. Because of a major means a promising trend. Another advantage is the collective force. What's more, China's cultural environment is suitable for the development of Special Education. Because in China, people are considered as a whole, which is a great humanistic concept	China was a poor country so it's hard for other people to help the disabled. We have traditional strengths, but we don't have enough materials and knowledge of this subject	Chinese culture provides distinctive characteristics of China's Special Education. We have traditional Chinese medical adjustments, including acupuncture. This is the support of Chinese culture. At the same time, we've got a lot of help from our government.	Chinese culture provides distinctive characteristics of China's Special Education. We have traditional Chinese medical adjustments, including acupuncture. This is the support of Chinese culture. At the same time, we've got a lot of help from our government.

Figure 4
Sample data extraction screenshot for needed areas for the development of special and inclusive education provision.
Status of special education II

Interviewee	Curriculum design	Regular education and inclusion	Teachers' qualification	Subtheme	
					Parents' awareness and economic level
Director and principal	The guidelines for children with moderate mental retardation, which were prescribed in textbooks and curricula at that time, played a great role in the initial stage of special education. A new round of curriculum reform began in 2011, but the relevance to special education was small. Little practicality. So we wrote our own textbooks, which we couldn't wait for, and the national curriculum wasn't always right for us	Special education needs to be tailored, but not in regular schools. But with the construction of this resource classroom, this situation will be improved. But it is still not enough to meet the needs of exceptional children	The purpose of our special education guidance center is to train teachers, who may not be competent enough. But they are not unqualified, as long as they are patient, loving and competent	Most parents know their children's educational needs, but some parents don't; they don't know exactly what the problem is and how to educate them. In fact, many obstacles can not be cured, only can improve, therefore, parents are easy to be deceived	I don't know a lot about that. It's easy to confirm cases now. But we don't have good enough education and resources afterwards. As for money teachers have background and service, they are different for each person. But we've got national subsidies on that
Principal	Some good schools already have great curriculum. But some new schools are lagging behind and they need a more unified standard; I think good teachers mean good curriculum. That's why it's difficult to devise good curriculum. Because that requires good teachers and principals with professional backgrounds	As for now it's not the case. Because it's really difficult. What they have for special kids meet the needs. But that depends on schools. And there is a huge difference among different schools.	On a whole, special education teachers' education backgrounds and experience meet the needs. But that varies as well. Integrated education teachers have background in the subject and Special Education. But they are not professional enough		

Results

Status of special education

Special education status was analyzed through factors related to the development of special education development in China, including suggestions for better provision, main strengths, main weaknesses, and unique features characterizing special education in China.

Results overview

Ten questions guided the discussion throughout the interview, but open discussion within these topics was also allowed. First, two questions asked the participants to tell a personal story about their motivations for working in special education. There were two administrators who moved from teaching to administration compared to the director and principal with 39 years of experience who was assigned. As reported by three practitioners, their reasons seemed to be like those reported by three academics, who also stated they chose to work in special education because of its challenges and because they believed it would offer a better job, except for the assistant professor with two years of experience in this field, who stated that he was mandated to work in this field.

The remaining questions addressed providing better special education, the strengths of special education in China, its weaknesses, and the unique characteristics that characterize special education in China. For each of the above four aspects categorized in the interpretation section, the interviewees stated several suggestions and factors (See Figure 5). As a follow-up to the first part of this topic, the second part focused on four different aspects: curriculum design, regular versus special education, the qualification of teachers, and lastly, parents' awareness and socioeconomic background (See Figure 6).

Characteristics of special and inclusive education

Better provision suggestions

Several suggestions were proposed by the participants towards better provision of special education (See Figure 5). These suggestions seem to be variable, but, interestingly, most participants think that most of them could be resolved through laws, policies, and regulations of special education.

Strengths

The participants also reported many factors as the main strengths of the current special education state. Although minor contradictions are observed between the suggestions for better provision and main strengths (e.g., spending more on special education and being funded), the rest of the factors seem logical and match the current state of special education in the nation.

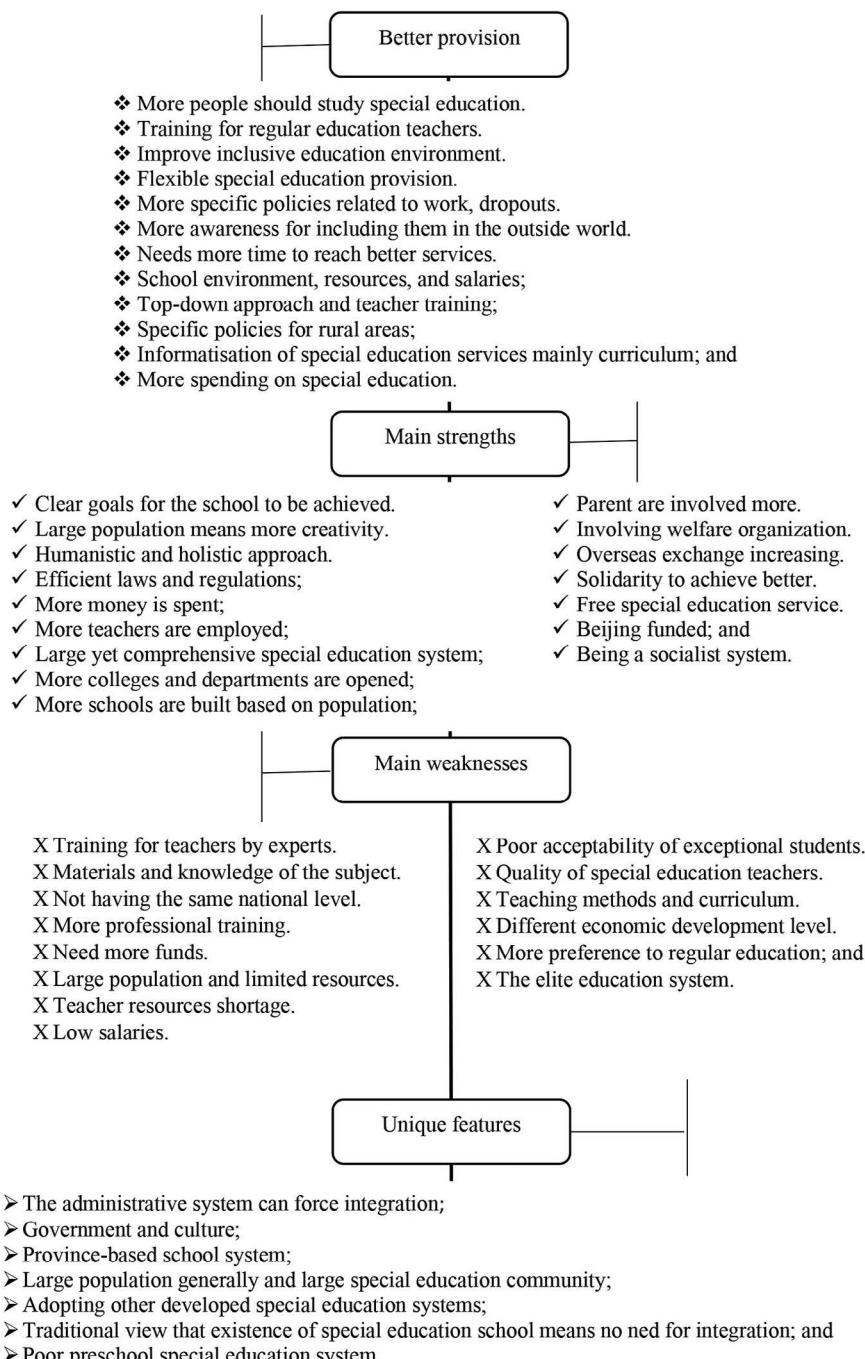
Weaknesses

To balance the elicited views from the participants and reach a comprehensive overview of special education development, the participants were also asked about the main weaknesses of special education. They expressed their concerns about different aspects. Interestingly, some of the participants indicated that there was more bias to regular education when it came to inclusive education. This could indicate an emerging pattern of special education that special education personnel tend to promote special education (segregation) instead of inclusion to keep their privileges which might be vanishing when merged with inclusive education.

Unique features

The participants were encouraged to discuss any features they thought might be unique to China. A significant view here is that the existence of special education contradicts the tendency towards inclusive education. Although this point was discredited by some participants who argued the relationship between special education and other forms of education was parallel. In other words, special education serves regular education by attempting to decrease the severity of disability level and then transferring students to regular education.

In short, the analysis of suggestions for better provision, main strengths, main weaknesses, and unique features in China's special education indicated a standard special education system manifesting pluses and minuses and country-specific features. The major argument is that enough laws, policies, and regulations do exist, but they are not accurately implemented. Another argument is that specific policies related to each province and the central fund for under-developing areas should be made towards a balanced and national special education system.

Figure 5*Status of special education I*

Challenges manifesting the status of special and inclusive education

Further analysis of the status of special education included other factors. While education is currently developing, more efficient and effective efforts should be put into developing special education in China because the designed curriculum does not match the needs of special education and inclusive education, inclusive education is negatively impacting regular education, teachers of special education and mainly those of regular education are not well-trained to teach special education in inclusive education classrooms, and parents do not have enough awareness about the needs of their children with special needs and are not financially prepared to meet their needs, wants and demands.

Curriculum

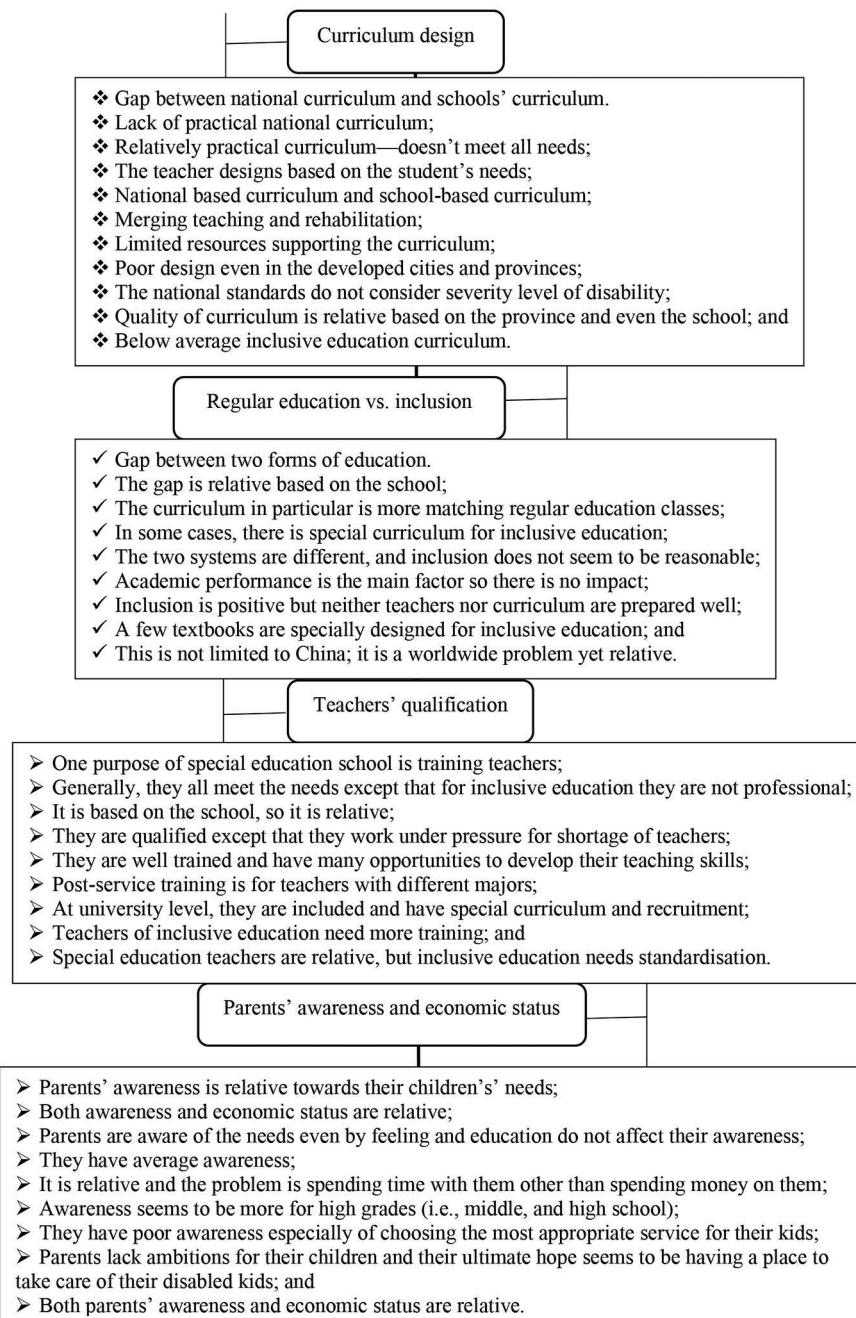
First, more efficient and effective efforts should be put into developing special education in China because the designed curriculum does not match the needs of special education and inclusive education. Although the flexibility of curriculum design matches the learners' different needs, it is still seen as a major weakness of the current curriculum of special education including all its categories.

Inclusive education impact on regular education

Additionally, inclusive education negatively impacts regular education. Despite this, "IDS-3" argued the other way claiming, that academic performance is the main factor, so there is no impact on regular education, and "PU-3" claimed that "this is not limited to China; it is a worldwide problem yet relative".

Teachers of special education and inclusive education

Also, more efficient and effective efforts should be put into developing special education in China because special education teachers and particularly regular education teachers are not well-trained to teach special education in inclusive education classrooms. Others think that "teachers of inclusive education need more training" and that "special education teachers are relative, but inclusive education needs standardization" (SES-1; IDS-1).

Figure 6*Status of special education II*

Parents' awareness of the needs of their children

Finally, parents do not have enough awareness about the needs of their children with special needs and are not financially prepared to meet their needs, wants, and demands. On the other hand, some disagree and believe that “they have poor awareness especially of choosing the most appropriate service for their kids” and “parents lack ambitions for their children and their ultimate hope seems to be having a place to take care of their disabled kids” (PU-1; PU-2).

Thus, while special education is leveling up to match the needs of the special education community and build a harmonious and productive society, more efficient and effective efforts should be put into developing special education in China.

Discussion

By conducting the current study, the authors sought to explore the current state of special education and inclusive education in China. These characteristics and challenges were explored through interviews with stakeholders. The findings of this study offered a comprehensive view of the special education system in China that contributed to a deeper understanding.

The findings include the following: 1) the various methods of providing special education are valuable, however further reforms are needed, including increasing salaries, issuing specific policies for developing and underdeveloped areas, 2) the current system has several strengths, such as parents' involvement, government funding, and more employment of teachers and staff, 3) the current system has several weaknesses, including the lack of training for teachers, gaps between provinces and cities, and parents' preference for regular education, 4) the Chinese context is unique due to compulsory integration laws, provincial school systems, and a large population.

Furthermore, they include other factors that must be addressed for the special education system to be improved. These include: 5) the curriculum does not match the needs of special education and inclusive education, 6) inclusive education negatively impacts regular education, 7) most special education teachers do not have the appropriate training to teach special education in inclusive education classes, and 8) parents are not adequately informed about the needs of their children with special needs, and they are not financially prepared to meet those needs.

The results of this study are consistent with recent research on special education and inclusive education. Several studies have reported significant progress in the provision of special education services in China (Alduais, 2020; Alduais et al., 2019; Alduais & Deng, 2019). Additionally, other studies have highlighted the current challenges of inclusive and special education described in our study, which increase during the pandemic outbreaks (Jia & Santi, 2021),

teacher conflict when transitioning into inclusive classes (Xie, Deng, & Zhu, 2021), and social support to inclusive education teachers (Xie, Deng, & Ma, 2021).

Several interpretations are possible to further comprehend the above findings. First, the existence of four types of special education, including direct inclusion in regular education, mainstreaming, segregation, and exclusion, indicates the existence of well-established legislation, laws, and policies. The parents of children with special educational needs have four options to enroll their children. Although these options are not fully optional for parents, as they depend on the enrolment procedures and the decision of the school after initial screening, these four options are continuous. Therefore, learners who are categorized as having minor problems are required to participate in the regular education system. Those reported as having minor difficulties, but still hindering their enrolment in regular education, are recommended to take mainstreaming classes before returning to regular classes. Special education schools are provided for those who have major disabilities (i.e., segregation). According to their progress and recovery, they may be transferred to either of the first two options. The most severely disabled children who cannot attend special education schools are excluded and provided with home education (i.e., exclusion). Therefore, it is evident that a large system of education with different forms of provision would require many staff, facilities, and costs. This would result in some shortcomings.

Second, the curriculum plays a crucial role in the development of any educational system. There appears to be confusion on two levels: first, there is no national curriculum, although there are national guidelines and policies. Secondly, the curriculum for special education, and more importantly, inclusive education, is not standardized. It is problematic for teachers and students alike to use the regular education curriculum for inclusive education. Thus, a third interpretation is that the expansion of special education could have a negative impact on the promotion of inclusive education. Like the impact of inclusive education on regular education, it impacts regular education via teachers who are not prepared to run inclusive classes or learners who are not prepared psychologically and socially to accept such an inclusive environment.

Fourth, parents must understand the needs of their children with special needs to ensure their future success. Although the evidence we collected indicated that parents in China are aware of these needs, whether educational, social, or psychological, the evidence also includes opposing views. It is also pertinent to note that the degree of awareness depends on the economic level and educational level of the parents. In rural areas, parents often choose to leave their children at home and limit their education to basic courses (primary school level) due to the cost of caring for such children.

In light of these interpretations, at least two implications are possible. A first step for the Chinese government would be to shift the development level for special education and inclusive education from quantity to quality and from macro to micro level. In other words, there should be more specific policies and more money allocated to bridge the gap among the various provinces in China. It is pertinent to establish specific policies for inclusive education classes and ensure that regular education teachers are ready to teach inclusive education classes. Secondly, the government spends a great deal on special education, which allows them to run a quadripartite system. A powerful economy, many people, a sophisticated educational system, and many persons with special education needs make this a compelling case. However, the current situation should also continue to advance the provision of services for special education, including the training of teachers.

