

## KVALITET ŽIVOTA DECE SA DISFAGIJOM I NJIHOVIH STARATELJA

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### SAŽETAK

Disfagija se definiše kao poremećaj gutanja koji se može javiti u sve tri faze gutanja (oralnoj, faringealnoj ili ezofagealnoj). Manifestuje se bolom pri gutanju, otežanim gutanjem, zaglavljenošću hrane u grlu ili grudima, gorušicom, vraćanjem hrane i/ili želudačne kiseline u grlo, redukcijom težine, promuklošću, itd. Primarni cilj ovog rada je analiza kvaliteta života kod dece sa disfagijom i njihovih staratelja, a sekundarni pružanje osnovnih smernica za unapređenje kvalitet njihovog života. Podaci su prikupljeni pretraživanjem sledećih baza podataka: *PubMed*, *Google Scholar Advanced Search* i Konzorcijum biblioteka Srbije za objedinjenu nabavku - KoBSON. Pregledom rezultata dosadašnjih istraživanja deca sa disfagijom imaju lošiji kvalitet života u poređenju sa vršnjacima. Roditelji koji osećaju bespomoćnost, jer ne mogu da pomognu svojoj deci, doživljavaju visok nivo stresa. Takođe, deci sa disfagijom nedostaje potrebna podrška od strane zdravstvenog sistema, tako da je neophodno osmisliti smernice za pomoć deci sa disfagijom u cilju ostvarivanja njihovog ličnog potencijala u funkcionalnom, emocionalnom i socijalnom domenu.

**Ključne reči:** disfagija, deca, staratelji, kvalitet života, stres, smernice

### Uvod

Disfagija se definiše kao poremećaj gutanja koji se može javiti u sve tri faze gutanja (oralna, faringealna ili ezofagealna). Manifestuje se bolom pri gutanju, otežanim gutanjem, zaglavljenošću hrane u grlu ili grudima, gorušicom, vraćanjem hrane i/ili želudačne kiseline u grlo, redukcijom težine, promuklošću, itd. Važno je napomenuti da svako dete sa disfagijom ima poremećaj hranjenja, ali svako dete sa poremećajem hranjenja nema disfagiju (1). Pedijatrijski poremećaj hranjenja deteta (engl. *Pediatric Feeding Disorder* – PFD) se definiše kao poremećaj koji se javlja u oralnoj fazi gutanja, koji nije u skladu sa kalendarskim uzrastom deteta. Ovaj poremećaj je obično povezan sa drugim medicinskim, nutritivnim i/ili psihosocijalnim disfunkcijama (2).

Do danas, prevalencija disfagije nije tačno utvrđena. Može se javiti kao primarni (izolovan od bilo kog drugog zdravstvenog stanja) i sekundarni poremećaj (kao deo kliničke slike drugog zdravst-

venog stanja). Takođe, može biti prisutna u sklopu razvojnih poremećaja koji imaju karakter doživotnih stanja, kao što su cerebralna paraliza, intelektualna ometenost, različiti sindromi, poput Daunovog sindroma, ili kao deo kliničke slike autizma (3). Disfagija je često prisutna kao deo kliničke slike stečenih poremećaja, kao što su traumatska povreda mozga, spinalna mišićna atrofija/distrofija, amiotrofična lateralna skleroza ili različiti maligniteti, koji su poslednjih godina sve prisutniji u dečijoj populaciji (4). Procenjuje se da se disfagija javlja kod čak 85% dece sa cerebralnom paralizom (5).

S obzirom na značaj hranjenja kao jedne od osnovnih fizioloških funkcija svakog čoveka, disfagija ima dalekosežne posledice na opšte zdravlje mladog organizma i njegovo blagostanje. Negativan uticaj na opšte zdravlje organizma definiše se kao narušavanje kvaliteta života u fizičkom, psihičkom ili socijalnom domenu (6,7). Kvalitet života dece dodatno je narušen usled narušenog zdravlja

