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- FRIENDSHIP AND SOCIAL INCLUSION OF ADULTS WITH ID
- SCIENCE EDUCATION PRACTICES FOR DEAF
- POVEZANOST SENZORNOG PROCESIRANJA DECE SA RAZVOJNOM DISFAZIJOM
- KORISNICI SLUŠNE AMPLIFIKACIJE I COVID-19
- APRAKSIJA I ALCHAJMEROVA BOLEST

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Self-assessment of friendships and social inclusion of adults with intellectual disabilities

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Introduction. Persons with intellectual disabilities often experience difficulties in achieving interpersonal relations and social inclusion, which are important aspects of quality of life. *Objectives.* This paper aims to examine the perspective of people with intellectual disabilities on friendships and social inclusion and identify factors which influence their development, with the ultimate goal of defining recommendations for improving support. *Methods.* A qualitative research approach was chosen to gain insight into participants' subjective experiences and views. For this purpose, an individual semi-structured interview was conducted with eight adults with mild and moderate intellectual disabilities. *Results.* Participants generally express satisfaction with their friendships and social involvement. They spend time with friends, mostly in the centre, where they are included in the daily program. They especially emphasize the importance of the emotional support they receive from friends. In addition to activities in the daily centre, participants play sports, but they spend most of their free time at home. The factors that negatively affect their social inclusion and friendships are overly protective parents, living conditions, and low motivation. The factors that promote both are parental support, the use of social media, and visiting different places in the community. *Conclusion.* Although participants are mostly satisfied with their friendships and social inclusion, they also express different needs. Being included in the daily centre has a positive impact on developing friendships and social inclusion, but at the same time, it is necessary to offer inclusive content in society and provide both formal and informal support in this area.

Keywords: friendships, social inclusion, intellectual disabilities, disability

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Introduction

Friendship is one of the greatest life values. A human is a social being and, as such, needs close relations with other people (Borčinović, 2009). Moreover, quality friendships lead to better mental health, greater resistance to stress, and better quality of life (Huić & Smolčić, 2016).

Research confirms that friends of people with intellectual disabilities (ID) have a vital role in their life (Fulford & Cobigo, 2018; Knox & Hickson, 2001; Morris, 2001; Zlatarić, 2014) and that spending time together makes them happy (Fulford & Cobigo, 2018). In addition to the family, friends represent the most important informal support in empowering people with ID, creating a positive image of themselves, and realizing valued social roles. Being a friend is one of the most important roles in their lives (Zlatarić, 2014). Some characteristics of friendships differ between the typical population and the population of people with ID. It has been shown that people with ID have fewer friends than the general population (Friedman & Rizzolo, 2018), friends are harder to find (Morris, 2001), friendships are most often made with people who also have intellectual disabilities (Callus, 2017; Emerson & McVilly, 2004; Knox & Hickson, 2001), and they assess these friendships with lower levels of quality, closeness, and positive reciprocity (Tipton et al., 2013). They participate in a limited number of joint activities that most often occur in public (Emerson & McVilly, 2004) and are related to organized services for people with disabilities (Callus, 2017). Some people with ID equate friends with family members and roommates (Bigby, 2008), while others clearly distinguish friendly from other types of relations (Callus, 2017; Fulford & Cobigo, 2018; Knox & Hickson, 2001). Many factors influence the establishment of friendly connections for people with ID, and the support of professional staff and family is the most important factor (Friedman & Rizzolo, 2018). Other factors are living situation, attitudes of the society, independence, the possibility of control over own life (Fulford & Cobigo, 2018), the level of adaptive behaviour (Emerson & McVilly, 2004), additional difficulties (Morris, 2001), and social skills (Little et al., 2019).

In the research by Fulford and Cobigo (2018), people with ID emphasized that life in the community, i.e., outside institutions, with the availability of a greater number of services and support programs and where it is possible to meet new people, facilitates the development and maintenance of friendships. This is where general social inclusion and the development of friendship establish a close connection. The concept of social inclusion has many components. The most important is belonging to a community that represents its own sense of real connection with the social and physical environment and the resources and services it provides (Hall, 2017). People with ID describe social inclusion as social acceptance, the possibility of using community services and having opportunities for contacting and meeting new people (Abbott & McConkey, 2006).

A lot of studies (Hall, 2017; Merrells et al., 2019; Minton et al., 2002) talk about the unsatisfactory level of social inclusion of people with ID, which is also confirmed by some Croatian research (Leutar et al., 2014; Bratković et al., 2018). Older people, people living with parents and in a housing institution are at a greater risk of social exclusion (Minton et al., 2002). On the other hand, there are positive consequences of the independent living movement (Bratković et al., 2018). In Croatia, various legal acts have been adopted that encourage the inclusion of people with disabilities in the community in the last few decades, such as strategic plans for deinstitutionalization and transformation of social welfare homes and the Act on Professional Rehabilitation and Employment of People with Disabilities NN 157/13 (NN 32/20). Various social services are provided, such as organized housing and personal assistance, but the capacities are limited and insufficient for the needs and number of people. A big problem is the lack of transition programs oriented towards involvement in the community and employment, which is why, after finishing school, the only option for many people with ID are daily programs, with limited opportunities for real social participation and community living.

Social inclusion is correlated with the quantity and quality of social support networks, often lower in people with ID than in a typical population (Forrester-Jones et al., 2006; Lippold & Burns, 2009; McCausland et al., 2017). Factors that positively affect social inclusion are educational opportunities, employment, good physical health, being informed about community services (Leutar et al., 2014), involvement in NGO programs (Zlatarić, 2014) and participation in meaningful activities (van Asselt-Goverts, 2015). Some factors which have a negative impact are overprotective family members and professional staff, life in rural areas, and the inability to use public transport (Abbott & McConkey, 2006).

Some studies show the positive impact of friendship on achieving social inclusion (Friedman & Rizzolo, 2018), and vice versa (Abbott & McConkey, 2006; Fulford & Cobigo, 2018; Zlatarić, 2014).

With increasing interest in these research topics, many studies still rely primarily on collecting data from an environment that knows people with ID well, i.e., their parents/guardians and/or support staff. Despite inclusive tendencies, there is a small number of studies that include the subjective perception of these persons (Abbott & McConkey, 2006; Callus, 2017; Fulford & Cobigo, 2018), although many of them can give self-statements.

Therefore, this paper aims to examine the perspective of people with ID on friendships and social inclusion, to identify the factors that make it easier or more difficult for them to achieve this, and possible ways of improving systematic and informal support of the environment in this area. Consistent with that aim, the following research questions were defined: *1) How do adults with ID define and experience friendships and their significance? 2) What are* *the personal experiences of adults with ID in terms of making and maintaining friendships? 3) In what ways and to what extent are adults with ID involved in their community? 4) How do personal and environmental factors affect the development and maintenance of friendships and social inclusion of adults with ID?*

Methods

Participants

Given the purpose of this research, the most appropriate method was intentional sampling. The criteria for selecting participants were the presence of a mild or moderate intellectual disability and the absence of significant communication difficulties that would make it impossible to conduct an individual interview. The study included eight adults with ID aged 29 to 50, four females and four males. Four participants have mild intellectual disability and four have moderate intellectual disability. According to the available documentation, four participants were diagnosed with additional diagnoses of mental health problems. All participants are users of the daily centre for rehabilitation and work activities at one NGO in Zagreb, the capital of the Republic of Croatia, so all participants know each other. Every day, they spend several hours in the daily centre where they participate in various occupational, creative, and sports activities. They all live in their family home with their parents or other family members. One participant has a partner, but only meets them at sports training which they attend together. None of them is employed, and only one participant helps in a family business.

Data Acquisition

A qualitative approach and a method of the individual semi-structured interview were applied to gain an in-depth insight into the experiences and views, i.e., the subjective perspective of the participants with ID. Due to the COVID-19 epidemiological measures, all interviews were held in the quiet open space in front of the NGO, where the participants felt more relaxed and safer and did not have to wear masks. Every interview took about an hour. Before conducting the interview, the authors of the paper created an Interview guide with main questions (Table 1) and specific sub-questions based on the key subjects described in studied literature about friendships and social inclusion of people with ID. The questions were formed in an easy-to-understand way, with simple words and short sentences and were further adapted to each participant as needed (explained in other words, repeated, different terms used, supplemented with examples). Each interview was recorded and later transcribed. After the interviews, the participants received certificates of appreciation for their participation and contribution to the research.

Table 1

The main questions (without sub-questions) asked in the interview

General information	1. How old are you? 2. Where do you live? 3. Who do you live with / who else lives with you? 4. Which people are important in your life?
Everyday activities	1. What do you do at home with your housemates? 2. In which activities do you participate in the daily centre and with whom?
Social inclusion	1. What are you doing in your free time? 2. Who do you spend your free time with? 3. Do you go to the store / shopping and what do you buy? 4. Do you use public transport? 5. Do you go to church / participate in religious activities? 6. Do you use a mobile phone, a computer and the Internet? 7. What kind of relations do you have with your neighbours? 8. Do you think you are sufficiently involved in your community?
Friendships	1. What does a good friend mean to you? 2. Do you have friends? 3. How do you know that these people are your friends? 4. How do you spend time with your friends? 5. Do you like hanging out with friends? 6. Do you sometimes have problems with your friends, disagree or argue? 7. Do you socialize with friends outside the daily centre? 8. How did you keep in touch with friends during the coronavirus pandemic? 9. How do you find new friends? 10. Did you have any friends with whom you are no longer in touch? 11. Would you like to have more friends / meet new friends? 12. Would you like something to change about your friendships?

Respect for Ethical Principles

Compliance with the Code of Conduct while selecting the participants and collecting data was ensured in several ways. A support person, an employee of the centre, presented the aim and methods of the research to users who met the selection criteria, and only those who showed interest were involved in the research. The Agreement between researchers and research participants was created in which the topic of the research, the procedure for conducting interviews, and the obligations and rights of participants and researchers were presented in a written form accessible to persons with ID, using simple words written in capital letters, the text divided in short paragraphs, and corresponding pictures.

Data Analysis

A qualitative framework analysis was used for data processing (Ritchie & Spencer, 1994, according to Srivastava & Thomson, 2009). With regard to the principles of this method, the following steps were carried out. Interview data were transcribed almost literally with some verbal content editing that was irrelevant for further analysis. Five subject areas were identified according to the research questions: *experience and significance of friendships*, *personal experiences in friendships*, *social inclusion*, *factors that make it difficult to develop friendships and social inclusion*, and *factors that promote the development of friendships and social inclusion*. The following process consisted of the following steps: identifying the topics, coding the statements, classifying the codes into tables according to the topics, and defining the corresponding categories.

Results

Table 2 shows the key results of the qualitative analysis, divided into subject areas, topics and categories.

Table 2

Subject areas, topics and categories obtained from the qualitative analysis

Subject area	Topics and categories
The experience and significance of friendships	The importance of friendships • *Socializing; Mental health; Closeness; Missing during separation; A sense of self-worth* Desirable characteristics of friends • *Having time for other person; Honesty; Respect; Helping; Listening; Sincerity; Politeness; Communicativeness; Likeability; Optimism; Non-argumentativeness; Inner qualities, not outer appearance; Giving praise* Undesirable characteristics of friends • *Argumentativeness; Disrespect; Unreliability; Jealousy; Gossip; Disinterest; Insincerity; Lateness; Annoyance; Lack of empathy*

Subject area	Topics and categories
Personal experiences in friendships	Celebrating birthdays • *With friends; With family; In the Association* Meeting friends • *In the Association; Neighbourhood; School; Leisure activities; Through other people* Joint activities with friends • *Socializing in the Association; Conversations; Walks; Going to cafes; Going to shopping centres; Going to the cinema; Visiting each other; Sport activities; Joking; Summer break* Mutual peer support • *Physical support; Emotional support; Care for health* Quarrels and disagreements • *Quarrels with friends; Quarrels with a partner* Wishes for the future • *Frequency of socializing; Number of friends; Common activities; Behaviour change*
Social inclusion	Realization of valued social roles • *Sports achievements; The role of the teacher; Participation in the family business; Independence in carrying out activities of daily life* Involvement in the Association • *Satisfaction; Activities* Organized leisure activities • *Swimming; Athletics* Free time at home • *Relaxation; Hanging out with family; Creative activities; Sport activities* Free time in the community • *Walks around the city; Going to the cinema; Walks in nature; Attending social events; Sport activities; Going to cafes; Going to church* Interpersonal relations • *Family members; Partners; Neighbours; Other people from the local community* Travel • *Traveling around the city; Excursions with the Association; Family trips* Use of modern technology • *Communication by mobile phone; Communication through social networks; Fun; Learning new skills* Wishes for the future • *Employment; Sport activities; Meeting famous people; Travelling; Using a computer*

Subject area	Topics and categories
Factors that make it difficult to develop friendships and social inclusion	Protective relationship of the family • *Prohibitions; Disrespect for autonomy and the right to choose* Own initiative and motivation Factors related to friends • *Lack of time to socialize; Starting their own families; The rare existence of true friends; Death of a friend* Lack of employment opportunities • *Inappropriate working hours; Deprivation of legal capacity* Physical environment • *Material conditions; Physical distance* Extraordinary circumstances (coronavirus and earthquakes) • *Cessation of participation in the usual activities; Negative feelings*
Factors that promote the development of friendships and social inclusion	Parental support • *Providing transport; Allowing socializing; Making adaptations* Social networks • *Keeping in touch during the coronavirus; The possibility of meeting new friends on the Internet* Meeting new friends in the community

The Experience and Significance of Friendships

Three topics were distinguished within this area: the importance of friendships, desirable and undesirable characteristics of friends, each with its own categories.

The results show that the participants' friends take a very important place in life, and socializing with them contributes to their mental health and lifts their mood: *"It is good to have company. To hang out, you are not alone." (3); "A friend will cheer you up, hang out with you, you can talk about love, football..." (5).* They appreciate the inner qualities of their friends more than their appearance: *"I look at the spirit, I don't care about the appearance, I care about what kind of man you are inside, not outside... Spirit, warmth, heart, that is the essence of a human." (5).* The desirable traits include honesty, sincerity, decency, non-contentiousness, respect, willingness to help and listen, likability, optimism, communicativeness, giving praise, and taking time for the other person. On the other hand, the undesirable traits are contentiousness, disrespect, unreliability, disinterest, jealousy, lack of empathy, dishonesty, duplicity, boredom, and being late.

Personal Friendships Experiences

The topics arising from the conversation about the participants' personal experiences related to friendships are celebrating birthdays, meeting friends, joint activities, mutual peer support, quarrels and disagreements, and wishes for the future.

The participants generally have a small number of friends: most say three-four friends, being very close to one or two of them. Together, they spend time in the usual friendly activities such as talking to each other, walking around the city, going to cafes, shopping centres and cinemas, and doing sports activities.

It is specific for these participants that they usually socialize on the premises of the association in which they spend their time every day, and less outside of it. This information is further confirmed by the fact that participants usually do not see their friends during the summer months (vacation). Moreover, they rarely visit each other at home. They also, in their own judgment, rarely quarrel with their friends. The arguments are short-lasting, and friends make up quickly. When they talk about helping each other, they distinguish between physical support in everyday life and emotional support, which they emphasize as particularly important: *"So that you can confide in him, have a shoulder to cry on, cheer you up when you are sad, hang out, tell a secret and so on." (5).* The topic they often mentioned that proved to be very important to them is the celebration of birthdays with friends.

All participants made friends in the daily centre, which is also the place where they made the most friends. Some clearly separate friends from the daily centre with whom they socialize in their free time from other members. However, one participant believes all members of the centre are their friends just because they are all a part of it. Friends outside the association are most often those they met earlier in school, on leisure activities, or through acquaintances and neighbours. Significantly, some of them do not have any friends outside the association.

Although they are mostly satisfied with their friendships, they also express wishes for improving the relations in the future: *"To go out with them more often." (1); "...to have more friends." (3); "To change their behaviour, not to be angry with each other." (4).* It should be noted, however, that some participants do not want any changes regarding their friendships and are satisfied with the current situation.

Social inclusion

In the Social inclusion thematic area, there are as many as nine topics: realization of valued social roles, involvement in the association, organized leisure activities, free time at home, free time in the community, interpersonal relations, travel, use of modern technology, and wishes for the future.

As said previously, all participants are members of the daily centre, where they spend several hours a day doing various work, creative, sports, and other activities. Apart from these usual activities, the association allows members to participate in various community events. The participants spend most of their free time at home but often go for walks with their family members and friends or alone; they go to cafes, cinemas, and social events and engage in sports. Most of them are involved in sports activities, e.g., in a swimming and/or athletic club, and participate in competitions. They say they mostly have very good close relationships with family members and relatives. However, they also mention positive and negative experiences with neighbours and other people they meet in the community. All participants use public transport independently, which significantly helps them move around the city. Excursions and trips outside the city, which they talked about, are organized mainly by the association, and furthermore, they go on holidays with their families. Everyone uses digital technology, some to communicate with others, and some for entertainment, i.e., playing games, watching videos, series and movies, listening to music, etc. Everyone except one participant has a mobile phone. One out of these seven participants uses it only for talking to their parents, but others also use it to communicate with their friends, mainly over social networks. They perform various socially valued roles that are important to them, most often emphasizing their sporting achievements, work and creative skills, and skills that enable being independent in daily life activities and being equal family members: *"We were in Zadar, I won three silver medals. I also won gold before, I have about 50-something medals." (5); "I go to the store alone when my mom needs something..." (1).; "We went to schools to teach children felting. It was good. Because we were the teachers, we taught." (1).* None of the participants is formally employed, but one is involved in a paid family business. Participants' wishes related to improving social inclusion are employment, going on trips, meeting famous people, and developing sports and computer skills: *"We thought about inclusion, my mom and I, but I don't know if I should get a job." (3); "Well, I'd like to get a little more involved in some sports. Here is my favourite wish: I would like to do cycling." (6).*

The Impact of Personal and Environmental Factors on the Development and Maintenance of Friendships and Social Inclusion

Factors that Make It Difficult to Develop Friendships and Social Inclusion

The following topics emerged from this thematic area: protective relationship of the family, own initiative and motivation, factors related to friends, lack of employment opportunities, physical environment, and extraordinary circumstances (coronavirus and earthquakes).

According to the self-statements of the participants, one of the main factors that negatively affects their social inclusion and friendships is the protective relationship of the family. Such a relationship is mainly related to the degree of independence of the person and is, in some cases, justified. However, sometimes it happens that family members unjustifiably deny a person with ID their right to choose. Their ability to socialize with friends is also limited by the characteristics of the physical environment, i.e., poor living conditions and a great distance between their homes. Some of the reasons for ending friendships are related to the characteristics of friends, the founding of their families, the lack of time for socializing, and the death of a friend. Their initiative and motivation, as well as the individual's traits and lifestyle, play a major role in making friends and engaging in community activities. For example, some of them describe themselves as not communicative and do not express desire to hang out with friends a lot. Participants also discussed problems with the lack of employment opportunities, deprivation of legal capacity, and unadjusted working conditions. Regarding the extraordinary circumstances they faced, the participants emphasized the impossibility of seeing friends and participating in the usual activities due to the coronavirus pandemic and earthquakes that affected the City of Zagreb: *"I would like corona to be over so that we can hang out normally in the evening, so that we can hug and kiss normally, be more cheerful..." (6).*

Factors that Promote the Development of Friendships and Social Inclusion

This thematic area was divided into three topics: parental support, social networks, and meeting new friends in the community.

Parental support has proven to be a very important factor in making and maintaining friendships and improving social inclusion. Parents support participants in several ways: by providing transportation, having a positive attitude towards participants seeing their friends, and designing adjustments that contribute to participants' autonomy in everyday life. The use of social networks contributes to friendships by enabling regular contact with existing friends and meeting new ones: *"We talked online in the group chat." (3); "...you can meet a new friend or more friends through it." (4).* The participants feel that the opportunity to make new friends also increases by visiting different places in the community.

Discussion

This research confirmed the findings of previous studies (Fulford & Cobigo, 2018; Knox & Hickson, 2001; Morris, 2001; Zlatarić, 2014) that friendships are very important to people with ID. The essential element of friendships for the participants is socializing. It has a good effect on their mental health and awakens positive feelings in them, as opposed to isolation.

The participants describe friendships not so differently from people without disabilities, which is also in line with previous findings (Callus, 2017; Fulford & Cobigo, 2018; Knox & Hickson, 2001). They emphasize enjoying joint activities and mutual support as the important qualities of friendships. They care about their friends' character, not their appearance. Brackenridge and McKenzie (2005) also state that people with ID deem personality traits the most important in friends, and the ones that determine whether they like the other person or not. The participants spend time with their friends doing the common friendly activities that usually take place in public spaces, which was also covered in the research by Emerson and McVilly (2004).

The specificity of this research is that all participants are members of the same association (daily centre), and this is where they met most of their friends. Some participants rarely see their friends outside the association and joint sports activities. Furthermore, although most have friends outside the association, several participants consider the association members their only friends and communicate with each other only during joint activities in the association. Fulford and Cobigo (2018) also mention that people with ID are often out of touch with their friends when they are physically separated. From all the above, we observe the positive effect of involvement in the day centre service on developing and maintaining friendships.

On the other hand, the fact that these associations/daily centres are segregated because they are intended exclusively for people with disabilities could be considered harmful. This reduces the opportunities for meeting and establishing relationships with people without disabilities. Bigby and Fyffe (2009) believe that the connections that people with ID make with other people with disabilities should not be neglected because each relationship brings some benefits. Of course, this does not mean we should not encourage expanding the social network and providing people with ID opportunities for new experiences and relationships with others in the community. Only when this is ensured can they make decisions more comprehensively, express their interests, and make better judgments about satisfaction with social inclusion and relationships.

Some participants expressed wishes regarding the scope and quality of friendship, but others are satisfied with the current situation and do not express the need for more friends or frequent encounters, which should be respected. As Bigby and Fyffe (2009) say, not all people are outgoing; some prefer to spend time alone or at home rather than in the community. However, we should remember that this can be the consequence of a lack of skills, experiences or insights into better possibilities.

As this research has shown, involvement in the day centre positively impacts general social inclusion. Almost all participants are involved in organized sports activities, which they most often joined after becoming members of the association, encouraged by the involvement of other members.

For some, hanging out with friends is the main reason for attending sports training.

Although it is objectively devastating that none of them, as graduated adults, had the possibility of employment, independence, or starting their own family, the participants are satisfied with realizing some other valued social roles that they consider very important. Thus, for example, they emphasize their admirable sports results, work, creativity, teaching skills, everyday life skills they use to contribute to their families, and other roles they are proud of and for which they are valued.

The participants show a high level of autonomy in using public transport, going to the store, and using money, which significantly contributes to better social inclusion. The use of public transport also makes seeing friends easier (Fulford & Cobigo, 2018). As Abbott and McConkey (2006) pointed out, learning everyday life skills is one possible way of reducing barriers to social inclusion.

The use of digital technology has proven to be the most common way of communicating and maintaining contact with friends, especially during restrictive epidemiological measures due to the pandemic of coronavirus.