Limitations

In this study, we explored the current state of special education and inclusive education provision in China from the perspective of stakeholders. This study does, however, have some limitations. First, it would have been more credible if parents of both special education and regular education students, and regular education teachers, had been included in the study. In addition, if stakeholders from the four provision methods were included: from regular education schools, inclusive classes, mainstreaming classes, and special education schools, the generated views would have had a greater likelihood of being substantiated.

Conclusion

The findings of this study uncovered the experiences and opinions of Chinese stakeholders concerning the characteristics and challenges of special education in China. Our study found that the current provision methods are comprehensive, but they need to be refined and standardized across the country. Several laws and policies need to be enacted by the government to address reported shortcomings in the curriculum, teacher training, gaps between the four forms of education, parents' awareness, and their socioeconomic standing. These challenges are present in any setting, let alone a country with such a large population as China. However, it becomes more evident when we consider that learners with Special Educational Needs have the right to live a quality life, learn, and belong to the world.

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Obezbeđivanje specijalne edukacije u Kini – Karakteristike i izazovi iz ugla zainteresovanih aktera

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Uvod: Učenicima s posebnim obrazovnim potrebama u Kini pruža se mogućnost indirektnog uključivanja u redovno obrazovanje (inkluzija), pohađanja specijalnih i redovnih odeljenja (mainstreaming), upisa u specijalne škole (segregacija) ili pohađanja kućne nastave (ekskluzija). Ovaj obećavajuće glomazni edukativni sistem ima nekoliko nedostataka, kao što su: neadekvatnost kurikuluma, suparništvo između trendova segregacije i inkluzije, priprema nastavnika i svest roditelja o potrebama svoje dece. *Ciljevi:* Sprovedeni su dubinski intervjuvi kako bi se ustanovile sve ove jake strane i nedostaci iz perspektive zainteresovanih aktera u Kini. *Metode:* Realizovano je devet dubinskih intervjuva sa različitim akterima u oblasti specijalne edukacije u Kini. *Rezultati:* Dobijeni nalazi su prezentovani kroz detaljnu analizu kojom je obezbeđen vizuelni pregled glavnih snaga, slabosti, predloga za poboljšanje aktuelnog stanja, kao i specifičnih karakteristika relevantnih za kineski kontekst. *Zaključak:* Rezultati istraživanja su dali doprinos razmatranju ove teme otkrivanjem dugogodišnjeg iskustva aktera u oblasti specijalne edukacije i isticanjem nekih od trenutnih nedostataka – kurikuluma, pripreme nastavnika, suparništva između specijalne i inkluzivne edukacije, kao i potrebe da se poveća svest roditelja o pravima njihove dece u smeru izgradnje inkluzivnijeg društva.

Ključne reči: specijalna edukacija, Kina, obezbeđivanje, inkluzija, defektolozi

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Objective indicators of quality of life in people with different visual status

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Introduction. Quality of life is a broad and complex construct. World Health Organization refers to it as an “individual’s perception of their position in life (...) in relation to their goals, expectations, standards, and concerns”. Reduced visual functions have a negative impact on the overall individual’s functioning. Difficulties in accessing visual information and problems in orientation and mobility create significant limitations in performing daily activities and lead to diminished opportunities for education, work, social participation, and leisure. Limited participation in the aforementioned areas with lower social interactions have a negative impact on the individual’s quality of life. However, it is unclear whether this construct of people with visual impairment is compromised due to reduced ability to perform daily activities or due to difficulties in establishing social interactions. *Objectives.* In an effort to indicate the consequences of visual impairment on quality of life, the goal of this research was to determine the objective quality of life in adults with different visual status when controlling the age. *Methods.* The Comprehensive Quality of Life Scale was used to evaluate the quality of life. The sample consisted of 175 people – 92 participants with visual impairment and 83 participants without structural or functional problems in the visual system. *Results.* Results of eight one-way ANCOVAs indicated a significant effect of visual status on Objective quality of life in total ($p < .001$) and on its four domains: Material well-being, Health, Productivity, Place in Community. *Conclusion.* The effects of different visual status on the observed construct revealed when age as a variable is controlled.

Keywords: objective quality of life, visual status, visual impairment, adults

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Introduction

Expression quality of life (QoL) was first used in the middle of the 20th century by politicians who promised voters that they would improve their quality of life by improving socio-economic status (Sheppard-Jones, 2003, as cited in Stanimirov, 2016). Over the past decades, the concept of QoL has changed. In the beginning, this concept was observed in the context of satisfying basic needs: possession of shelter, food, clothes. However, with the economy strengthening, this notion expanded and included the pursuit of happiness and attainment of general well-being (Yusoff, 2020). The next step was to consider health status, i.e., introduce the concept of health-related QoL. However, this construct is much broader than the conditions of housing, material resources, or health (Stanimirov, 2016; Stanimirov et al., 2014).

Quality of Life Concept

There is no single universally accepted definition of QoL, although there were many attempts to define this construct and relate it to different meanings such as: happiness, life satisfaction, well-being (Trillo & Dickinson, 2012). However, its meaning depends on the context it is used in (Jones et al., 2019). The World Health Organization (WHOQOL group, 1995, p. 1405) refers to the concept of QoL as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns”.

“Overall”, “global” or “general” quality of life, is a broad, multidimensional construct created by the interaction of several domains, which include physical (disease symptoms and medical treatment), functional (self-care, activity level, daily living activities), social (contacts and interpersonal relationships) and psychological domain (cognitive functions, emotional status, well-being, life satisfaction, happiness) (Trillo & Dickinson, 2012; WHOQOL group, 1995) as well as an economic and political domain (Revicki et al., 2000). Depending on the desired generalization level, the number of QoL domains varies. In the literature, the most often listed domains are: interpersonal relationships, participation in society, personal development, physical, material, and emotional well-being, self-determination, (basic) rights, environment, family, rest and recreation, and security. The World Health Organization group in charge of the quality of life assessment (WHOQOL group, 1995) as key domains of QoL identifies: physical and psychological health, independence level, personal beliefs, social relations, and individuals’ attitude towards the important environmental aspects. Felce & Perry (1995, as cited in Verdugo et al., 2012) proposed a QoL model in which domains were ranked in the order of importance: physical, material, social well-being, development and activity, and emotional well-being. Certainly, the number of domains is by far less important than the fact that their set should

represent a complete construct of QoL (Verdugo et al., 2005, as cited in van Hecke et al., 2018).

Verdugo et al. (2005, as cited in Verdugo et al., 2012) believe that the QoL domains relate to the sense of personal well-being. Schalock (2004, as cited in van Hecke et al., 2018) agrees with them, saying that the term QoL "domain" refers to a set of factors that make up overall well-being. Surely, quality of life should be viewed as satisfaction in the life domains that are especially important to an individual (American Occupational Therapy Association, 2020). With regard to that, QoL can be viewed objectively and subjectively. The two-dimensional character of the QoL concept refers to generally accepted standards in the social discourse of a person's life (objective dimension), as well as the level of personal satisfaction in different domains by their significance (subjective dimension) (Cummins, 1997). Additionally, this construct should not be considered a static characteristic because social standards or personal satisfaction may change over time (Moons et al., 2006).

Impact of vision impairment on quality of life

Reduced visual functions have a negative impact on the overall functioning of the individual. Difficulties in accessing visual information, together with problems in orientation and mobility, have significant limitations in performing daily activities (Jablan et al., 2016) and lead to diminished opportunities for education, social participation and work (Ejiakor et al., 2019; Khorrami-Nejad et al., 2016; Yibekal et al., 2020). Various issues are related to the education of visually impaired learners. For example, they require specific strategies that address their unique learning needs, especially difficulties in acquiring literacy (Grbovic et al., 2022; Lange et al., 2021). If we focus on the social aspects, the limitation of this sensory system is associated with restrained social integration and required higher support levels (Brown & Barrett, 2011). Besides that, visual impairment has markedly negative effects on the level of independence in performing everyday activities, such as going to store, caring for children, taking care of oneself and the household, using public transport, engaging in leisure activities, etc. (Stanimirov et al., 2020). Undoubtedly, daily living activities can be major obstacles for people with visual impairment since they are unable to carry them out, or need support from family members to accomplish them (Jones et al., 2019). Besides difficulties with functioning in different life aspects, visual impairment is often associated with emotional problems and the occurrence of depression and anxiety (Giloyan et al., 2015; Nayeni et al., 2021), as well as poorer overall health, which are especially frequent in people with moderate to severe visual impairment (Crews et al., 2016; Elsman et al., 2019). All of the above can lead to a diminished sense of personal well-being.

Limited participation in educational, professional, daily, and leisure activities along with lower social interactions have a direct negative impact on the individual's QoL (Brown & Barrett, 2011; Gyawali et al., 2012; Komolafe, 2016; Lin & Yu, 2012). However, it is still unclear whether the QoL of people with visual impairment is compromised due to reduced ability to perform daily activities or due to difficulties in establishing social interactions (Brown & Barrett, 2011; Jones et al., 2019; Lin & Yu, 2012). Furthermore, there is the possibility that QoL can be influenced by some additional, nonvisual factors: differences in economic status, lifestyles, cultural values, health care system availability, physical and mental health (Trillo & Dickinson, 2012). Thus, it is clear that the effects of visual impairment on QoL vary across communities, cultures, and locations and are reflected in the individual's economic, social, and psychological life (Khorrami-Nejad et al., 2016).

One of the important factors that may affect QoL among both the general population and persons with disability is age. Several studies found a negative correlation between QoL and aging (Brown & Barrett, 2011; Ćwirlej-Sozańska et al., 2018; La Grow et al., 2013). Aging in people with disabilities means that there is a necessity to optimize interventions to help them maintain or improve the level of their QoL, which may imply some discrepancies in QoL between this group and the general population. In an effort to indicate the consequences of visual impairment on QoL in our country, this research aimed to determine the objective QoL in adults with different visual status when controlling the age.

Method

Participants

The sample consisted of 175 people of both genders, aged 19 to 65 ($M = 35.19$, $SD = 10.65$), with different visual status. Based on the degree of visual deterioration, two groups of participants met the WHO criteria (WHO, 2020) for visual impairment: blind ($n = 46$, $M = 34.09$, $SD = 12.36$) and those with low vision ($n = 46$, $M = 36.11$, $SD = 8.95$). The third group consisted of 83 participants ($M = 35.29$, $SD = 10.56$) without structural or functional problems in the visual system. The excluding criterion for the sample formation was the presence of additional disorders or impairments that could impact QoL, for example, intellectual or physical disability, hearing impairment, serious health or psychiatric conditions.

The results obtained using the chi-square test showed no statistically significant differences between the participants with regard to gender, i.e., males and females were equally represented in all three categories of the participants ($\chi^2 = 3.19$, $df = 2$, $p = .20$).

Procedure

The research was realized among members of the Association of the Blind, Belgrade, and the Association of the Blind, Vojvodina. Verbal consent was given by

92 members, after which an individual interview was arranged. A telephone interview was organized for 30 participants who were prevented from coming in person. Sighted participants were found through personal contacts, and this subsample was formed by a snowball method. All participants were guaranteed anonymity and the use of data solely for scientific purposes. Also, it was emphasized that they could cancel their participation at any time.

The researcher read the statements and questions to the participants with visual impairment and wrote down their answers. There was no time limit, and the participants could ask for assistance with any question they did not fully understand. As for the sighted participants, they filled out the questionnaire by themselves in an online form.

Instruments

A questionnaire was constructed for the purpose of this research to collect sociodemographic data on the participants (gender, age, level of education, work status and degree of visual impairment),

The *Comprehensive Quality of Life Scale, 5th Edition (ComQol-A)*; Cummins, 1997), was used to evaluate quality of life. This scale was designed for use with the general adult population for assessing two dimensions of quality of life – objective and subjective. The instrument consists of seven domains (for each of the two dimensions): material well-being, overall health condition, productivity, intimacy, safety, place in the community, and emotional well-being. Each of the domains is represented by three items, and the participants gave their answers on assertion on a five-point Likert scale. The results are obtained by adding up three corresponding raw scores for each of the seven domains, and the total score of the objective QoL is formed following the instructions from the instrument guidelines. The scale has good internal consistency with Cronbach's alpha values of .84 (Cummins, 1997). A part of the Questionnaire that evaluates quality of life based on objective criteria had acceptable internal consistency ($\alpha = .51$).

Statistical data analysis

Descriptive statistics techniques were used to show central tendency and variability measures. One-way univariate analysis of covariance (ANCOVA) was used to examine the differences among the participants after controlling the age. Data were analyzed using the statistical software package SPSS, version 21.

Results

The participants' objectively perceived quality of life was analyzed using the Comprehensive Quality of Life Scale. Since assumptions for using multivariate analysis of covariance were not met, a series of one-way univariate analyses of covariance (ANCOVA) was applied to examine the differences in objective quality of life aspects between low-vision, blind, and sighted participants after controlling the age.

Descriptive measures (means and standard deviations) for three groups, along with adjusted means and standard errors for QoL domains and ANCOVA results, are displayed in Table 1.

Table 1

Descriptive statistics QoL domains (adjusted means and standard errors after controlling the age) and ANCOVA results

QoL domain	Visual status	M	SD	M _{adj.}	SE	F (2,172)	p	η ²
Material well-being	Low vision	62.14	11.35	62.12	1.67	3.71	.026	.042
	Blind	63.04	8.72	63.07	1.29			
	Sighted	67.37	13.16	67.37	1.44			
Health	Low vision	73.19	8.59	73.45	1.27	123.47	< .001	.591
	Blind	66.12	8.68	65.81	1.28			
	Sighted	91.87	11.49	91.90	1.26			
Productivity	Low vision	58.57	13.34	58.38	1.97	6.00	.003	.066
	Blind	54.47	14.92	54.70	2.20			
	Sighted	63.42	14.18	63.40	1.56			
Intimacy	Low vision	76.45	18.62	76.70	2.75	.34	.71	.004
	Blind	75.00	20.41	74.70	3.01			
	Sighted	77.31	15.42	77.34	1.69			
Safety	Low vision	82.07	8.60	82.29	1.29	2.00	.14	.023
	Blind	84.60	12.17	84.34	1.79			
	Sighted	80.22	12.46	80.25	1.37			
Emotional well-being	Low vision	68.12	17.77	68.01	2.62	1.29	.28	.015
	Blind	65.22	15.35	65.35	2.26			
	Sighted	63.15	16.47	63.14	1.81			
Place in community	Low vision	14.97	4.71	15.03	0.70	7.34	.001	.079
	Blind	12.72	5.41	12.65	0.80			
	Sighted	11.78	4.17	11.79	0.46			
Objective QoL – total	Low vision	68.53	6.61	68.60	0.97	9.66	< .001	.102
	Blind	65.78	7.27	65.70	1.07			
	Sighted	70.86	5.86	70.87	0.64			

A series of eight one-way ANCOVAs were conducted to compare the domains of objective quality of life and objective quality of life in total between three groups of participants with different visual status (low vision, blind, and sighted), controlling the participants' age. Results displayed in Table 1 indicate significant effect of visual status on Objective QoL in total ($p < .001$) and on four domains of objective quality of life: Material well-being ($p = .026$), Health ($p < .001$), Productivity ($p = .003$), Place in Community ($p = .001$). According to partial Eta squared value ($\eta^2 = .591$), the participants' visual status has the strongest (but moderate) impact on health as a quality of life domain. In other cases, size effects should be considered small since partial Eta squared values vary from .042 to .102.

In cases where F statistics were significant, Bonferroni post hoc tests revealed how three groups of participants differ in each quality of life's domain. Comparing the means adjusted for age showed a significant difference in Material well-being scores between sighted and low vision participants ($p = .047$), with higher scores in the group of subjects without visual impairment. Previously it was pointed out that visual status among all quality of life aspects strongly influenced health. In this domain, sighted participants have significantly higher scores compared to low vision and blind groups ($p = .001$). The health of participants with visual impairment also differs regarding the severity of the impairment: blind people have significantly lower scores than those with low vision ($p < .001$). In the domain of Productivity, significant differences are observed between sighted and blind participants ($p = .003$) with lower scores in the group of the blind. Interestingly, visually impaired participants evaluate their place in the community higher than sighted participants. In this quality of life domain, significant differences are observed between low vision and blind participants ($p = .045$) as well as between low vision and sighted participants ($p = .001$), with the highest in the group of low-vision and the lowest in sighted participants. Finally, when it comes to the general measure of objective quality of life, post-hoc test revealed a significant difference between blind and sighted participants ($p < .001$), with higher scores in the latter.

Discussion

According to WHO (2020) and The International Classification of Diseases 10th Revision (*ICD 10*; WHO, 2010), 285 million people around the world have visual impairment (blindness or low vision). Almost 30% of people with visual impairment are within economically active population. Still, the majority of them are older than 60 years, which means that visual impairment is a common and depleting health problem among adults. With the tendency of global population aging, the number of vision loss cases is expected to continue rising (Ejiakor et al., 2019; Jablan et al., 2016).

In the context of QoL, visual impairment leads to restrictions in many daily living aspects and has significant negative effects on many QoL domains (professional, functional, and social life, as well as physical and emotional well-being). These findings are supported by the fact that older people with visual impairments (especially those with a greater degree of impairment) have lower scores on instruments that assess QoL compared to peers who do not have visual impairment (Brown & Barrett, 2011; La Grow et al., 2013). However, some studies have not found a negative impact of visual impairment on QoL. Adigun et al. (2014) state that most of their participants with visual impairment (almost 80%) have good overall quality of life. Results of studies in this field are not consistent, especially when it comes to data on differences between QoL and the degree of visual impairment or observed QoL domains, i.e., although

general QoL may be perceived as good, some differences in individual domains can exists. Our study shows statistically significant differences between blind participants and participants without visual impairment, which confirms the tendency of deteriorating QoL with decreasing visual abilities. However, in our research, there are no statistically significant differences in objective QoL in total between blind participants and those with low vision, which is surprising since many studies point out that blind people face serious autonomy and independence difficulties (orientation and mobility difficulties included) (Adigun et al., 2014; Jablan et al., 2016). Even though Finger et al. (2011) stated that mild visual impairment could lead to lower QoL, the absence of statistically significant differences between people with low vision and people without visual impairment in our research does not confirm that. Findings like this can be explained with the “disability paradox” – a term proposed by Albrecht and Devlieger (1999). This term refers to the situation where people with disabilities tend to report high quality of life, despite the fact that disability degrades many aspects of living. They tend to perceive their social world as structured and understandable, consider that they have enough resources to face everyday problems they encounter, and, in the end, they find the motivation to manage disability (Vuletić et al., 2016).