## QUALITY OF LIFE IN CHILDREN WITH DYSPHAGIA AND THEIR CAREGIVERS

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### SUMMARY

Dysphagia is defined as a swallowing disorder that can occur in all three phases of swallowing (oral, pharyngeal or esophageal). It is manifested as pain while swallowing, difficulty swallowing, feeling of food stuck in the throat or in the chest, heartburn, regurgitation of food and/or stomach acid, weight loss, hoarseness, etc. The primary aim of this study is to analyze the quality of life in children with dysphagia and their caregivers, while the secondary aim is to provide basic guidelines for improving the quality of their life. Data were collected by searching the following databases: PubMed, Google Scholar Advanced Search and Consortium of Serbian Libraries for Coordinated Purchase (Serbian: KoBSON). The review of previous research results has shown that children with dysphagia have a worse quality of life in comparison to their peers. Parents, who feel helpless because they cannot help their children, experience high levels of stress. Also, children with dysphagia lack the necessary support from the health system, and therefore, it is necessary to create guidelines to help children with dysphagia aimed at realizing their personal potentials in the functional, emotional and social domain.

Key words: dysphagia, children, caregivers, quality of life, stress, guidelines

### Introduction

Dysphagia is defined as a swallowing disorder that can occur in all three phases of swallowing (oral, pharyngeal, esophageal). It is manifested as pain while swallowing, difficulty swallowing, feeling of food stuck in the throat or in the chest, heartburn, regurgitation of food and/or stomach acid into the throat, weight loss, hoarseness, etc. It is important to note that every child with dysphagia has a feeding disorder, but not every child with a feeding disorder has dysphagia (1). Pediatric feeding disorder (PFD) is defined as a disorder that occurs in the oral phase of swallowing, which is not in accordance with the child's age. This disorder is usually associated with other medical, nutritional and/or psychosocial dysfunctions (2).

The prevalence of dysphagia has not been precisely determined so far. It can occur as a primary (isolated from any other medical condition) and a secondary disorder (as part of the clinical picture of another medical condition). Also, it can occur as

part of developmental disorders that have the character of lifelong conditions, such as cerebral palsy, intellectual disability, different syndromes, such as Down's syndrome, or as part of the clinical picture of autism (3). Dysphagia is often present as part of the clinical picture of acquired disorders, such as traumatic brain injury, spinal muscular atrophy/dystrophy, amyotrophic lateral sclerosis or various malignancies, which have been increasingly present in the pediatric population in recent years (4). It has been estimated that dysphagia occurs in as many as 85% of children with cerebral palsy (5).

Considering the importance of feeding as one of the basic physiological functions of every human being, dysphagia has far-reaching consequences on the general health and well-being of the young organism. A negative impact on the general health of the organism is defined as the impairment of the quality of life in the physical, psychological and social domain (6,7). Children's quality of life is fur-

u ishrani i rizika od prerane smrti usled gušenja ili aspiracione pneumonije (8).

U cilju održavanja opšteg zdravlja deteta i prevencije aspiracije (udisanja) primenjuju se kompenzacione intervencije, kao što su modifikacija tečnosti i hrane koju treba svakodnevno unositi, promena veličine zalogaja i promena teksture hrane (4,9). Pored toga što se na ovaj način obezbeđuje opšte zdravlje mladog organizma, ove kompenzacione intervencije mogu dovesti do određenih zdravstvenih komplikacija. Naime, smanjen unos tečnosti može dovesti do naknadne dehidracije organizma (10). To znači da kompenzacione tehnike s jedne strane omogućavaju da se na neki način očuva zdravlje organizma, a sa druge strane smanjuju osećaj uživanja u obroku, koji je prateći osećaj svakog obroka kod dece. Na ovaj način se dodatno narušava kvalitet života dece sa disfagijom (11).

Klinička slika disfagije i kompenzatorne tehnike koje se koriste u lečenju disfagije kod dece mogu negativno uticati na kvalitet njihovog života (12). Razumevanje problema sa kojima se suočavaju ova deca i članovi njihovih porodica posebno je važno za celokupno društvo i pomaže u osmišljavanju boljih smernica i intervencija koje će poboljšati kvalitet života ove grupe stanovnika. *Dodril i Estrem* ističu da su problemi sa hranjenjem koje mogu imati odrasli podjednako česti kod dece sa disfagijom. Naime, ova deca prijavljuju čest umor od jela, smanjeno uživanje u hranjenju i izbegavanje mnogih situacija, kao što su rođendani, proslave i drugi javni događaji (13).