Although the causal link cannot be reliably determined, it is interesting that participants who use less or no social networks and cell phones for texting are the same ones who see friends less often in their spare time and vice versa. Similarly, it could be observed from talking with the participants that several who have fewer friends and socialize with them less often also cite fewer joint activities in the community. On the other hand, we can assume that people who spend more time in the community automatically have a greater chance to make friends. Of course, we cannot conclude with certainty whether the achieved friendships have a positive effect on social inclusion or the opposite, but the previous research speaks in favour of a mutual positive impact (Abbott & McConkey, 2006; Friedman & Rizzolo, 2018; Zlatarić, 2014).

The results of this research indicate specific factors that contribute to or prevent the development of friendships and social inclusion of people with ID. One of the most significant is parental support or, on the other hand, overprotection. There is a need to make more appropriate services available and improve the quality of support by applying person- and family-centred planning models. In this context, it is necessary to educate and encourage parents to provide more opportunities for their adult children with ID to participate in making choices and decisions in everyday life.

Although work plays an important role in every person's life, there are many problems and reduced employment opportunities for people with ID. Instead, they are in the social welfare system. Bratković et al. (2019) confirm the numerous benefits of employment of these persons, which also contribute to their social inclusion, from involvement in purposeful activities and the realization of socially valued roles to the expansion of the social network.

Research Limitations

There are several research limitations that may have influenced the obtained results obtained. First, all participants express willingness to talk about their friendships and social inclusion, they are members of the same association, i.e., social service in the form of a daily program, and most of them also participate in jointly organized leisure activities. In addition, all participants live in their family homes and are residents of a large urban environment, which brings numerous advantages related to the available public infrastructure, such as transport connectivity and various services and public events. Therefore, future research should include more participants with different living and daily activities experiences, as well as demographic characteristics. Since this qualitative research was done on a small sample, it is important to emphasize that the results cannot be generalized to the broader population of people with ID. Although this paper considers the experiential perspective of people with ID as the most important, for more accurate insights, it is important to compare the perspective of people from their immediate environment, especially for people with a higher degree of disability.

Conclusion

"I think having a friend is great for your brain. With no friends, we would die. It is not good not to have friends." (5) There are one of the participants' statements that confirm the importance of friendships for people with ID. The results of the analysis show that friends most often hang out in the day centre and do not often visit at home. They rarely quarrel and especially value the emotional support of their friends. Birthday celebrations with friends are particularly important to them.

Involvement in the day centre has a positive impact on general social inclusion, because, through the association, people with ID participate in various events. In addition, encouraged by the participation of other users of the day centre, they joined sports activities during which they socialize with friends.

None of them is employed, married or has children, but the participants fulfil other valued social roles, such as achieving enviable sports results, independence in everyday life, independence in using public city transport, going to the store and using money, etc, which are essential elements for achieving better social inclusion. Social support in this research has also proved to be a particularly significant, if not indispensable, factor in the development of social connections and relationships of people with ID.

It is evident that programs and organized activities intended for people with ID, such as those offered by NGOs and sports clubs, contribute to the realization of friendships and social inclusion. However, the results open a number of questions related to the full realization of social inclusion and connections with people who are not users of the centres, including people without disabilities. Apart from the unquestionable need for further development of such resources, there is also an even greater need for designing inclusive, non-segregating content and services in society. One of the main prerequisites of independent living is the development of a supported employment model and other innovative programs where people with ID can expand their autonomy, informal circle of support and friendships. Through different projects in the local community, people with ID can be encouraged to individually engage in activities of interest intended for all citizens, e.g., organized leisure activities, cultural and sports events in the community, volunteering, etc. Frequent socializing is important for making friends, so it is necessary to encourage a person to get involved in activities that are held regularly or more than once, where they will see the same people and develop a relationship with them. Furthermore, there is great significance in using digital technology for maintaining communication with friends and following events in the community. Generally, we need more initiatives and proactive operations based on the principles of socially responsible community mobilization.

In addition, it is necessary to create specific programs for empowering people with ID to build friendships, with a special emphasis on improving communication, social and emotional competencies. The education of experts and family members of people with ID is of particular importance, on the one hand, aimed at raising awareness of the significance of friendships and social inclusion for the individual's quality of life, and on the other, at creating strategies for providing support in this field.

It can be concluded that to improve interpersonal relations, especially friendships, and social inclusion of people with ID, it is important to simultaneously work on the further development and improvement of systems and quality of support towards more inclusive and independent living opportunities, on educating the environment and sensitizing society, as well as on building and strengthening personal competences of people with ID. In doing so, it is necessary and must not be neglected to respect the personal perspective and encourage the self-determination of people with ID, to realize their aspirations, wishes, needs, and rights fully, both in this and other life areas.

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Samoprocena prijateljstva i socijalne inkluzije odraslih osoba sa teškoćama u intelektualnom funkcionisanju

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Uvod: Osobe sa teškoćama u intelektualnom funkcionisanju se često suočavaju sa poteškoćama u razvoju međuljudskih odnosa i socijalne inkluzije, koji su važni činioci kvaliteta života. *Cilj:* Ovaj rad ima za cilj da ispita perspektivu osoba sa teškoćama u intelektualnom funkcionisanju o prijateljstvu i socijalnoj inkluziji i da identifikuje faktore koji utiču na njihov razvoj, sa krajnjim ciljem definisanja preporuka za unapređenje podrške. *Metode:* Odabran je kvalitativni istraživački pristup kako bi se stekao uvid u subjektivna iskustva i stavove učesnika. U tu svrhu je sproveden individualni polustrukturirani intervju sa osam odraslih osoba sa lakim i umerenim stepenom intelektualne ometenosti. *Rezultati:* Učesnici, generalno, izražavaju zadovoljstvo svojim prijateljstvima i društvenom uključenošću. Vreme uglavnom provode sa prijateljima u centru, gde su uključeni u dnevni program. Posebno ističu važnost emocionalne podrške koju primaju od prijatelja. Pored aktivnosti u dnevnom centru, učesnici se bave sportom, ali većinu slobodnog vremena provode kod kuće. Faktori koji negativno utiču na njihovu socijalnu inkluziju i sklapanje prijateljstava su: prezaštićujući odnos roditelja, uslovi života i njihova niska motivacija. Faktori koji promovišu i jedno i drugo su podrška roditelja, upotreba društvenih medija i posete različitim mestima u zajednici. *Zaključak:* Iako su učesnici uglavnom zadovoljni kvalitetom prijateljstava i socijalnom uključenošću, oni izražavaju i različite potrebe. Uključivanje u dnevne centre pozitivno utiče na razvoj prijateljstva i socijalne inkluzije, ali je istovremeno potrebno ponuditi inkluzivne sadržaje u zajednici, te pružiti formalnu i neformalnu podršku u ovoj oblasti.

Ključne reči: prijateljstvo, socijalna inkluzija, osobe sa teškoćama u intelektualnom funkcionisanju, invalidnost

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Science education practices for deaf and hard-of-hearing students in Indonesia

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Introduction. Traditionally, the curriculum for deaf learners mainly involved language acquisition at the expense of other academic subjects. Currently, their subjects also include other disciplines, like science, to enrich students' knowledge related to human life. *Objective*. This study aims to describe the implementation of school science practices and identifies the challenges in improving science education in special schools for deaf and hard-of-hearing (DHH) students as a guide for improving inclusive education of these students. *Methods.* The sample included four principals and six classroom science teachers from five DHH schools, using purposive sampling in the five schools that provide education for DHH students in three regencies of Regional V Banyumas, Central Java, Indonesia. Data were gathered through interviews, field observations, and artifacts. *Results*. The teachers use various teaching strategies and rely on visual and hands-on activities for DHH students. The schools provide sign language interpreters and speech-development programs as support for teachers and DHH students. All teachers need professional development in teaching collaboration opportunities to develop their expertise in teaching DHH students. The policy implementation, instructional strategies, resources, and teacher qualifications were found to be extrinsic factors. *Conclusion*. The teachers need support from the government to include them in relevant training programs and prepare teachers with special or inclusive education knowledge by adding courses in university-level education for all prospective teachers. The results are insightful for DHH students, science educators, and policymakers.

Keywords: Deaf and Hard-of-Hearing students, education practices, inclusive education, science education

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Introduction

The international community has assessed the progress of and challenges facing the attainment of the Education for All (EFA) and Sustainable Development Goal 4 (SDG 4) to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all by 2030. The educational sector has started to develop and implement effective strategies toward achieving SDG 4. Analyzing issues and challenges in global education, such as in science education, 'Science for all' should involve concepts and approaches that contribute to the various dimensions of science education that meet the needs and limitations of students' conditions (UNESCO, 2015).

This study is a direct response to students' decreasing motivation and interest in science learning. Many students consider science to be complicated because it contains abstract and theoretical knowledge (Buabeng & Ntow, 2010). Some studies have shown that the subject of science has traditionally been neglected in the curriculum for deaf learners (McIntosh et al., 1994; Molander et al., 2001; Moores & Martin, 2006). Until recently, the curriculum prioritized language acquisition at the expense of other academic subjects limiting students' learning in other fields, including scientific literacy (Khoo & Kang, 2022). Science education should be accessible to all learners, including children with special needs, to promote inclusive science practices (Atika et al., 2018). As a field of study that examines nature, science is strongly related to human life. Thus, every person must understand science or at least have basic scientific literacy.

Scientific literacy is necessary for everyone as it enables people to use scientific information to make everyday life choices (Yakwal & Keswet, 2018). However, the mastery of scientific literacy by students is still minimal. This can be shown based on the results of students' scientific literacy achievement in PISA (Program for International Student Assessment). Indonesia is included in a low level, specifically the bottom 10 positions, when scientific literacy is a very important factor in determining the quality of education in a country (OECD, 2014). Basic scientific literacy has been applied by some people in their daily lives to help their life activities, such as cooking using coal. Mastery of scientific literacy can also be correlated with the ability to understand scientific concepts. If someone understands the concepts of science that he has learned, then that person will also be able to apply science in everyday life (Supena et al., 2021). In addition, mastery of scientific literacy is also correlated with critical thinking skills. This is because someone who has good scientific literacy skills will be more critical and selective in filtering and solving the problems they face (Braund, 2021). Thus, science and its applications have an important role in solving problems in everyday life.

Scientific literacy consists of three aspects: scientific knowledge or concepts, scientific processes, and situation or context that needs to be instilled in every student so that they can be embedded in the ability to model logic and science in solving problems. Therefore, to ensure that students achieve a minimum level of science literacy, science is one of the main subjects in both general and special education from elementary school to junior high school (You et al., 2021). This is consistent with the results of previous observational studies in two Indonesian special schools, which showed that schools only focused on curriculum learning materials. Therefore, students, especially those with special needs, such as students who are deaf and hard of hearing (DHH), consider science boring and uninteresting (Donnellan & Mathews, 2021).

In addition, based on observation of deaf and hard-of-hearing (DHH) students learning in science classrooms, it appears that language and communication skills development takes priority in the learning process. DHH students sometimes have trouble with learning science, especially when it comes to understanding scientific terminology, because science learning is not thoroughly taught to DHH students. To help students develop better learning habits, critical thinking to construct understanding, and a greater grasp of scientific literacy, teachers must provide more explanations, relevant examples, and science instructions that emphasize meaningful learning (Yore, 2000). This needs to be instilled and strengthened in students who have special needs. Every student, especially those with special needs, must be able to solve every problem they face with scientific concepts to be able to think rationally (Majeed et al., 2021).

Special steps are needed to instill scientific literacy in students who have special needs. This is because students with special needs take longer to understand the instructions given by each teacher or instructor (Steed & Leech, 2021). Given the importance of the treatment given to students with special needs to strengthen scientific literacy, this study aims to explore the science education practices of DHH Indonesia schools to answer the needs of students related to inclusive science education and to find out the challenges faced by DHH students and educators in science learning. Specifically, this study answers the following questions (1) How is science learning integrated into the classroom for DHH students? (2) How do special schools provide science education for DHH students? (3) What strategies are applied by principals and teachers to improve science education practices for DHH students? (4) What are the challenges for DHH students and educators in learning science?

Methods

General background

This study used a qualitative method that relies on text and image data, involving unique data analysis steps and drawing on diverse designs (Creswell, 2014). According to McMillan & Schumacher (2006), qualitative research describes and analyses people's individual and collective social actions, beliefs, thoughts, and perceptions. The qualitative method used here utilizes specific protocols for recording data and analyzing information through multiple steps. A multiple case study design was chosen to examine several cases in their natural context and to understand their similarities and differences (Baxter & Jack, 2008). A case study design is appropriate for investigating science education for deaf learners from the perspective of educators as it can provide an in-depth understanding of participants' views, beliefs, and perceptions. Furthermore, the case studies are appropriate for exploratory and discovery-oriented research', to examine under-researched topics (Saxena, 2021).

In this study, science education practices in the following areas guided the data collection and analysis. Teaching, classroom science instruction practices, school support and intervention practices for science education, and teacher collaboration in special schools for DHH students were examined with the aim of improving inclusive science practices for these students. Data were gathered from five schools located in three regencies in Central Java, Indonesia, i.e., 3 schools from urban areas and 2 schools from suburban areas that provide educational services for DHH students. An inductive approach was followed to explore how special schools implement science education practices in different contexts and to draw subsequent conclusions by identifying patterns in the data obtained from different schools (Farquhar, 2012; Stake, 2010). The following subsections provide a detailed discussion of the selection of case study sites and participants and the collection and analysis of data.

Participants

Principals and secondary-level special education science teachers were purposefully selected as participants from five special schools that provide education for DHH students from three regencies in Regional V Banyumas, Central Java, Indonesia. A request for participation was sent to potential participants through a letter based on their role in the school as a school principal or science teacher. Four principals and six classroom science teachers for DHH students agreed to be interviewed (Table 1). Four teachers were observed while they taught science in the classroom. For ethical considerations, all participants were assured of confidentiality and anonymity. Additionally, every participant was informed about the study's aims and methods, any possible conflict of interest, institutional affiliations of the researcher, and source of funding, and gave consent to participate.

Table 1

Background Profiles of the Participants

Participants Code	Code Description	Gender	Age	Education Background	Level of Education	Teaching Experience*
P1	Principals	Female	42 y.o	Special Education	Master	15 years
P2	Principals	Male	45 y.o	Special Education	Master	17 years
P3	Principals	Male	43 y.o	Special Education	Bachelor	16 years
P4	Principals	Male	46 y.o	Special Education	Bachelor	20 years
T1	Science Teachers	Female	32 y.o	Mathematics	Bachelor	8 years
T2	Science Teachers	Male	41 y.o	Mathematics	Bachelor	15 years
T3	Science Teachers	Female	44 y.o	Mathematics	Bachelor	16 years
T4	Science Teachers	Female	25 y.o	Early Childhood	Bachelor	2 years
T5	Science Teachers	Female	40 y.o	Special Education	Bachelor	13 years
T6	Science Teachers	Male	45 y.o	Science	Bachelor	18 years

*Teaching DHH students or typically developing students

Data collection and analysis

The study was conducted from September to October 2017 using multiple data collection methods. The data collection process started with school visits, followed by science classroom observations in DHH schools, interviews with principals and teachers, and the collection of artifacts and available documents in the selected schools (i.e., lesson plans, worksheets, and textbooks). Data were collected through interviews with four principals and six secondary level-special education science teachers for DHH students. The interview process was conducted using the instrument in the interview guide (Table 2). The interviews were semi-structured and contained open-ended questions. Six secondary level-special education science teachers for DHH students had to answer all the questions (Q1-Q13) about the teaching-learning process related to science lessons for DHH students based on their knowledge and experiences, while the principals focused on questions Q11-Q12 related to learning support facilities in DHH schools. For the sake of confidentiality, the names of the participants were made anonymous by code P1-P4 for principals and T1-T6 for science teachers.

Table 2

Questions List for Participants

Question Code	Questions
Q1	Could you tell me about your educational background?
Q2	How long have you been teaching natural science in a special school for DHH students?
Q3	How to communicate with your students in classroom learning?
Q4	What is the curriculum used in a natural science classroom?
Q5	How about learning methods used in natural science learning so that DHH students can play an active role in learning?
Q6	What factors influence your students' learning strategies in science learning in class?
Q7	Do you have students who have difficulty learning and participating in learning in your class? What kinds of difficulties did they experience?
Q8	Based on your experience, what are the challenges of teaching DHH students in a science learning classroom?
Q9	Have you previously received courses related to special education?
Q10	What are the strategies you conduct to face the problems in science learning for DHH students?
Q11	What about the learning support facilities for DHH students in schools?
Q12	Has the government provided sufficient learning resources and other supporting facilities to assist you in creating inclusive science learning for DHH students?
Q13	Is there anything else you'd like to add?

The data obtained from each school visit were used to construct the initial descriptive narrative in response to the research questions. According to Kunene and Sepeng (2017), qualitative data analysis is a relatively systematic process of coding, categorizing, and interpreting data' to explain a single phenomenon of interest. The data gathered from interviews, observations, and artifact collection was triangulated to obtain a logical pattern to identify the current situation of science education practices for DHH students in the participating schools. To improve internal validity and reliability, peer examination and member checking were conducted (Morse, 2015). The latter involved drafting individual case study reports for each school and forwarding them to the schools for any comments and corrections.

Results and Discussion

The analysis of the collected data aimed to describe the participating schools' science practices for DHH students and to identify challenges in improving science education for such students in special schools aiming to give some kind of a guide for inclusive education of those students. To clarify the existing research findings, the data were organized and presented here according to the following themes: classroom practices, school support practices, and teacher collaboration.

Classroom practices

Various findings related to science instructional strategies in classroom practices were obtained from the selected schools (Table 3). The interviews revealed that all junior secondary schools for DHH students used a ‘thematic’ curriculum that combined all subjects into a single theme. The curriculum for the senior secondary schools for DHH students in the studied region was still under discussion by the relevant educational bureau at the time of data collection. Therefore, teachers in these schools referred to material that had already been taught in earlier grades, and they shared information with other schools. To meet DHH students’ needs, teachers also implemented curriculum adaptation and modification.

Furthermore, there were differences among teachers regarding their teacher preparation programs and specialty areas. Of the six classroom science teachers for DHH students, three had completed a mathematics education program, and the other three had each completed an early childhood education program, a special needs education program, and a science education program. Classroom teachers in special schools generally teach all subjects, including science. New teachers who had not completed a science education or special education program experienced difficulties in teaching science concepts to DHH students due to their limited experience and knowledge regarding science and/or students with special needs. This negatively affected students’ acquisition of scientific literacy based on the poor performance in science assessments taken by students. Teachers’ ability to teach science subjects is crucial. The teachers’ use of appropriate learning models could allow DHH students to learn and master science process skills (Ediyanto et al., 2018).

Overall, DHH students’ classroom science learning activities were found to be the same as general education activities. DHH students’ school learning activities prioritize language acquisition and skills development to prepare them to live independently in society. However, students are still taught other subjects, such as science, to enrich their knowledge and prepare them for the National Exam in Indonesia. Based on interviews with science teachers, it was found that all DHH students in the selected schools could read and write well in the classroom. However, the teachers said that students had limited scientific literacy and experienced difficulties in learning science because of their hearing constraints. The importance of literacy, asserts that it ‘enables very young children to think, develop ideas, communicate, and reflect’ (Andrews et al., 2004). However, it is well-documented that deaf learners generally experience significant difficulties in acquiring literacy skills (Andrews et al., 2004; Lang &

Albertini, 2001; Moores & Martin, 2006; Scheetz, 2004). Nevertheless, DHH students can improve their knowledge of science concepts through suitable learning models adapted to their abilities (Ediyanto et al., 2018).

Table 3

Interview Results Related to the Classroom Practices

Question Code	T1	T2	T3	T4	T5	T6
Q3	I'm trying to learn sign language to communicate with DHH students. However, students are also trained with lip reading.	Using sign language and lip-reading.	Sign language and using lip reading can be used to communicate.	I'm trying to learn sign language and found it difficult,	Students and teacher can use sign language and lip-reading.	We use sign language, lip-reading and written communication.
Q4	Thematic for junior high school.	Thematic for junior high school.	Thematic for junior high school.	Thematic for junior high school.	Thematic for junior high school.	Thematic for junior high school.
Q5	Learning is more emphasized on everyday skill and mastery of language.	Language acquisition and skills development. We also use various learning media based on visual characteristic,	We focus on contextual learning by conducting outdoor activities.	The important thing is how students can master the skills used in their lives.	Use more textbooks, pictures, slides, and lip-reading.	Science learning focuses on language acquisition and is essential for imparting skills relevant to everyday life.
Q6	Related to the student's abilities, schools' facilities, and teacher's abilities.	According to the students' and teachers' abilities.	Learning facilities and our abilities to teach DHH students.	Learning innovations and adaptations are carried out according to the circumstances of the students and the ability of the teacher.	According to the students' and teachers' abilities. Also, school facilities.	Learning strategies adapted to the student's ability of hearing, reading, and writing. Subsequently modified in accordance with the teacher's proficiency and the availability of learning support resources.

Based on classroom observations, it was found that students learned by paying attention to the teacher's explanation (sign language or lip-reading), rewriting the content being taught in their notebook, drawing models, grouping information in tables, and engaging in discussions and question-and-answer sessions with the teacher. When communicating with DHH students, all interviewed teachers try to use sign language, and some teachers combine it with lip reading and written communication. Teachers can use oral models or sign language models of communication with DHH students. Teachers whose students used lip-reading assumed that the technique could help students communicate with people in general because not all people can understand and use sign language. Regarding sign language, it was found that there were differences in the sign language used by students. Most of them tended to use local sign language that differs from one place to another. This can lead to misconceptions among students and the incorrect or inadequate acquisition of scientific concepts and literacy.

The findings from one classroom indicated that the DHH students lacked interest and motivation in science learning. It was because the time allocation for one science lesson is 70 minutes. The science material discussed is the concept of work and energy. At that time, the teacher taught directly without using supporting learning media. In this classroom, the students did not pay sufficient attention to the teacher's explanations and were bored during lessons. This is in line with the study conducted by Mahmutović & Hadžiefendić (2020) which found that deaf and hard of hearing students usually have a lower level of motivation to learn. Based on the teacher interviews, all teachers agreed that linking science concepts with relatable and straightforward daily life applications would be more meaningful for DHH students. The science, technology, and social learning approach can make science more useful, exciting, and appropriate for real-life applications, enabling DHH students to learn abstract science concepts (Atika et al., 2018). Therefore, teachers must be more creative in using different strategies that can help them impart science concepts to DHH students more easily and coherently.

Other findings related to learning activities show that different teachers use different strategies. Teachers used various learning media and subject matter content according to their availability in schools. A teacher used pictures, posters, and videos to explain science content to students, and some teachers allowed students to use Internet-enabled computers to explore their curiosity. In some classrooms, teachers asked students to engage in outdoor activities such as growing plants together. Teachers adjusted their methods to the science content being taught and relied on visual and hands-on activities appropriate for DHH students. According to Zainuddin et al. (2009), DHH students can learn through guided visualization and have strong visual communication abilities.