According to scores obtained on the Comprehensive Quality of Life Scale, this research determined a significant effect of visual status (blindness, low vision, and no visual impairment) on four (out of seven) aspects of objective quality of life: Material well-being, Health, Productivity and Place in Community, and visual status has the strongest impact on Health as the quality of life domain. This practically means that, in everyday life, participants from the general population visit doctors less often, use less medication, and have fewer health problems than people with visual impairments. Also, participants with low vision achieve higher scores in the Health domain, which indicates that they have a better health status compared to the blind participants. These results confirm previous findings (Crews et al., 2016; Elsman et al., 2019) about frequent health issues in people with visual impairment.

As expected, participants without visual impairments are more satisfied with their material well-being and productivity – domains which indicate the standard of living and economic security, compared to participants with visual impairments. Studies show that, from the aspect of economic security, there is a high unemployment rate and lower income in the population of people with visual impairments (compared to sighted ones). This economic situation can lead to many problems. For example, people with visual impairment could become financially dependent on family members (Amedo et al., 2016; Brown & Barrett, 2011). Furthermore, they can often be in the situation to ask for help, which decreases the ability to maintain equity in the exchange with others, or can be related to a feeling of uncertain future, low sense of self-worth, and a

feeling that they are not an active and contributing family (and society) member (Khorrami-Nejad et al., 2016). An explanation can be found in the following: there are not many career opportunities (i.e., opportunities for being productive) for blind people. They are usually offered the job of a masseur or administrative worker, which does not always correspond to their competencies and level of education. Also, that can lead to a lack of desire to even apply for a job (Vučetić et al., 2016). Unlike the blind, people with low vision have a wider range of employment opportunities, which is primarily related to the fact that, when the path of functioning, learning, and applying knowledge is primarily visual, it is much easier to accommodate and adapt the educational approach and, later in life, workplace.

With regard to the Place in the community domain, people with low vision have the highest results and people from the general population the lowest, i.e., statistically significant differences are observed between those two groups of participants. The explanation can be found in the questionnaire itself. In other words, the situations listed in the questionnaire that the participants had to assess are such that they are not in line with the socio-economic conditions in our country (e.g., how often in the past month they went to the theater, to a sports game, had lunch outside the house, etc.). Regardless of their visual status, all of our participants rarely engaged in such activities (once or twice a month), which explains the low score in this domain. Also, one of the questions was related to whether the participants were members of a society or association. Participants with visual impairment from our sample are active members of the Association of the Blind, unlike people from the general population (who do not participate in the work of any organized association/society). More specifically, people with low vision are involved in the activities and work of associations of the blind, and because they have fewer difficulties in mobility and orientation, they do not need assistance for participation. Hence, people from the aforementioned population value this aspect of QoL more than the blind. We believe that these somewhat unusual results of statistically significant differences between people with low vision and people from the general population can be explained by this fact.

The Intimacy domain refers to establishing and maintaining connections with family and friends, while emotional well-being is related to individuals' happiness. Participants without visual impairment have higher results in the Intimacy domain than those with visual impairment, specifically the blind ones, although the observed differences were not statistically significant. Tseng et al. (2018) showed that, because of hindered communication and interaction, blindness can cause social isolation and, therefore, less built connections with family members and friends and less perceived social support. On the other hand, participants with low vision have some residual vision, which can empower the QoL domain related to establishing and maintaining social relationships and social integration (Vučetić et al., 2016). When it comes to the

Emotional well-being domain, where blind people and people with low vision have higher scores than participants from the general population (although observed differences were not statistically significant), there is a possibility that participants with visual impairment considered themselves happy, regardless of the differences in other domains of QoL – they are satisfied with what they have, they do not feel that they are missing something, which is in line with the aforementioned disability paradox.

As for the Safety domain, there is a question of how the participants understood the (safety) concept itself. Many viewed it as safety in the sense of avoidance of accidents while walking and doing everyday activities (Vučetić et al., 2016). However, a sense of safety can also be understood as a general feeling of safety within the living environment, without stressing any existing impairments, which was the case in this Scale. In our sample, statistically significant differences were not noticed. However, it is worth mentioning that the highest score was obtained by the group of blind participants, which can be related to the constant layout in living environment, with some of the established routines which make their life more predictable and, hence, easier, so the feeling of safety is higher in this population.

The results presented in this paper reveal the effects of visual impairment on QoL when age as a variable that may influence this construct is controlled. Furthermore, some socio-economic indicators (educational status, employment status, income level, possession of real estate) or psychosocial status (family functioning dimensions, social networks extent, and strength) could also shape QoL and its domains. According to that, we recommend evaluating some of these factors in future research. Examining different aspects of QoL can provide information on the impact of a vision loss on functioning in society, particularly related to daily life activities. More in-depth research in this field would be valuable in supporting people with visual impairment obtain satisfactory QoL levels since it is society's responsibility to support their participation.

With significant social changes that occurred in the second half of the 20th century, the concept of QoL among people with disabilities became a topic of interest. However, research on the general, objective quality of life of people with visual impairment is scarce.

When comparing the results of this study with previous research, it should be noted that the difference in results could stem from cultural and temporal differences. The expectation of objective QoL of our participants, compared to people with visual impairment from different decades and other countries, is likely to be different. Also, the limitation of this study is related to the data collection method – since a face-to-face interview was conducted, there is a question of whether the participants answered honestly or were embarrassed to discuss some topics. Additionally, self-reporting can depend on several factors: participants' mood, cultural norms, tendency to exaggerate when describing their characteristics.

Conclusion

Over the last few decades, significant attention has been given to the concept of QoL in people with disabilities. Visual impairment can undoubtedly have a major impact on people's lives, limiting their functioning (education, independent life, social life, health status, etc.) and well-being. Usually, equal significance is given to both subjective and objective indicators of QoL. With no desire to diminish the importance of subjective QoL indicators, we believe it is necessary to consider the objective QoL indicators in more detail. The objective QoL component is described as a result of interactions between people and the environment in the context of the culture and community in which the participants live. Also, it is less affected by the personal attitude of an individual. The most obvious negative effect of visual impairment on quality of life is perceived in the following domains: material well-being, productivity, and health, where the greatest effects were disclosed in the Health domain. However, the results were somewhat unexpected in the Place in the community domain. Blind participants rated their place in the community lower than the remaining two groups of participants. However, the rates in participants with low vision are higher than those in sighted participants, probably due to their perception of their role in the associations of the blind as high-valued. Considering all the challenges blind people face in everyday life, our study confirmed the negative effect of blindness on objective QoL in total.

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Objektivni indikatori kvaliteta života kod osoba s različitim vidnim statusom

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Uvod: Kvalitet života je širok i složen konstrukt. Svetska zdravstvena organizacija ga definiše kao „percepciju pojedinca o sopstvenom položaju u životu (...) u odnosu na njegove ciljeve, očekivanja, standarde i interesovanja“. Snižene vidne funkcije imaju negativan uticaj na celokupno funkcionisanje osobe. Teškoće u pristupu vizuelnim informacijama i problemi u orijentaciji i kretanju stvaraju značajna ograničenja u obavljanju svakodnevnih aktivnosti i dovode do smanjenih mogućnosti za obrazovanje, rad, učešće u društву i aktivnostima slobodnog vremena. Ograničeno učešće u navedenim oblastima zajedno s nižim socijalnim interakcijama ima negativan uticaj na kvalitet života pojedinca. Međutim, nejasno je da li je ovaj konstrukt kod osoba sa oštećenjem vida kompromitovan zbog smanjene sposobnosti obavljanja svakodnevnih aktivnosti ili zbog poteškoća u uspostavljanju socijalnih interakcija. *Cilj:* U nastojanju da se ukaže na posledice oštećenja vida na kvalitet života, cilj ovog istraživanja je bio utvrditi objektivan kvalitet života odraslih osoba s različitim vizuelnim statusom, kada se kontroliše starost. *Metode:* Za procenu objektivnog kvaliteta života korišćena je Sveobuhvatna skala kvaliteta života. Uzorak je činilo 175 odraslih osoba, od toga 92 ispitanika sa oštećenjem vida i 83 ispitanika bez strukturalnih ili funkcionalnih problema u vizuelnom sistemu. *Rezultati:* Rezultati osam ANCOVA analiza ukazali su na značajan uticaj vizuelnog statusa na objektivni kvalitet života u celini ($p < .001$) i na njegova četiri domena: materijalno blagostanje, zdravlje, produktivnost i mesto u zajednici. *Zaključak:* Prisutni su efekti različitog vizuelnog statusa na posmatrani konstrukt kada se kontroliše starost kao varijabla.

Ključne reči: objektivni kvalitet života, vidni status, oštećenje vida, odrasli

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Socijalno poželjno odgovaranje i stavovi prema osobama s intelektualnom ometenošću kod studenata edukacije i rehabilitacije

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Uvod: Istraživanja sugeriraju da postoji veza između socijalno poželjnih odgovora i stavova prema osobama s ometenošću. *Ciljevi:* Osnovni cilj istraživanja je ispitati povezanost između ispoljene sklonosti studenata edukacije i rehabilitacije da daju socijalno poželjne odgovore, ispoljene nelagodnosti i straha u interakcijama i učestalosti kontakta sa osobama s intelektualnom ometenošću. Posebni ciljevi istraživanja su ispitati da li postoje razlike u ispoljavanju socijalno poželjnih odgovora, nelagodnosti i straha i učestalosti kontakta u odnosu na godinu studija i studijski program, ispitati povezanost nelagodnosti i straha i učestalosti kontakta uz kontrolisanje socijalno poželjnih odgovora, te utvrditi koje varijable utiču na ispoljavanje nelagodnosti i straha. *Metode:* Istraživanje je sprovedeno na prigodnom uzorku od 100 studenata edukacije i rehabilitacije. Prvu i drugu godinu pohađa 71.0% studenata, dok treću i četvrtu godinu pohađa 29.0%. Specijalnu edukaciju i rehabilitaciju pohađa 58.0% studenata, Logopediju i audioligu 27.0% i Poremećaje u ponašanju 15.0%. *Rezultati:* Postoji slaba negativna povezanost nelagodnosti i straha sa sklonošću ka socijalno poželjnim odgovorima, učestalošću kontakta i godinom studija. Korelacija između nelagodnosti i straha i učestalosti kontakta statistički je značajna i onda kada se kontroliše socijalno poželjno odgovaranje. Razlike ne postoje u odnosu na studijski program. U odnosu na godinu studija razlike postoje u ispoljavanju nelagodnosti i straha, gde studenti prve i druge godine postižu najviši skor. Najveći uticaj na ispoljeni nivo nelagodnosti i straha imaju sklonost ka davanju socijalno poželjnih odgovora i godina studija. *Zaključak:* U budućim istraživanjima stavova prema osobama sa ometenošću treba uzeti u obzir sklonost ka socijalno poželjnim odgovorima i nastojati ga kontrolisati.

Ključne reči: stavovi, nelagodnost i strah, učestalost kontakta, socijalno poželjno odgovaranje, studenti edukacije i rehabilitacije

Uvod

U društvima i kulturama u kojima prevladavaju pozitivni stavovi prema osobama sa ometenošću može postojati sklonost pojedinaca ka davanju socijalno poželjnih odgovora (SPO). SPO se definira kao tendencija davanja pozitivnih samoopisa (Paulhus, 2002) ili kao sklonost ispitanika da u određenim uslovima odgovaraju na pitanja u društveno poželjnijem pravcu nego u situacijama kad odgovaraju iskreno (Richman et al., 1999). Može se reći da socijalno poželjni odgovori predstavljaju tendenciju ljudi da daju pretjerano pozitivne odgovore, uskladene sa trenutnim socijalnim normama i standardima.

Iako se u literaturi često ističe da može postojati veza između ispoljenih stavova prema osobama sa ometenošću i sklonosti ka davanju SPO (Antonak & Livneh, 1995, 2000; Lu et al., 2020), vrlo je malo istraživanja koja su se bavila ispitivanjem ove veze. Malobrojna istraživanja, rađena uglavnom na populaciji studenata, pokazuju neusaglašene rezultate. Istraživanje provedeno na populaciji južnokorejskih studenata pokazalo je da je sklonost ka davanju SPO povezana sa kognitivnim i afektivnim aspektima ispoljenih stavova prema osobama sa ometenošću, ali ne i bihevioralnim (Kim et al., 2015). Kim i saradnici (Kim et al., 2015) zaključuju da sklonost ka davanju SPO utiče na ispoljavanje stavova studenata. Rezultati istraživanja koje je sprovedeno u Poljskoj pokazali su da ne postoji povezanost između sklonosti ka davanju SPO i stavova, ali da postoji negativna povezanost između sklonosti ka davanju SPO i socijalne distance (Kowalska & Winnicka, 2013). Međutim, autori upozoravaju da se radi o veoma slaboj korelaciji i da je moguće da je statistička značajnost posledica velikog uzorka ispitanika, te zaključuju da dobijeni rezultati ukazuju na minimalnu vezu između sklonosti ka davanju SPO i stavova prema osobama sa ometenošću. U istraživanju sprovedenom u Etiopiji utvrđeno je da studenti ne pokazuju sklonost ka davanju SPO kada su u pitanju stavovi prema osobama sa ometenošću (Getachew, 2011). Dobijene rezultate autorica objašnjava time da je u etiopijskoj kulturi opšte prihvaćeno odbijanje osoba sa ometenošću, pa studenti nemaju potrebu menjati svoje odgovore kako bi bili društveno poželjniji. U istraživanju stavova japanskih studenata prema osobama sa intelektualnom ometenošću (IO) nije pronađena povezanost između stavova i sklonosti ka davanju SPO (Horner-Johnson et al., 2002), te autori zaključuju da sklonost ka davanju SPO nije uticala na stavove studenata. U Australiji je sprovedeno istraživanje stavova studenata, profesionalaca koji rade sa osobama s ometenošću i opšte populacije, u kojem je utvrđeno da na odgovore nije uticala sklonost ka davanju SPO (Yazbeck et al., 2004). Naprotiv, pokazalo se da su ispitanici sa nižim skorom na skali za procenu sklonosti ka davanju SPO imali pozitivniji stav prema osobama sa IO (Yazbeck et al., 2004).

Istraživanja povezanosti stavova studenata prema osobama sa ometenošću i sklonosti studenata ka davanju SPO nisu do sada rađena na prostoru Bosne i Hercegovine, te je ovo prvo istraživanje ove vrste. Subjekti istraživanja su

studenti edukacije i rehabilitacije¹, jer je poznavanje stavova budućih stručnjaka od izuzetne važnosti. Pre svega stručnjak mora biti svestan vlastitih stavova prema osobama sa ometenošću (Antonak & Livneh, 2000), te je bitno da budući stručnjaci još tokom studija razviju pozitivne stavove (Tait & Purdie, 2000). Istraživanja pokazuju da pozitivnije stavove prema osobama sa ometenošću ispoljavaju studenti koji pokazuju interesovanje da u budućnosti rade sa osobama s ometenošću (Horner-Johnson et al., 2002), studenti koji pohađaju specijalnu edukaciju (Haimour, 2012) i studenti „pomažućih profesija” (Milačić-Vidojević i sar., 2010). Nekoliko istraživanja stavova studenata (specijalne) edukacije i rehabilitacije provedeno je na prostoru Bosne i Hercegovine i Srbije, koja pokazuju da studenti ispoljavaju blago pozitivne stavove prema osobama sa ometenošću (Brojčin i sar., 2015), izrazito pozitivne stavove prema osobama sa IO (Nikolić, 2021) i da se osećaju donekle prijatno ili u proseku prijatno u interakcijama sa osobama s ometenošću (Brojčin i sar., 2015; Banković i sar., 2019). Studenti specijalne edukacije i rehabilitacije generalno imaju visok stepen suošćenja i nizak stepen zabrinutosti u interakciji sa osobama s ometenošću (Brojčin i sar., 2014).

Ovo istraživanje usmereno je na ispitivanje stavova prema osobama sa IO koje su odabранe zbog toga što istraživanja pokazuju da se, u odnosu na druge oblike ometenosti, IO i mentalna oboljenja svrstavaju u društveno najmanje prihvaćene kategorije (Kaljača i Dučić, 2011; Yuker, 1988). Recentnije istraživanje pokazuje da su četiri uobičajena stereotipa o osobama sa IO „prijateljski”, „u potrebi za podrškom”, „neinteligentni” i „dosadni” (Pelleboer-Gunnink et al., 2019).

U ovom istraživanju, pored ispitivanja sklonosti studenata ka davanju SPO i stavova, ispitivana je učestalost kontakta, kao i njena povezanost sa druge dve ispitivane varijable. Učestalost kontakta odabrana je kao varijabla jer istraživanja pokazuju da osobe koje su imale bliske kontakte sa osobama s ometenošću ispoljavaju i pozitivnije stavove prema ovim osobama (Gething, 1991; Malak, 2013; Pace et al., 2010; Tait & Purdie, 2000).

Osnovni cilj istraživanja je ispitati povezanost između ispoljene sklonosti studenata edukacije i rehabilitacije da daju SPO, ispoljene nelagodnosti i straha u interakcijama i učestalosti kontakta sa osobama sa IO. Posebni ciljevi istraživanja su ispitati da li postoje razlike u ispitivanim varijablama u odnosu na godinu studija i studijski program, ispitati povezanost između ispoljene nelagodnosti i straha studenata i učestalosti kontakta uz isključivanje uticaja sklonosti ka davanju SPO i utvrditi koje varijable imaju najveći uticaj na ispoljenu

1 U radu se koristi termin „studenti edukacije i rehabilitacije” shodno nazivu fakulteta koji studenti pohađaju. Uzorak čine studenti Edukacijsko-rehabilitacijskog fakulteta Univerziteta na Tuzli, na kojem postoje tri studijska programa (Specijalna edukacija i rehabilitacija, Logopedija i audiologija, Poremećaji u ponašanju). Ne koristi se pojам „studenti specijalne edukacije i rehabilitacije”, jer bi se termin u tom slučaju odnosio samo na studente studijskog programa Specijalna edukacija i rehabilitacija.

nelagodnost i strah studenata edukacije i rehabilitacije. Ovim istraživanjem se želi utvrditi da li sklonost ka davanju SPO doista utiče na stavove prema osobama sa IO, te da li pri istraživanjima stavova prema osobama sa IO, pa i prema osobama sa ometenošću uopšte, treba uzeti u obzir ovu varijablu.