Sagledavanje nalaza dosadašnjih istraživanja o kvalitetu života dece sa disfagijom je od posebnog značaja za osmišljavanje budućih smernica za poboljšanje kvaliteta njihovog života. Shodno tome, primarni cilj ovog rada je analiza rezultata dosadašnjih istraživanja o kvalitetu života dece sa disfagijom i njihovih staratelja, a sekundarni postavljanje osnovnih smernica u cilju poboljšanja kvaliteta njihovog života.

## Metode

Pretraga radova obavljena je uz pomoć dostupnih baza podataka *PubMed*, *Google Scholar Advanced Search* i Konzorcijuma biblioteka Srbije za objedinjenu nabavku – KoBSON. Tokom pretrage korišćene su sledeće ključne reči: disfagija kod dece, kvalitet života i disfagija kod dece, kompen-

zatorne tehnike kod disfagije, podrška deci sa disfagijom, smernice za disfagiju kod dece i kvalitet života staratelja dece sa disfagijom. Pretraživanje je urađeno za period 2001-2024. godine. U analizu su uključeni samo oni radovi koji su bili napisani na engleskom jeziku.

## Dijagnostika pedijatrijske disfagije

Suočavanje sa brojnim izazovima koje disfagija donosi deci i njihovim porodicama podstiče istraživače da detaljno analiziraju ovo zdravstveno stanje. Zbog svoje multidisciplinarnosti, disfagija kod dece ne podleže klasičnom dijagnostičkom pristupu, kao što je to slučaj sa dijabetesom ili urođenim srčanim oboljenjima. U cilju dijagnostikovanja disfagije obično se, pored anamneze i kliničkog pregleda, traži mišljenje gastroenterologa (ezofagoskopija, RTG jednjaka sa kontrastom, evaluacija gutanja fleksibilnim endoskopom), otorinolaringologa (laringoskopija), endokrinologa (ultrazvuk štitaste žlezde, hormonski status), pulmologa (bronhoskopija, RTG grudnog koša), a nekada i pregled od strane drugih specijalista (neurologa, psihijatra, dr.).

Disfagija može se zasnivati na medicinskim problemima, psihosocijalnim problemima ili razvojno-senzornim problemima (hiposenzitivnost/preosetljivost) na određenu teksturu hrane. Na tabeli 1 prikazani su dijagnostički kriterijumi za pedijatrijski poremećaj hranjenja (2). Disfunkcija u nekom od domena (medicinski, nutritivni, veštine hranjenja i psihosocijalni) u poremećaju hranjenja dece ima dalekosežne posledice na kvalitet života pojedinca i njegove porodice. Oštećenja u jednom domenu mogu uticati na nastanak poremećaja u bilo kom drugom (2).

## Kvalitet života dece sa disfagijom

Upoređujući zadovoljstvo kvalitetom života dece sa disfagijom i dece koja imaju druga stanja, kao što su transplantacija bubrega ili akutna insuficijencija jetre, uočeno je da deca sa disfagijom imaju lošiji kvalitet života (14,15). Ovo se može dovesti u vezu sa činjenicom da je proces hranjenja jedna od osnovnih fizioloških funkcija koja se uspostavlja aktivnom interakcijom dece i roditelja u ranom detinjstvu. Svaki poremećaj u ovoj funkciji stvara osećaj straha i razočaranja kod roditelja. Tokom svakodnevnih aktivnosti roditelji nesvesno projektuju svoje negativne emocije na dete. Pro-

ther impaired due to impaired health related to nutrition and the risk of premature death due to suffocation or aspiration pneumonia (8).

In order to maintain the child's general health and prevent aspiration (inhalation), compensatory interventions are implemented, such as modification of liquids and food that should be taken every day, changing the size of morsels and changing the texture of food (4,9). In addition to ensuring the general health of the young organism in this way, these compensatory interventions can lead to certain health complications. Namely, reduced fluid intake can lead to subsequent dehydration of the body (10). This means that compensatory techniques, on the one hand, allow the health of the organism to be preserved in some way, and on the other hand, they reduce the feeling of enjoyment of the meal, which is the accompanying feeling of every meal in children. In this way, the quality of life of children with dysphagia is additionally impaired (11).