So, it is understandable that the teachers in our study have focused on visual stimuli tools as a strategy for teaching DHH students.

Furthermore, some studies have found that diverse learning methods, such as experimental and inquiry methods, can be applied to science learning for DHH students (Flores & Rumjanek, 2015; Gormally, 2017; Kurz et al., 2015; Zainuddin et al., 2009). Experimental and inquiry-based laboratory methods have been found to have increased DHH students' interest in science learning. Most DHH students who participated in experimental activities presented language refinement and increased self-esteem and self-confidence (Flores & Rumjanek, 2015). Moreover, inquiry-based laboratory learning could help DHH students enjoy hands-on activities and improve their ability to collaborate with peers (Gormally, 2017).

Based on DHH students' opinions gathered through the interview in the observed classrooms, they preferred learning science through experiments and demonstrations using simple props; however, none of the observed schools had science laboratories to support DHH students in learning and practicing science experiments as in regular schools. Regarding this, Ediyanto et al. (2017) asserted that the school environment could be a "learning laboratory". However, support facilities such as science laboratories have not been adapted and optimized for children with special needs in special schools. The lack of opportunity to conduct experiments in science laboratories has resulted in DHH students' low competence in science (Ediyanto et al., 2018). This has, in turn, hindered the development of their science process skills and their interest in science.

School support practices

All selected schools provided various in-class and out-of-class science support programs to implement inclusive science practices appropriate for DHH students' needs (Table 4).

Some support programs were common among all schools. Based on the observation in science learning, the learning process in one school was carried out according to a learning group system. Each learning group consisted of an average of five to seven students with a classroom teacher. This proportion is ideal based on the teacher-student ratio of 1:10 for students with mild disabilities (Ediyanto et al., 2017) since there are limitations in the number of teachers and classrooms available. If there are less than 10 students in the same grade, then that grade is combined with other grades at the same educational level. According to this system, students in the first, second, and third grades who are at one educational level (junior or senior secondary school) can be combined into one learning group. The other observed schools separated third-grade students to prepare them for the National Exam, which includes science as one of the subjects. All observed schools claimed that they had additional classes and extra learning materials for DHH students to prepare them for the National Exam, ensuring that they pass the exam with good results.

Table 4

Interview Results Related to the Schools Support Practices

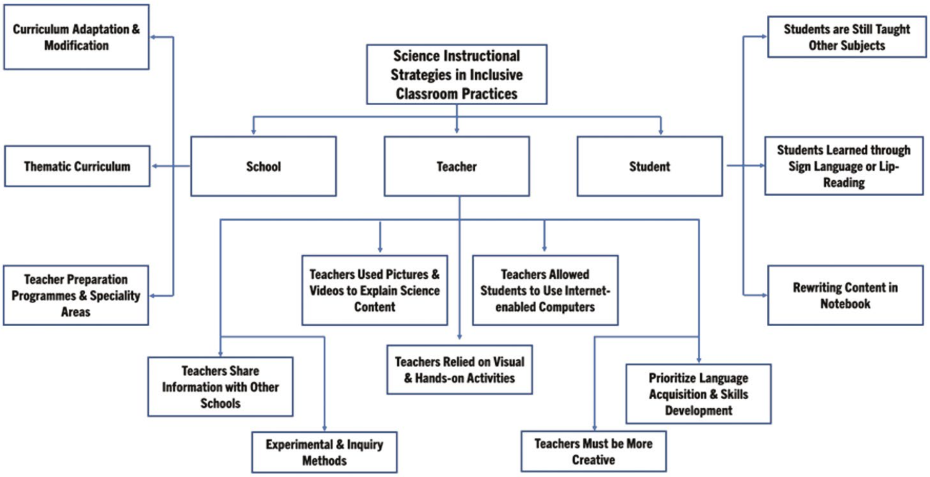
Question Code	T1	T2	T3	T4	T5	T6
Q11	Our school has a library and a few computers, which are not many.	There is a library in the school, but not many books and only a few computers.	We have books and some computer.	There are books and computers to support learning.	We need a science laboratory for practicum. In our school there are some books and few computers.	Learning support facilities include books and computers, but we do not have a science laboratory.
Q12	We have an interpreter. But not all time stand by at school.	There are interpreters who help students' self-development.	Yes, of course. As I mentioned earlier	An interpreter really helps the implementation of learning in my class.	Yes, of course.	Of course, as I mentioned before. And, we have an interpreter to help teacher and students communicate with each other.

The selected schools also had other learning support facilities, which included learning resources such as books and computers. However, it was observed that the schools had a limited number of books appropriate for DHH students' needs; students who wished to borrow a book usually had to wait a long time for the book to be returned by another student. Moreover, the issue of computer availability in special schools also needs to be addressed to ensure that all students' needs are met. Some schools only have a few computers, so students have to take turns using the computers during learning. The condition of such support facilities in the observed schools indicates the need for an improvement in science learning resources for DHH students to enhance their scientific literacy and science process skills. Appropriate support facilities can help teachers impart science concepts to DHH students more efficiently (Ediyanto et al., 2018).

Additionally, DHH students, who usually use sign language, generally have strong visual communication abilities (Zainuddin et al., 2009). The interviews with the four school principals revealed that each selected school had one sign language interpreter, although the interpreter was not always available at the school. During learning activities, these interpreters helped teachers interpret the sign language used by students. Another support facility was a speech-development program to improve DHH students' ability to speak clearly. This program was mandatory for DHH students in each of the observed schools. Meanwhile, science instructional strategies in school support practices can be shown as shown in Figure 1.

Figure 1

Science Instructional Strategies in School Support Practices



Teacher collaboration

All teachers need professional development opportunities to help them develop their knowledge, skills, and practice. Collaboration provides teachers with an opportunity to develop their expertise and knowledge, allowing them to share and adjust their expectations of all students (Basister & Kawai, 2018). Teacher collaboration in the observed schools included cooperation between not only teachers and educators from the same school but also those from other schools in different areas. Special education teachers or special school principals hold a meeting once a month—a teacher network forum for special education teachers—to share their pedagogical practices and experiences related to teaching DHH students. The teacher forum is the most familiar and widely used professional development practice for teachers in Indonesia because it covers all geographical areas, urban and rural (Tanang & Abu, 2014). In Indonesia, the teacher forum is a local government initiative aimed to empower teachers, improve teaching quality, and provide a platform for teachers to share their experiences, which can help them solve their problems in teaching activities (Supriadi, 1998).

Further, limitations in the availability of different learning media in the observed schools did not restrict teachers' creativity in devising effective learning methods for students. The teacher forum is intended to help teachers reform classroom practices, mediate in the development of teacher competencies, encourage innovation in the classroom and school management, and effectively collaborate with relevant professional organizations (Lai & Cheung, 2015). Table 5 shows the interview result of six teachers.

Table 5

Interview Results Related to the Teacher Collaboration

Question Code	T1	T2	T3	T4	T5	T6
Q9	No	No	No	No	Yes	No
Q10	In our regency, there is teacher forum that holds regular meetings once a month.	Share the problems with other teachers	Conducting teacher forum.	Collaborating with expert.	Following professional organizations, such as teacher forum for special education teachers,	We can collaborate with expert and following teacher forum programs.
Q13	It is important for prospective teachers to get courses or seminars about special needs students	Courses on inclusion or children with special needs must be studied in higher education.	Teachers need to attend seminars or training related current job.	It is necessary to learn knowledge about children with special needs and important to attend related seminars.	Teachers need to attend seminars to develop skills according to their current job.	Prospective teachers need to take courses on inclusion or children with special needs must be studied in higher education.

Regarding teacher preparation programs, all interviewed teachers agreed that courses related to inclusive practices needed to be added to such programs. Five of the six interviewed teachers claimed that they had limited knowledge and experience in teaching students with special needs. The interviewed teachers had only completed a general education program. They had not done any special or inclusive education courses, even though they were still recruited to teach in a special school. This can be proven by documenting interviews with teachers as shown in Figure 2.

Figure 2

Interviewing Teachers who Teach DHH Students (Documentation at Schools in Banjarnegara, Regional V Banyumas, Central Java, Indonesia)

Figure 3

Science Instructional Strategies in Teacher Collaboration

The interviewed teachers also expressed some other needs. They stated that they wanted more opportunities to participate in national and international training. Indonesia's Ministry of Education and Culture has established a center for teacher training focused on early childhood and special education (PPPPTK TK and PLB) that conducts teacher training at the national level. Additionally, the center also sends selected teachers to attend short courses at overseas universities. After receiving training from Widyaiswara (teacher trainers) and completing the overseas short courses, these teachers share their experiences with other teachers. Hopefully, this program will be sufficient to mitigate this disparity among teachers, even in rural areas. Meanwhile, science instructional strategies in teacher collaboration can be shown as shown in Figure 3.

Challenges Faced by DHH Students and Teachers

The analysis of the obtained data revealed the challenges faced by DHH students and educators in science learning (Table 6). Based on the discussion in the previous section, it can be said that the following intrinsic factors are liable to create challenges in providing inclusive science education for DHH students in the studied region. Low scientific literacy, differences in the sign language used in the teaching-learning process, and lack of interest and motivation among DHH students were found to be challenges faced in science learning for DHH students. These factors are inherent to students and are related to their science learning experience. Moreover, extrinsic factors related to aspects that are not under the control of DHH students also pose serious challenges. These factors include an incomplete senior high school science curriculum, limited science learning resources (i.e., books, computers, and science laboratories), and lack of teacher or educator qualifications.

Low scientific literacy is a key barrier for deaf learners in acquiring scientific knowledge, values, and skills. Science education can help learners develop the ability to think objectively, reason, investigate, reflect, analyze, and synthesize. Deaf learners should also be provided with the opportunity to develop these skills, which can improve their quality of life (Brice & Strauss, 2016). The current findings indicate that acquiring science education involves serious challenges for many deaf learners. However, these challenges may not be restricted to difficulties in the acquisition of scientific knowledge, values, and skills. They also involve low scientific literacy, differences in the use of sign language, lack of cognitive engagement, and limited resources, which affect deaf learners' acquisition of knowledge. Thus, deaf learners may understand scientific principles and concepts but may encounter difficulties in communicating their abilities effectively.

Regarding the challenges related to special education teachers' abilities to teach science to their students, these can be effectively addressed with support from the government in the form of teacher training for both in-service and pre-service teachers. It is also important to include additional courses at the university level, which can provide future teachers with the knowledge of appropriate methods to teach students with diverse and special needs (Pokhrel & Chhetri, 2021). Teachers need to be prepared to deal with a diverse group of students in schools, and relevant training should be provided not only in special education teaching programs but also in all other teacher preparation programs. Future research should conduct in-depth observations in other regions in Indonesia to determine the general condition of inclusive science education in a larger area.

Table 6

Interview Results Related to the Challenges Faced by Teachers

Question Code	Questions	T1	T2	T3	T4	T5	T6
Q7	Do you have students who have difficulty learning and participating in learning in your class? What kinds of difficulties did they experience?	DHH students lack motivation during learning.	Some students are not interested and feel bored in science learning.	Students have low scientific literacy and lack motivation.	Students are not interested and feel bored in science learning.	Students use different sign language during science learning and have low motivation.	Students have low scientific literacy and use different sign language.
Q8	Based on your experience, what are the challenges of teaching DHH students in science learning classroom?	Low scientific literacy, differences in the use of sign language.	Lack of cognitive engagement, which affect deaf learners' acquisition of knowledge.	Limited resources in science learning.	Lack of cognitive engagement.	Differences in the use of sign language	Low scientific literacy, differences in the use of sign language

It is hoped that the results of this study will serve as a guide for inclusive practices in science education for DHH students. Additionally, this study will be significant to special schoolteachers as it can provide practical strategies for addressing the diverse needs of DHH students in a special or inclusive classroom. The benefits associated with the various science education methods reported here can also provide schools in Indonesia and in other countries with an effective intervention strategy that can be adopted across all schools to generate enhanced learning outcomes. This could be beneficial not only for DHH schools but also for regular schools or even inclusive schools that accept students with similar conditions. This study may also be helpful for educational leaders and administrators in science education and special education as it can increase their awareness of different schools' strengths and weaknesses in designing suitable approaches to improve science education practices for DHH students. Finally, this study can also help future researchers identify appropriate teaching and learning practices for further investigation. Furthermore, more research at a larger scale and with more participants is required so that data on inclusive science learning practices more fully reflects Indonesia's situation.

Conclusions

Educating all learners to enable them to contribute to a world that is increasingly dependent on science and technology requires that science education includes DHH students. This study focused on science education practices in special schools for DHH students that help promote science for all students. The science education practices observed in the five selected schools indicate that teachers use various teaching strategies that rely on visual and hands-on activities. These activities are suited to meet DHH students' needs and prepare them for real-life challenges after completing secondary school. Existing support at the school level, such as the availability of sign language interpreters and the speech-development program, can improve the teaching-learning process for both teachers and DHH students. Regarding support facilities for science learning activities, the observed schools provide relevant textbooks and computers for students, although their numbers are still limited.

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Obrazovna praksa u poučavanju prirodnih nauka za gluve i nagluve učenike u Indoneziji

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Uvod: Nastavni plan i program za gluve učenike uglavnom je, tradicionalno, dominantno uključivao usvajanje jezika na račun drugih akademskih predmeta. Obrazovanje ovih učenika, trenutno, uključuju i druge predmete, poput prirodnih nauka, kako bi obogatili njihovo znanje u vezi sa životom ljudi. *Cilj:* Ova studija ima za cilj da opiše primenu obrazovne prakse u oblasti obrazovanja prirodnih nauka i identifikuje izazove u poboljšanju ove oblasti obrazovanja u specijalnim školama za gluve i nagluve (DHH) učenike kao vodič za unapređenje inkluzivnog obrazovanja ovih učenika. *Metode:* Učesnici su bili četiri direktora i šest nastavnika prirodnih nauka iz pet DHH škola, koristeći namerno uzorkovanje u pet škola koje pružaju obrazovanje za DHH učenike u tri regije V Banjumas, Centralna Java, Indonezija. Podaci su prikupljeni putem intervjua, terenskih opservacija i artefakata. *Rezultati:* Nastavnici koriste različite nastavne strategije i oslanjaju se na vizuelne i praktične aktivnosti prilikom obrazovanja DHH učenika. Škole obezbeđuju podršku tumača za znakovni jezik i programe za razvoj govora kao podršku, kako nastavnicima, tako i učenicima DHH. Svim nastavnicima je potrebno profesionalno usavršavanje u nastavnom radu kako bi razvili svoju stručnost za podučavanje učenika DHH-a. Utvrđeno je da su implementacija politike, strategije nastave, resursi i kvalifikacije nastavnika ekstrinzični faktori. *Zaključak:* Neophodno je obezbediti podršku vlade pri uključivanju u relevantne programe obuke i pripreme nastavnika koji su edukovani za rad u specijalnom ili inkluzivnom obrazovanju, kroz usavršavanje univerzitetskog obrazovanja za sve buduće nastavnike.

Ključne reči: gluvi i nagluvi učenici, obrazovne prakse, inkluzija, prirodne nauke

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Povezanost senzornog procesiranja dece sa razvojnom disfazijom sa sagorevanjem i samopoštovanjem roditelja

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Uvod: Teškoće senzornog procesiranja mogu predstavljati rizik za razvoj jezičkih i govornih poremećaja u najranijem periodu i nužno zahtevaju pomoć stručnjaka i kontinuirano angažovanje roditelja u radu sa detetom, što može dovesti do pojave sagorevanja kod roditelja i pada njihovog samopoštovanja, uz nemogućnost adekvatne pomoći ne samo detetu već i sebi. *Cilj:* Cilj istraživanja bilo je ispitivanje povezanosti senzorne osetljivosti dece sa razvojnom disfazijom sa karakteristikama roditelja. *Metode:* Uzorak je činilo 50 roditelja dece uzrasta od tri do šest godina. U istraživanju su korišćeni upitnici za procenu karakteristika senzornog procesiranja: Dečiji senzorni profil 2, Roditeljski inventar sagorevanja, Rozenbergova skala samopoštovanja. U obradi podataka korišćene su mere deskriptivne statistike i Pirsonov koeficijent korelacije. *Rezultati:* Rezultati istraživanja pokazuju da je nivo roditeljskog sagorevanja relativno nizak – roditelji pokazuju visok stepen lične posvećenosti ($M = 4.16$, $SD = .67$), srednji nivo emocionalne iscrpljenosti ($M = 2.34$, $SD = .78$) i nizak nivo emocionalnog distanciranja ($M = 1.72$, $SD = .72$) – ali i da ih odlikuje niže samopoštovanje ($M = 3.11$, $SD = .34$). Takođe, samopoštovanje i sagorevanje nisu međusobno povezani. Na senzornom profilu skale bihevioralnih elemenata veoma visoko međusobno koreliraju, dok intenzitet korelacija u dimenzijama osnovnog sistema procesiranja oscilira i postoji slaba povezanost opšteg samopoštovanja roditelja na dimenzijama procesiranje položaja tela i ponašanje vezano za senzorno procesiranje. *Zaključak:* Rezultati su razmatrani u kontekstu praktičnih pedagoških implikacija s obzirom na to da ukoliko se teškoće ne otklone u predškolskom periodu, može doći do odgađanja polaska deteta u školu ili dugoročnih teškoća pri učenju i savladavanju školskog gradiva.

Ključne reči: poremećaji govora, razvojna disfazija, senzorni profil, specifične jezičke smetnje

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Uvod

Razvojna disfazija definiše se kao specifičan jezički poremećaj koji karakterišu nemogućnost adekvatnog razvoja govora uprkos prosečnoj ili natprosečnoj neverbalnoj inteligenciji, adekvatnom funkcionisanju sluha i vida i odsustvu neuroloških problema. Bojanin (1985) razvojnu disfaziju definiše kao poremećaj razvoja ekspresivnog govora (jezičke produkcije) i receptivnog govora (jezičkog razumevanja) i označava razgrađen ili nedograđen govor, praćen poremećajima u artikulaciji, leksici, semantici i gramatičkom sistemu. Vladisavljević (1987) ukazuje na značaj posmatranja razvojne disfazije u širem kontekstu, navodeći da su razvojne disfazije složen sindrom fizioloških, lingvističkih, ali i edukativnih i socijalnih problema sa osnovnim poremećajem u verbalnoj komunikaciji, jer ne postoji mogućnost izgradnje jezičkog sistema. Deficit u razvoju govora je dugotrajan: podaci studije Tomblina i saradnika (Tomblin et al., 1997) ukazuju da na uzrastu pet-šest godina oko 7% dece ima taj problem. Rapin i saradnici (Rapin, et al. 1992) ustanovili su da u oblasti Otave 19% petogodišnje dece koja idu u vrtić ima odložen govor i usvajanje jezika. Prema podacima Enderbija i Emersona (Enderby & Emerson, 1996) učestalost dece uzrasta od tri do devet godina sa govorno jezičkim poteškoćama je 968 : 100.000. Lazarević (2010) navodi da je u Institutu za eksperimentalnu fonetiku i patologiju govora u Beogradu 1988. godine objavljen podatak da je 10% dece u periodu od 10 godina imalo razvojnu disfaziju. Krstić (2002), na osnovu pregleda stranih istraživanja, navodi da su specifični jezički poremećaji prisutni kod 5–7% dece, od čega razvojne disfazije čine 2–3%. U našoj populaciji Aleksić i saradnici (2002) navode potvrđenu dijagnozu razvojne disfazije kod 14% dece uzrasta 3–7 godina, koja su bila pacijenti Instituta za mentalno zdravlje. Kašić (2002) u uzorku dece tipičnog razvoja otkriva čak 16.8% sa usporenim jezičkim razvojem, koja potencijalno nisu prepoznata niti tretirana kao neki od specifičnih jezičkih poremećaja, što govori o tome da jezičke smetnje često mogu ostati neprimećene (ukoliko nisu u pitanju teži oblici, poput verbalne auditivne agnozije ili verbalne dispraksije, ili ukoliko im roditelji i osobe iz okruženja ne pridaju značaj), ponekad sa drastičnim dugoročnim posledicama po dete i njegovu okolinu. Tako su Nešić i saradnici (2011) na uzorku učenika uzrasta devet i deset godina sa područja Kosova i Metohije dobili da je kod 7.64 % prisutan neki govorno-jezički poremećaj, od čega najviše disleksija (15.49%), a najmanje razvojna disfazija (1.41%). Učitelji, koji su bili ispitanici, u svom radu identifikovali su 12 oblika govorno-jezičkih poremećaja, a kod 92.85% dece kod kojih je registrovan poremećaj je bio prisutan i pre polaska u školu. Vajk (Wyke, 1997) razvojnu disfaziju definiše kao spor, nepotpun i pogrešan razvoj jezika kod dece koja nemaju upadljive neurološke ili psihijatrijske poremećaje, a podrazumeva i odsustvo drugih smetnji koje bi mogle biti osnova usporenog ili ometenog usvajanja govora. S druge strane, poremećaji u razvoju govora često se javljaju zajedno sa drugim nelingvističkim deficitima, kao što su motorne i kognitivne teškoće ili problemi u ponašanju, problemi auditivne percepcije, verbalnog pamćenja, poteškoće praćenja brzog govora odraslih govornika, vizuelne percepcije, prostorne orijentacije i pažnje (Lazarević, 2006a; Ullman & Pierpont, 2005; Zorić i sar., 2021). Istraživanja u oblasti disfazije ukazuju na karakteristične disocijacije između bitnih komponenti verbalne funkcije, koje se mogu ispoljavati, na primer, kao nesklad između obima razumevanja i produkcije, razumljivosti govora, opsega rečnika i gramatičnosti, ukupne govorne sposobnosti i sposobnosti prisećanja reči (Rapin et al., 1992). U kliničkoj slici razvojne disfazije dominiraju: problemi auditivne percepcije, verbalnog pamćenja, poteškoće praćenja brzog govora odraslih govornika, problemi sekvence (redosleda), vizuelne percepcije, prostorne orijentacije i pažnje i jezički problemi – fonološki i artikulacioni, gramatički i problemi vezani za semantiku i strukturu reči (Lazarević, 2006b).

Svi navedeni podaci ukazuju na to da deca sa razvojnom disfazijom imaju problem sa senzornom integracijom, u celini ili bar u nekim njenim aspektima. Senzorna integracija je proces organizovanja vizuelnih, auditivnih, olfaktornih, gustativnih, vestibularnih, taktilnih i proprioceptivnih informacija koji omogućava adekvatno svakodnevno funkcionisanje (Stein et al., 2009). Proces senzornog integrisanja odvija se spontano i kod većine ljudi omogućava nesmetano funkcionisanje. Međutim, neke osobe mogu imati teškoće senzorne integracije, koje se najčešće ogledaju u osetljivosti senzornog procesiranja. Povećana osetljivost centralnog nervnog sistema na određene stimulacije često se referiše i kao hipersenzitivnost i smatra se genetski uslovljenom karakteristikom temperamenta, koja je zastupljena kod 15–20% populacije (Aron & Aron, 1997). Osobe sa visokom osetljivošću imaju niži prag reaktivnosti na stimulaciju i dublje kognitivno obrađuju informacije, što može rezultirati prekidom drugih aktivnosti (Boterberg & Warreyn, 2016). Na primer, ukoliko je dete auditivno osetljivo, u prisustvu buke ili pri javljanju određenih zvukova može prekinuti igru ili neku drugu aktivnost i nastojati da se udalji od izvora zvuka ili da priguši zvuk (npr. držanjem ruku na ušima).