Metode

Uzorak

Istraživanje je sprovedeno na prigodnom uzorku od 100 studenata prvog ciklusa studija Edukacijsko-rehabilitacijskog fakulteta Univerziteta u Tuzli. U odnosu na godinu studija studenti su podeljeni u dve grupe, gde prvu grupu čine studenti prve i druge godine (71.0%) i drugu grupu čine studenti treće i četvrte godine studija. Uzorak nije ujednačen u odnosu na godinu studija ($\chi^2 = 17.64$, $df = 1$, $p < .001$). U odnosu na studijski program najviše je studenata studijskog programa Specijalna edukacija i rehabilitacija (58.0%), zatim slede studenti studijskog programa Logopedija i audiologija (27.0%) i studenti studijskog programa Poremećaji u ponašanju (15.0%). Rezultati hi-kvadrat testa ($\chi^2 = 29.54$, $df = 2$, $p < .001$) pokazuju da uzorak nije ujednačen u odnosu na godinu studija. U uzorku dominiraju studentice (93.0%).

Instrumenti

Sklonost ka davanju SPO procenjena je Upitnikom za procenu socijalno poželjnih odgovora (*The Scale for Social Desirability – SDS*; Crowne & Marlowe, 1960), koji se sastoji iz 33 ajtema. Ispitanici odgovaraju na svaku tvrdnju tako da se izjasne da li je ona za njih istinita ili neistinita. Viši rezultat ukazuje na veću sklonost ka davanju SPO. Na uzorku ovog istraživanja vrednost Krombahovog alfa koeficijenta iznosila je .69.

Stepen nelagodnosti i straha procenjen je primenom subskale Nelagodnost i strah iz Skale interakcije sa osobama s ometenošću (*Interaction with Disabled Persons Scale – IDP*; Gething, 1991a). Izvorna skala sastoji se od 20 ajtema sa čijim tvrdnjama ispitanici izražavaju različit stepen slaganja, od 1 „apsolutno se ne slažem” do 6 „apsolutno se slažem”. Istraživanja faktorske strukture skale pokazuju nedoslednost, te autorica skale utvrđuje postojanje pet do šest faktora (Gething, 1991), dok se u drugim istraživanjima utvrđuje da skala sadrži tri faktora (Thomas et al., 2003), četiri (Tait & Purdie, 2000) i pet faktora (Iacono et al., 2009). Kao najstabilniji faktori, nezavisno od broja faktora, izdvajaju se dva: Nelagodnost u socijalnim interakcijama i Saosećanje (Forlin et al., 1999; Gething, 1994). Slična dvofaktorska struktura dobijena je i na uzorku studenata studijskih programa Medicine, Specijalne edukacije i rehabilitacije i Zdravstvene nege Medicinskog fakulteta u Foči (Bakoč i sar., 2018), koje autori nazivaju *Empatiјa* (osam ajtema: 1, 2, 3, 4, 5, 7, 8 i 13) i *Nelagodnost i strah* (devet ajtema: 6, 9, 11, 12, 16, 17, 18, 19, 20). S obzirom na to da je na uzorku studenata sa prostora BiH dobijeno dvofaktorsko rešenje, odlučeno je da se isto koristi i u ovom istraživanju. Za potrebe ovog istraživanja korištena je subskala Nelagodnost i strah, koja ima dobru pouzdanost

na uzorku ovog istraživanja ($\alpha = .87$). Subskala je prilagođena za ovo istraživanje tako da je pojam „ometenost” zamjenjen pojmom „intelektualna ometenost”. Viši skorovi ukazuju na veći stepen nelagodnosti i straha u interakcijama sa osobama s IO.

Učestalost kontakta studenata sa osobama s IO procenjena je Skalom za procenu kontakta sa osobama s ometenošću (*The Contact with Disabled Persons Scale – CDP*; Yuker & Hurley, 1987). Skala je Likertovog tipa sa vrednostima od 0 „nikad” do 5 „veoma često”. Učestalost kontakta može biti niska (skorovi od 20 do 60) i visoka (skorovi preko 60). Skala je prilagođena za ovo istraživanje tako da je pojam „ometenost” zamjenjen pojmom „intelektualna ometenost”. Dobivena vrednost Krombahovog α koeficijenta na uzorku ovog istraživanja je .88.

Procedura istraživanja

Studenti su upitnike popunjavalii tokom nastave, a istraživanje je sprovedeno u oktobru 2019. godine. Pre popunjavanja upitnika studenti su informisani o cilju istraživanja, upoznati da učešće nije obavezno i da je anonimno. Svi studenti prisutni na nastavi tokom prikupljanja podataka pristali su da učestvuju u istraživanju.

Obrada podataka

Odgovori studenata predstavljeni su deskriptivnom statistikom. Provera normalnosti distribucija skorova izvršena je Kolmogorov–Smirnovim testom, koji je pokazao da od normalne distribucije odstupaju rezultati za nelagodnost i strah ($p = .023$) i učestalost kontakta ($p = .038$), dok ne odstupaju za sklonost ka davanju SPO ($p = .111$). Za testiranje razlika u odnosu na godinu studija primenjen je Man–Vitnijev U-test, a u odnosu na studijski program Kraskal–Volisov H-test. Povezanost među varijablama ispitana je primenom point-biserijalne korelacije i parcijalne korelacije, a linearna regresiona analiza korištena je kako bi se utvrdilo koje variable imaju najveći uticaj na ispoljenu nelagodnost i strah.

Rezultati

Mere deskriptivne statistike sklonosti studenata edukacije i rehabilitacije da daju SPO, ispoljavanja nelagodnosti i straha u interakcijama i učestalosti kontakta sa osobama s IO predstavljeni su u Tabeli 1.

Tabela 1

Mere deskriptivne statistike sklonosti studenata edukacije i rehabilitacije da daju SPO, ispoljavanja nelagodnosti i straha u interakcijama i učestalosti kontakta sa osobama s IO

Varijable	AS	SD	Min	Max
Socijalno poželjni odgovori	20.78	4.30	7	30
Nelagodnost i strah	26.85	9.26	9	44
Učestalost kontakta	47.05	11.99	21	73

Studenti ispoljavaju visoku sklonost ka davanju SPO ($AS = 20.78$). U interakcijama sa osobama s IO ispoljavaju umerenu nelagodnost i strah ($AS = 26.85$). Međutim, standardna devijacija ($SD = 9.26$), minimalan rezultat ($min = 9$) i maksimalan rezultat ($max = 44$) ukazuju na raspršenost rezultata. Učestalost kontakta studenata sa osobama s IO je u proseku niska, a vrednost standardne devijacije ($SD = 11.99$) ukazuje na raspršenost rezultata, što potvrđuje i raspon skorova od 21 do 73.

Tabela 2

Razlike u ispoljavanju nelagodnosti i straha, učestalosti kontakta i sklonosti ka davanju SPO u odnosu na studijski program

Varijable	Studijski program			Kraskal-Volis H	p
	SER	LA	PUP		
Nelagodnost i strah	AS	25.64	29.07	27.53	.24
	SD	9.54	7.73	10.45	
Učestalost kontakta	AS	48.02	45.93	29.00	.61
	SD	12.44	11.63	11.24	
SPO	AS	20.64	21.44	20.13	.62
	SD	4.46	3.75	4.78	

Napomena: SER – Specijalna edukacija i rehabilitacija, LA – Logopedija i audiologija, PUP – Poremećaji u ponašanju, broj stupnjeva slobode iznosio je 2

Rezultati predstavljeni u Tabeli 2 pokazuju da ne postoje razlike u ispoljavanju nelagodnosti i straha, učestalosti kontakta i sklonosti ka davanju SPO kod studenata edukacije i rehabilitacije u odnosu na studijski program. Rezultati Kraskal–Volisovog H-testa nisu statistički značajni ni za jednu od ispitivanih dimenzija ($ps > .05$).

Tabela 3

Razlike u ispoljavanju nelagodnosti i straha, učestalosti kontakta i sklonosti ka davanju SPO kod studenata edukacije i rehabilitacije u odnosu na godinu studija

Varijable	Godina studija		Man-Vitni U	p
	I i II	III i IV		
Nelagodnost i strah	AS	28.55	22.69	631.00
	SD	8.93	8.86	
Učestalost kontakta	AS	45.65	50.41	787.50
	SD	12.33	10.59	
SPO	AS	20.76	20.83	1005.50
	SD	4.52	3.70	

Rezultati predstavljeni u Tabeli 3 pokazuju da statistički značajne razlike u odnosu na godinu studija postoje kada je u pitanju ispoljavanje nelagodnosti i straha ($U = 631.00, p = .002$). Studenti prve i druge godine studija postižu više skorove ($AS = 28.55$) od studenata treće i četvrte godine ($AS = 22.69$). Statistički značajne razlike ne postoje u odnosu na učestalost kontakta i sklonost ka davanju SPO ($ps > .05$).

Tabela 4

Rezultati ispitivanja povezanosti između sklonosti studenata edukacije i rehabilitacije ka davanju SPO, ispoljene nelagodnosti i straha u interakcijama i učestalosti kontakta sa osobama s IO

Varijable	SPO	Nelagodnost i strah	Učestalost kontakta
SPO	/		
Nelagodnost i strah	-.26**	/	
Učestalost kontakta	-.05	-.19*	/

Napomena: * $p < .05$, ** $p < .01$

Rezultati korelacije predstavljeni u Tabeli 4 pokazuju da statistički značajna slaba negativna korelacija postoji između sklonosti ka davanju SPO i nelagodnosti i straha ($r = -.26, p < .01$), dok statistički značajna korelacija ne postoji između sklonosti ka davanju SPO i učestalosti kontakta. Statistički značajna slaba negativna korelacija utvrđena je i između nelagodnosti i straha i učestalosti kontakta ($r = -.19, p < .05$). U cilju isključivanja uticaja sklonosti ka davanju SPO na povezanost nelagodnosti i straha i učestalosti kontakta izračunata je parcijalna korelacija, koja je pokazala da je korelacija između nelagode i straha i učestalosti kontakta značajna i onda kada se pod kontrolom drži sklonost ka davanju SPO ($r = -.22, p < .05$).

S obzirom na to da su rezultati pokazali da u ispoljavanju nelagodnosti i straha postoje razlike u odnosu na godinu studija, urađena je point-biserijalna korelacija između ove dve varijable. Rezultati su pokazali da između nelagodnosti i straha i godine studija postoji statistički značajna slaba negativna korelacija ($r = -.29, p < .01$).

Na osnovu značajnosti utvrđenih korelacija sprovedena je linearna regresiona analiza, kako bi se utvrdilo koje varijable imaju najveći uticaj na ispoljavanje nelagodnosti i straha u interakcijama sa osobama s IO kod studenata edukacije i rehabilitacije.

Rezultati testiranja prvog modela, u kojem su prediktori učestalost kontakta i godina studija, pokazuju da je model statistički značajan ($F = 5.72, df1 = 2, df2 = 97, p = .004$), te da objašnjava 11% varijanse promjenljive (Tabela 5). Statistički značajan prediktor je godina studija ($\beta = -0.26, p = .009$). Rezultati testiranja drugog modela (Tabela 5), u kojem je dodata prediktorska varijabla SPO, pokazuju da je model statistički značajan ($F = 6.95, df1 = 3, df2$

$= 96, p < .001$). Statistički značajna su dva prediktora sklonost ka davanju SPO ($\beta = -0.27, p = .004$) i godina studija ($\beta = -0.26, p = .008$). Regresioni model objašnjava 18% varijanse promjenljive, a povećanju procenta objašnjena varijanse doprinosi varijabla SPO.

Tabela 5

Rezultati regresije analize varijabli koje imaju najveći uticaj na ispoljavanje nelagodnosti i straha u interakcijama sa osobama s IO kod studenata edukacije i rehabilitacije

Prediktori	Nelagodnost i strah		
	R^2	$F(p)$	$\beta(p)$
Učestalost kontakta	.11	5.72 (.004)	-.15 (.123)
Godina studija			-.26 (.009)
SPO			-.27 (.004)
Učestalost kontakta	.18	6.95 (< .001)	-.17 (.081)
Godina studija			-.26 (.008)

Diskusija

Studenti ispoljavaju umerenu nelagodnost i strah u interakciji sa osobama s IO, što je i očekivano shodno tome da su odabrali edukaciju i rehabilitaciju kao svoju buduću profesiju. Slične rezultate na populaciji studenata specijalne edukacije i rehabilitacije dobili su i Banković i saradnici (2019), dok su u nekim istraživanjima rezultati pokazali da studenti osjećaju blagu nelagodnost u interakciji sa osobama s ometenošću (Brojčin i sar., 2014; Brojčin i sar., 2015). Mogući razlozi ove nekonzistentnosti u rezultatima istraživanja nelagodnosti i straha u interakcijama su u tome da su navedena istraživanja provedena u različitim društvenim kontekstima (Beograd, Foča, Tuzla) i činjenici da su istraživanja uključivala studente različitih godina studija (uključeni samo studenti završnih godina ili samo prve godine studija, ili studenti različitih godina studija). Rezultati istraživanja su pokazali da se studenti tri studijska programa ne razlikuju u pogledu ispoljavanja nelagodnosti i straha. Banković i saradnici (2019), također, ne nalaze razlike u ispoljavanju nelagodnosti i straha u interakcijama sa osobama s ometenošću kod studenata specijalne edukacije i rehabilitacije u odnosu na smer studija. Razlike u ispoljavanju nelagodnosti i straha postoje u odnosu na godinu studija, te studenti prve i druge godine studija postižu najviše skorove kada je u pitanju nelagodnost i strah. Međutim, moguće je da je ovakav rezultat posledica strukture samoga uzorka istraživanja, jer studenti prve i druge godine studija čine 71% uzorka istraživanja. Zbog toga bi istraživanje trebalo ponoviti na ujednačenijem uzorku studenata u odnosu na godinu studija. U istraživanju Bankovića i saradnika (2019) se ne nalaze razlike u ispoljavanju nelagodnosti i straha u odnosu na godinu studija.

U ovom istraživanju pokazalo se da studenti edukacije i rehabilitacije iskazuju nisku učestalost kontakta sa osobama s IO. Razlike u pogledu učestalosti kontakta ne postoje u odnosu na godinu studija i studijski program. Rezultat je iznenađujući, jer se očekivalo da studenti kroz praktičnu nastavu imaju učestalije kontakte sa osobama s IO, posebno studenti viših godina i studenti studijskog programa Specijalna edukacija i rehabilitacija. Rezultati ukazuju na potrebu da se analizira studijski program Specijalna edukacija i rehabilitacija u pogledu sati i kvalitete praktične nastave. Nisku učestalost kontakta studenata specijalne edukacije i rehabilitacije sa osobama s ometenošću utvrdili su i Brojčin i saradnici (2015), ali su pronašli razlike u odnosu na godinu studija; studenti četvrte godine imali su znatno više kontakata sa osobama s ometenošću.

Rezultati istraživanja pokazali su da studenti ispoljavaju visoku sklonost ka davanju SPO, te da ne postoje razlike u pogledu sklonosti ka davanju SPO u odnosu na godinu studija i studijski program. U dostupnim istraživanjima koja su se bavila ispitivanjem povezanosti sklonosti ka davanju SPO i stavova, ne izveštava se o stepenu sklonosti ispitanika da daju SPO (Horner-Johnson et al., 2002; Kim et al., 2015; Kowalska & Winnicka, 2013; Yazbeck et al., 2004). Jedino istraživanje koje izveštava o stepenu sklonosti studenata da daju SPO je istraživanje provedeno u Etiopiji, u kojem studenti postižu niži skor na upitniku za procenu SPO (Getachew, 2011). Razlike u rezultatima između ovog istraživanja i istraživanja provedenog u Etiopiji mogu se objasniti kulturnoškim i društvenim razlikama, a koje se pre svega odnose na opšteprihvaćene društvene stavove prema osobama sa ometenošću.

Utvrđeno je da postoji statistički značajna slaba negativna povezanost između sklonosti ka davanju SPO i nelagodnosti i straha u interakciji sa osobama s IO. Do sličnih rezultata došli su Kim i saradnici (2015), koji nalaze slabu negativnu povezanost između kognitivne i afektivne domene stavova i sklonosti ka davanju SPO, te je sklonost ka davanju SPO povezana sa pozitivnijim stavovima. Kovalska i Vinicka (Kowalska & Winnicka, 2013) u svom istraživanju nalaze povezanost između sklonosti ka davanju SPO i socijalne distance, dok ne nalaze povezanost između sklonosti ka davanju SPO i stavova. Dobijeni rezultati u ovom istraživanju, kao i u analiziranim istraživanjima, ukazuju na potrebu detaljnije analize uticaja sklonosti ka davanju SPO na sve tri komponente stavova studenata edukacije i rehabilitacije (afektivnu, kognitivnu i bihevioralnu). Postoje i istraživanja provedena na populaciji studenata koja ne nalaze povezanost između sklonosti ka davanju SPO i stavova prema osobama sa ometenošću (Getachew, 2011; Horner-Johnson et al., 2002; Yazbeck et al., 2004).

U istraživanju se pokazalo da postoji statistički značajna slaba negativna povezanost između nelagodnosti i straha i učestalosti kontakta, te da je povezanost značajna i onda kada se pod kontrolom drži sklonost ka davanju SPO. Zanimljivo je da istraživanja na uzorcima studenata specijalne edukacije i

rehabilitacije iz Foče pokazuju da ne postoji povezanost između nelagodnosti i straha i učestalosti kontakta (Banković i sar., 2019; Brojčin i sar., 2015). Moguće objašnjenje razlika u rezultatima ovog i navedenih istraživanja je populacija sa ometenošću na koju su istraživanja bila usmerena. Ovo istraživanje usmereno je na osobe sa IO, dok su navedena istraživanja bila usmerena na osobe sa ometenošću uopšteno.

Dobijeni rezultati istraživanja, koji pokazuju da postoji povezanost između ispoljavanja nelagodnosti i straha i učestalosti kontakta, kao i da studenti izveštavaju o niskoj učestalosti kontakta sa osobama s IO, nameću zaključak da je potrebno povećati učestalost kontakta studenata sa osobama s IO. Jedan od načina za povećanje učestalosti kontakta studenata je povećanje sati praktične nastave, posebno na višim godinama studija. Međutim, istraživanja pokazuju da su studenti čiji su kontakti sa osobama s ometenošću bili vezani samo za praksu, imali negativnije stavove od studenata koji su imali kontakte sa ovim osobama i u privatnoj sferi (Hickson, 1995). S druge strane, istraživanja pokazuju da volonterski rad sa osobama s ometenošću pozitivno utiče na promenu stavova (Ford et al., 2017; Fort, 2014; Jefferson et al., 2018). Zbog toga, osim povećanja sati praktične nastave, studente treba poticati da volontiraju u udruženjima, institucijama, događajima i sl. koji se bave osobama sa IO, gde će imati priliku da budu u manje formalnom odnosu sa osobama s IO i gde će moći bolje upoznati osobe sa IO. U budućim istraživanjima trebalo bi pri ispitivanju kontakta jasno uspostaviti razliku između formalnog i neformalnog kontakta, te ispitati koji od ova dva oblika kontakta značajnije utiče na stavove studenata.

Rezultati regresione analize pokazali su da najveći uticaj na ispoljenu nelagodnost i strah u interakcijama sa osobama s IO kod studenata edukacije i rehabilitacije imaju sklonost ka davanju SPO i godina studija. Međutim, regresioni model objašnjava samo 18% varijanse promjenljive, što znači da su na ispoljenu nelagodnost i strah u studenata uticali i drugi faktori. Također, uticaj godine studija, zbog toga što studenti prve i druge godine čine 71% uzorka, treba uzeti sa rezervom i proveriti u budućim istraživanjima. Sklonost ka davanju SPO ima veći standardizirani regresioni koeficijent nego godina studija, te se može konstatovati da je imao nešto veći uticaj na ispoljenu nelagodnost i strah kod studenata. Dobijeni rezultati ovog istraživanja pokazuju da sklonost ka davanju SPO utiče na ispoljavanje nelagodnosti i straha, te da bi u budućim istraživanjima stavova prema osobama sa IO, odnosno osobama sa ometenošću uopšte, trebalo uvrstiti i ovu varijablu i nastojati je kontrolisati.

Dobijene rezultate treba sagledati u odnosu na ograničenja istraživanja koja se vezuju uz uzorak. U uzorku su dominirale studentice, te se nije mogao ispitati uticaj pola na merene varijable. Također, uzorak je obuhvatio samo studente Edukacijsko-rehabilitacijskog fakulteta Univerziteta u Tuzli, te bi u bilo poželjno proširiti uzorak i na studente drugih univerziteta iz BiH koji studiraju slične studijske programe. Dakle, radi se o prigodnom uzorku

istraživanja i stoga je ograničena generalizacija rezultata na širu populaciju studenata edukacije i rehabilitacije.

Zaključak

Rezultati istraživanja pokazali su da studenti edukacije i rehabilitacije ispoljavaju umerenu nelagodnost i strah u interakcijama sa osobama s IO, da imaju nisku učestalost kontakta sa osobama sa IO i da su skloni ka davanju SPO. Utvrđeno je da postoji slaba negativna povezanost nelagodnosti i straha sa sklonosću ka davanju SPO, učestalošću kontakata i godinom studija, te da se kontrolisanjem sklonosti ka davanju SPO povećava povezanost između nelagodnosti i straha i učestalosti kontakta. Razlike u odnosu na godinu studija nađene su samo za nelagodnost i strah, gde se pokazalo da najviši skor postižu studenti prve i druge godine. Razlike u odnosu na studijski program nisu nađene ni na jednoj od merenih varijabli. Najveći uticaj na ispoljeni nivo nelagodnosti i straha imaju sklonost ka davanju SPO i godina studija. S obzirom na to da sklonost ka davanju SPO utiče na ispoljavanje nelagodnosti i straha, u budućim istraživanjima stavova prema osobama sa ometenošću treba uzeti u obzir i ovu varijablu i nastojati je kontrolisati. Dobijeni rezultat u pogledu slabe učestalosti kontakta studenata edukacije i rehabilitacije sa osobama s IO ukazuju na potrebu analiziranja studijskih programa u odnosu na sate praktične nastave i uopšte kvalitete samih vežbi, posebno studijskog programa Specijalna edukacija i rehabilitacija. Pored nastojanja da se kroz sam studij poveća učestalost „formalnih“ kontakata studenata edukacije i rehabilitacije sa osobama sa IO, potrebno je kontinuirano poticati studente na „neformalne“ kontakte, koji se mogu ostvariti kroz volonterski rad studenata. Dobijene rezultate zbog ograničenja istraživanja vezanih za uzorak treba uzeti sa rezervom, te zbog toga postoji potreba za daljim istraživanjem ove problematike.

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Socially desirable responses and attitudes towards people with intellectual disabilities in education and rehabilitation students

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Introduction. Research suggests a link between socially desirable responses (SDR) and attitudes towards people with disabilities. **Objectives.** The main aim was to examine the relationship between the expressed tendency of education and rehabilitation students to give socially desirable responses, the expressed discomfort and fear in interactions, and the frequency of contact with people with intellectual disabilities. The specific objectives of the research were: to examine whether there was a difference in the manifestation of socially desirable responses, discomfort and fear, and the frequency of contact with regard to the year of study and the study program; to examine the relationship between discomfort and fear and the frequency of contact while controlling socially desirable responses; to determine which variables affected the expression of discomfort and fear. **Methods.** The survey was conducted on a convenient sample of 100 students of education and rehabilitation. Seventy-one percent of students attended the first and second year, while 29.0% attended the third and fourth year. Fifty-eight percent of students attended Special Education and Rehabilitation, 27.0% attended Speech and Language Pathology and Audiology, and 15% attended Behavioral Disorders. The Scale for Social Desirability, the Interaction with Disabled Persons Scale, and the Contact with Disabled Persons Scale were applied. **Results.** The results showed a weak negative correlation between discomfort and fear and the propensity to SDR, frequency of contact, and the year of study. The correlations between discomfort and fear and the frequency of contact were statistically significant even when socially desirable responses were controlled. There were no differences with regard to the study program. The difference regarding the year of study existed in the manifestation of discomfort and fear, where first and second-year students achieved the highest score. The tendency to give socially desirable responses and the year of study had the greatest impact on the expressed level of discomfort and fear. **Conclusion.** Future research on attitudes towards people with disabilities should consider the tendency towards socially desirable responses and try to control it.

Keywords: attitudes, discomfort and fear, frequency of contact, socially desirable responses, students of education and rehabilitation

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Očekivana podrška porodice i prijatelja roditeljima dece sa smetnjama u razvoju

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Uvod: Neformalna i formalna podrška roditeljima dece sa smetnjama u razvoju ima višestruk uticaj na porodično funkcionisanje i zadovoljstvo životom članova porodice.

Cilj: Cilj istraživanja je utvrđivanje u kojoj meri roditelji dece sa smetnjama u razvoju očekuju podršku od porodice i prijatelja. *Metod:* Uzorak u istraživanju činilo je 65 roditelja dece sa smetnjama u razvoju, većina su bile majke ($f=62, P=95.4\%$). Ispitivanje očekivane podrške članova porodice i prijatelja izvršeno je korišćenjem skale Socijalna podrška – ponašanje (The Social Support Behaviors – SS-B; Vaux et al., 1987). *Rezultati:* Primenom deskriptivne statistike utvrđeno je da roditelji manje računaju na podršku prijatelja, podrška porodice je u prvom planu. Roditelji dece sa višestrukom ometenošću, nezaposleni i roditelji koji žive u seoskoj sredini imaju niža očekivanja od ostalih grupa da će ih podržati porodica i prijatelji. Najniža očekivanja imaju u segmentu finansijske i fizičke podrške. *Zaključak:* Na svih pet dimenzija podrške (emotivna, socijalna, fizička, finansijska i savetodavna) od članova šire porodice očekuje se veći stepen pomoći. Analiza pojedinačnih ajtema u okviru navedenih dimenzija ukazuje na postojanje različitog stepena očekivanja u okviru iste dimenzije, što je posledica specifičnosti zahteva.

Ključne reči: roditelji dece sa smetnjama u razvoju, podrška, porodica, prijatelji

Uvod

Socijalna podrška kao multidimenzionalni konstrukt koji čine fizička pomoć, deljenje informacija, instrumentalna, emotivna i psihološka podrška roditeljima dece sa smetnjama u razvoju prilično je bila zanemarena u medicinskom modelu ometenosti (Boyd, 2002), kao i značaj sagledavanja socijalnih i fizičkih okolnosti u kojima se radaju i žive ova deca (Moffatt et al., 2019). Fizička i instrumentalna podrška od članova šire porodice, zajedno

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sa emotivnom i psihološkom, veoma je značajna i za roditelje dece tipičnog razvoja (Mitchell, 2007, 2008; Yamashiro & Matsukura, 2015). O tome svedoči i istraživanje na uzorku od 600 porodica u Srbiji, koje je pokazalo da 80.2% roditelja smatra da bi im obezbeđivanje dodatnog znanja i podrške u vezi sa vaspitanjem dece bilo veoma korisno, a 76.0% smatra da bi im mnogo značilo da su u važnim fazama razvoja deteta mogli da dobiju dodatne informacije o roditeljstvu i razvojnim potrebama deteta. Roditelji koji su imali prilike da potraže savet, najčešće su se obraćali svojim roditeljima, psiholozima i braći i sestrama i u 95.9% slučajeva smatraju da im je to bilo značajno (UNICEF, 2014).

Za suočavanje sa svakodnevnim zahtevima podizanja i vaspitanja deteta sa smetnjama u razvoju roditeljima je veoma značajna formalna i neformalna podrška, naročito afektivna i funkcionalna bliskost između majke i bake (Trindade et al., 2020). Formalnu podršku roditelji dobijaju od terapeuta, lekara i drugih stručnjaka koji su deo timova sa kojima sarađuju, a neformalnu od porodice, prijatelja, volontera, udruženja roditelja i nevladinih organizacija (Boyd, 2002; Stanimirović i sar., 2012). Neformalnu podršku koju pružaju porodica i prijatelji po pravilu karakteriše poseban oblik zajedništva, koji na više načina obogaćuje život roditelja i deteta sa smetnjama u razvoju, jer je u njenoj osnovi prirodna potreba da se uradi nešto za svoje bližnje (Lindblad et al., 2007). Intenziviranjem neformalne podrške može, do neke mere, da se izbegne narušavanje privatnosti porodice, koja nastaje ulaskom stručnjaka u porodični dom (Borges & Pereira, 2019).

Prihvatanje novonastale situacije i podrška bliskih osoba umnogome zavise od toga u kojoj je meri nakon rođenja deteta sa smetnjama u razvoju došlo do promene porodičnih odnosa. Neke porodice se lakše prilagođavaju na novonastalu situaciju, te to ne utiče radikalno na kvalitet življenja, dok druge karakterišu psihopatološki odnosi ili se veze među njenim članovima kidaju (Jaspard, 2002). Neretko očevi roditelji „okriviljuju“ majku za detetove smetnje (Seligman & Darling, 2007). To može da bude povod za distanciranje roditelja od ostalih članova porodice, jer je bračna kohezija bitan činilac za ublažavanje posledica stresa koji se učestalije javlja kod majki (Vučinić i Andđelković, 2021). Na povezanost stresa i podrške ukazuje i zaključak da majke koje ne dobijaju adekvatnu socijalnu podršku u odnosu na majke koje su zadovoljne podrškom iz formalnih i neformalnih izvora ispoljavaju značajno viši nivo roditeljskog stresa (Milić Babić, 2019).

Za prihvatanje novonastale situacije i dijagnoze i za prevazilaženje posledica stresa neophodno je da roditelji, nakon rođenja deteta sa smetnjom u razvoju, nastave komunikaciju sa prijateljima. Podrška bliskih prijatelja, sa kojima su ranije razmenjivali iskustva, delili prijatne i prevazilazili teške trenutke, značajna je za emocionalno i psihosocijalno blagostanje roditelja dece sa smetnjama u razvoju (Bray et al., 2017). Njihova podrška ima uticaj na

porodično funkcionisanje, kao i na zadovoljstvo roditelja životom (Cuzzocrea et al., 2015), doprinosi ličnom rastu i razvoju kroz iskustveno učenje i unapređivanje veština rešavanja problema (Shilling et al., 2013). Neformalna podrška može pozitivno da utiče na decu sa smetnjama u razvoju i druge članove porodice (Canary, 2008). Grupe podrške koje čine roditelji dece sa smetnjama u razvoju, psihološki centri, savetnici različitih specijalnosti, zaposleni u službama za socijalni rad i članovi volonterskih organizacija takođe predstavljaju značajan resurs za prevazilaženje svakodnevnih teškoća (Heiman, 2002). One, uz opštu podršku socijalne sredine, doprinose unapređivanju veze između partnera, članova porodice, ali i ostvarivanju pozitivne komunikacije i povezanosti između majke i deteta sa smetnjama u razvoju. I porodica i prijatelji pružaju emotivnu i savetodavnu podršku, obezbeđuju socijalnu participaciju, pri čemu članovi porodice više pružaju materijalnu i fizičku pomoć, uključujući brigu za zdravlje, lečenje i čuvanje deteta (Bennett et al., 1996).

Podrška koju dobijaju roditelji dece sa smetnjama u razvoju postaje značajan prediktor kvaliteta života (Davis & Gavidia-Payne, 2009). Zadovoljstvo podrškom je tesno povezano sa psihofizičkim blagostanjem osobe, jer pruža osećaj sigurnosti, podstiče optimizam i omogućava lakše rešavanje svakodnevnih zahteva povezanih sa brigom o deci (Leutar i Raić, 2002, prema Milić Babić, 2013) i pozitivnim ishodima roditeljstva (Findler, 2000). Roditeljima dece sa smetnjama u razvoju baka i deke i ostala rodbina koja živi u blizini već u prvim danima detetovog života mogu da pruže različite oblike pomoći (Pit-ten Cate et al., 2007). Oni su prve osobe koje roditelji kontaktiraju nakon saznanja da kod njihovog deteta postoji smetnja u razvoju i imaju ključnu ulogu u pružanju neformalne podrške. Roditeljima dece sa smetnjama u razvoju najviše znači podrška koju im nude majke, ili majčini roditelji (Trute, 2003). Majke koje nemaju podršku sopstvenih roditelja posebno su ranjive (Crettenden, et al., 2018). Na uključenost baka i deka u podizanje deteta utiču njihovo zdravstveno stanje, blizina stanovanja, nivo razumevanja teškoća i afektivna vezanost između njih i njihovog odraslog deteta, pa je zbog toga važno da budu informisani o situaciji svog unuka/e, kao i da je postoji dobra međugeneracijska komunikacija (Lee & Gardner, 2010). Zdravstvene teškoće kod baka po majci negativno se odražavaju na nivo praktične i emocionalne podrške, kao i na kvalitet odnosa sa čerkom (Crettenden, et al., 2018). Podrška koju pružaju baka i deke i drugi članovi šire porodice nekada može da ima i kontraefekat, što je najčešće povezano sa neslaganjem oko odluka vezanih za dete ili organizaciju života (Mitchell, 2007).

Podrška koju roditelji dece sa smetnjama u razvoju mogu da dobiju (очекuju) od svojih bližnjih, ali i od šire okoline, može značajno da im olakša prihvatanje situacije i planiranje budućih koraka i dodatno da ih osnaži za donošenje važnih odluka. Svest o tome da mogu da se oslone na nekoga postaje naročito važna u kriznim situacijama, npr. kada im se saopštavaju loše

informacije vezane za stanje kod deteta, kada dolazi do promena u planu tretmana ili kada im predstoje dugi boravci u ustanovama za rehabilitaciju (Nuri et al., 2020). Uverenje da mogu da računaju na dostupnost navedenih vidova podrške može da doprinese jačanju osećanja lične dobrobiti i da deluje kao zaštitni faktor od stresa u procesu prilagođavanja na određenu životnu situaciju (Milić Babić, 2019; Pelchat et al., 2005). Informacije o podršci koju roditelji dece sa smetnjama u razvoju očekuju od porodice i prijatelja značajne su stručnjacima za osmišljavanje strategija i umrežavanje ove podrške sa formalnom. Jedino tako može da se odgovori na složene zahteve roditeljstva i roditeljima dece sa smetnjama u razvoju obezbedi neophodna podrška.

Cilj rada

Cilj ovog istraživanja je utvrđivanje u kojoj meri roditelji dece sa smetnjama u razvoju očekuju podršku od porodice i prijatelja, a u odnosu na neke sociodemografske karakteristike.

Metode

Uzorak

Uzorak u istraživanju činilo je 65 roditelja dece sa smetnjama u razvoju, uglavnom majke ($f = 62, P = 95.4\%$). Skoro svi roditelji su u braku ($f = 60, P = 92.3\%$). Nešto više od polovine živi u gradskoj sredini ($f = 37, P = 56.9\%$), dok ostali žive u selu ili prigradskom naselju na teritoriji Republike Srbije. Od ukupnog broja dve trećine roditelja su u radnom odnosu ($f = 44, P = 67.7\%$). Najveći broj roditelja ima decu sa višestrukim smetnjama ($f = 42, P = 64.6\%$), dok je kod dece ostalih prisutna smetnja u jednom domenu (motorika, vid, sluh, govor).

Instrumenti za prikupljanje podataka

Za prikupljanje podataka o elementima očekivane podrške od članova porodice i prijatelja korišćena je skala *Socijalna podrška – ponašanje* (The Social Support Behaviors – SS-B; Vaux et al., 1987). Skala se sastoji od 45 pitanja na koja roditelji daju odgovore, uzimajući u obzir prethodno iskustvo i očekivanja u kojoj meri bi im porodica i prijatelji pružili podršku u nekoliko domena. Uz neznatno jezičko prilagođavanje tvrdnji, ova skala je koristan alat za otkrivanje glavnih stresora u porodičnom funkcionisanju, a osim očekivane podrške, može da se proceni i dostupna podrška. Skala je podeljena u pet subskala, kojima se procenjuje emotivna (deset ajtema), socijalna (sedam ajtema), fizička (osam ajtema), finansijska (osam ajtema) i savetodavna podrška (dvanaest ajtema). Roditelji daju odgovore na petostepenoj skali Likertovog tipa (1 – niko to ne bi uradio, 5 – skoro svi bi to uradili). Ispitanik odvojeno popunjava upitnik za porodicu i prijatelje. Na nivou cele skale, u okviru ovog istraživanja, utvrđen je visok nivo pouzdanosti ($\alpha = .97$). Za prikupljanje sociodemografskih podataka korišćen je posebno konstruisan upitnik.