Pregledom literature može se uvideti da auditivno procesiranje ima važnu ulogu u jezičkom i govornom razvoju i da smetnje auditivnog procesiranja predstavljaju potencijalni rizik za razvoj jezičkih i govornih poremećaja (Dunn & Benett 2002; Dunn, et al., 2002). Slabije auditivno procesiranje predstavlja nemogućnost da se diskriminišu verbalne instrukcije ili razgovor od pozadinske buke (Moore, 2007). Postoje podaci koji pokazuju da deca sa razvojnom disfazijom imaju teškoće u obradi auditivnih informacija u veoma bučnim prostorijama (Van der Linde, 2008). Prema nalazima Van der Linde (Van der Linde, 2008), deca sa razvojnom disfazijom dominantno imaju povišenu senzornu osetljivost i u poređenju sa decom tipičnog razvoja, imaju viši nivo osetljivosti u svim senzornim domenima. Njih karakterišu slične senzorne teškoće koje postoje kod dece sa poremećajem hiperaktivnosti i deficita pažnje (ADHD) i poremećajem iz spektra autizma, ali uz manju osetljivost taktilnog i oralno-senzornog procesiranja.

Istraživanje Njumejerea i saradnika (Newmeyer et al., 2009) pokazuje da se kod dece sa suspektnom verbalnom apraksijom, u poređenju sa decom tipičnog razvoja, takođe registruje povišena senzorna osetljivost.

Uloga roditelja u razvoju dece kako tipičnog razvoja, tako i dece sa razvojnim smetnjama, vrlo je važna. Međutim, kod dece sa razvojnim teškoćama pred roditelje se stavljaju posebni zahtevi koji se odnose na rad sa detetom, što podrazumeva saradnju sa logopedom. U tom smislu zadatak roditelja je da u svoje postupke implementiraju preporuke logopeda, što podrazumeva aktivnu saradnju. Iako se u literaturi naglašava značaj roditelja za uspešnost defektološkog tretmana (Kaiser & Hancock, 2003), nailazi se na nedostatak istraživanja u ovom polju, posebno kada su u pitanju deca sa razvojnom disfazijom i teškoće senzorne integracije. Stoga ćemo se osvrnuti na neke ranije nalaze koji se odnose na roditelje dece sa poremećajem iz spektra autizma i drugim teškoćama. Rezultati nekih ranijih istraživanja pokazuju da se roditelji dece sa poremećajem iz spektra autizma suočavaju sa visokim nivoom stresa i emocionalnim sagorevanjem (Elçi, 2004). S druge strane, ima istraživanja koja pokazuju da je emocionalno sagorevanje majki dece sa poremećajem iz spektra autizma izraženije u odnosu na emocionalno sagorevanje majki dece sa poremećajima sluha, ali da je u oba slučaja veće emocionalno sagorevanje praćeno težom kliničkom slikom (Varghese & Venkatesen, 2013). Dosadašnja istraživanja pokazuju da je kod dece sa poremećajem pažnje i hiperaktivnošću (ADHD) težina simptoma povezana sa roditeljskim stresom i osećajem samoefikasnosti (Heath et al., 2015) i da se kod roditelja dece sa poremećajem iz spektra autizma registruje niži kvalitet života i samopoštovanja u odnosu na roditelje dece tipičnog razvoja (Lu et al., 2015).

Stoga je predmet ovog istraživanja bio je da se ispita senzorno procesiranje kod dece sa razvojnom disfazijom, kao i povezanost senzorne osetljivosti deteta sa karakteristikama roditelja koje mogu biti značajne za vaspitni rad sa detetom i implementaciju preporuka stručnjaka. Ciljevi istraživanja su bili: utvrditi izraženost osnovnih domena senzornog procesiranja i utvrditi povezanost senzornih karakteristika deteta sa roditeljskim sagorevanjem i samopoštovanjem.

S obzirom na izloženu teorijsku osnovu i ciljeve ovog istraživanja, postavljene su sledeće hipoteze:

1. kod dece sa razvojnom disfazijom javljaju se povišene vrednosti prilikom procene senzorne osetljivosti – skorovi na senzornoj osetljivosti,
2. postoji korelacija između senzorne osetljivosti dece i nivoa sagorevanja roditelja,

3. postoji korelacija između senzorne senzorne osetljivosti dece i opšteg samopoštovanja roditelja.

Metode

Uzorak i procedura

Uzorak je činilo 50 roditelja oba pola dece uzrasta od tri do šest godina (M = 4.9, SD = .81) sa dijagnostikovanom razvojnom disfazijom od logopeda. Uzorak je bio prigodan budući da je obuhvatao samo roditelje dece koja imaju dijagnostikovanu isključivo razvojnu disfaziju i koja su u logopedskom tretmanu. Popunjavanje instrumenata je bilo dobrovoljno. Podaci su prikupljeni u Zavodu za psihofiziološke poremećaje i govornu patologiju „Prof. dr Cvetko Brajović”, uz prethodno obezbeđenu saglasnost za sprovođenje istraživanja. Ispitanici su dobili precizna objašnjenja i uputstva neposredno pre testiranja i bili su informisani o načinu i svrsi prikupljanja podataka. Senzorni profl, kao instrument koji je upotrebljen u ovom istraživanju za procenu senzornog procesiranja, podrazumeva da roditelj daje podatke o detetu, procenjujući koliko često deca u svakodnevnom funkcionisanju manifestuju određene reakcije i oblike ponašanja.

Instrumenti

Dečiji senzorni Profil 2 (The Child Sensory Profile - 2; Dunn, 2014) primenjen je za procenu karakteristika senzornog procesiranja kod dece. Instrument se sastoji od 86 tvrdnji zadatih uz petostepenu skalu (ocena 1 – nikad; ocena 2 – retko; ocena 3 – ponekad; ocena 4 – često; ocena 5 – uvek), pri čemu viši skorovi ukazuju na veću osetljivost određenog sistema procesiranja. Instrument predstavlja reviziju originalnog Senzornog profila (The Sensory Profile; Dunn, 1999) i namenjen je deci uzrasta od tri godine do 14 godina i 11 meseci. Pored osnovnih sistema procesiranja (auditivno, vizuelno, taktilno, vestibularno čulo, položaj tela i čulo ukusa), instrumentom su obuhvaćeni i bihevioralni elementi (vladanje, pažnja i socijalno-emocionalna dimenzija). Instrument je pokazao zadovoljavajuću pouzdanost u originalnom istraživanju (Dunn, 2014), kao i u pilot istraživanju primenjenom u Srbiji (Roknić i Vuković, 2021), dok u disertaciji, za čije potrebe je preveden, ne nalazimo ove podatke (Nenadović, 2020). Svi ajtemi podeljeni su u devet subskala: 1) Auditivno procesiranje, 2) Vizuelno procesiranje, 3) Taktilno procesiranje, 4) Procesiranje kretanja, 5) Procesiranje položaja tela, 6) Oralno-senzorno procesiranje, 7) Ponašanje vezano za senzorno procesiranje, 8) Socijalno-emocionalne reakcije vezane za senzorno procesiranje, 9) Pažnja u reakcijama vezanim za senzorno procesiranje. Svaka subskala sadrži različit broj potvrdnih rečenica, za koje je potrebno obeležiti u kojoj meri se njihova tvrdnja odnosi na dete koje se procenjuje. Na osnovu dobijenih sirovih skorova postoji mogućnost razvrstavanja profila na četiri kategorije: Traženje, Izbegavanje, Osetljivost i Registrovanje. Za svaku od ove četiri kategorije moguće je sabrati sirove skorove i potom označiti da li dobijeni sumarni skor date kategorije pripada grupi „Mnogo manje od drugih”, „Manje od drugih”, „Kao većina drugih”, „Više od drugih” i „Mnogo više od drugih”. U ovoj studiji korišćeni su samo sirovi podaci sa subskala. Pouzdanost subskala u aktuelnom istraživanju iznosila je: oralno – senzorno procesiranje α = .92, socijalno – emocionalne reakcije vezane za senzorno procesiranje α = .86, pažnja u reakcijama vezanim za senzorno procesiranje α = .85, taktilno procesiranje α = .84, auditivno procesiranje α = .83, vizuelno procesiranje α = .80, procesiranje kretanje α = .75, ponašanje vezano za senzorno procesiranje α = .73, procesiranje položaja tela α = .57.

Roditeljski inventar sagorevanja *Parental Burnout Inventory* (PBI, Roskam, Raes & Mikolajczak, 2017) predstavlja adaptiranu verziju upitnika sagorevanja *Maslach Burnout Inventory* (MBI; Maslach and Jackson, 1981), u kom su 22 pitanja upitnika MBI prilagođena roditeljskom kontekstu i ulozi roditelja (npr. „Kao roditelj osećam se emocionalno iscrpljeno”). PBI se sastoji od tri subskale: emocionalno distanciranje (osam pitanja, npr. „Više ne mogu da pokažem svojoj deci koliko ih volim”), emocionalne iscrpljenosti (osam pitanja, npr. „Kao roditelj osećam se emocionalno iscrpljeno”) i lične posvećenosti (šest pitanja, npr. „Osećam da sam kao roditelj dobar uzor svojoj deci”). Pored adaptacije sadržaja pitanja, revidirana je i subskala faktora depersonalizacije u subskalu emocionalnog distanciranja. Kao pokazatelji sagorevanja mogu se koristiti i ukupni skor na skali, kao i rezultati na svakoj od tri ponuđene subskale. Za ocenjivanje u originalnom instrumentu korišćena je sedmostepena Likertova skala: 0 – nikada; 1 – nekoliko puta godišnje; 2 – jednom mesečno i manje; 3 – nekoliko puta mesečno; 4 – jednom sedmično; 5 – nekoliko puta sedmično; 6 – svaki dan. U ovom istraživanju korišćena je petostepena Likertova skala budući da je bliža našoj populaciji i da je informativnija po pitanju tačnosti odgovora, bez mešanja vremenske dimenzije u davanje odgovora (od 1 – nikada do 5 – uvek). Veći skor na subskalama emocionalno distanciranje i emocionalna iscrpljenost predstavlja i veći stepen sagorevanja, kao i niži skor na skali lične posvećenosti. Pouzdanost subskala u aktuelnom istraživanju iznosila je: lična posvećenost α = .88, emocionalna iscrpljenost α = .87 i emocionalno distanciranje α = .62.

Skala opšteg samopoštovanja (Rosenberg Self-Esteem Scale, RSE; Rosenberg, 1965) sastoji se od 10 pitanja kojima se procenjuje nivo opšteg samopoštovanja odraslih (npr. „Želeo bih da više poštujem sebe”). Za ocenjivanje u originalnom instrumentu korišćena je četvorostepena Likertova skala (od 1 – potpuno se slažem do 4 – uopšte se ne slažem). U našem istraživanju korišćena je petostepena Likertova skala budući da je bliža našoj populaciji i da je informativnija po pitanju tačnosti odgovora (od 1 – nikada do 5 – uvek). Veći skor na subskali predstavlja i veći nivo samopoštovanja, a skala sadrži i inverzna pitanja. Uspešno je adaptirana i do sada je već korišćena u nekoliko domaćih istraživanja (Marić, 2005a, b; Latković, et al., 2009; Sari et al., 2013). Pouzdanost skale je iznosila α = .62.

Statistička obrada podataka

Za opis parametara od značaja u zavisnosti od njihove prirode korišćena je dekriptivna statistika, a za testiranje povezanosti između parametara korišćen je Pirsonov koeficijent korelacije. Statistička obrada odrađena je u statističkom paketu SPSS 24.

Rezultati

Analizirajući osnovne deskriptivne pokazatelje senzornih karakteristika možemo konstatovati da su zabeležene uglavnom niske vrednosti na svim parametrima senzornog profila (Tabela 1).

Tabela 1

Pouzdanost i deskriptivni parametri Senzornog profila, Roditeljskog inventara sagorevanja i Skale opšteg samopoštovanja roditelja

Subskale Senzornog profila 2	min	max	M	SD
Auditivno procesiranje	1.00	3.50	2.13	.74
Vizuelno procesiranje	1.00	3.67	2.12	.75
Taktilno procesiranje	1.00	2.91	1.77	.61
Procesiranje kretanja	1.00	3.00	1.95	.60
Procesiranje položaja tela	1.00	2.50	1.51	.41
Oralno-senzorno procesiranje	1.00	3.90	2.09	.97
Ponašanje vezano za senzorno procesiranje	1.22	3.33	2.23	.58
Socijalno-emocionalne reakcije vezane za senzorno procesiranje	1.07	3.71	2.36	.71
Pažnja u reakcijama vezanim za senzorno procesiranje	1.00	2.90	2.09	.64
Subskale sagorevanja				
Emocionalno distanciranje	1.00	3.88	1.72	.72
Emocionalna iscrpljenost	1.00	3.88	2.34	.79
Lična posvećenost	2.67	5.00	4.06	.77
Opšte samopoštovanje	2.90	5.00	3.10	.24

Roditelji pokazuju nisko emocionalno distanciranje, umerenu emocionalnu iscrljenost i prilično visoku ličnu posvećenost, dok je njihovo samopoštovanje nisko. Pirsonovim koeficijentom korelacije ispitali smo da li su merene karakteristike roditelja u statistički značajnoj korelaciji sa senzornim karakteristikama dece (Tabela 2).

Tabela 2

Povezanost senzornih karakteristika dece sa roditeljskom procenom sagorevanja i samopoštovanja

	Emocionalna iscrpljenost	Lična posvećenost	Auditivno procesiranje	Vizuelno procesiranje	Taktilno procesiranje	Procesiranje kretanja	Procesiranje položaja tela	Oralno-senzorno procesiranje	Ponašanje vezano za senzorno procesiranje	Socijalno-emocionalne reakcije vezane za senzorno procesiranje	Pažnja u reakcijama vezanim za senzorno procesiranje	Opšte samopoštovanje
Emocionalno distanciranje	$.62^{**}$	$-.50^{**}$	$.40^{**}$	$.28^{*}$	$-.29^{*}$	$.32^{*}$	.23	.28	$.31^{*}$	$.48^{**}$	.27	-.09
Emocionalna iscrpljenost		$-.62^{**}$	$.64^{**}$	$.38^{**}$	-.10	$.56^{**}$	$.42^{**}$	$.60^{**}$	$.57^{**}$	$.74^{**}$	$.50^{**}$	-.06
Lična posvećenost			$-.40^{**}$	-.19	.05	$-.36^{*}$	-.24	-.15	$-.34^{*}$	$-.50^{**}$	$-.30^{*}$	-.01
Auditivno procesiranje				$.73^{**}$	$.33^{*}$	$.83^{**}$	$.53^{**}$	$.81^{**}$	$.69^{**}$	$.65^{**}$	$.84^{**}$	-.16
Vizuelno procesiranje					$.29^{*}$	$.66^{**}$	$.50^{**}$	$.65^{**}$	$.39^{**}$	$.40^{**}$	$.64^{**}$	-.13
Taktilno procesiranje						$.33^{*}$	$.41^{**}$	$.31^{*}$	.18	.07	$.35^{*}$	.06
Procesiranje kretanja							$.81^{**}$	$.74^{**}$	$.79^{**}$	$.80^{**}$	$.85^{**}$	.05
Procesiranje položaja tela								$.57^{**}$	$.64^{**}$	$.64^{**}$	$.64^{**}$	$.30^{*}$
Oralno-senzorno procesiranje									$.66^{**}$	$.68^{**}$	$.82^{**}$	-.25
Ponašanje vezano za senzorno procesiranje										$.82^{**}$	$.70^{**}$	$.29^{*}$
Socijalno-emocionalne reakcije vezane za senzorno procesiranje											$.69^{**}$	.10
Pažnja u reakcijama vezanim za senzorno procesiranje												-.24

** $p < .01$. * $p < .05$

Kada je u pitanju senzorni profil, skale bihevioralnih elemenata međusobno veoma visoko koreliraju, dok intenzitet korelacija u dimenzijama osnovnog sistema procesiranja oscilira, od r = .29 za taktilno i vizuelno procesiranje do r = .83 za procesiranje kretanja i auditivno procesiranje. Povezanost dva segmenta senzornog profila je veoma različita, pa tako, na primer, dimenzije ponašanje vezano za senzorno procesiranje i socijalno-emocionalne reakcije vezane za senzorno procesiranje uopšte nisu povezane sa dimenzijom taktilno procesiranje, dok postoji visoka povezanost auditivnog procesiranja i pažnje u reakcijama vezanim za senzorno procesiranje r = .84. Dobijeni rezultati pokazali su da postoji međusobno visok stepen korelacije između subskala roditeljskog sagorevanja, a da stepen sagorevanja nije povezan sa nivoom opšteg sampoštovanja. Na subskali Dečijeg senzornog profila procesiranje položaja tela i ponašanje vezano za senzorno procesiranje postoji slaba povezanost sa samopoštovanjem roditelja.

Diskusija

Budući da je cilj istraživanja bio da se ispitaju karakteristike osnovnih domena senzornog procesiranja kod dece sa razvojnom disfazijom i njihova povezanost sa roditeljskim sagorevanjem i samopoštovanjem, najpre ćemo se osvrnuti na osnovne deskriptivne pokazatelje. Polazeći od prethodnih istraživanja drugih autora (Lazarević, 2008; Newmeyer et al., 2009; Van der Linde, 2008), očekivali smo da će kod dece sa razvojnom disfazijom biti prisutan relativno visok nivo senzorne osetljivosti, posebno u auditivnom domenu, budući da je auditivno procesiranje jedan od najboljih indikatora senzorne osetljivosti (Dunn, 2014). Stoga nije iznenađujuće što je u našem istraživanju jedino osetljivost u ovom domenu dosledno povezana sa svim varijablama (osim samopoštovanja). Kod dece sa teškoćama u senzornom procesiranju, posebno u domenu auditivne percepcije i vestibularnog sistema, razvoj govora može biti narušen, što prouzrokuje kašnjenje u govorno-jezičkom razvoju i može dovesti do artikulacionih poremećaja (Tung et al., 2013). Značajni aspekti akustičke obrade mogu biti odlučujući za adekvatnu normalnu percepciju govora. Ako je akustička obrada narušena tokom govorno-jezičkog razvoja, to će značajno ometati razvoj jezika (Tallal et al., 1991).

U poređenju sa rezultatima Nenadovićeve (2020), koje je rađeno na identičnom uzrastu, može se zaključiti (budući da su dati podaci samo za osnovne sisteme procesiranja) da je auditivno procesiranje gotovo identično sa rezultatima koji su u njenom istraživanju imali ispitanici sa specifičnim jezičkim poremećajima, a da su rezultati dobijeni na ostalim subskalama bili znatno veći, naročito oralno-senzorno procesiranje. Stoga je moguće da je međusobna povezanost auditivnog procesiranja sa drugim domenima (poput pažnje u reakcijama vezanim za senzorno procesiranje i oralno-senzorno procesiranje) pre ono što određuje mogućnost procesiranja deteta per se, nego samo informativni podatak o njegovom postignuću na auditivnom procesiranju. Takođe, skorovi na svim subskalama dece sa razvojnom disfazijom bili su viši u odnosu na skorove dece sa tipičnim razvojem, ali su se razlikovali i od rezultata dece sa poremećajima iz spektra autizma dobijenim u istraživanju Nenadovićeve (2020), što potencijalno ukazuje na je kvalitet procesiranja direktno uslovljen vrstom razvojnog problema. Deca sa razvojnom disfazijom imala su gotovo identične skorove na subskalama vizuelno procesiranje sa skorovima dece sa poremećajima iz spektra autizma, dok su na ostalim subskalama deca sa razvojnom disfazijom imala niže skorove, naročito auditivnog i taktilnog procesiranja. U istraživanju u kom su poređeni rezultati na Dečijem senzornom profilu 2 dece sa poremećajima iz spektra autizma i dece sa tipičnim razvojem (Roknić i Vuković, 2021), rezultati dece sa razvojnom disfazijom bliži su rezultatima dece sa tipičnim razvojem. Ispostavilo se i da je uzrast deteta bitna varijabla koja utiče na smanjenje skorova na subskalama osnovnih sistema procesiranja, i to u većoj meri kod dece tipičnog razvoja (budući da se uzorak sastojao od dece predškolskog i osnovnoškolskog uzrasta).

Jedno od objašnjenja ovih rezultata je da su u aktuelnom istraživanju u pitanju deca koja su aktivno uključena u logopedski tretman i da pritom nemaju pridružene poremećaje koji bi ih maskirali, ali se razlikuju od dece koja nemaju problem u razvoju. Svakako, ne treba zanemariti okolnost da su svi podaci u istraživanju prikupljeni od roditelja, uključujući i podatke koji se odnose na senzornu osetljivost dece, te je moguće i postojanje sklonosti roditelja ka davanju socijalno poželjnijih informacija, kao i svesnog (npr. usled osećaja sramote ili straha od odbačenosti) ili nesvesnog negiranja (nepridavanje pažnje, ideja da će „to doći na svoje mesto", „još je mali/mala", „kad poraste" i podsećanje na druge primere poteškoća koji su uspešno rešeni, a koji su donekle slični) određenih senzornih teškoća i drugih odstupanja u razvoju deteta. Posebno se kao objašnjenje ističe mogućnost delovanja mehanizma roditeljske krivice, odnosno stigme lošeg roditelja koju javnost nameće roditelju deteta sa poremećajima u razvoju, proglašavajući ga direktno odgovornim za nastanak poremećaja ili pak za nedovoljno dobrog roditelja koji se ne trudi dovoljno oko sopstvenog deteta (Francis, 2012), tim pre što je u aktuelnom istraživanju dobijeno da je opšte samopoštovanje roditelja predškolske dece sa razvojnom disfazijom sniženo. Stigma lošeg roditelja može dovesti do razvoja osećanja roditeljskog samookrivljavanja zbog razvojnih problema deteta (Eaton et al., 2016), čak i kada ne postoji egzaktna osuda javnosti konkretne osobe, već ona o sebi prosuđuje na osnovu karakteristika stigme (Ferriter & Huband, 2003). S druge strane, osećaj roditeljskog samookrivljavanja (self-blame) ogleda se u tome da roditelji misle da su mogli i da je trebalo da urade više za svoju decu koja imaju razvojni problem, što je povezano sa slabljenjem osećanja lične dobrobiti, dimenzija self-koncepta i samoefikasnosti, ali i povišenim nivoima depresije i sagorevanja (Huang et al., 2010; Kuhn & Carter, 2006; Moses, 2010).