Procedura istraživanja

Upitnici korišćeni za prikupljanje podataka su objedinjeno postavljeni na Gugl platformu, a zatim prosleđeni udruženjima roditelja dece sa smetnjama u razvoju, koji su u okviru svojih grupa na društvenim mrežama delili link. Učešće roditelja u istraživanju bilo je dobровoljno i anonimno. Podaci su prikupljeni u periodu od februara do maja 2021. godine, nakon čega je pristup upitnicima zatvoren.

Obrada podataka

Statistička obrada podataka izvršena je u programu SPSS Statistic 25. Korišćena je deskriptivna statistika (učestalost, aritmetička sredina i standardna devijacija). Kako je Šapiro–Vilkov test pokazao da postoji odstupanje od normalne raspodele, sprovedena je neparametrijska analiza putem Man–Vitnijevog U i Kraskal–Volisovog testa.

Rezultati istraživanja

Roditeljsko vrednovanje pet vidova očekivane podrške od članova šire porodice, sudeći prema maksimalnim i prosečnim vrednostima, kreće se oko ocene četiri (minimalno 3.35, maksimalno 4.16). To znači da roditelji od porodice imaju dosta visoka očekivanja u ponuđenim oblastima kada im zatreba podrška. Nezaposleni roditelji, roditelji dece sa višestrukim smetnjama i roditelji iz seoskih i prigradskih sredina niže su vrednovali sve vidove podrške (Tabela 1), međutim razlike između aritmetičkih sredina nisu statistički značajne (Tabela 2).

Tabela 1

Deskriptivni pokazatelji očekivane porodične podrške na pojedinim subskalama

Varijabla	Grupe	Socijalna (max 35)		Emotivna (max 50)		Fizička (max 40)		Finansijska (max 40)		Savetodavna (max 60)	
		AS	SD	AS	SD	AS	SD	AS	SD	AS	SD
Radni status	Zaposleni	27.38	6.58	38.59	10.46	31.77	7.75	31.75	8.28	45.52	13.12
	Nezaposleni	24.81	9.50	34.62	13.50	28.05	11.27	27.51	11.13	43.38	16.29
Smetnje	Jedna smetnja	28.48	6.74	40.26	10.48	33.30	7.60	32.78	7.98	48.35	13.07
	Višestruke smetnje	25.50	8.01	35.69	11.53	29.07	9.61	29.09	9.96	41.90	14.46
Mesto stanovanja	Grad	27.95	7.06	39.32	11.03	32.16	8.06	31.73	8.23	46.46	13.15
	Selo	23.50	8.90	33.88	12.76	27.66	11.25	28.05	11.38	40.11	15.90
	Prigradsko naselje	26.90	6.49	36.00	10.78	29.90	8.02	29.70	9.79	43.10	14.61

Tabela 2

Vrednosti statistika i pripadajućih nivoa značajnosti (Man–Vitnijeve i Kraskal–Volisove analize) – očekivana porodična podrška

	Socijalna		Emotivna		Fizička		Finansijska		Savetodavna	
	U	p	U	p	U	p	U	p	U	p
Radni status	398.50	.37	395.00	.34	381.00	.25	373.00	.20	398.00	.36
Smetnje	362.00	.09	359.00	.08	354.50	.07	382.50	.16	350.00	.06
Mesto stanovanja	3.39	.18	2.94	.23	2.04	.36	1.09	.57	2.35	.31

Roditeljsko vrednovanje očekivane podrške prijatelja na svim subskalama slično je vrednovanju porodične podrške (Tabela 3). Naime, roditelji dece sa višestrukim smetnjama, nezaposleni i oni koji žive u seoskim i prigradskim sredinama niže su vrednovali očekivanu podršku prijatelja od podrške koju očekuju od članova šire porodice i familije. Prema rezultatima koji su dobijeni primenom Man–Vitnjevog i Kraskal–Volisovog testa ne postoji statistički značajna razlika u vrednovanju očekivanih vidova podrške od prijatelja i porodice, u odnosu na mesto boravka i radni status roditelja, kao ni u odnosu na vrstu smetnje kod deteta (Tabela 4).

Tabela 3

Deskriptivni pokazatelji očekivane podrške od prijatelja na pojedinim subskalama

Varijabla	Grupe	Socijalna (max 35)		Emotivna (max 50)		Fizička (max 40)		Finansijska (max 40)		Savetodavna (max 60)	
		AS	SD	AS	SD	AS	SD	AS	SD	AS	SD
Radni status	Zaposlen	27.07	6.60	37.64	9.53	29.22	7.42	27.29	7.60	44.23	11.84
	Nezaposlen	22.24	9.37	31.05	13.22	24.66	11.02	23.66	10.55	36.66	16.30
Smetnje	Jedna smetnja	26.35	8.22	36.87	12.58	28.61	9.61	26.96	9.56	43.08	15.59
	Višestruke smetnje	25.05	7.73	34.76	10.45	27.28	8.60	25.66	8.34	41.07	12.82
Mesto stanovanja	Grad	26.86	7.56	37.35	11.10	28.51	8.70	26.78	8.62	43.62	13.75
	Selo	22.27	8.29	31.83	11.44	25.28	9.93	24	9.09	38.11	14.10
	Prigradsko naselje	26.30	7.21	35.30	10.52	29.40	7.65	27.50	8.81	41.60	13.30

Tabela 4

Vrednosti statistika i pripadajućih nivoa značajnosti (Man–Vitnijeve i Kraskal–Volisove analize) – očekivana porodična podrška

	Socijalna		Emotivna		Fizička		Finansijska		Savetodavna	
	U	p	U	p	U	p	U	p	U	p
Radni status	343.00	.09	334.50	.07	374.00	.21	371.50	.20	345.00	.10
Smetnje	415.00	.35	404.00	.27	430.00	.46	433.50	.49	407.00	.29
Mesto stanovanja	4.37	.11	4.18	.12	2.05	.35	1.52	.46	2.77	.25

Analizom pojedinačnih tvrdnji (Prilog 1) može se uočiti da je na svim ajtemima višim ocenama vrednovana očekivana podrška porodice. Roditelji dece sa smetnjama u razvoju najmanje očekuju pomoć u nekim segmentima fizičke i finansijske podrške, i to naročito ukoliko je neophodno da od prijatelja pozajme novac (ajtemi 29, 32 i 33), da im prijatelji kupe nešto od garderobe (ajtem 30). Roditelji dece sa smetnjama u razvoju takođe smatraju da ne bi mogli da se osline na prijatelje kada bi im bila potrebna pomoć vezana za brigu o kući ili kućnim ljubimcima (ajtem 19), kada bi bili prinuđeni da pozajme skupe stvari poput automobila ili nekih alata (ajtemi 20 i 22), kao ni da bi im, ako se nađu u stanju potrebe, ponudili da ostanu kod njih (ajtem 25).

Kada je u pitanju socijalni domen podrške, roditelji imaju veća očekivanja od članova uže i šire porodice u pogledu spremnosti da podele zajedničko vreme sa njima (ajtemi 12 i 15) nego od prijatelja. Očekivanja od prijatelja u pokazivanju saosećanja i pružanja podrške kroz istrajavaće u borbi sa nekim aktuelnim problemom takođe su nešto niže vrednovana (ajtemi 5 i 9). Savetodavna podrška više se očekuje od članova porodice nego od prijatelja, naročito kada je neophodno doneti neku odluku ili naći rešenje za neki problem ili situaciju i razmotriti postojeće opcije (ajtemi 41, 42, 43 i 45).

Diskusija

Podrška roditeljstvu je svaki vid intervencije koji ima za cilj redukovanje stresa kod roditelja i daje doprinos njihovom socijalnom, fizičkom i emocionalnom blagostanju (Molinuevo, 2013). Za roditelje dece sa smetnjama u razvoju socijalna podrška je značajan činilac prevladavanja stresa povezanog sa brojnim činiocima, kao što je prihvatanje novonastale situacije, iznalaženje načina komunikacije sa detetom, identifikovanje njegovih potreba i slično (Boyd, 2002; Findler & Ben-Ari, 2003; Lopez et al., 2008).

Procena porodičnih resursa i resursa na koje roditelji deteta sa smetnjama u razvoju mogu da se osline ako im zatreba pomoć, deo je sistema organizacije rada u ranoj intervenciji (Krstić i sar., 2017). Zahvaljujući sagledavanju potencijalnih izvora podrške programi rada sa roditeljima i detetom mogu

da se kreiraju sveobuhvatno i da se roditeljima obezbede oni vidovi pomoći koji će im olakšati suočavanje sa izazovima odgajanja deteta sa smetnjama u razvoju. Sistemsko organizovanje formalne i neformalne podrške ima za cilj unapređivanje kvaliteta porodičnog života i odnosa roditelj–dete, jer je roditeljska briga, osim na trenutnu situaciju, usmerena i na budućnost deteta i njegovo funkcionisanje u stalno menjajućim okolnostima (Heiman, 2002). Sa odrastanjem se javljaju nova pitanja vezana za prognozu oboljenja ili stanja, tretman, funkcionisanje deteta u budućnosti, posebno kod roditelja dece sa višestrukim smetnjama, što kumulativno ima negativan uticaj na kvalitet roditeljstva (Barnett et al., 2003). Neformalna podrška baka i deka je veoma bitna, jer su njihovo sopstveno roditeljstvo, opšte životno iskustvo i vreme koje imaju na raspolaganju izuzetno značajni izvori samopouzdanja u traganju za informacijama i resursima formalne podrške, za razliku od njihove odrasle dece koja su previše zauzeta svakodnevnim brigama, čuvanjem ostale dece, vođenjem domaćinstva, profesionalnim obavezama (Moffatt et al., 2019). Komplikovane administrativne procedure u zdravstvenim, socijalnim i obrazovnim ustanovama bakama i dekama uglavnom ne predstavljaju problem, oni mogu svojoj deci da pruže instrumentalnu i savetodavnu podršku i odvedu drugo dete na godišnji odmor (Beudin & Schneider, 2012).

Prema rezultatima našeg istraživanja roditelji dece sa smetnjama u razvoju očekuju viši stepen podrške od članova porodice nego od prijatelja. Podrška članova šire porodice je od velikog značaja za kvalitet života i porodičnog funkcionisanja, a podrška prijatelja doprinosi samo emotivnom blagostanju, zaključeno je u studiji Dejvisa i Gavidija-Pejna (Davis & Gavidia-Payne, 2009). Isti autori zaključili su da se od porodice očekuje mnogo više u pogledu svih vrsta podrške (finansijska, fizička, emotivna, socijalna, savetodavna), što je donekle kompatibilno sa rezultatima našeg istraživanja, gde se od prijatelja najmanje očekuje fizička i finansijska podrška.

Roditelji imaju priliku da sa članovima porodice dele svoja osećanja, informacije vezane za stanje kod deteta i osećaju se sigurnije ako njima povere brigu o detetu (Pit-ten Cate et al., 2007). Prema rezultatima našeg istraživanja roditelji dece sa smetnjama u razvoju imaju dosta visoka očekivanja u pogledu podrške od svojih bližnjih (pored fizičke i finansijske, očekuju i savetodavnu i emotivnu podršku), dok su, na primer, rezultati jednog istraživanja pokazali da je neformalna podrška bila znatno veća za bake koje odgajaju unuke tipičnog razvoja, nego za one koje brinu o unucima sa smetnjama u razvoju (Kresak et al., 2014).

Imajući u vidu teškoće sa kojima se suočavaju roditelji dece sa višestrukom ometenošću postojala je pretpostavka da oni očekuju veći stepen podrške u odnosu na roditelje čije dete ima jednu smetnju u razvoju, što rezultati nisu pokazali. Rezultati nekih ranijih studija pokazali su da članovi šire porodice ne pružaju podršku roditeljima dece sa smetnjama u razvoju zbog nesuglasica u

porodičnim odnosima, koji datiraju od ranije, a ne zbog ometenosti kod deteta (Mirfin-Veitch et al. 1996; Mirfin-Veitch & Bray 1997, sve prema Mitchell, 2007), pa nije isključeno da je i u našem istraživanju to slučaj, što treba proveriti korišćenjem adekvatnih istraživačkih procedura. Podatak da roditelji koji žive u seoskoj sredini očekuju niži stepen podrške i od porodice i od prijatelja, u odnosu na roditelje iz prigradskih i gradskih sredina, može se povezati sa načinom porodičnog života i potencijalno prisutnom stigmom. Izolovanost ovih porodica može dodatno negativno da se odrazi na roditeljstvo, jer druženje sa roditeljima koji prolaze sličan put omogućava razmenu iskustva i diskutovanje o pozitivnim aspektima roditeljstva deteta sa smetnjama u razvoju (Bray et al., 2017). Fokusiranje na praktična rešenja i jake strane u životu može da redukuje stres, prvenstveno kod majke, kao i podrška prijatelja koja je dragocena kada je posvećena pozitivnim aspektima života (Trute et al., 2010).

Zaposleni roditelji, u poređenju sa nezaposlenima, smatraju da bi dobili viši stepen podrške i od porodice i od prijatelja ako bi im zatrebala, što je prema nekim autorima povezano sa činjenicom da im komunikacija na radnom mestu omogućava da sačuvaju veze sa prijateljima i kolegama koji mogu da budu značajan resurs emotivne i savetodavne podrške (Cuzzocrea et al., 2015). Ipak neki rezultati svedoče da roditelji dece sa smetnjama u razvoju prijatelje i komšije ne smatraju pouzdanim izvorom podrške i zato majke napuštaju posao kako bi mogle da se posvete detetu (Valentine, 1993, prema Bennett et al., 1996). Napuštanjem posla roditelji gube svoje dotadašnje prijatelje i ostvaruju poznanstva sa drugim roditeljima dece sa smetnjama u razvoju, koje upoznaju u bolnicama ili centrima za rehabilitaciju (Heiman, 2002).

Pojedini vidovi podrške imaju različite ishode. Emocionalna podrška može da utiče na nivo stresa, savetodavna na izbegavanje stresnih situacija i efikasnije rešavanje problema (Crettenden et al., 2018; Vaux, et al., 1987), što je za roditelje dece sa smetnjama u razvoju višestruko značajno. Stoga je zadatak stručnjaka da prepoznaju vrednost neformalne podrške, prvenstveno one koju pružaju bake i deke, te da dodatno unaprede njihovu ulogu (Kaczmarek, 2021).

Zaključak

Istraživanje je sprovedeno u cilju utvrđivanja stepena podrške koju roditelji dece sa smetnjama u razvoju očekuju od porodice i prijatelja. Na osnovu analize rezultata zaključeno je da su očekivanja od porodice, u poređenju sa očekivanjima od prijatelja, veća u okviru svih pet dimenzija podrške (emotivna, socijalna, fizička, finansijska i savetodavna). Analiza pojedinačnih ajtema u okviru navedenih dimenzija podrške ukazuje na postojanje razlika u nivou očekivanja, što je posledica specifičnosti zahteva koje bi trebalo da ispune članovi šire porodice. Roditelji dece sa smetnjama u razvoju od prijatelja najmanje očekuju pomoći u nekim segmentima fizičke i finansijske podrške.

Praćenjem razlika u odnosu na odabrane sociodemografske varijable zaključeno je da su nezaposleni roditelji, roditelji dece sa višestrukim smetnjama i roditelji iz seoskih i prigradskih sredina niže vrednovali sve vidove podrške, ali razlike između aritmetičkih sredina nisu statistički značajne ni u jednoj od ispitivanih dimenzija.

Imajući u vidu da je istraživanjem obuhvaćena samo očekivana podrška od porodice i prijatelja, narednim istraživanjima treba obuhvatiti i postojeću (konkretnu) podršku i dovesti je u odnos sa relevantnim sociodemografskim varijablama (broj dece u porodici, veličina porodice, socioekonomski status, slobodno vreme i zdravlje roditelja, potpuna/nepotpuna porodica i sl.). Podaci dobijeni poredenjem stepena očekivane i dobijene formalne i neformalne podrške i podaci koji bi bili rezultat dubinskih, polustrukturiranih intervjuja o iskustvu roditelja vezanim za podršku predstavljali bi značajan orijentir za kreiranje sveobuhvatnog sistema podrške.

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Family and friends' expected support to parents of children with disabilities

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Introduction. Informal and formal support to parents of children with disabilities affects family functioning and life satisfaction of family members in many ways. *Objective.* The aim of this research was to determine the extent to which parents of children with disabilities expected support of their family and friends. *Methods.* The sample included 65 parents of children with disabilities, most of whom were mothers ($N = 62, P = 95.4\%$). The Social Support Behaviors – SS-B scale (Vaux et al., 1987) was used to examine the expected support of family and friends. *Results.* Descriptive statistics showed that parents counted on family members' support much more than on their friends' support. Parents of children with multiple disabilities, unemployed parents, and those who lived in rural areas had lower expectations regarding family and friends' support compared to other groups. Their expectations were the lowest in the segments of financial and physical support. *Conclusion.* Extended family members were expected to provide greater help in all five support dimensions (emotional, social, physical, financial, and counselling). The analysis of individual items within these dimensions indicates the existence of various expectation levels within the same dimension, which is the result of specific requirements.

Keywords: parents of children with disabilities, support, family, friends

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Prilog 1*Distribucija uzorka prema proceni podrške porodice i prijatelja*

Funkcija podrške	Tvrđnje	Ocena %				
		1 niko	2	3	4	5 svi
Emotivna	1. Smirio bi me kada sam uznemiren/a	10.8*	9.2	15.4	33.8	30.8
		15.4**	9.2	15.4	41.5	18.5
	2. Našalio bi se kako bi me oraspoložio	6.2	12.3	18.5	26.2	36.9
		6.2	12.3	10.8	43.1	27.7
	3. Slušao bi ako imam potrebu da pričam o svojim osećanjima	9.2	13.8	15.4	26.2	35.4
		9.2	12.3	13.8	35.4	29.2
	4. Ohrabrio bi me kada treba da uradim nešto teško	7.7	6.2	26.2	21.5	38.5
		9.2	15.4	16.9	24.6	33.8
	5. Pokazao bi mi da razume kako se osećam	7.7	16.9	20.0	21.5	33.8
		10.8	13.8	26.2	27.7	21.5
Socijalna	6. Zagrljio bi me ili na drugi način pokazao da brine	7.7	9.2	13.8	23.1	46.2
		7.7	13.8	13.8	26.2	38.5
	7. Ne bi me osuđivao	6.2	20.0	13.8	23.1	36.9
		6.2	10.8	26.2	27.7	29.2
	8. Pokazao bi empatiju kada sam uznemiren/a	7.7	10.8	23.1	20.0	38.5
		7.7	16.9	24.6	30.8	20.0
	9. Ostao bi pored mene kada sam u nekom problemu	9.2	4.6	16.9	24.6	44.6
Socijalna		9.2	10.8	20.0	36.9	23.1
	10. Pokazao bi naklonost prema meni	7.7	7.7	20.0	30.8	33.8
		9.2	10.8	20.0	36.9	23.1
	11. Predložio bi mi nešto da skrenem misli sa problema	12.3	20	21.5	13.8	32.3
		12.3	20.0	16.9	27.7	23.1
	12. Posetio bi me ili bi me pozvao kod sebe	6.2	10.8	13.8	27.7	41.5
		12.3	10.8	18.5	33.8	24.6
	13. Ručali bismo ili večerali zajedno	9.2	7.7	9.2	27.7	46.2
Socijalna		12.3	9.2	9.2	29.2	40.0
	14. Išao bi u bioskop ili na koncert sa mnom	7.7	15.4	15.4	29.2	32.2
		9.2	10.8	13.8	32.3	33.8
	15. Proveo bi lepo vreme sa mnom	7.7	4.6	13.8	32.3	41.5
		6.2	12.3	13.8	33.8	33.8
Socijalna	16. Želeo bi da razgovara sa mnom	6.2	9.2	16.9	26.2	41.5
		4.6	13.8	13.8	30.8	36.9
	17. Nazvao bi me samo da čuje šta radim	4.6	13.8	9.2	27.7	44.6
		3.1	16.9	13.8	40.0	26.2

Funkcija podrške	Tvrđnje	Ocena %				
		1 niko	2	3	4	5 svi
Fizička	18. Povezao bi me kada je to potrebno	10.8	3.1	7.7	36.9	41.5
		6.2	13.8	16.9	29.2	33.8
	19. Brinuo bi o mojoj kući, ljubimcima, kada je to potrebno	12.3	15.4	13.8	23.1	35.4
		24.6	15.4	20.0	23.1	16.9
	20. Pozajmio bi mi auto ukoliko mi zatreba	9.2	7.7	7.7	30.8	44.6
		9.2	15.4	20.0	29.2	26.2
	21. Pomogao bi u slučaju selidbe ili nekog drugog velikog posla	9.2	7.7	9.2	32.3	41.5
		9.2	12.3	12.3	33.8	32.3
	22. Pozajmio bi mi opremu ili alat ako su mi potrebni	7.7	7.7	9.2	35.4	40.0
		7.7	12.3	13.8	36.9	29.2
Finansijska	23. Pokazao bi mi kako da uradim nešto što ne znam	6.2	12.3	18.5	29.2	33.8
		9.2	9.2	26.2	29.2	26.2
	24. Razgovarao bi sa drugim ljudima da dogovori nešto za mene	9.2	12.3	15.4	26.2	36.9
		10.8	12.3	26.2	27.7	23.1
	25. Ponudio bi mi da ostanem kod njega ukoliko mi je to potrebno	7.7	9.2	9.2	32.3	41.5
		12.3	13.8	21.5	30.8	21.5
	26. Platio bi ručak ako nemam novca	4.6	4.6	15.4	27.7	47.7
		9.2	9.2	9.2	35.4	36.9
	27. Platio bi mi piće ukoliko nemam novca	7.7	6.2	7.7	29.2	49.2
		7.7	12.3	7.7	35.4	36.9
	28. Pomogao bi mi oko neophodne kupovine	7.7	7.7	10.8	36.9	36.9
		15.4	7.7	16.9	38.5	21.5
	29. Pozajmio bi mi novac na neograničeno vreme	9.2	10.8	9.2	27.7	43.1
		12.3	16.9	24.6	33.8	12.3
Socijalna	30. Kupio bi mi garderobu ukoliko nemam novca	7.7	10.8	13.8	32.3	35.4
		15.4	18.5	27.7	24.6	13.8
	31. Poklonio bi mi stvari koje su mi potrebne	7.7	10.8	9.2	35.4	36.9
		9.2	15.4	23.1	32.3	20.0
Emocijonalna	32. Pozajmio bi mi novac i rekao da zaboravim na to	16.9	9.2	12.3	30.8	30.8
		24.6	18.5	23.1	27.7	6.2
	33. Pozajmio bi mi veliku sumu novca	18.5	7.7	10.8	38.5	24.6
		21.5	23.1	21.5	26.2	7.7

Funkcija podrške	Tvrđnje	Ocena %				
		1 niko	2	3	4	5 svi
Savetodavna	34. Dao bi mi predloge kako da saznam više o nekoj situaciji	9.2 7.7	9.2 12.3	21.5 16.9	29.2 35.4	30.8 27.7
	35. Predložio bi način na koji nešto mogu da uradim	9.2 6.2	7.7 15.4	16.9 16.9	32.3 32.3	33.8 29.2
	36. Dao bi mi savet šta da uradim	6.2 7.7	13.8 15.4	12.3 16.9	29.2 30.8	38.5 29.2
	37. Pomogao bi mi da saznam šta je najbolje da uradim	7.7 9.2	10.8 12.3	16.9 23.1	27.7 27.7	36.9 27.7
	38. Pomogao bi mi da donesem valjanu odluku	12.3 12.3	10.8 20.0	16.9 26.2	27.7 20.0	32.3 21.5
	39. Pomogao bi mi da shvatim šta se dešava	7.7 7.7	13.8 13.8	20.0 20.0	26.2 33.8	32.3 24.6
	40. Uputio bi me kome da se obratim za pomoć	10.8 10.8	10.8 9.2	13.8 18.5	29.2 30.8	35.4 30.8
	41. Rekao bi mi koje su mi opcije i izbori	10.8 10.8	9.2 9.2	32.3 32.3	26.2 26.2	21.5 30.8
	42. Naveo bi mi razloge zašto nešto treba ili ne treba da uradim	10.8 10.8	12.3 9.2	10.8 23.1	30.8 29.2	35.4 27.7
	43. Pokazao bi mi najbolji i najbrži način da nešto uradim	6.2 7.7	16.9 16.9	9.2 24.6	33.8 27.7	33.8 23.1
	44. Rekao bi mi šta da radim	9.2 10.8	15.4 12.3	12.3 29.2	29.2 23.1	33.8 24.6
	45. Pomogao bi mi da rešim problem	6.2 9.2	13.8 13.8	15.4 27.7	27.7 24.6	36.9 24.6

Napomena: * podrška porodice, ** kurziv – podrška prijatelja



Govorno-jezički deficiti kod dece sa selektivnim mutizmom – uzrok, komorbiditet ili posledice?

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Uvod: Selektivni mutizam (SM) je poremećaj koji se opisuje u okviru dve dimenzije – psihološke i logopediske. Najveći broj istraživačkih radova posvećen je psihološkoj dimenziji SM. Međutim, u novije vreme sve veći broj istraživanja ukazuje na značajno oštećenje govorno-jezičkih sposobnosti kod dece sa SM, kao i na moguću povezanost teškoća u razvoju jezičkih sposobnosti i pojave SM na školskom uzrastu. **Cilj:** Cilj ovog rada je pregled literature o govorno-jezičkim deficitima kod dece sa SM u svrhu razjašnjenja uzročno-posledičnih veza između jezičkih i anksioznih poremećaja. **Metode:** Za pretragu literature korišćene su baze Konzorcijuma biblioteka Srbije i relevantni internet pretraživači. **Rezultati:** U literaturi je dostupno devet istraživačkih studija govorno-jezičkih sposobnosti kod dece sa SM. Najčešći potvrđeni poremećaji govorno-jezičkog razvoja su razvojni jezički poremećaj mešovitog i ekspresivnog tipa, razvojni fonološki poremećaj i deficiti jezičkog procesiranja, koji se značajno češće javljaju kod dece sa SM u odnosu na decu sa anksionznim poremećajima bez prisustva SM i decu tipičnog razvoja. Ovi deficiti povezani su sa teškoćama u ovladavanju akademskim veštinama, ali i sa teškoćama u socijalnim veštinama i rizikom pojave bihevioralnih problema na školskom uzrastu. **Zaključak:** Iako su postojeće studije pružile dragocen uvid u neke aspekte govorno-jezičkog razvoja dece sa SM, još uvek nije razjašnjen odnos jezičkih deficitata i simptoma anksionznosti kod ove dece tokom različitih razvojnih perioda. Posebno nedostaju istraživanja o ranom govorno-jezičkom razvoju, koja bi mogla rasvetliti kompleksnu uzročno-posledičnu dinamiku jezičkih i anksionznih poremećaja koje ispoljavaju deca sa SM.

Ključne reči: selektivni mutizam, govorno-jezički deficiti, etiološki faktori, komorbiditet

Uvod

Selektivni mutizam (SM) je psihijatrijsko stanje koje se obično javlja tokom detinjstva i karakteriše ga odsustvo govora u određenim javnim situacijama u kojima se očekuje da dete govori (npr. u školi), dok je u drugim

situacijama (npr. u kući) govor deteta sasvim normalan. Da bi se postavila dijagnoza SM prema DSM-5 (American Psychiatric Association [APA], 2013) potrebno je da je selektivno odsustvo govora prisutno najmanje jedan mesec. Izostanak govora u određenim situacijama koji ne perzistira dugo može se sa razvojne tačke gledišta smatrati normalnim. Dalje, prema DSM-5 izostanak govora se ne može pripisati nedostatku znanja govornog jezika potrebnog u socijalnoj situaciji. Pored toga, ovaj poremećaj se ne može bolje objasniti drugim poremećajem komunikacije i ne može se pripisati poremećaju iz spektra autizma, šizofrenije ili nekom drugom psihiatrijskom poremećaju. Na kraju, da bi se dijagnostikovao SM potrebno je da se javi u tolikoj meri da omesta svakodnevno funkcionisanje deteta, tj. da ga odsustvo govora sprečava da dobro funkcioniše u školi ili u socijalnim odnosima (APA, 2013). Iako se najčešće javlja na predškolskom uzrastu (Cunningham et al., 2004; Steffenburg et al. 2018), obično se ne dijagnostikuje do uzrasta između sedam i devet godina (Remschmidt et al., 2001; Standart & Le Couteur, 2003).

I nova verzija Međunarodne klasifikacije bolesti (ICD-11; World Health Organization [WHO], 2020) opisuje SM kao poremećaj koji karakteriše dosledna selektivnost u govoru, gde dete pokazuje adekvatnu jezičku kompetenciju u određenim društvenim situacijama (obično kod kuće), ali dosledno ne govori u drugim (obično u školi). Poremećaj mora trajati najmanje mesec dana, sa izuzetkom prvog meseca provedenog u školi, i mora se ispoljiti u meri koja omesta obrazovna postignuća ili društvenu komunikaciju. Neuspeh u govoru nije posledica nepoznavanja jezika ili jezičke udobnosti koja se zahteva u određenoj društvenoj situaciji (npr. različiti jezici se govore u školi i kod kuće).

SM se javlja u različitim kulturama i pogoda decu iz svih društvenih slojeva. Podaci iz strane literature ukazuju na to da SM spada u grupu retkih poremećaja u detinjstvu, sa prevalencijom između 0.47 i 0.76% (Viana et al., 2009), većom učestalosti javljanja kod devojčica u odnosu od 1.5 do 2.6 prema 1 (Black & Uhde, 1995; Kristensen, 2000), kao i većom učestalosti javljanja kod dece iz imigrantskih porodica (Elizur & Perednik, 2003). Štaviše, kod dece iz imigrantskih porodica SM mora trajati najmanje šest meseci i javiti se i na maternjem i na stranom jeziku kako bi se isključilo da nedostatak govora nije posledica slabog poznавања jezika ili prolazna reakcija na prilagođavanje novom okruženju (Toppelberg et al., 2005). S druge strane, u Srbiji ne postoje zvanični podaci o učestalosti pojave SM, niti je ovaj poremećaj značajnije proučavan.

Spektar simptoma koji su identifikovani kao SM datira iz 19. veka. Nemački lekar Kusmaul prvi je, 1877. godine, opisao poremećaj u okviru kojeg deca nisu govorila u određenim situacijama, iako su imala sposobnost govora. Taj poremećaj nazvao je „aphasia voluntaria”, smatrajući da su ova deca svojevoljno odlučivala da ne govore (Kopp & Gillberg, 1997; Kussmaul, 1877). Moric Tramer (Tramer, 1934), švajcarski dečji psihijatar, upotrebio je

termin „elektivni mutizam” da bi opisao istu konstelaciju simptoma, takođe ističući uverenje da se ova deca odlučuju da ne govore (Dow et al., 1995). Iako je Međunarodna klasifikacija bolesti i srodnih zdravstvenih problema (ICD-10 – WHO, 1994) zadržala termin „elektivni mutizam”, u četvrtom izdanju Dijagnostičkog i statističkog priručnika Američkog psihijatrijskog udruženja (DSM-IV; APA, 1994) termin „elektivni” zamjenjen je terminom „selektivni”, usmeravajući fokus na činjenicu da ova deca ne govore u određenim situacijama ili u prisustvu određenih pojedinaca, ali i naglašavajući da je nedostatak govora specifičan za kontekst. Izmena termina prihvaćena je u jedanaestom izdanju Međunarodne klasifikacije bolesti i srodnih zdravstvenih problema (WHO, 2020).

Klinički posmatrano deca sa SM čine vrlo heterogenu grupu (Kearney & Rede, 2021) i često ispoljavaju kašnjenje u kognitivnom, govorno-jezičkom i/ili motoričkom razvoju (Cleator & Hand, 2001; Kristensen, 2000; Manassis et al., 2007). Kliničku sliku dodatno komplikuje to što obrasci negovorenja kod dece sa SM mogu varirati od toga da neka deca možda nikada neće razgovarati van kuće, neka mogu razgovarati sa nekoliko odabralih ljudi, neka mogu samo šaputati, a neka ne govore samo sa osobama koje nisu ranije srela (Klein et al., 2013). Pored toga, procena govorno-jezičkog razvoja kod ove dece predstavlja poseban izazov, s obzirom na to da je klinička procena jedna od socijalnih situacija u kojima ova deca najčešće ispoljavaju mutizam (McInnes et al., 2004). Uzimajući u obzir to da se SM manifestuje rano u razvoju, ograničen govor deteta u određenim situacijama i njegov uticaj na razvoj jezika zahteva pažljivo razmatranje.

Cilj ovog rada je detaljan pregled literature o govorno-jezičkom razvoju dece sa SM, uključujući fenomenologiju i procenu, a u svrhu razjašnjenja kliničke slike ovog poremećaja. Pored navedenog, cilj je i da se iznese teorijski koncept SM iz logopedske perspektive i istaknu mogući nedostaci u istraživanju i praksi.

Metode

Za pretragu dostupne literature korišćene su elektronske baze podataka dostupne preko Konzorcijuma biblioteka Srbije za objedinjenu nabavku (KoBSON). Od dostupnih baza korišćene su PsycINFO, PubMed (Medline) i Web of Science. Radovi su pretraživani prema sledećim ključnim rečima prevedenim na engleski jezik: selektivni mutizam, elektivni mutizam, socijalna fobija, govorno-jezički deficiti, govorno-jezički razvoj, prediktori, procena, etiologija. U pretrazi su korišćene kombinacije navedenih ključnih reči. Pretragom je nađeno devet istraživačkih studija koje su procenjivale govorno-jezičke sposobnosti kod dece sa SM. Pregled autora istraživanja, uzorka, korišćenih instrumenata i rezultata prikazan je u Tabeli 1.