Međutim, sniženo samopoštovanje roditelja nije bilo povezano sa sagorevanjem. Čini se da su roditeljske sposobnosti prevladavanja stresa i sopstveni kapaciteti prilično dobro očuvani, budući da je emocionalna iscrpljenost umerena i da imaju visoku ličnu posvećenost i nisko emocionalno distanciranje. Rezultati istraživanja su pokazali da su različite dimenzije roditeljskog sagorevanja povezane sa različitim domenima senzorne osetljivosti. Naime, veće emocionalno distanciranje roditelja povezano je sa višom osetljivošću deteta u domenima: auditivno, vizuelno i procesiranje kretanja, ponašanje vezano za senzorno procesiranje i socijalno-emocionalne reakcije vezane za procesiranje. Manje emocionalno distanciranje roditelja povezano je sa slabije razvijenim procesiranjem kretanja deteta. Viša emocionalna iscrpljenost roditelja povezana je sa višom senzornom osetljivošću dece u svim domenima, osim procesiranja kretanja deteta. Veća posvećenost roditelja ukazuje na manju osetljivost dece u domenima: auditivno i procesiranje kretanja, ponašanje vezano za senzorno procesiranje i socijalno-emocionalne reakcije vezane za procesiranje, socijalno-emocionalna dimenzija i pažnja u reakcijama vezanim za senzorno procesiranje. Što je veće samopoštovanje roditelja, to je veća osetljivost deteta u domenima: procesiranje položaja tela i ponašanje vezano za senzorno procesiranje. Sa praktične strane ovi podaci ukazuju na to da visoka senzorna osetljivost dece može uticati na psihološko blagostanje roditelja. Roditeljsko sagorevanje, pored toga što se manifestuje u vidu nedostatka pažnje, strpljenja i aktivne posvećenosti detetu, može voditi i ka zanemarujućim ili nasilnim postupcima (Mikolajczak et al., 2018). U tom smislu roditeljsko sagorevanje može predstavljati prepreku za adekvatno vaspitanje dece sa razvojnim smetnjama i implementaciju defektoloških preporuka u kućnom okruženju, što za posledicu može imati i manju uspešnost tretmana (Kaiser & Hancock, 2003).

Roditelji dece sa poteškoćama u razvoju, za razliku od roditelja dece koja nemaju razvojne probleme, moraju u većoj ili manjoj meri da se prilagođavaju specifičnim zahtevima koje nameće razvojni problem sa kojim se deca suočavaju (ponekad je u pitanju i više problema). Rođenje deteta sa smetnjom u razvoju čini roditeljsku ulogu drugačijom od uobičajene. Roditelji se često sasvim neočekivano nađu u poziciji donosioca teških odluka, a novonastalu situaciju prate i neizvesnost i stres. Osim drugačijeg funkcionisanja porodičnog sistema (Hall et al., 2012), uloga i obaveza koje roditelj ima – nažalost, najčešće majka – u skladu sa svojom kulturološkom odgovornošću, kako navode mnogi autori (Brock, 2017; Dimoski, 2012; Dragojević i Milačić Vidović, 2011; Duarte et al., 2005; Eisenhower et al., 2005; Estes et al., 2009), roditelj je u velikoj meri zavisan od potencijala koje poseduje u svojoj bližoj okolini, bilo da je u pitanju šira porodica, prijatelji, povremeni programi pomoći. Pposebno u ranim fazama intervencije ovog tipa imaju uticaj na povećanje samopoštovanja i blagostanja roditelja, kao direktna prevencija razvoja depresivnosti (Trivette et al., 2010), a ne samo dostupnosti medicinskih institucija i stručnjaka različitih profila (Brown et al., 2006; Davis & Gavidia-Payne, 2009). Pri svemu tome roditelji su primorani da vrše različite modifikacije: preseljenja, promene posla, organizacija slobodnog vremena, uklapanje sa obavezama druge dece, ponekad i odustajanje od proširenja porodice usled straha da neće moći adekvatno da izađu u susret potrebama deteta sa razvojnim poteškoćama ili druge dece koja nemaju te poteškoće, kao i straha da se i kod sledećeg deteta ne ponovi situacija identičnog ili nekog novog razvojnog poremećaja (Luijkx, et al., 2017; Mencap, 2001; Tadema & Vlaskamp, 2010). Sve ovo zavisi od kapaciteta porodice kao socijalne jedinice, sredine i okolnosti u kojima se nalaze, ali i ličnosti samog pojedinca koji se nalazi u ulozi roditelja. Obično se ti potencijali razmatraju u odnosu na pol, starost, obrazovanje, crte ličnosti (Glidden et al., 2010; Lawenius & Veisson, 1996; Perez et al., 2018; Steinhausen et al., 2013; Yamada et al, 2007) ili neki aspekt mentalnog zdravlja (najčešće su istraživani anksioznost i depresivnost (Bitsika et al., 2013; Claudia & Sandu, 2006; Gallagher & Hanningan, 2014; Tak, 2018)), kao i različiti aspekti stresa vezanog za roditeljstvo kod roditelja sa decom sa poremećajima u razvoju (Crnic et al., 1983; Dabrowska & Pisula, 2010; Dumas et al., 1991)). Specifičnost razvojne disfazije, naspram ostalih smetnji u razvoju (fizičkog hendikepa, intelektualnih poteškoća, Daunovog sindroma, ADHD, poremećaja iz spektra autizma), jeste to što u većini domena svakodnevnog funkcionisanja ne postoji karakterističan i uočljiv hendikep za osobe koje su u površnom kontaktu sa detetom. Stoga razvojna disfazija često može ostati neprimećena sve do polaska u školu i testiranja za prvi razred, a ponekad i poteškoće u učenju i napredovanju u školi učitelji ili roditelji, koji ne znaju za problem deteta, pripisuju njegovim ličnim faktorima (uzrast, slaba koncentracija, lenjost itd.). Stoga se obaveze i trud oko deteta koje je na prvi pogled bez razvojnih problema i ima normalan razvoj, mogu odraziti na samopoštovanje roditelja, doživljaj sopstvene nekompetentnosti i niže vrednosti u odnosu na druge, kao i na prezasićenost obavezama koje roditeljstvo nosi, uz dodatne obaveze oko deteta sa poremećajem u razvoju, naročito ukoliko se roditelji trude, a željeni rezultat izostaje, kasni ili nije u skladu sa angažmanom i očekivanjima roditelja. Tada može doći do pojave sagorevanja roditelja, što se može odraziti na kvalitet rada i komunikacije sa detetom, ali i sa ostatkom porodice i dovesti do situacije u kojoj je pomoć neophodna ne samo detetu već i samom roditelju. Tako Dimoski (2015) smatra da rehabilitacija dece sa ometenošću u razvoju u izvesnom smislu treba da podrazumeva i rehabilitaciju roditelja. To je moguće postići pružanjem i osnaživanjem postojeće podrške roditeljima. 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). Socijalna podrška roditeljima dece sa smetnjama u razvoju, koja predstavlja multidimenzionalni konstrukt koji čine fizička pomoć, deljenje informacija, instrumentalna, emotivna i psihološka podrška, prilično je bila zanemarena u medicinskom modelu ometenosti (Boyd, 2002), kao i značaj sagledavanja socijalnih i fizičkih okolnosti u kojima se rađaju i žive ova deca. Takođe, podrška koju roditelji dobijaju može se podeliti na formalnu (institucije i stručnjaci različitih profila) i neformalnu (šira porodica, prijatelji, susedi, volonteri, udruženja i organizacije). Socijalna podrška koju dobijaju roditelji dece sa smetnjama u razvoju postaje značajan prediktor njihovog kvaliteta života, zadovoljstva životom i doprinosi njihovom ličnom rastu i razvoju (Cuzzocrea et al.,2015; Davis & Gavidia-Payne, 2009; Shilling et al., 2013). Istraživanja dosledno pokazuju da roditelji smatraju da ne dobijaju dovoljno kvalitetnu podršku obrazovnih i zdravstvenih ustanova sa kojima sarađuju u brizi o deci (Case, 2000; Davies & Hall, 2005; Pain, 1999; Soodak & Ervin, 1995). U Srbiji vrlo malo roditelja koristi bilo kakav oblik podrške upućen njima direktno, a kao najčešće prepreke izdvajaju se: neodgovarajuće vreme održavanja programa, manjak slobodnog vremena usled stalne brige o detetu, kao i nedostatak informacija o postojanju takvog programa (Rajić i sar., 2015).

Prisustvo adekvatnih oblika socijalne podrške može biti objašnjenje za rezultate da kod roditelja dece sa razvojnom disfazijom gotovo da nije prisutno emocionalno distanciranje i iscrpljenost i da je prisutan visok stepen lične posvećenosti. Postoje i druga istraživanja koja govore o tome da nije nužna pojava negativnih efekata na mentalno zdravlje roditelja u porodicama sa decom koja imaju smetnje u razvoju (Crnic et al., 2017; Hastings et al., 2005; Olsson & Hwang, 2001; Singer, 2006), dok treći tip istraživanja ukazuje na to da, osim samog problema u razvoju, i način manifestacije problema može biti značajan za nivo stresa kod roditelja. Naime, bihevioralni elementi, više nego oštećenja i ograničeno funkcionisanje osnovnih sistema procesiranja – čula, može dovesti do povišenog nivoa stresa ili narušavanja mehanizama prevladavanja (coping) roditelja (Hastings & Johnson, 2001; Milačić Vidojević, 2008). Roditelji, u ličnom smislu, nisu odustali od pružanja adekvante pomoći svom detetu, ali je ipak njihovo opšte samopoštovanje narušeno. To se delimično može objasniti prirodom razvojnog poremećaja, u kom često razvojna disfazija nije toliko uočljiva okolini, kao kod drugih poremećaja, a opet roditelj je prisiljen da potraži pomoć stručnjaka i institucija, što ga uvlači u medicinski model, ali onemogućava da u potpunosti postigne kvalitet života koji je prisutan u porodicama dece sa tipičnim razvojem.

Nedostaci istraživanja su svakako mali uzorak i nedostatak drugih grupa za poređenje. Osim toga, u narednim studijama bilo bi poželjno uzeti u obzir i socijalno-demografske varijable roditelja i dece. Neki od faktora koji bi mogli imati ulogu posrednika i uticati na rezultate su i vrsta poremećaja, pridružene teškoće/dijagnoze, socijalno-ekonomski status roditelja, pol deteta, a ne samo roditelja (neka istraživanja pridaju naročitu pažnju tome) (Tabassum

& Mohsin, 2013), dostupnost institucionalne podrške, dužina tretmana itd. Prednost istraživanja je razmatranje specifičnosti razvojne disfazije u širem kontekstu, budući da je mali broj istraživanja u našoj zemlji tome posvećen (Čabarkapa i sar., 2013; Lazarević, 2006a; 2007, 2010; Savić i sar., 2010; Zorić i sar., 2021). Takođe, prednost istraživanja može biti i ispitivanje sindroma sagorevanja kod roditelja i samopoštovanja roditelja, kao značajnih faktora koji indirektno mogu uticati na kvalitet rada sa detetom i kvalitet porodičnog života u celini, što takođe do sada nije istraživano. Biti roditelj deteta sa problemima u razvoju je značajno zahtevnije od roditeljstva dece tipičnog razvoja, samim tim što je opterećeno činiocima kao što su specifične potrebe deteta i pojačani zahtevi u vezi sa dodatnim vidovima podrške, što često utiče na smanjenje roditeljskih kapaciteta za adekvatnu brigu o detetu.

Kreiranje prirodne atmosfere, igre i spontano sprovođenje praktičnih vežbi od strane roditelja može posredno uticati na poboljšanje kvaliteta porodičnog života i komunikacije, osim što će doprineti poboljšanju efekata tretmana kod deteta. Udaljavanje od pasivnog, medicinskog pristupa i izlazak iz zatvorenih institucija je prvi korak ka inkulziji deteta sa poremećajem, u ovom slučaju sa razvojnom disfazijom. Aktivno delovanje i postizanje uspeha učinilo bi da se roditelji osećaju ispunjenije i da imaju utisak da nisu pasivni posmatrači, već aktivni učesnici razvoja sposobnosti i potencijala svog deteta, što zbog stavljanja poremećaja u prvi plan može pasti u senku i ostati neiskorišteno. Treba istaći i to da je upravo period od tri do šest godina period intenzivnog, pa i skokovitog psihomotornog razvoja, kao i razvoja senzorne integracije koja je ispitivana senzornim profilom. Senzornim procesiranjem organizuju se čulni podražaji registrovani u našem telu ili okolini. Dosadašnja istraživanja su pokazala da su teškoće senzornog procesiranja učestalije kod osoba sa razvojnim poremećajima nego kod dece tipičnog razvoja, koja postižu niže skorove senzornog obrade i pokazuju manje problema u svim čulnim domenima u okviru senzornog procesiranja.

Deca sa razvojnom disfazijom se po svojim rezultatima razlikuju u odnosu na decu tipičnog razvoja, iako je njihovo senzorno procesiranje u manjoj meri problematično u odnosu na decu sa drugim poremećajima, ali ipak postoji prostor za adekvatne intervencije, naročito na ranom uzrastu, kako bi se njihovo zaostajanje u odnosu na decu tipičnog uzrasta smanjio, što bi svakako uticalo na poboljšanje samopoštovanja njihovih roditelja, popravljanjem slike o sopstvenoj vrednosti kao roditelja. Podrška roditeljima predstavlja sastavni deo programa rane intervencije, međutim treba napomenuti da su strukturirani programi podrške kod nas još uvek retkost i da brojne teškoće prate njihovu organizaciju i pristupačnost roditeljima. Stoga se još jednom nameće značaj pravovremene dijagnostike i rane intervencije u radu sa decom sa rizikom, budući da mnoga deca sa razvojnom disfazijom bivaju prepoznata i uključena u tretman tek u momentu polaska u školu. Izuzev težih oblika disfazija (kao što je verbalna auditivna agnozija) i naročito onih koje izrazitije obuhvataju ekspresivni govor (npr. verbalna dispraksija), jezičke smetnje često mogu ostati neprimećene, ponekad sa drastičnim i dugoročnim posledicama po dete i njegovu okolinu. Zato je saradnja roditelja, psihologa, logopeda i učitelja u ovom slučaju od posebnog značaja jer je u funkciji napretka deteta.

Zaključak

Rezultati dobijeni na uzorku roditelja dece sa dijagnostikovanom razvojnom disfazijom pokazuju niži nivo samopoštovanja, te se stoga nameće potreba za savetodavnim radom sa roditeljima senzorno osetljivije dece, što može doprineti da roditelj bolje razume teškoće deteta i posledično poveća roditeljsko samopouzdanje. To može biti ostvareno preporučivanjem određene literature roditelju ili ukazivanjem na određene vežbe ili aktivnosti koje se mogu praktikovati u kućnom setingu i svakodnevnim aktivnostima. To može biti dragoceno jer, iako nije stručnjak, adekvatno usmeren roditelj može imati bolji i detaljniji uvid u detetove preferencije i navike i intervenisati u svim onim svakodnevnim životnim situacijama koje logopedu nisu dostupne. Terapijske intervencije stručnjaka (u slučaju razvojne disfazije naročito logopeda) u značajnoj meri se oslanjaju na roditelja kao „koterapeuta", ali se u ovim intervencijama zanemaruje psihičko stanje samog roditelja, kao i njegovi opšti kapaciteti da poverene zadatke i tempo izvođenja u potpunosti realizuje na zadovoljavajući način.

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The relationship of sensory processing of children with developmental dysphasia with burnout and self-esteem of parents

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Introduction. Sensory processing difficulties can pose a risk for the development of language and speech disorders in the earliest period and require professional intervention and intense involvement of parents in homework with children with developmental dysphasia, which might cause parental burnout and lower level of their self-esteem when parents are not able to help, not only the children, but themselves too. *Aim*. The aim of the research was to examine the relationship between the sensory sensitivity of children with developmental dysphasia and the characteristics of parents. *Method*. The sample consisted of 50 parents of children aged 3 to 6 years. The following questionnaires were used in the research to assess the characteristics of sensory processing: The Child Sensory Profile 2, Parental Burnout Inventory, and Rosenberg Self-Esteem Scale. Measures of descriptive statistics and Pearson’s correlation coefficient were used in data processing. *Results*. The results of the research show that the level of parental burnout is relatively low (parents showed a high level of personal accomplishment (M = 4.16, SD = .67), mild level of emotional exhaustion (M = 2.34, SD = .78) and low level of emotional distancing (M = 1.72, SD = .72), but also that they are characterized by lower self-esteem (M = 3.11, SD = .34). Also, self-esteem and burn-out are not related. On the Sensory Profile, subscales of behavior elements are highly correlated, while the intensity of correlations in subscales of the basic system of processing oscillates. There is a weak correlation between the general self-esteem of parents with subscales of body posture and behavior. *Conclusion*. The obtained results were discussed in the context of practical pedagogical implications, considering that if the difficulties in the child’s functioning are not eliminated in the preschool period, the child’s departure to school may be delayed, or long-term difficulties in learning may appear.

Keywords: speech disorder, developmental dysphasia, sensory profile, special language disorder

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Izazovi odraslih korisnika slušne amplifikacije tokom pandemije Covid-19

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Uvod: Pandemija Covid-19 uticala je u značajnoj meri na mnoge aspekte života ljudi, posebno u oblasti zdravstvene nege i socijalne zaštite. Mnoge starije osobe ograničile su kretanje, posete porodici i društvene aktivnosti u strahu od zarazne bolesti koja može imati veoma ozbiljne posledice. Dodatno mere opreza, u smislu fizičkog distanciranja i obaveze nošenje zaštitnih maski, postavile su pred osobe oštećenog sluha jedinstven izazov utičući na intenzitet i kvalitet govornog signala uz narušenu mogućnost ščitavanja govora sa lica i usana sagovornika. *Cilj:* Istraživanje je imalo za cilj da ispita u kojoj meri su se korisnici slušne amplifikacije odraslog životnog doba susretali sa različitim izazovima tokom trajanja pandemije Covid-19. *Metode:* Za potrebe ovog istraživanja konstruisan je poseban upitnik, a ispitanici su svoje odgovore davali na trostepenoj skali Likertovog tipa. *Rezultati:* Rezultati istraživanja pokazali su da je jedan od glavnih izazova ispitanika tokom pandemije bila komunikacija sa drugim ljudima. Kao poseban problem efikasne komunikacije ispitanici su istakli široku upotrebu zaštitnih maski i izbegavanje komunikacije sa nepoznatim ljudima iz straha da se neće razumeti. Ispitanici su naglasili problem promena u slušanju putem slušnih aparata tokom pandemije, kao i propratne oscilacije raspoloženja prema korišćenju same amplifikacije. Iako je većina ispitanika bila zadovoljna mogućnošću servisiranja i popravke slušnih aparata, nijedan ispitanik nije naveo mogućnost podrške u vidu auditorne rehabilitacije. *Zaključak:* Pandemija korona virusa istakla je potrebu za razvijanjem mreže alternativnih metoda i pristupa u pružanju surdoloških usluga njenim korisnicima, koja bi trebalo da bude prepoznata kao dodatni oblik pružanja usluga u oblasti savetodavnog rada, rehabilitacije, rešavanja svakodnevnih problema sa slušnim pomagalima. Takav način rada omogućio bi nesmetanu stručnu podršku korisnicima slušne amplifikacije ne samo u ekstremnim situacijama kakva je pandemija već i u redovnim okolnostima svima kojima iz različitih razloga takva podrška do sada nije bila uvek dostupna.

Ključne reči: oštećenje sluha, amplifikacija, gluvi i nagluvi, treće doba, pandemija

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Uvod

Prema navodima Centra za kontrolu i prevenciju bolesti oštećenje sluha predstavlja treće po redu hronično zdravstveno stanje kod odraslih osoba, a po svojoj prevalenci je značajno učestalije od dijabetesa ili kancera (Center for Disease Control and Prevention, 2018). Svetska zdravstvena organizacija ističe da čak 430 miliona ljudi širom sveta živi sa oštećenjem sluha koje zahteva određenu vrstu stručne pomoći, a procene su da će se taj broj gotovo udvostručiti do kraja 2050. godine ako se ne preduzmu adekvatne mere prevencije i brige o slušnom zdravlju (World Health Organisation, 2021). Oštećenje sluha daleko prevazilazi senzornu patologiju, a kod odraslih osoba tesno je povezano sa kvalitetom društvenog života, profesionalnim i ekonomskim statusom pojedinca. Nedostatak ili ograničenje auditivnog inputa značajno utiče na kognitivne sposobnosti i procesiranje govora ne samo dece na ranom uzrastu (Nikolić et al., 2019; Ostojić-Zeljković, & Nikolić, 2018) već i odraslih osoba starijeg životnog doba (Wilson et al., 2017). Zbog neposrednog uticaja oštećenja sluha na komunikaciju gluve i nagluve osobe su značajno sklonije društvenoj izolaciji i depresiji u odnosu na čujuću populaciju, što potvrđuju mnoga istraživanja (Huang et al., 2020; Mick, Kawachi, & Lin, 2014; Shukla et al., 2020 prema Littlejohn et al., 2022; Teece et al., 2022). Gluve i nagluve osobe u određenoj meri mogu prevazići ove smetnje, ali samo uz adekvatnu stručnu podršku, amplifikaciju i rehabilitaciju. U razvijenim zemljama u kojima je prevalenca oštećenja sluha velika i samim tim potreba za stručnom (surdološkom i audiološkom) podrškom veća, pristup službama može biti ograničen, što posebno dolazi do izražaja u ekstremnim situacijama kakva je pandemija (Çildir, Tokgoz-Yilmaz, 2022).

Početkom 2020. godine Svetska zdravstvena organizacija upozorila je na opasnost od globalnog širenja zaraze novim oblikom respiratornog virusa korona (SARS-Co V-2), a ubrzo zatim, u martu, proglasila je pandemiju. Tokom prvih meseci pandemije vlada Republike Srbije uvela je niz restriktivnih mera i proglasila vanredno stanje, dok je nekoliko dana kasnije usledila i potpuna zabrana kretanja osobama starijim od 65 godina. Iako je vanredno stanje ukinuto nakon 52 dana, stroge mera opreza, preporuke socijalnog distanciranja, obaveze nošenja zaštitnih maski i/ili vizira ostale su na snazi pune dve godine (Poverenik za informacije od javnog značaja i zaštitu podataka o ličnosti, 2020), a u zdravstvenim ustanovama ove mere (nošenje zaštitnih maski i/ili vizira) i dalje su na snazi. Pandemija Covid-19 uticala je u značajnoj meri na mnoge aspekte života ljudi, posebno u oblasti zdravstvene nege i socijalne zaštite. Mnoge starije osobe ograničile su kretanje, posete porodici i društvene aktivnosti u strahu od zarazne bolesti koja može imati veoma ozbiljne posledice (Teece et al., 2022). Pored toga, nošenje zaštitnih maski postavilo je pred osobe oštećenog sluha jedinstven izazov utičući na intenzitet i kvalitet govornog signala i značajno narušavajući mogućnost ščitavanja govora sa lica i usana sagovornika (Chodosh et al., 2020; Goldin et al. 2020; Homans, & Vroegop, 2022; Poon, & Jenstad, 2022; Vos et al., 2021). Zadatak ovog istraživanja bio je da ispita na koji način su mere opreza, upotreba zaštitnih maski i preporuke socijalnog distanciranja u sklopu pandemije uticale na brigu o sluhu odraslih gluvih i nagluvih osoba, njihovu adekvatnu amplifikaciju, komunikaciju sa drugim ljudima, kao i na dostupnost surdoloških usluga tokom trajanja pandemije. Istraživanje je imalo za cilj da ispita u kojoj su se meri korisnici slušne amplifikacije odraslog i starijeg životnog doba susretali sa različitim izazovima tokom trajanja pandemije Covid-19.