Tabela 1
Pregled istraživanja govorno-jezičkih sposobnosti kod dece sa SM

Autori	Godina	Uzorak	Instrumenti	Procenjene sposobnosti	Rezultati
Cleator & Hand 2001	SM (<i>n</i> = 5) serija studija slučaja	LARSP Peabody Picture Vocabulary Test Test of Auditory Comprehension of Language - Revised Reynell Developmental Language Scales - Fonologija Revised (Verbal Comprehension section) Smit-Hand Articulation and Phonology Evaluation (SHAPE)	Ekspresivna sintaksa Semantika Četvoro od petoro dece ispoljilo je testkoće u jednoj ili više procenjenih govorno-jezičkih sposobnosti	Govorni činovi Prozodija i glas Fluentnost govora	
Kristensen	2000	SM (<i>n</i> = 54) TR (<i>n</i> = 108)	Peabody Picture Vocabulary Test WISC-R Boston Naming Test Reynell Developmental Language Scales	Razumevanje govora Raspont kratkotračne verbalne memorije Imenovanje	68% dece sa SM imalo je neki tip govorno-jezičkog poremećaja, naspram 13% TR dece
Steinhausen & Juži	1996	SM (<i>n</i> = 100)	Kohortna studija – podaci iz medicinske dokumentacije	/	42.1% dece sa SM imalo je neki od govorno-jezičkih poremećaja
Manassis et al.	2007	SM (<i>n</i> = 44) bez SM (<i>n</i> = 23) TR (<i>n</i> = 19)	APPeabody Picture Vocabulary Test Lindamood Auditory Conceptualization Test (LACT) The Test of Reception of Grammar (TROG)	Razumevanje govora Fonološka svesnost Receptivne sintakške sposobnosti	Deca sa SM imala su značajno lošija postignuća na svim procenjenim jezičkim sposobnostima, u poređenju sa druge dve grupe

McInnes et al.	2004	SM (<i>n</i> = 7) SF bez SM (<i>n</i> = 7)	WISC-R Children's Communication Checklist (CCC) Peabody Picture Vocabulary Test Clinical Evaluation of Language Fundamentals - 3 (CELF-3) Lindamood Auditory Conceptualization Test (LACT) Strong Narrative Assessment Procedure (SNAP) WISC-R	Receptivne jezičke sposobnosti Fonološka svesnost Ekspresivne jezičke sposobnosti na planu narativnog diskursa u narativnom diskursu uprkos dobrim receptivnim jezičkim sposobnostima	Deca sa SM imala su značajno lošija postignuća od dece sa socijalnom fobijom na svim procenjenim jezičkim sposobnostima
Kristensen & Oerbeck	2006	SM (<i>n</i> = 32) TR (<i>n</i> = 62)		Raspon verbalne memorije	Deca sa SM imala su značajno lošija postignuća u odnosu na kontrolnu grupu
Manassis et al.	2003	SM (<i>n</i> = 14) SF bez SM (<i>n</i> = 9)	WISC-R Children's Communication Checklist (CCC) Peabody Picture Vocabulary Test Lindamood Auditory Conceptualization Test (LACT) Clinical Evaluation of Language Fundamentals - 3 (CELF-3)	Receptivne jezičke sposobnosti Fonološke sposobnosti Fiziološko merenje centralnog auditivnog procesiranja	Deca sa SM bila su lošija od dece sa socijalnom fobijom na svim procenjenim jezičkim sposobnostima
Bar-Haim et al.	2004	SM (<i>n</i> = 16) TR (<i>n</i> = 16)	Jezičko procesiranje procesiranja	Socioverbalne komunikativne veštine	Deca sa SM imala su značajno lošija postignuća na svim merenjima jezičkog procesiranja
Carbone et al.	2010	SM (<i>n</i> = 44) Međoviti AP bez SM (<i>n</i> = 65)	Verbal and Nonverbal Social Behavior Measures		Deca sa SM imala su značajno lošija postignuća u odnosu na druge dve grupe

Napomena: TR – tipičan razvoj, SM – selektivni mutizam, AP – anksiozni poremećaji, SF – socijalna fobija

Rezultati sa diskusijom

Aktuelno stanovište o uzrocima SM

U pogledu etiologije SM najčešće se navode multifaktorski činioci, većinom povezani sa psihološkom dimenzijom razvoja deteta (Dimoski, 2016). To je uslovljeno rezultatima istraživanja koji su ukazali na visok procenat povezanosti SM i socijalne fobije (npr. Chavira et al., 2007; Cunningham et al., 2006; Sharp et al., 2007). Shodno tome, u literaturi postoji nekoliko psiholoških teorija koje objašnjavaju nastanak SM (Dimoski, 2016). Kohanova i saradnici (Cohan et al., 2008) navode da deca sa SM spadaju u jednu od tri grupe dece sa anksioznim poremećajem: 1. anksiozna – blago opoziciona (mutizam se ispoljava u slučajevima kad postoji pritisak na dete da govori); 2. isključivo anksiozna i 3. anksiozna sa odloženom komunikacijom. Međutim, postoje podaci koji ne podržavaju stav da je SM manifestacija socijalne fobije. Naime, rezultati istraživanja Melfsena i saradnika (Melfsen et al., 2006) pokazali su da deca sa SM imaju značajno manji stepen anksioznosti u poređenju sa decom koja imaju socijalnu fobiju, i u kvalitativnom, i kvantitativnom obimu. Dodatno, navedena klasifikacija podrazumeva da dete u nekoj meri svojevoljno izbegava da govori, kao oblik opozicionog ponašanja, što nije u skladu sa kliničkom slikom SM. I podaci iz studija prevalencije anksioznosti kod dece sa SM ne ukazuju konzistentno na to da su ova dva poremećaja nužno povezana. Naime, većina podataka o povezanosti SM i socijalne fobije potiče iz istraživanja sa malim uzorkom ispitanika (7–44) (Manassis et al., 2007; McInnes et al., 2004; Nowakowski et al., 2011; Oerbeck et al., 2014; Yeganeh et al., 2006; Young et al., 2012). S druge strane, podaci iz studija u kojima je obuhvaćen veći uzorak ispitanika ukazuju na oprečne podatke. Naime, podaci iz istraživanja Stejnhausena i Juzijeve (Steinhausen & Juzi, 1996) na uzorku od 100 ispitanika sa SM ukazuju na prevalenciju od 66% dece koja ispoljavaju simptome anksioznosti. Međutim, u studiji Fordove i saradnika (Ford et al., 1998) od 153 dece samo je 12% ispitanika ispoljavalo anksiozne oblike ponašanja. Iako anksioznost može biti faktor koji doprinosi pojavi SM, ovaj simptom ne objašnjava zašto se kod dece sa SM manifestuje baš na planu govora, a ne u nekom drugom obliku ponašanja.

SM i govorno-jezički poremećaji

Iako je u literaturi značajno veća pažnja posvećena povezanosti SM i anksioznih poremećaja, sve je više podataka koji ukazuju na govorno-jezičke poremećaje kao moguće uzročnike pojave SM. Naime, sad već postoji priličan broj istraživanja koja su pokazala da deca sa SM mogu ispoljavati značajno kašnjenje u razvoju kognitivnih, govorno-jezičkih i motoričkih sposobnosti (Cleator & Hand, 2001; Kolvin & Fundudis, 1981; Kristensen, 2000; Steinhausen

& Juzi, 1996). Podaci iz istraživanja pokazuju da govorno-jezičke poremećaje ili usporen govorno-jezički razvoj ispoljava od 30 do 50% dece sa SM (Kolvin & Fundudis, 1981; Kristensen, 2000; Steinhagen & Juzi, 1996). U istraživanju Kristensenove (Kristensen, 2000), kojim je obuhvaćeno 54 ispitanika sa SM i 108 ispitanika kontrolne grupe, rezultati su pokazali da se govorno-jezički poremećaji javljaju značajno češće kod dece sa SM (68, nasuprot 13%). Dodatno, 17% ispitanika imalo je simptome mešovitog (receptivno-ekspresivnog) tipa razvojnog jezičkog poremećaja, 12% simptome razvojnog jezičkog poremećaja ekspresivnog tipa i 43% razvojnog fonološkog poremećaja (Kristensen, 2000).

U pogledu detaljnijeg profila jezičkih deficitova, rezultati studije Manassisove i saradnika (Manassis et al., 2007) pokazali su da deca sa SM imaju značajno lošija postignuća na planu receptivnog vokabulara, fonološke svesnosti i sintaksičkih sposobnosti, u poređenju sa decom koja imaju anksiozni poremećaj i decom tipičnog razvoja. Takođe, deca sa SM ispoljavaju teškoće i na planu narativnog diskursa. Naime, rezultati istraživanja Mekinesove i saradnika (McInnes et al., 2004) pokazali su da deca sa SM prilikom prepričavanja priče produkuju značajno kraće, lingvistički jednostavnije i manje raznovrsne narrative, u poređenju i sa decom tipičnog razvoja, i sa decom koja imaju socijalnu fobiju. Rezultati studija narativnog diskursa impliciraju i pragmatske teškoće kao potencijalne uzročnike pojave SM (Hipolito & Johnson, 2021).

Podaci iz istraživanja ukazuju da deca sa SM najčešće ispoljavaju receptivne jezičke deficitove, koji se mogu javiti u obimu od subkliničkih pa do kliničkih formi razvojnih jezičkih poremećaja (Kristensen, 2000; Kristensen & Oerbeck, 2006; Manassis et al., 2003; McInnes et al., 2004). Pored deficitova receptivnih jezičkih sposobnosti, deca sa SM često ispoljavaju i teškoće na planu sposobnosti jezičkog procesiranja, poput deficitova auditivnog procesiranja (Bar-Haim et al., 2004) i deficitova na planu auditivne verbalne memorije (Kristensen & Oerbeck, 2006). Teškoće u razvoju jezičkih sposobnosti, kao i deficiti jezičkog procesiranja na predškolskom uzrastu, mogu dovesti do ozbiljnijih komunikativnih i teškoća u ovladavanju veštinama čitanja i pisanja na školskom uzrastu. Čak i suptilni jezički deficiti mogu dovesti do produbljivanja deficitova na planu jezičkih sposobnosti višeg nivoa, što značajno utiče na akademsku postignuća (McInnes et al., 2004). S druge strane, veliki broj dece sa razvojnim jezičkim poremećajem ispoljava značajne deficitove jezičkih sposobnosti i na školskom uzrastu (Drljan & Vuković, 2017, 2019), a nivo razvijenosti jezičkih sposobnosti pozitivno korelira sa nivoom socijalne zrelosti kod ove dece (Vuković, I. & Vuković, M., 2007). Dodatno, deficiti na planu receptivnih jezičkih sposobnosti u većoj meri ometaju funkcionalisanje i mogu biti izvor velike frustracije kod deteta, u poređenju sa deficitima ekspresivnih jezičkih sposobnosti. Pored toga, u prilog stanovištu da u osnovi SM mogu biti jezički mehanizmi govore i podaci u literaturi koji ukazuju na to da bilingvizam predstavlja značajan faktor rizika za pojavu ovog poremećaja kod dece sa

osetljivim jezičkim sistemom (Cucinotta et al., 2014; Le Pichon & de Jonge, 2016).

Dostupni podaci iz literature ukazuju na to da deca sa SM mogu ispoljavati i teškoće na planu socijalnih sposobnosti, pogotovo onih jezički zavisnih. Naime, rezultati studije Karboneove i saradnika (Carbone et al., 2010) pokazali su da deca sa SM imaju značajno niži nivo socijalne komunikativne kompetentnosti i verbalnih socijalnih veština u poređenju sa decom koja imaju anksiozni poremećaj i decom tipičnog razvoja. Naime, niži nivo socijalne kompetencije i verbalnih socijalnih veština može biti vezan za samu kliničku sliku SM. Međutim, razlike u ovom domenu između dece sa SM i dece sa anksioznim poremećajem impliciraju moguć uticaj jezičkih deficitata na socijalne veštine ove dece. Pored toga, veliki broj istraživanja pokazao je da deca sa razvojnim jezičkim poremećajem ispoljavaju značajne teškoće na planu socijalne kompetencije i socijalnih veština na predškolskom i školskom uzrastu, ali i u odrasлом periodu (npr. Conti-Ramsden & Botting, 2004; Drljan et al., 2015; Durkin & Conti-Ramsden, 2007; Snowling et al., 2006). Pored toga, adolescenti sa razvojnim jezičkim poremećajem ispoljavaju i značajno viši nivo stresa u socijalnim situacijama (Wadman et al., 2011), a teškoće na planu socijalnih i pragmatskih veština često su posledica deficitata strukturalnih aspekata jezika koji karakterišu ovaj poremećaj (Drljan, 2017). Od specifičnih deficitata jezičkih sposobnosti, teškoće na planu receptivnih predstavlja najveći rizik za ispoljavanje socijalnih i bihevioralnih teškoća na školskom uzrastu (Cohen et al., 1993), kao težeg oblika specifičnih smetnji u učenju (Simkin & Conti-Ramsden, 2006). Takođe, receptivne jezičke sposobnosti visoko pozitivno koreliraju sa socijalnim sposobnostima i kod dece tipičnog razvoja (Benner et al., 2007). Navedeni podaci impliciraju uzročno-posledičnu vezu između jezičkih deficitata i simptoma koji karakterišu SM. Naime, jezički poremećaji na predškolskom uzrastu često dovode do teškoća u socijalnoj komunikaciji na školskom uzrastu, što posledično dovodi do povećanog nivoa frustracije i komorbiditeta sa anksioznim poremećajima.

Odnos jezičkih deficitata i socijalne anksioznosti kod dece sa SM

Rezultati prethodnih istraživanja ukazuju na značajne razlike između SM i socijalne fobije, uprkos određenih sličnosti u etiologiji i simptomima. Naime, etiologija SM nije u potpunosti razjašnjena, a SM se značajno razlikuje od anksioznih poremećaja zato što je povezan sa većom prevalencom jezičkih poremećaja. S druge strane, još uvek nije jasno da li razvojni jezički poremećaji ili subklinički jezički deficiti dovode do povećanja nivoa anksioznosti kod dece sa SM u određenim komunikativnim situacijama, ili je u pitanju komorbiditet dva poremećaja. Moguće objašnjenje je i da SM dovodi do deprivacije razvoja jezičkih sposobnosti na školskom uzrastu. Na primer, s obzиром na to da dete sa SM često ne govori u školskom okruženju, neće postavljati pitanja i zahtevati

pojašnjenja od učitelja i nastavnika. To može rezultovati nižim akademskim postignućima. Dodatno, sa primarnog porodičnog okruženja na predškolskom uzrastu, stimulacija razvoja jezičkih sposobnosti pomera težište na školsko okruženje kada deca započnu formalno obrazovanje. Razvoj socijalno-komunikativnih i pragmatskih sposobnosti na školskom uzrastu u velikoj meri zavisi od interakcije dece sa vršnjacima. Moguće je i da deca sa SM koja nemaju istoriju jezičkih poremećaja na predškolskom uzrastu ispolje jezičke deficite na školskom uzrastu usled nedovoljne komunikacije sa vršnjacima, kao i nedovoljno raznovrsne komunikativne interakcije sa drugima.

Međutim, visoka učestalost govorno-jezičkih poremećaja kod dece sa SM u literaturi novijeg datuma još uvek se razmatra sa aspekta komorbiditeta (Muris & Ollendick, 2021). Naime, broj istraživanja u kojima su proučavane jezičke sposobnosti ove dece izuzetno je mali. Jedno od mogućih objašnjenja velike disproporcionalnosti u istraživanju jezičkih i anksioznih poremećaja kod dece sa SM je u različitoj metodologiji. Prisustvo anksioznih poremećaja kod ove dece moguće je istražiti primenom intervjua koji popunjavaju roditelji i druge bliske osobe, a većina istraživanja u ovoj oblasti upravo se bazira na ovakvoj vrsti procene (Muris & Ollendick, 2021). S druge strane, jezička procena dece sa SM značajno je kompleksnija i zahteva visok stepen obuke kliničara koji prikuplja podatke. S obzirom na to da je klinička situacija često jedna od socijalnih situacija u kojima ova deca ispoljavaju mutizam, detaljna govorno-jezička procena zahteva obuku roditelja za uzimanje adekvatnog uzorka spontanog govora ili čak primenu mernih instrumenata (Muris & Ollendick, 2021). Pored toga, procena govorno-jezičkih sposobnosti je multidimenzionalna i zahteva pažljivo merenje i analizu svih aspeka jezika, fonoloških, morfosintakških, leksičko-semantičkih i pragmatskih. Takva procena traje dugo i zahteva primenu velikog broja instrumenata, kao i kombinaciju primene direktnih mernih instrumenata i strukturalne opservacije u slučaju pragmatskih sposobnosti. Naveden je jedan od mogućih razloga zašto postoji mali broj istraživačkih studija u širem vremenskom okviru, koje nisu dovoljne za izvođenje pouzdanih zaključaka, prvenstveno o opsegu jezičkih deficita koje ova deca ispoljavaju, a zatim i o odnosu jezičkih i anksioznih poremećaja koji karakterišu SM.

Postojeće studije pružile su početni uvid u jezičku dimenziju SM, ali su možda postavile više pitanja nego što su dale pouzdanih odgovora. Potrebno je još empirijskih studija poređenja dece sa SM i dece sa anksioznim poremećajima kako bi se bolje razumele sličnosti i razlike u načinu na koji se poremećaji ispoljavaju i utiču na funkcionisanje dece. Takođe, neophodno je i istražiti odnos jezičkih sposobnosti i anksioznih oblika ponašanja kod ove dece. Istraživanja ovog tipa još uvek nisu dostupna u literaturi, a jedina bi mogla razjasniti kompleksnu uzročno-posledičnu dinamiku jezičkih i anksioznih poremećaja, evidentno prisutnu kod dece sa SM.

Zaključak

SM je poremećaj koji se nalazi na raskršću između dečije psihopatologije i govorno-jezičkih poremećaja. Studija detaljnije analize simptoma povezanih sa anksioznosću i govorno-jezičkim deficitima nema mnogo u literaturi, i većina saznanja iz ove oblasti potiče iz radova sa malim brojem ispitanika. Pored toga, testiranje govorno-jezičkih sposobnosti dece sa SM predstavlja poseban izazov, kako u kliničkom, tako i u metodološkom smislu. Bez obzira na to, postojeće studije dale su značajan doprinos razumevanju ovog poremećaja i odredile pravce istraživanja. Potrebno je detaljnije istražiti odnos između anksioznosti, kognitivnih i jezičkih sposobnosti u različitim periodima razvoja dece sa SM. Naime, nije još uvek jasno da li jezički deficiti utiču na pojavu anksioznosti koja se najviše ispoljava u domenu komunikacije, ili rani simptomi anksioznosti utiču na jezički razvoj ove dece, predisponirajući ih za SM.

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Speech and language deficits in children with selective mutism – cause, comorbidity, or consequences?

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Introduction. Selective mutism (SM) is a disorder described from two aspects, psychological and language disorders. Researchers mainly focused on the psychological dimension of SM. However, there is an increasing number of studies indicating a significant speech and language (SL) impairment in children with SM and the possible connection between difficulties in language development and the occurrence of SM at school age. *Objective.* The aim of this paper was to review available research on SL deficits in children with SM, in order to clarify the cause-and-effect relationships between language and anxiety disorders in these children. *Methods.* Databases of the Library Consortium of Serbia and relevant Internet search engines were used for the literature search. *Results.* Nine research studies on SL abilities in children with SM are available in the literature. Mixed and expressive types of developmental language disorder, developmental phonological disorder, and language processing deficits are the most common SL impairments in children with SM. They occur significantly more frequently in children with SM than in children with anxiety disorders without SM and typically developing children. These deficits are often associated with learning disorders, social skills difficulties, and the risk of behavioral problems at school age. *Conclusion.* Existing studies have provided valuable insights into some aspects of the SL development in children with SM. However, the relationship between language deficits and anxiety symptoms is still not clear. Research on the early SL development in these children, which could shed light on the complex cause-and-effect dynamics of language and anxiety disorders seen in children with SM, is particularly scarce.

Keywords: selective mutism, speech-language deficits, etiological factors, comorbidity

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