Metode

Istraživanje je sprovedeno od oktobra 2021. do februara 2022. godine u predstavništvima distributera slušnih pomagala, gde se stručnjaci iz oblasti amplifikacije bave procenom stanja sluha, određivanjem i podešavanjem slušnih aparata, kao i konsultativnim radom. Uzorak istraživanja je bio prigodan, a učešće ispitanika bilo je na dobrovoljnoj bazi. Konačan uzorak činilo je 49 korisnika slušne amplifikacije. Na osnovu analize dostupne literature, u skladu sa postavljenim zadacima i ciljem istraživanja, autori su konstruisali upitnik pod nazivom „Usluga i podrška korisnicima slušnih aparata tokom pandemije Covid-19" (Prilog 1). Pitanja su se odnosila na izazove korisnika slušne amplifikacije koji su u istraživanjima stranih autora najčešće identifikovani tokom pandemije (Tabela 1), a posebno interesovanje ovog rada bilo je usmereno na ispitivanje u kom obimu su zdravstvena politika i restriktivne mere vlade Republike Srbije uticale na brigu o slušnom zdravlju, subjektivni doživljaj teškoća u slušanju, komunikaciju i dostupnost surdoloških usluga njenim korisnicima u Srbiji. Ispitanici su odgovore davali na trostepenoj skali Likertovog tipa – slažem se, niti se slažem / niti se ne slažem, ne slažem se.

Ukoliko nisu koristili određenu vrstu surdološke usluge tokom pandemije, ispitanici su mogli da izostave odgovor na postavljeno pitanje. Podaci o ispitanicima (pol, starost, mesto stanovanja) i karakteristikama njihovog oštećenja sluha (dijagnoza, stepen auditivne smetnje, trajanje problema sa sluhom, dužina korišćenja slušnog aparata, vrsta i tip aparata, vrsta komunikacijskih smetnji) takođe su prikupljeni pomoću upitnika.

Obrada podataka je tehnički sprovedena pomoću odgovarajućeg softvera (*Excel for Microsoft 365*, ver. 2205; *SPSS*, ver. 26). Korišćene su metode deskriptivne statistike za kategoričke podatke (frekvencije, procenti, koeficijenti kontigencije), za numeričke podatke (mere centralne tendencije i mere disperzije), kao i odgovarajuće metode inferencijalne statistike (χ^2 test, Man–Vitnijev U-test, Kruskal–Volisov H-test).

Tabela 1

Prikaz pitanja iz upitnika „Usluga i podrška korisnicima slušnih aparata tokom pandemije Covid-19”

Broj	Pitanje
1.	Da li ste primetili promene u slušanju putem slušnog aparata tokom Covid-19 pandemije?
2.	Da li ste imali problema da zakažete pregled/proveru sluha tokom pandemije?
3.	Da li ste imali mogućnost da dođete do lekara u Kliničkom centru radi dijagnostike sluha i naloga za nabavku pomagala tokom pandemije?
4.	Da li su vam šalteri i komisije RFZO-a bili dostupni tokom pandemije radi ostvarivanja prava nabavke slušnog pomagala?
5.	Da li ste imali mogućnost popravke/servisa slušnog aparata tokom Covid-19 pandemije?
6.	Da li ste imali mogućnost za vežbe slušanja (auditorni trening) u nekoj ustanovi tokom Covid-19 pandemije?
6*	Ako je odgovor DA, navedite ustanovu
7.	Da li ste primetili promene u komunikaciji tokom Covid-19 pandemije?
8.	Da li ste primetili promene raspoloženja vezane za korišćenje slušnog aparata tokom Covid-19 pandemije?
9.	Da li ste osećali ličnu nesigurnost/strah zbog potencijalne zaraze prilikom odlaska na kontrolu/podešavanje SA?
10.	Da li mislite da je nošenje maski za lice uticalo na Vašu komunikaciju sa drugim ljudima (npr. izbegavate razgovor sa ljudima kada nose maske u prodavnici, pošti...)?

Rezultati

Opis uzorka

Ukupan uzorak istraživanja činilo je 49 ispitanika. U tabeli koja sledi (Tabela 2) dat je pregled glavnih karakteristika ispitanika i njihovog slušnog oštećenja.

Tabela 2

Prikaz deskriptivnih mera karakteristika uzorka

Karakteristike uzorka (*N*=49)	
Pol, *n* (%)	
Muški	22 (44.9%)
Ženski	27 (55.1%)
Prosečna starost (godine)	
M (SD)	65.47 (19.84)
Mdn	71
Rang	20–96
Starosna kategorija, *n* (%)	
Mlađi od 65 godina	18 (36.7%)
Stariji od 65 godina	31 (63.3%)
Mesto pružanja surdoloških usluga, *n* (%)	
U glavnom gradu	41 (83.7)
U manjem gradu	8 (16.3%)
Dijagnoza slušnog oštećenja, *n* (%)	
SNHL	48 (98%)
Otoskleroza	1 (2%)
Stepen oštećenja sluha, *n* (%)	
Lak	1 (2%)
Umeren	6 (12.2%)
Srednje težak	26 (53.1%)
Težak	13 (26.5%)
Veoma težak	3 (6.1%)
Vrsta amplifikacije	
BTE	41 (83.7%)
MiniRITE	3
Kanalni aparati	5
Dužina korišćenja slušne amplifikacije	
M (SD)	7.78 (6.77)
Mdn	
Rang	21

*SNHL – senzorineuralno oštećenje sluha; BTE – zaušni slušni aparat; MiniRITE – mali zaušni slušni aparat sa risiverom u uvu

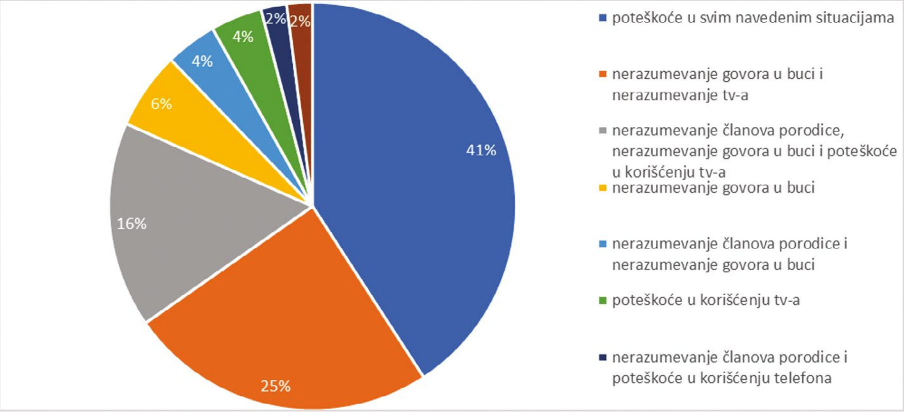
Prosečna starost ispitanika u uzorku bila je 65.47 godina, pri čemu je čak 2/3 uzorka pripadalo starosnoj grupi preko 65 godina. Gotovo svi ispitanici iz uzorka imali su dijagnostikovano obostrano, trajno, senzorineuralno oštećenje sluha (98%), a samo kod jedne ispitanice dijagnostikovana je konduktivna nagluvost izazvana otosklerozom. Imajući u vidu starosnu strukturu uzorka kod većine ispitanika radilo se o prezbiakuziji (staračkoj nagluvosti). U odnosu na stepen oštećenja sluha najveći broj ispitanika imao je potvrđeno oštećenje sluha srednje teškog stepena (53.1%), teškog (26.5%), umerenog (12.2%)

i veoma teškog stepena (6.1%), dok je samo jedan ispitanik imao oštećenje sluha lakog stepena. Ovakva heterogenost uzorka bila je donekle očekivana s obzirom na učestalost oštećenja sluha različitog stepena u populaciji nagluvih osoba, ali i u odnosu na preporuke za amplifikaciju i efikasnost slušnih aparata kod nagluvosti različitog stepena. U skladu sa tim, najveći broj ispitanika iz našeg uzorka su korisnici digitalnih zaušnih slušnih aparata (83.7%). Prosečna dužina korišćenja slušne amplifikacije u ispitivanom uzorku bila je 7.78 godina.

Ispitanici su pitani i sa kakvim se izazovima suočavaju u različitim komunikacijskim situacijama, kao što su: komunikacija sa članovima porodice, razumevanje govora u buci, korišćenje telefona ili razumevanje govora putem televizora. Većina ispitanika je navela poteškoće u svim navedenim komunikacijskim situacijama, čak njih dvadesetoro (40.8%), poteškoće u tri od četiri komunikacijske situacije navelo je osam ispitanika (16.3%), dok je poteškoće u dve situacije navelo njih 16 (38.6%). Kao najčešće poteškoće ispitanici su navodili nerazumevanje govora u buci i putem televizora (Grafikon 1).

Grafikon 1

Teškoće u komunikaciji korisnika slušne amplifikacije



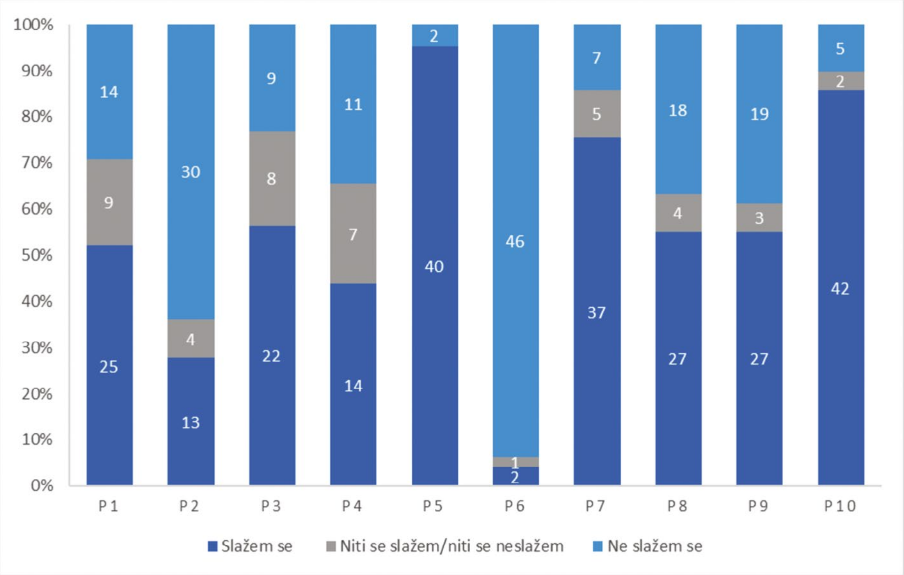
Učestalost komunikacijskih smetnji je sasvim očekivano bila značajno veća kod osoba sa većim stepenom slušnog oštećenja, a statističku značajnost ove veze potvrdili su rezultati hi-kvadrat testa [$c^2(12, n=49)=0.39, p=.03,$ *fi*=0.68].

Analiza izazova korisnika slušne amplifikacije tokom pandemije

Kako bi ispitali u kojoj meri su se korisnici slušne amplifikacije susretali sa različitim izazovima u pristupu surdološkim uslugama tokom trajanja pandemije Covid-19, primenjen je upitnik posebno konstruisan za potrebe ovog istraživanja. Na Grafikonu 2 prikazana je procentualno izražena mera slaganja ispitanika sa određenim pitanjima/tvrdnjama koje su se odnosile na organizaciju i/ili dostupnost određenih surdoloških usluga tokom trajanja pandemije kovida 19.

Grafikon 2

Mera slaganja ispitanika sa pitanjima iz upitnika



Legenda: P1 – promene u slušanju putem slušnog aparata; P2 – problem pri zakazivanju pregleda/provere sluha; P3 – dostupnost dijagnostike i mogućnost nabavke slušnog aparata; P4 – dostupnost komisije RFZO za nabavku slušnog pomagala; P5 – mogućnost servisiranja slušnog aparata; P6 – mogućnost auditornog treninga; P7 – izazovi u komunikaciji; P8 – promene motivacije vezane za korišćenje slušnog aparata; P9 – osećaj lične nesigurnosti/straha pri odlasku na kontrolu ili fitting aparata; P10 – uticaj nošenja maski na komunikaciju sa drugim ljudima.

Promene u slušanju putem slušnog aparata tokom pandemije

Prvo pitanje u upitniku odnosilo se na iskustvo slušanja putem slušnog aparata tokom trajanja pandemije Covid-19 (pitanje 1). Najveći broj korisnika slušne amplifikacije (n=25, 51%) izjasnio se da jeste osetio promene u slušanju, njih 18.4% (n=9) bilo je neodlučno, dok se 28.6% (n=14) izjasnilo da nisu primetili promene u slušanju putem slušnog aparata tokom trajanja pandemije. Ispitujući razlike u iskustvu ispitanika u odnosu na pol, hi-kvadrat test nezavisnosti nije pokazao značajnu vezu između stavova muškaraca i žena kada su u pitanju promene u slušanju putem slušnog aparata tokom trajanja pandemije [c^2(1, n=49)=0.19, p=.61, fi=0.19]. Primenom Man-Vitnijevog U-testa nisu utvrđene statistički značajne razlike između muškaraca i žena ni prema drugim pitanjima o izazovima sa kojima su se susretali tokom trajanja pandemije Covid-19.

Dostupnost surdoloških usluga tokom pandemije iz ugla korisnika

Većina ispitanika (n=30, 61.2%) smatrala je da nije imala problem pri zakazivanju pregleda ili provere stanja sluha (pitanje 2), njih 8.2% (n=4) ostalo je neutralno, dok se 26.5% (n=13) izjasnilo da jeste imalo takvih poteškoća tokom pandemije. S druge strane, značajan broj ispitanika (n=22, 44.9%) smatrao je da je tokom pandemije bio otežan pristup tercijarnim zdravstvenim ustanovama (Kliničkom centru) radi dijagnostike stanja sluha, dobijanja naloga za slušna pomagala ili rehabilitacije (pitanje 3), dok su ostali ispitanici smatrali su da nije bilo takvih problema (n=9, 18.4%) ili su ostali neutralni po ovom pitanju (n=8, 16.3%). U vezi sa tim ispitanici su pitani i da li su im bile dostupne filijale i komisija Republičkog fonda za zdravstveno osiguranje (RFZO) tokom trajanja pandemije kako bi ostvarili pravo na nabavku ili zamenu slušnog pomagala (pitanje 4). Mišljenja ispitanika su bila podeljena: 28.6% (n=14) smatralo je da su im šalteri RFZO-a bili dostupni, dok je 22.4% (n=11) smatralo da nisu. Sedamnaest ispitanika nije dalo odgovor na ovo pitanje, pa smo pretpostavili da nisu ni bili u situaciji (potrebi) da u prethodnom periodu menjaju svoje slušno pomagalo. Kruskal–Volisov test otkrio je statistički značajnu razliku u stavu ispitanika prema dostupnosti komisije i šaltera RFZO radi zamene ili nabavke novih slušnih aparata između grupa ispitanika koji su korisnici slušnih aparata različiti vremenski period (I grupa < 2 godine; II grupa 2–5 godina; III grupa 5–10 godina; IV ≥10 godina), pri čemu su korisnici koji koriste slušne aparate manji broj godina imali pozitivnije mišljenje o mogućnosti nabavke/zamene slušnih aparata od ispitanika koji su korisnici slušne amplifikacije veći broj godina [c^2=(3, n=49)=8.79, p=.03]. Naknadni testovi pokazali su statističku značajnost razlike samo između grupe ispitanika koji su najmanji broj godina i grupe ispitanika koji su najveći broj godina korisnici slušne amplifikacije (U=13.5, z=-2, p=.045, r=.3), pri čemu je veličina ovog uticaja bila srednja.

Ispitujući da li su imali mogućnost popravke ili servisiranja slušnih pomagala tokom trajanja pandemije (pitanje 5), skoro svi ispitanici (n=40, 95.2%) su se složili da su imali takvu mogućnost, dok se njih sedmoro izjasnilo da nije imalo potrebu popravke i servisiranja svog slušnog pomagala tokom trajanja pandemije. Po pitanju rehabilitacije slušanja (auditivnog treninga) nakon nabavke ili zamene slušnog aparata skoro svi ispitanici iz ispitivanog uzorka složili su se da nisu imali takvu mogućnost tokom trajanja pandemije korona virusa (pitanje 6). Na pitanje da li su imali mogućnost stručnog savetovanja, podrške ili rehabilitacije „na daljinu" i ako jesu da navedu na koji način je takav vid podrške realizovan (pitanje 6a), nijedan ispitanik nije dao pozitivan odgovor.

Promene u komunikaciji i korišćenju slušnog pomagala tokom pandemije

Veliki broj ispitanika (*n*=37, 75%) ispitivanog uzorka izjasnio se da je primetio promene u komunikaciji tokom pandemije (pitanje 7), petoro (10.2%) je bilo neodlučno, dok je njih sedmoro (14.3%) izjavilo da nije primetilo promene u komunikaciji tokom trajanja pandemije. Daljom analizom utvrđeno je da je grupa ispitanika mlađih od 65 godina češće navodila da je primetila promene u komunikaciji tokom pandemije u odnosu na ispitanike starije od 65 godina. Pomoću Man–Vitnijevog U-testa utvrđeno je i da je razlika u stavovima ove dve grupe ispitanika statistički značajna (U=198, z=-2.23, p=.026, r=0.319), pri čemu je veličina ovog uticaja godina starosti prema Koenovom kriterijumu bila srednja. Kada su u pitanju promene u raspoloženju u vezi sa korišćenjem slušnog aparata tokom trajanja pandemije (pitanje 8), nešto više od polovine ispitanika zapazilo je takve promene (*n*=27, 55.1%), četvoro (8.2%) ispitanika je bilo neodlučno, a 19 (38.8%) je smatralo da nije zapazilo takve promene. Ispitujući dalje uticaj starosti ispitanika na odnos prema korišćenju slušnog aparata, dobijeno je da su ispitanici mlađi od 65 godina češće navodili promene u raspoloženju prema korišćenju slušnog aparata u odnosu na ispitanike starije od 65 godina. Međutim, Man–Vitnijev U-test nije otkrio statističku značajnost razlike između stavova ove dve grupe ispitanika (U=202.5, z=-1.79, p=.07), uz mali uticaj r=.25 uzrasta ispitanika. Analizirajući dalje rezultate dobijeno je da korisnici kod kojih oštećenje sluha traje duže od pet godina, u većoj meri primećuju promene raspoloženja u vezi sa korišćenjem slušne amplifikacije u odnosu na ispitanike čije oštećenje sluha traje manji broj godina [$c^2(3, n=49)=6.72, p=.028$]. Naknadne analize potvrdile su da je grupa korisnika čije oštećenje traje između dve i pet godina u manjoj meri smatrala da je pandemija uticala na njihovo raspoloženje u vezi sa korišćenjem slušne amplifikacije u odnosu na grupu ispitanika čije oštećenje sluha traje između pet i deset godina (U=49.5, z=-2.21, p=.027, r=.32) i grupe čije oštećenje sluha traje duže od 10 godina (U=48, z=-2.87, p=.01, r=.41).

Najveći broj ispitanika (*n*=42, 85.7%) smatrao je da je nošenje zaštitnih maski uticalo na njihovu komunikaciju sa drugim ljudima, te da su izbegavali razgovor sa ljudima koji nose masku u prodavnici, pošti i na drugim javnim mestima (pitanje 10). Samo dva (4.1%) ispitanika bila su neodlučna, a njih petoro (10.2%) je smatralo da nošenje maski nije imalo uticaj na komunikaciju sa drugim ljudima. Nije bilo statistički značajnog uticaja ispitivanih karakteristika ispitanika u odnosu na procenu mere poteškoća u komunikaciji sa drugim ljudima usled nošenja zaštitnih maski.

Osećaj lične nesigurnost i straha zbog potencijalne zaraze prilikom odlaska na kontrolu

Više od polovine ispitanika (55.1%) imalo je osećaj lične nesigurnosti i straha od potencijalne zaraze prilikom odlaska na kontrolu sluha ili na podešavanje slušnog aparata (pitanje 9), njih troje (6.1%) bilo je neodlučno po tom pitanju, dok je 19 (38.8%) ispitanika smatralo da nije imalo osećaj nesigurnosti i straha od potencijalne zaraze korona virusom tokom pandemije. Daljom analizom nije utvrđena statistička značajnost uticaja pola, starosti, mesta stanovanja ispitanika, niti karakteristika samog slušnog oštećenja i amplifikacije na osećaj lične nesigurnosti i straha kod ispitanika.

Diskusija

Istraživanje je ispitivalo u kojoj meri su se korisnici slušne amplifikacije odraslog i starijeg životnog doba susretali sa različitim izazovima u uslovima pandemije Covid-19, pre svega u smislu brige o sluhu i slušnom zdravlju, amplifikacije, komunikacije sa drugim ljudima, dostupnosti surdoloških usluga. Rezultati su pokazali da je jedan od glavnih izazova sa kojim su se ispitanici susretali odnosio na komunikaciju sa drugim osobama. Veliki broj ispitanika obuhvaćenih uzorkom primetio je promene u komunikaciji usled pandemije, pri čemu su promene u komunikaciji češće navodili ispitanici mlađeg životnog doba u odnosu na stariju. Ovakvi rezultati bili su donekle očekivani s obzirom na pretpostavku od koje smo pošli pri podeli uzorka na dve starosne kategorije, a to je da je većina ispitanika odraslog životnog doba (mlađih od 65 godina) radno angažovana te da su neminovno uključeni u veći broj socijalnih interakcija u toku jednog dana u odnosu ispitanike starijeg životnog doba (starije od 65 godina). Kao poseban problem u efikasnoj komunikaciji tokom trajanja pandemije ispitanici su istakli rasprostranjenu upotrebu zaštitnih maski, kao i da su izbegavali komunikaciju sa nepoznatim ljudima (u pošti, apoteci, prodavnici i na drugim javnim mestima). Komplementarne rezultate navode i mnogi drugi istraživači (Brown et al., 2021; Chodosh et al.,2020; Corey et al., 2020; Goldin et al., 2022; Homans, & Vroegop, 2020; Poon, & Jenstad, 2021; Ten Hulzen, & Fabry, 2020; Vos et al., 2021), čija su istraživanja potvrdila da, pored toga što su korisne u suzbijanju transmisije uzročnika infekcija, zaštitne maske ometaju ščitavanje sa usana sagovornika i narušavaju značajne vizuelne informacije u komunikaciji (Brown et al., 2021; Cohn et al., 2021 prema Teece et al., 2022), atenuiraju tonove visoke frekvencije (Corey et al., 2020; Vos et al., 2021 prema Lalonde, 2022), narušavajući razumevanje govora naročito u uslovima buke (Brown et al., 2021; Homans, & Vroegop, 2020; Poon, & Jenstad, 2021). Poredeći iskustva korisnika kohlearnih implanata i korisnika slušnih aparata tokom pandemije sa populacijom uredno čujućih ispitanika, Tis i saradnici (Teece et al., 2022) dobili su rezultat da korisnici slušnih pomagala izražavaju statistički značajno veću meru zabrinutosti da stupe u konverzaciju sa osobom koja nosi zaštitnu masku iz straha da je neće razumeti dok govori, a u prilog tome govore i naši rezultati. Mnoga istraživanja potvrdila su da se zaštitne maske ponašaju kao nisko propusni filteri koji atenuiraju tonove visokog spektra (između 2.000 i 7.000 Hz) za 4 do čak 12 dB, u zavisnosti od tipa maske, čime je dodatno korisnicima slušne amplfikacije narušeno razumevanje govora (Corey et al., 2020; Goldin et al., 2022; Ten Hulzen, & Fabry, 2020).

Ispitanici u ovom istraživanju istakli su i promene u slušanju putem slušnih aparata tokom pandemije, pri čemu je većina ispitanika navela promene raspoloženja vezane za korišćenje svojih slušnih pomagala. Promene raspoloženja, u tom smislu, češće su navodili korisnici amplifikacije u grupi mlađoj od 65 godina u odnosu na korisnike starijeg životnog doba, ali i oni čije je iskustvo slušanja putem amplifikacije bilo duže od pet godina. Rezultati istraživanja Alkuda i saradnika (Alqudah et al., 2021) pokazalo je da su korisnici amplifikacije statistički značajno kraće vreme koristili svoja slušna pomagala tokom pandemije (naročito u vreme trajanja lockdown-a) nego pre nje, navodeći kao glavne razloge za to teškoće u pristupu servisima za popravku i podešavanje slušnih aparata ili prekid rehabilitacije slušanja kao posledicu pandemije. Ova vrsta stručne podrške za korisnike slušne amplifikacije predstavlja veoma važan vid brige o sluhu i slušnom zdravlju. Naime, promene koje se dešavaju na bilo kom aspektu procesa slušanja (kognitivnom, bihevioralnom ili afektivnom) mogu dovesti gluvu i nagluvu osobu u potrebu za dodatnom surdološkom podrškom u vidu podešavanja ili promene modela amplifikacije i/ili dodatne auditorne rehabilitacije. Nasuprot rezultatima Alkuda i saradnika, rezultati našeg istraživanja pokazali su zadovoljstvo korisnika mogućnošću servisiranja i popravke slušnih pomagala (usluga koje su dostupne u okviru većine predstavništva distributera slušnih pomagala) u vreme pandemije. Međutim, značajan broj ispitanika u uzorku naveo je teškoće u pristupu tercijarnim ustanovama (Kliničkim centrima) u kojima se obavlja sveobuhvatna procena stanja sluha, propisuju nalozi za slušne aparate i realizuje rehabilitacija slušanja. Suprotstavljenost stavova naših ispitanika, koja se iz prikazanih rezultata može zapaziti, kao i značajan broj „neodlučnih" ispitanika po pitanju dostupnosti usluga u okviru tercijarnih ustanova i RFZO filijala, govori u prilog nedovoljnoj informisanosti korisnika slušnih pomagala o dostupnosti državnih ustanova i usluga koje pružaju tokom pandemije. U svojoj studiji Geta (Gaeta, 2020) je slične rezultate istraživanja objasnila kao posledicu povećanog opterećenja zdravstvenih ustanova izazvanu pandemijom Covid-19, pri čemu je svakodnevna klinička praksa nužno pretrpela značajne promene zbog angažovanja značajnog broja zdravstvenih radnika u kovid sistemima.

Iskustvo života u uslovima pandemije Covid-19 naučilo nas je mnogim lekcijama, pa i da se rad „na daljinu" može efikasno koristiti kada obe strane imaju pristup i veštinu korišćenja savremenih tehnologija. Mnoga istraživanja naglasila su prednosti komunikacije „na daljinu" uz pomoć različitih aplikacija za video-pozive, koje pružaju mogućnost auditivnog treninga, vežbi govora, savetovanja i rešavanja manjih problema sa slušnim pomagalima. Autori su posebno isticali prednost konverzacije putem video-poziva: nije potrebna zaštitna maska, svaki učesnik u konverzaciji ima svoj mikrofon, intenzitet govora se može lako podesiti, deljenje ekrana može olakšati komunikaciju sa više sagovornika, a ponekad su dostupni i titlovi u realnom vremenu (Teece et al., 2022). Na ovaj način moguće je prevazići mnogobrojne izazove korisnika amplifikacije koji su identifikovani i u rezultatima našeg istraživanja, kao što su: promene u svakodnevnom slušanju, komunikaciji (posebno one izazvane nošenjem maski), dostupnost određenih ustanova, ali i strah od zaraze korisnika. Za pitanje razvoja surdološke i audiološke prakse ovo ima posebno važno mesto i pruža potencijal za dalji razvoj u smislu korišćenja prednosti savremenih tehnologija, pre svega telekomunikacija, u svakodnevnoj praksi (Coco, 2020; Manchaiah et al., 2021).

Zaključak

Pandemija Covid-19 istakla je potrebu za razvijanjem mreže inovativnih metoda i pristupa u pružanju surdoloških usluga njenim korisnicima, koja bi trebalo da bude prepoznata kao dodatni oblik pružanja usluga u oblasti savetodavnog rada, rehabilitacije, rešavanja svakodnevnih (manjih) problema sa slušnim pomagalima. Analiza rezultata našeg istraživanja, ali i mnogih drugih studija koje su se bavile ovom temom, nametnula je ideju o razvoju telesurdološke, teleaudiološke i telerehabilitacione prakse. Da bi bilo moguće realizovati ovakav način rada, neophodno je podići svest stručnjaka (pre svega surdologa, audiologa) o mogućnostima i prednostima alternativnog načina rada, ali i unaprediti njihova znanja i veštine u oblasti koja je već pokazala svoje dobre strane u zemljama koje su je tokom pandemije razvile. Osim toga, veoma je važno da ovakav vid rada bude zakonski prepoznat i da ove vrste usluga takođe budu pokrivene zdravstvenim osiguranjem. Na taj način bilo bi omogućeno nesmetano pružanje stručne podrške korisnicima slušne amplifikacije ne samo u uslovima ekstremne situacije kakva je pandemija, već i u redovnim okolnostima svim korisnicima kojima je iz različitih razloga (zbog mesta stanovanja, hroničnih bolesti i dr.) takva podrška do sada uglavnom bila nedostupna.

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Challenges of adult users of hearing amplification during the Covid-19 pandemic

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Introduction. The Covid-19 pandemic has considerably affected many aspects of human life, especially healthcare and social services. The contacts of elderly people with family and friends, as well as their social activities, have been drastically reduced due to fear of contagious diseases with potentially serious consequences. Preventive measures of physical distancing and obligatory protective masks have brought additional challenges for hearing-impaired persons because of the decreased intensity and muffled quality of speech signals as well as the lack of visual cues because of the face masks. *Objective.* The study aimed to identify the challenges that adult hearing aid users faced during the Covid-19 pandemic. *Methods.* A special questionnaire was developed for the purpose of this study with a 3-point Likert type of scale. *Results.* The results of the study have shown that effective communication with other people during the pandemic was a great challenge for hearing-impaired participants. They pointed out the use of face masks and avoidance of communication with other people due to the fear of misunderstanding others. The participants noticed some changes in listening with hearing aids as well as mood swings and compliance to hearing aids. Most of the participants were satisfied with the access to hearing aids, fitting, and repair services, but none of them had access to rehabilitation and advisory support. *Conclusion.* The Covid-19 pandemic revealed the need for developing a network for alternative methods and approaches in surdology to provide advisory and rehabilitation services for hearing-impaired people as well as technical support for hearing aid users. That would be the way to provide ongoing support for hearing aid users, not only in extreme situations, such as the pandemic, but to increase the accessibility of those services in everyday life for all users.

Keywords: hearing impairment, amplification, deaf and hard of hearing, seniors, pandemic

Prilog 1

Usluga i podrška korisnicima slušnih aparata tokom pandemije Covid-19

(Nikolić, Ostojić Zeljković, 2020)

Opšti podaci o ispitaniku						
1.	Ime i prezime (dovoljni su i inicijali)					
2.	Pol	Ž		M		
3.	Godina rođenja					
4.	Mesto stanovanja, mesto dobijanja surdoloških usluga					
5.	Dijagnoza *nije obavezno					
6.	Stepen auditivne smetnje	Laka nagluvost	Umerena nagluvost	Srednja nagluvost	Teška nagluvost	Veoma teška nagluvost
7.	Vrste komunikacijske smetnje (u kućicu sa strane obeležite poteškoće sa kojima se susrećete)	Nerazumevanje govora članova porodice				
		Nerazumevanje govora u buci				
		Poteškoće u korišćenju telefona				
		Poteškoće u korišćenju TV-a				
		Poteškoće u svim navedenim situacijama				
8.	Trajanje problema sa sluhom (zaokružite tačan odgovor)	Manje od 2 godine	Od 2 do 5 godina	Od 5 do 10 godina	Više od 10 godina	
9.	Godina od kada ste korisnik slušnog aparata (navedite godinu nabavke slušnog aprata)					
10	Vrsta i tip aparata koji koristite * nije obavezno					

Upitnik

	Pitanje	Slažem se	Donekle se slažem / ne slažem	Ne slažem se
11.	Da li ste primetili promene u slušanju putem slušnog aparata tokom Covid-19 pandemije?			
12.	Da li ste imali problema da zakažete pregled/ proveru sluha tokom pandemije?			
13.	Da li ste imali mogućnost da dođete do lekara u Kliničkom centru radi dijagnostike sluha i naloga za nabavku pomagala tokom pandemije?			
14.	Da li su vam šalteri i komisije RFZO-a bili dostupni tokom pandemije radi ostavrivanja prava nabavke slušnog pomagala?			
15.	Da li ste imali mogućnost popravke/servisa slušnog aparata tokom Covid-19 pandemije?			
16.	Da li ste imali mogućnost za vežbe slušanja (auditorni trening) u nekoj ustanovi tokom Covid-19 pandemije?			
6*	Ako je odgovor DA navedite ustanovu			
17.	Da li ste primetili promene u komunikaciji tokom Covid-19 pandemije?			
18.	Da li ste primetili promene raspoloženja vezane za korišćenje slušnog aparata tokom Covid-19 pandemije?			
19.	Da li ste osećali ličnu nesigurnost/strah zbog potencijalne zaraze prilikom odlaska na kontrolu/ podešavanje SA?			
20.	Da li mislite da je nošenje maski za lice uticalo na Vašu komunikaciju sa drugim ljudima (npr. izbegavate razgovor sa ljudima kada nose maske u prodavnici, pošti...)?			
Dodatne primedbe/komentari				

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Klinički oblici apraksije kod osoba sa Alchajmerovom bolešću

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Uvod: Alchajmerova bolest je najčešći tip demencije. Apraksija može biti jedan od simptoma Alchajmerove bolesti. Apraksija je tradicionalno uvršćena kao jedan od neuropsiholoških pokazatelja Alchajmerove bolesti, zajedno sa poremećajima pamćenja, afazijom i agnozijom. Zastupljena je od početnih faza ove bolesti. *Cilj:* Osnovni cilj ovog istraživanja je utvrditi tipove apraksija kod osoba sa Alchajmerovom demencijom i ukazati na značaj rane rehabilitacije ovih pacijenata. *Metode:* Uzorak je činilo 15 pacijenata sa Alchajmerovom demencijom (amnestički tip – više domena) uzrasta od 50 do 85 godina. Ispitivanje je obavljeno u skladu sa definisanim kriterijumima u Poliklinici Antamedica u Beogradu. *Rezultati:* Rezultati istraživanja pokazuju da su kod pacijenata sa Alchajmerovom bolešću i u prvom i u drugom stadijumu oštećene: vremenska orijentacija, pažnja, računanje, prisećanje, imenovanje, pisanje i kopiranje figura. Pacijenti imaju oštećenu sposobnost razumevanja govornog i pisanog jezika. Na testu verbalne vizuelne diskriminacije nisu uočeni deficiti. *Zaključak:* Procena apraksija postala je važan aspekt neurodegenerativnih bolesti i glavni indikator za psihoterapiju i radnu terapiju, doprinoseći kvalitetu života starijih, prvenstveno sa kognitivnim padom.

Ključne reči: Alchajmerova bolest, apraksija, demencija

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Uvod

Procenjuje se da 4–5% ljudi starijih od 65 godina ima demenciju. Posle 65. godine prevalenca naglo raste i udvostručava se svakih pet godina. Velika učestalost u starijem životnom dobu predstavlja veliko opterećenje za negovatelje, čak i čitave porodice, ali i za društvo u celini. Četiri najčešća tipa demencije su: Alchajmerova bolest (AB), vaskularna demencija (VaD), demencija sa Levijevim telima (DLT) i frontotemporalne demencije (FTD) (Pavlović, 2016). Prema procenama Svetske zdravstvene organizacije, očekuje se znatno povećanje prevalencije demencija zbog sve većeg porasta populacije starijih osoba. Procenjeno je da u svetu, prema podacima za 2018. godinu, najmanje 50 miliona ljudi živi sa AB (Alzheimer's Disease International (Az), 2018).

Alchajmerova bolest (AB) je najčešći tip demencije (oko 60%) i spada u primarne degenerativne demencije kortikalnog tipa. Etiologija, sem u retkim naslednim formama, nije poznata. Postoji veći broj faktora rizika za nastanak ove bolesti, od kojih se mnogi preklapaju sa drugim tipovima demencija. Teško je sa sigurnošću postaviti dijagnozu. Sigurna AB je samo ona koja je dokazana patohistološki (Pavlović, 2016). Alchajmerova bolest obično napreduje sporo (sporije nego ostali tipovi demencija), ali može i brzo napredovati (Geschwind et al., 2008). Klinička slika AB razvija se kroz tri karakteristična stadijuma. Prvi stadijum obuhvata period od prve do četvrte godine bolesti i naziva se amnestički stadijum. Karakterišu ga poremećaji pamćenja, uz poremećaje jezičkih funkcija, sniženje sposobnosti apstraktnog mišljenja, deficiti planiranja i pojave sekundarnih znakova bolesti, kao što su razdražljivost, depresivnost i prenaglašenost premorbidnih karakteristika. Drugi stadijum traje od desete godine bolesti i karakteriše se pogoršanjem poremećaja pamćenja, afazijom, apraksijom i agnozijom. U ovom stadijumu dolazi do izraženih poremećaja prostorne orijentacije, teške amnezije i izmene ponašanja. Osnovne senzomotorne funkcije su očuvane, ali je moguća pojava dezinhibicionih fenomena i lakših znakova ekstrapiramidnih poremećaja. Treći stadijum obuhvata period 7–14. godine bolesti i označava trajno nesamostalno stanje. Dolazi do potpunog gubitka sposobnosti komunikacije bolesnika sa okolinom, gubitka kontrole sfinktera i akinezije. Bolest je neizlečiva i u trećem stadijumu obično nastupa smrt zbog različitih komplikacija (Vuković, 2011).

Apraksija može biti jedan od simptoma Alchajmerove bolesti. Obično se smatra da se ona javlja tokom kasnijeg stadijuma bolesti, okarakterizovanim kao afazio-aprakso-agnostičkim sindromom. Međutim, kada je reč o tipovima apraksije, naučne studije su pokazale da se ideomotorna apraksija pojavljuje tokom najranije faze AB i da to može biti relevantno za njeno rano dijagnostikovanje (Chainay et al., 2006). Apraksija je tradicionalno uvršćena kao jedan od neuropsiholoških pokazatelja AB, zajedno sa poremećajem pamćenja, afazijom i agnozijom. Pronađena je asimetrična povezanost između apraksije tokom progresije AB i apraksije i sposobnosti izvođenja aktivnosti iz svakodnevnog života (Vidoni, 2019).

Apraksija se definiše kao stečeni deficit izvršenja pokreta koji ne može biti objašnjen motornim ili senzornim oštećenjem (Chainay et al., 2006). To je poremećaj izvođenja složenih, veštih, naučenih pokreta ruku i organa orofacijalne regije (voljnih svrsishodnih motornih radnji), koji nisu uslovljeni slabošću, ataksijom, akinezijom, deaferentacijom, poremećajem tonusa ili položaja (smetnji koordinacije), nevoljnim pokretima, senzitivnim deficitima, demencijom, poremećajem razumevanja govora, nesaradnjom, niti su prisutne agnozije i značajniji intelektualni deficiti (Pavlović, 2016). Apraksija može da se shvati kao neka vrsta motorne agnozije jer bolesnici nemaju slabost mišića (primarna motorna kora je očuvana), ali ipak ne mogu da vrše vešte pokrete. Ona je od velikog prognostičkog značaja jer ometa aktivnosti svakodnevnog života. Apraksija se retko identifikuje kao izolovani primarni poremećaj (Vuković, 2011). Klinički se apraksija relativno retko prepoznaje i to iz više razloga: postojanje motornog deficita (hemipareza) može da maskira apraksiju; često prisutna anozognozija za ovaj poremećaj i nepotpun klinički pregled i poznavanje problema (Pavlović, 2016).

Osnovni cilj ovog istraživanja je utvrditi tipove apraksija kod osoba sa Alchajmerovom demencijom i ukazati na značaj njihove rane rehabilitacije.

Metod

Uzorak istraživanja

Uzorak sačinjava 15 ispitanika sa Alchajmerovom demencijom starosnog doba od 50 do 85 godina.

Kriterijumi za raspodelu na dva stepena demencije, prema težini, urađeni su prema Mini mental testu (MMSE, Folstein et al., 1975) – procena opštih kognitivnih sposobnosti i određivanje težine demencije, kao i prema standardizovanoj neurološkoj proceni, gde ispitanici sa I stepenom demencije odgovaraju ranom (amnestičkom) stadijumu, a ispitanici sa II stepenom odgovaraju srednjem (razvijenom) stadijumu demencije; nivo III stepena demencije, koji odgovara odmakloj (teškoj) demenciji, nije obuhvaćen istraživanjem. Svi ispitanici dali su saglasnost za učešće u istraživanju i istraživanje je obavljeno u skladu sa etičkim standardima.

Vreme i mesto istraživanja

Istraživanje je sprovedeno 2017. godine u Beogradu, u Poliklinici Antamedica. Istraživanje je prospektivno i ispitanici su uključeni u istraživanje po slobodnom izboru u odnosu javljanja na pregled. Zadata je neuropsihološka baterija koja je sadržala 20 testova; nije bilo odbijanja učestvovanja u istraživanju, ali se testiranje u nekim slučajevima moralo prekinuti zbog blagovremeno otkrivenih perceptivnih deficita. Inkluzioni i ekskluzioni kriterijumi za ispitanike u ovom istraživanju prikazani su u Tabeli 1.

Tabela 1

Inkluzioni i ekskluzioni kriterijumi istraživanja

Kriterijumi za uključivanje	Kriterijumi za isključivanje
Demencija Alchajmerovog tipa	Ostali tipovi neurodegenerativnih oboljenja (druge demencije); ranija oboljenja CNS-a, uključujući i TOM, kičmene moždine i ranije MU; postojanje vizuelnih i auditivnih perceptivnih oštećenja
Rani (amnestički) i srednji (razvijena demencija) stadijum AB	Odmakla (teška demencija) AB
MMSE na skoru početnog (20–24) i srednjeg stadijuma (11–19); BKP na skoru (21–28)	MMSE na skoru kasnog stadijuma (0–10)
Životno doba od pozne zrelosti (50–65. godina), srednje starosti (71–80) do pozne starosti (81 – do kraja života)	Osobe mlađe od 50 godina
Koordinacija uredna; Intencioni tremor – ne postoji do blagog	Postojanje motornih deficita (hemiplegije/hemipareze); tremor koji onemogućava izvršavanje zadataka

Varijable

Nezavisne varijable ovog istraživanja su: dominantna/nedominantna ruka, tranzitivni/netranzitivni pokreti, tremor, dvodimenzionalni objekti / dvodimenzionalni objekti sa perspektivom, crtanje na nalog / kopiranje po modelu.

Zavisne varijable ovog istraživanja su: svi testovi iz tabele 1, vreme izvođenja, broj (ne)tačnih pokreta, pokreti od/ka telu, izvođenje zadatka, reakciono vreme, jasnoća, zakrivljenost, mikrografija, perspektiva, udruženi pokreti, ukočenost pokreta, ikoničnost pokreta, dinamičnost pokreta, motorne perseveracije, greške ogledalskog tipa, greške prostornog tipa, razumevanje odnosa ruku.

Instrumenti istraživanja

Osim slobodnog intervjua, koji se odvijao po unapred postavljenim principima, izvršena je neurološka klinička procena motorike i senzibiliteta, kao i neurobihevioralna procena izgleda, ponašanja i emocija. U cilju istraživanja praksija kod osoba sa Alchajmerovom demencijom primenjeni su sledeći instrumenti: Mini mental test za demencije (MMSE) (Folstein et al., 1975); Test za procenu gestualne lateralizovanosti ruke (pet standardnih zadataka); Test za vizuelnu diskriminaciju (subtest neverbalnog dela sa slikama i subtest verbalnog dela sa rečima)[1]; Bostonski dijagnostički test za afazije (BDAE) (Moberg et al., 2000); Test za procenu dinamičke praksije „pesnica, brid, dlan” prema Luriji (Luria 3 step test); Test za procenu ideomotorne praksije (po pet zadataka za procenu tranzitivnih pokreta usmerenih ka telu i od tela, i po pet zadataka za procenu netranzitivnih pokreta umerenih ka telu i od tela); Test za procenu ideacione praksije (pet zadataka sa korišćenjem realnih objekata); Test za procenu orofacijalne praksije (pet zadataka iz BDAE za procenu oralne neverbalne spretnosti, Moberg et al., 2000); Test za procenu konstrukcione praksije i vizuoprostornih sposobnosti (crtanje na nalog i kopiranje dvodimenzionalnih objekata; crtanje na nalog i kopiranje dvodimenzionalnih objekata sa perspektivom); Test za procenu praksije poze prema Luriji (pet standardnih poza – semikvantitativno).

Ispitivanje je obavljeno u skladu sa definisanim kriterijumima u Poliklinici Antamedica u Beogradu. Uzorak je formiran postepeno, mali je i nije homogen, odnosno obuhvata ispitanike sa različitim stepenom kognitivnog oštećenja. Postupak ispitivanja je podrazumevao rad sa neurologom i neuropsihologom, ali i uzimanje heteroanamnestičkih podataka od negovatelja ispitanika, odnosno samih ispitanika.

Statistička obrada podataka

Za statističku obradu korišćeni su programski paketi: IMB SPSS Statistics 23 i Microsoft Office 2013. Korišćen je neparametarski Wilkoksonov test parova. Podaci su prikazani tabelarno. Izabrani nivo značajnosti je 0.05.

Rezultati

Stanje opštih kognitivnih sposobnosti i određivanje težine, odnosno stepena demencije ispitan je Mini mental testom za demencije (MMSE) (Folstein et al., 1975). Statistička značajnost prikazana je u Tabeli 2. Rezultati pokazuju da postoji statistički značajna razlika u prosečnom broju bodova na subtestovima MMSE: temporalne orijentacije, pažnje i računanja, prisećanja, imenovanja, pisanja i kopiranja figure. S druge strane, daljom analizom utvrđeno je da se prosečan broj bodova na subtestovima MMSE – specijalne orijentacije, ponavljanja, izvršavanja trostrukog naloga i čitanja – ne razlikuje značajno od maksimalnog broja bodova na tim testovima.

Procena razumevanja jezika ispitana je Bostonskim dijagnostičkim testom za afazije (BDAE, Moberg et al., 2000) – subtestom razumevanja govora – izvođenjem petostepenog naloga. Statistička značajnost prikazana je u Tabeli 2. Rezultati pokazuju da postoji statistički značajna razlika u prosečnom broju bodova na subtestu izvođenja petostepenog govornog naloga.

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[1] Svi testovi u kojima autori nisu navedeni preuzeti su iz: Pavlović, D. (2013). *Neuropsihološka dijagnostika*. Orion art, Cicereto štampa.

Procena vizuelne percepcije ispitana je Testom za vizuelnu diskriminaciju (deo testa BDAE, Moberg et al., 2000). Test se sastoji iz neverbalnog dela sa slikama i verbalnog dela sa rečima. Statistička značajnost prikazana je u Tabeli 2. Rezultati pokazuju da postoji statistički značajna razlika u prosečnom broju bodova na subtestu neverbalne vizuelne diskriminacije. Takođe, ni prosečan broj bodova na subtestu verbalne vizuelne diskriminacije ne razlikuje se značajno od maksimalnog broja bodova na tim testovima.

Deficiti kognitivnih sposobnosti ispitanika prikazani su postojanjem statistički značajnih razlika u prosečnom broju bodova dobijenih na subtestovima MMSE.

Tabela 2

Prosečni brojevi bodova koje su pacijenti postigli na MMSE, Testu za procenu vizuelne percepcije i Testu za procenu razumevanja govornog jezika

	N	Aritmetička sredina	Maksimum bodova	Standardna devijacija	P
Temporalna orijentacija	15	2.6667	5	1.71825	0.000*
Spacijalna orijentacija	15	4.6667	5	0.72375	0.096
Pamćenje	15	3	3	–	–
Pažnja i računanje	15	2.93	5	1.79	0.001*
Prisećanje	15	1	3	1.19	0.000*
Imenovanje	15	1.86	3	0.52	0.000*
Ponavljanje	15	0.80	1	0.41	0.082
Izvršavanje trostrukog naloga	15	2.80	3	0.56	0.189
Čitanje	15	0.93	1	0.26	0.330
Pisanje	15	1.00	1	0.00	0.000*
Kopiranje figure	15	2.80	1	0.56	0.000*
BDAE – razumevanje govora – petostruki nalog	15	4.33	5	0.89	0.012*
Neverbalna vizuelna diskriminacija	14	2	3	1.11	0.005*
Verbalna vizuelna diskriminacija	15	6.46	7	1.12	0.088

*statistički značajno na nivou 0.05 ($p < 0.05$) ; N – broj pacijenata

Prosečan broj tačnih pokreta dominantnom rukom je dva i on se statistički značajno razlikuje od maksimalnog broja tačnih pokreta dominantnom rukom. Broj tačnih pokreta nedominantnom rukom je dva, a maksimalan broj je pet. Iz toga sledi da postoji statistički značajna razlika ($p < 0.05$). Prosečan broj netačnih pokreta dominantnom rukom je nula i on se statistički značajno ne razlikuje od minimalnog broja netačnih pokreta dominantnom rukom.

Prosečan broj netačnih pokreta nedominantnom rukom je 1 i on se statistički značajno razlikuje od minimalnog broja netačnih pokreta nedominantnom rukom (Tabela 3).

Deficiti dinamičke (melokinetičke) apraksije ogledaju se u postojanju statistički značajnih razlika u prosečnim brojevima bodova između pokreta izvedenih dominantnom i nedominantnom rukom u odnosu na maksimalni broj tačnih pokreta. Deficiti melokinetičke apraksije se, takođe, uočavaju i prilikom broja netačnih pokreta nedominantnom rukom u odnosu na minimalan broj mogućih netačnih odgovora.

Tabela 3

Izvođenje serijskih pokreta ruku – Procena dinamičke (melokinetičke) praksije

	Dominantna ruka		**Nedominantna ruka**	
	Srednja vrednost	Min. – Maks.	Srednja vrednost	Min. – Maks.
Vreme izvođenja (sekunde)	10	0–10	10	0–10
Broj tačnih pokreta	2	0–6	2	0–5
Broj netačnih pokreta	0	0–3	1	0–3

Broj bodova izvedenih tranzitivnih pokreta ka telu je četiri, dok je broj bodova tranzitivnih pokreta izvedenih od tela 4.06. Globalno posmatrano, prosečno nema značajne razlike u broju bodova između izvođenja tranzitivnih i netranzitivnih pokreta rukama. Postoji značajna razlika u prosečnim brojevima bodova između tranzitivnih (4) i netranzitivnih (8.80) pokreta izvedenih ka telu. Takođe, postoji značajna razlika u prosečnim brojevima bodova između tranzitivnih (4.06) i netranzitivnih (9.26) pokreta izvedenih od tela. Nema značajne razlike u prosečnom broju bodova kod netranzitivnih pokreta između pokreta ka telu (8.80) i od tela (9.26) (Tabela 4).

Deficiti ideomotorne apraksije ogledaju se u postojanju statistički značajnih razlika u prosečnim brojevima bodova između izvođenja tranzitivnih i netranzitivnih pokreta izvedenih ka telu i izvedenih od tela.

Tabela 4

Izvođenje ideomotornih pokreta ruku – Procena ideomotorne praksije

	Tranzitivni pokreti		Netranzitivni pokreti		
	Srednja vrednost	Min. – Maks.	Srednja vrednost	Min. – Maks.	P
Ka telu (broj bodova)	4	0–10	8.80	0–10	0.000*
Od tela (broj bodova)	4.06	0–6	9.26	0–5	0.000*
Koristi ruku kao objekat (N)	15		15		

*statistički značajno na nivou 0.05 (p< 0.05)

Ispitanici su u proseku osvojili prosečnu vrednost od 8.93 boda za izvođenje zadataka. Ovim je pokazano da je izvođenje pokreta na verbalnu instrukciju uz korišćenje realnih predmeta veoma uspešno. Maksimalni broj bodova koji su ispitanici mogli da ostvare na ovom testu je 10. Za uspešno izveden zadatak dobijalo se 2 poena, za delimično uspešno izveden zadatak 1 poen i za neuspelo izvođenje 0. Od ispitanika se zahtevalo sledeće: da iseku hartiju makazama, da otvore katanac ključem, da pokažu na koji način koriste telefonsku slušalicu (kako se javljaju na telefon), kako turpijom turpijaju nokte i kako češljem češljaju kosu. Kod 10 ispitanika vreme reakcije izvođenja zadatka bilo je odgovarajuće, dok je kod pet ispitanika vreme reakcije produženo. Zaključuje se da je kod većine ispitanika vreme reakcije odgovarajuće. Kod devet ispitanika je uočen tremor, dok kod šest ispitanika tremor nije postojao. Istraživanje je, međutim, pokazalo da tremor nije uticao na performanse izvođenja zadataka (Tabela 5).

Dakle, na osnovu statističke obrade dobijenih rezultata zadataka koje su ispitanici izvodili na verbalnu komandu, uočava se da je ideaciona praksija kod većine naših ispitanika odgovarajuća.

Tabela 5

Izvođenje ideacionih pokreta ruku – Procena ideacione praksije

	N	**Aritmetička sredina**	**Min. – Maks.**	**Standardna devijacija**
Izvođenje zadatka (br. bodova)	15	8.93	0–10	2.71
		Procentualne vrednosti		
Reakciono vreme: odgovarajuće	10	67%		
Produženo	5	33%		
Ukupno	15	100%		
Tremor Da	9	60%		
Ne	6	40%		

Prosečan broj bodova na testu orofacijalne praksije je 9.66. Ispitanici su mogli dobiti najviše 2 poena po zadatku ukoliko su ga u potpunosti korektno izveli, 1 poen ako je facijalni pokret prepoznatljiv, ali loše postavljen ili ukoliko pokazuje motornu perseveraciju i 0 poena za nepostojanje i/ili neprepoznatljivost pokreta. Vrste pokreta koji su zabeleženi kod ispitanika raščlanjene su na osnovu postignutih bodova na testu.

Na osnovu istraživanja ni kod jednog ispitanika se ne uviđaju udruženi pokreti. Perseveracije pravi 10 ispitanika, dok njih pet nije ispoljavalo perseverativne greške. Međutim, dinamičnost pokreta se primećuje kod svih pacijenata. Ukočenost pokreta nije prisutna ni kod jednog ispitanika, a kod svih ispitanika ikoničnost je potpuna. Kao ni u izvođenjima manuelnih pokreta, tremor nije uticao ni na performanse izvođenja mimičnih pokreta (tabela 6).

Deficiti bukofacijalne praksije prikazani su u Tabeli 6.

Tabela 6

Izvođenje bukofacijalnih pokreta – Procena bukofacijalne praksije

	Da	**Ne**
	N	N
Udruženi pokreti	0	15
Ukočenost	0	15
Ikoničnost	15	0
Dinamičnost	15	0
Perseveracije	10	5

Postojanje perspektive na crtežima znači da su ispitanici nacrtali oba objekta sa perspektivom, a njeno nepostojanje može biti nepostojanje na jednom ili na oba objekta. Kod pet ispitanika primećuje se pojava zaobljavanja uglova prilikom kopiranja dvodimenzionalnih objekata. Prilikom kopiranja dvodimenzionalnih objekata sa perspektivom, kod četiri ispitanika se uočava zaobljavanje uglova. Svi ispitanici crtaju jasno dvodimenzionalne objekte, a čak 12/15 njih jasno crta dvodimenzionalne objekte sa perspektivom prilikom crtanja na nalog. Od 15 ispitanika, njih 13 kopira jasno dvodimenzionalne objekte i isti broj njih jasno kopira dvodimenzionalne objekte sa perspektivom. Kopiranje dvodimenzionalnih objekata jasno je odradilo 13 ispitanika, a iste objekte na nalog jasno su nacrtali svi pacijenti iz uzorka. Svi ispitanici jasno crtaju, a 13 jasno kopira dvodimenzionalne objekte, što znači da kod dvodimenzionalnih objekata ne važi da je jasnoća nacrtanih konstrukcija (sa i bez perspektive) veća prilikom kopiranja u odnosu na crtanje po nalogu. Kod dvodimenzionalnih objekata sa perspektivom na nalog crta jasno 12 ispitanika, a jasno kopira njih 13. Ono što je, takođe, u istraživanju pronađeno jeste da ispitanici sa AB jasnije crtaju kvadrat na nalog nego što taj isti kvadrat kopiraju po modelu. Samo jedan ispitanik crta perspektivu kod dvodimenzionalnih objekata koji je imaju (kod oba objekta – kocka i kućica), 10 ispitanika ne crta perspektivu samo kod jednog objekta, a četvoro njih ne crta perspektivu ni kod jednog objekta (ni na kocki, ni na kućici). Takođe, devet ispitanika kopira dobro objekte sa perspektivom, troje njih kopira perspektivu samo na jednom objektu, a troje ispitanika ne kopira perspektivu uopšte. Što se tiče mikrografije, 10 ispitanika crta umanjene dvodimenzionalne crteže (trougao, krug i kvadrat), dok su samo kod njih pet ovi objekti adekvatne veličine. Kod dvodimenzionalnih objekata sa perspektivom (kocke i kućice) tek manje od polovine uzorka (šest ispitanika) crta ih umanjeno (Tabela 7).

Greške prilikom izvođenja konstrukcionih aktivnosti prikazane su u Tabeli 7.

Tabela 7

Izvođenje konstrukcionih aktivnosti – Procena konstruktivne praksije

		Crtanje na nalog	**Kopiranje**
		N	**N**
Dvodimenzionalni objekti	Jasnoća		
	Da	15	13
	Ne	0	2
	Zaobljavanje uglova		
	Da	5	5
	Ne	10	10
	Mikrografija		
	Ima	10	
	Nema	5	
Dvodimenzionalni objekti sa perspektivom	Jasnoća		
	Da	12	13
	Ne	3	2
	Zaobljavanje uglova		
	Da	6	4
	Ne	9	11
	Perspektiva		
	Ima	1	9
	Nema 1 obj	10	3
	Nema 2 obj	4	3
	Mikrografija		
	Ima	6	
	Nema	9	

Prilikom ispitivanja praksije poza, maksimalan broj bodova koji je ispitanik mogao da dobije po zadatku je 2, i to onda kada je izvedeni pokret u potpunosti kompatibilan sa pozom koju je predstavio ispitivač. Bodovi su se gubili ukoliko je ispitanik napravio adekvatan pokret, ali ne uzimajući u obzir odnos leve i desne ruke (greška ogledalskog tipa), ili ukoliko ispitanik razume da treba da napravi istu poziciju ruku koju je ispitivač napravio, ali u pokušajima napravi određenu pozu ruku koja se može opisati kao greška prostorne distorzije. Bez bodova su ostajali ispitanici koji nisu razumeli zadatak ili kod kojih su postojala oba tipa grešaka. U proseku postoje dve greške ogledalskog tipa, a maksimalan broj grešaka ovog tipa je pet, što znači da ovaj tip grešaka postoji kod ispitanika sa AB. S druge strane, prosečno postoji samo jedna greška prostornog tipa, dok je maksimalan broj ovih grešaka pet. Time zaključujemo da se i ovaj tip grešaka takođe javlja u Alchajmerovoj demenciji. Što se tiče razumevanja odnosa leve i desne ruke, osam ispitanika iz našeg uzorka razume odnos ruku, a njih sedam ne. Time vidimo da više od polovine ispitanika iz uzorka razume odnos leve i desne ruke pri pokušaju da postave istu pozu ruku koju je postavio i ispitivač (Tabela 8).

Svi tipovi grešaka koje su ispitanici pravili prilikom ispitivanja praksije poza prikazani su u Tabeli 8.

Tabela 8

Procena praksije poze

	N	Minimum	Maksimum	Sr. vr.
Ukupan broj bodova	15	1	10	6.3333
Greške ogledalskog tipa	15	0	5	2
Greške prostornog tipa	15	0	5	1
Razumevanje odnosa ruku	Da Ne	8 7		

Diskusija

Iako demencija predstavlja veoma čest klinički sindrom, područje demencija je doskora bilo u senci interesovanja kliničara i istraživača. Zanemarivanju ove oblasti doprineo je pesimistički stav u pogledu ishoda ove bolesti, s obzirom na činjenicu da su demencije uglavnom neizlečive, kao i da demencija obično počinje blagim, neprimetnim simptomima, koje okolina obolelog ne prepoznaje i uglavnom ih pripisuje „prirodnom" procesu starenja. Kao posledica toga često prođe i više godina pre nego što se oboleli uputi lekaru i započne dijagnostički i terapijski postupak. Povećanje populacije starijih osoba, sve evidentnije poslednjih godina, dovelo je do značajnog porasta broja demencija, zbog čega se danas u svetu ulaže mnogo rada i novca da se pronađe adekvatniji način lečenja i za poboljšanje kvaliteta života osoba sa demencijom osoba (Vuković, 2011).

Uprkos rasprostranjenosti i važnosti dijagnostikovanja Alchajmerove bolesti, ovoj temi posvećeno je malo pažnje. Alchajmerova bolest se karakteriše deficitom u dve ili više oblasti kognicije sa progresivnim pogoršanjem pamćenja i drugih kognitivnih funkcija. Tokom razvoja bolesti dolazi do progresivnog pogoršanja drugih specifičnih kognitivnih funkcija, kao što su jezik (afazija), motoričke veštine (apraksija) i percepcija (agnozija), pa je testiranje ovih kognitivnih funkcija ključni deo dijagnostičke procene demencije (Ward et al., 2015).

Rezultati našeg istraživanja na testu kojim su ispitivane opšte kognitivne sposobnosti i određivana težina demencije su statistički značajni za subtestove MMSE: vremenske orijentacije, pažnje i računanja, odloženog prisećanja, imenovanja, pisanja i kopiranja figure ukrštenih petouglova, dok se na subtestovima MMSE: prostorne orijentacije, ponavljanja, izvršavanja trostrukog naloga i čitanja rezultati ne razlikuju značajno od maksimalnog broja bodova na tim testovima. Rezultati istraživanja pokazuju, takođe, da su kod ispitanika sa Alchajmerovom bolešću i u prvom i u drugom stadijumu oštećene: vremenska orijentacija, pažnja, računanje, prisećanje, imenovanje, pisanje i kopiranje figura. S druge strane, u ovim stadijumima bolesti ostale kognitivne funkcije ostaju relativno očuvane. Dalja analiza dobijenih rezultata pokazala je da ispitanici sa Alchajmerovom bolešću imaju oštećenu sposobnost razumevanja govornog i pisanog jezika, što je pokazano niskim postignućima na Bostonskom dijagnostičkom testu za afazije. Niži broj bodova od očekivanog utvrđen je i na Testu za procenu vizuelne percepcije – subtest neverbalne vizuelne diskriminacije. S druge strane, na testu verbalne vizuelne diskriminacije nisu uočeni deficiti. Ove razlike na testu vizuelne percepcije ne mogu se smatrati konačnim, budući da ispitanici nisu bili podjednako spremni za izvršenje svih tipova zadataka. Ispitanici su lakše prihvatili verbalne nego neverbalne zadatke. Kod neverbalnih zadataka često bi se branili lošim vidom, nemanjem naočara i sl. Međutim, kliničkom opservacijom primećeno je da ispitanici nemaju oštećenje vida u meri koje bi ih onemogućilo u izvršavanju zadataka neverbalne vizuelne percepcije. Ovo istraživanje ima izvesna ograničenja, s obzirom na to da je uzorak mali i nehomogen. S tim u vezi, nije moguća generalizacija dobijenih rezultata na svu populaciju starih osoba, kao ni mogućnost izvođenja zaključaka. Pored navedenih ograničenja, iz dobijenih rezultata može se pretpostaviti koji tipovi apraksija se dominantno javljaju kod osoba sa Alchajmerovom bolešću.

Istraživanje koje je proučavalo ideomotornu apraksiju kod pacijenata sa Alchajmerovom bolešću pokazalo je da pacijenti sa AB često poseduju izraženiji deficit u oblasti ideomotorne apraksije od pacijenata sa moždanim udarom prilikom pokretanja udova nakon slušne komande, zatim pri izvođenju intranzitivnih pokreta udova, a podjednako oštećeni pri izvođenju tranzitivnih pokreta (Park, 2017).

Istraživanja su, takođe, pokazala da su pacijenti sa AB imali lošije rezultate od zdravih kontrola na testovima procene apraksije. Ovaj lošiji učinak bio je nezavisan od faktora kao što su uzrast i školovanje. Važno je istaći da je apraksija, posebno ideomotorni tip, bila češća među pacijentima sa AB (Ward et al., 2015).

Neuspeh da se napravi razlika između zdravih starijih osoba i onih sa AB može biti posledica činjenice da se apraksija obično ne uočava u ranim stadijumima bolesti. Međutim, procena apraksije je korisna u dijagnozi demencije, ali ona svakako nije odlučujući faktor, jer normalno starenje podrazumeva i postepeno opadanje kognitivnih funkcija (Lesourd et al., 2013; Reis et al., 2008, Torres et al., 2009).

Istraživanja su pokazala da Alchajmerova bolest (AB) ima dugu pretkliničku fazu, tokom koje se njena karakteristična patologija akumulira, funkcije pacijenta opadaju, ali su simptomi nedovoljni da bi opravdali kliničku dijagnozu demencije. Sve je više izveštaja o nekognitivnim simptomima ove bolesti, uključujući i gubitak motoričke funkcije, za koje se izveštava da su povezani sa AB. Kognitivni i motorički pad, koji su u vezi sa godinama starosti, mogu imati zajedničku uzročnost. Štaviše, osobe sa kliničkom dijagnozom AB mogu predstavljati „vrh ledenog brega”, pošto patologija same bolesti takođe može predstavljati značajan deo kognitivne i motoričke disfunkcije koja se trenutno smatra „normalnim starenjem” kod starijih osoba bez demencije (Buchman, 2011).

Zaključak

Procena apraksija je postala važan aspekt neurodegenerativnih bolesti, ali i glavni indikator za psihoterapiju i radnu terapiju doprinoseći kvalitetu života starijih osoba, prvenstveno sa kognitivnim padom. Veoma je važno proceniti apraksiju kako bi se pristupilo adekvatnom i pravovremenom planiranju rehabilitacije, koja značajno može doprineti poboljšanju kvaliteta života kod osoba sa Alchajmerovom bolešću.

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Clinical forms of apraxia in patients with Alzheimer's disease

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Introduction. Alzheimer's disease is the most common form of dementia. Apraxia can be one of the symptoms of Alzheimer's disease. Apraxia is defined as an acquired deficit in the execution of movements that cannot be explained by motor or sensory impairments. *Aim.* The main aim of this research is to determine the types of apraxia in people with Alzheimer's dementia and to point out the importance of early rehabilitation of these patients. *Method.* The sample consists of 15 patients with Alzheimer's dementia (amnestic type – multiple domains) aged from 50 to 85 years. In addition to the free interview, which follows predetermined principles, a neurological clinical assessment of motor skills and sensitivity and a neurobehavioral assessment of appearance, behavior, and emotions were conducted. The examination was conducted according to the established criteria at the Antamedica Polyclinic in Belgrade. *Results.* The results of our study show that patients with Alzheimer's disease are impaired in both the first and second stages: time orientation, attention, arithmetic, remembering, naming, writing, and copying figures. On the other hand, other cognitive functions are relatively well preserved in these stages of the disease. Patients with Alzheimer's disease have an impaired ability to understand spoken and written language. In contrast, no deficits were found on the verbal-visual discrimination test. *Conclusion.* Assessment of apraxia has become an important aspect of neurodegenerative diseases and a main indicator for psychotherapy and occupational therapy, contributing to the quality of life of the elderly, primarily with cognitive decline.

Keywords: Alzheimer's disease, apraxia, dementia

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