The clinical picture of dysphagia and compensatory techniques that are used to treat dysphagia in children can negatively affect the quality of their life (12). Understanding the problems encountered by these children and their family members is particularly important for the whole society and helps in designing better guidelines and interventions that will improve the quality of life of this population group. Dodrill and Estrem emphasize that feeding problems that can be experienced by adults are equally common in children with dysphagia. Namely, these children report frequent fatigue caused by eating, reduced enjoyment while eating and avoidance of many situations, such as birthdays, celebrations, and other public events (13).

Reviewing the findings of previous studies on the quality of life of children with dysphagia is of particular importance for creating future guidelines for improving their quality of life. Accordingly, the primary aim of this study is to analyze the results of previous studies on the quality of life of children with dysphagia and their caregivers, and the secondary aim is to establish basic guidelines aimed at improving their quality of life.

## Methods

The studies were searched using the available databases PubMed, Google Scholar Advanced Search and Consortium of Serbian Libraries for Co-

ordinated Purchase (Serbian: KoBSON). During the search, the following key words were used: dysphagia in children, quality of life and dysphagia in children, compensatory techniques in dysphagia, support for children with dysphagia, guidelines for dysphagia in children and quality of life of caregivers of children with dysphagia. The search was carried out for the period 2001-2024. Only those studies that were written in English were included in the analysis.

## Diagnostics of pediatric dysphagia

Facing the numerous challenges, which dysphagia brings to children and their families, prompts researchers to analyze this medical condition in detail. Due to its multidisciplinary nature, dysphagia in children is not subject to the classic diagnostic approach, as is the case with diabetes or congenital heart diseases. In order to diagnose dysphagia, in addition to anamnesis and clinical examination, usually the opinion of a gastroenterologist is required (esophagoscopy, esophagram, flexible endoscopic evaluation of swallowing), as well as the opinion of an otorhinolaryngologist (laryngoscopy), endocrinologist (X-ray scanning the thyroid gland, hormonal status), pulmonologist (bronchoscopy, a chest X-ray), and sometimes the examination of other specialists (neurologist, psychiatrist, etc.).

Dysphagia can be based on medical problems, psychosocial problems, or developmental-sensory problems (hyposensitivity/hypersensitivity) related to certain food texture. Diagnostic criteria for the pediatric feeding disorder are shown in Table 1 (2). Dysfunction in some of the domains (medical, nutritional, feeding skills, psychosocial) in the pediatric feeding disorder has far-reaching consequences on the quality of life of an individual and his family. Damage in one domain can affect the occurrence of disorders in any other domain (2).

## Quality of life of children with dysphagia

Comparing the satisfaction with the quality of life of children with dysphagia and children with other conditions, such as kidney transplantation or acute liver failure, it was observed that children with dysphagia had worse quality of life (14,15). This can be related to the fact that the feeding process is one of the basic physiological functions that are established by the active interaction between

**Tabela 1.** Predloženi dijagnostički kriterijumi za pedijatrijski poremećaj hranjenja (prilagođeno na osnovu reference 2)

A) Smetnja u oralnoj fazi uzimanja hrane, koja nije u skladu sa uzrastom, traje bar 2 nedelje i povezana je sa jednom ili više sledećih disfunkcija:

Medicinska disfunkcija, o čemu svedoči bilo šta od navedenog:	Nutritivna disfunkcija, o čemu svedoči bilo šta od navedenog:	Disfunkcija povezana sa veštinom hranjenja, o čemu svedoči bilo šta od navedenog:	Psihosocijalna disfunkcija, o čemu svedoči bilo šta od navedenog
Kardiorespiratorni zastoj tokom oralnog unosa hrane	Neuhranjenost	Potreba za modifikacijom teksture tečnosti ili hrane	Aktivno ili pasivno izbegavanje deteta tokom unosa hrane ili hranjenja
Aspiracija ili aspiracijska pneumonija	Nedostatak specifičnih nutrijenata ili značajno ograničen unos jednog ili više nutrijenata zbog smanjene raznovrsnosti ishrane	Korišćenje modifikovane pozicije ili opreme tokom hranjenja	Neadekvatno upravljanje od strane staratelja detetovim potrebama za hranjenjem i/ili ishranom
	Oslanjanje na enteralnu ishranu ili oralne suplemente za održavanje ishrane i/ili hidratacije	Korišćenje modifikovanih strategija hranjenja	Poremećaj društvenog funkcionisanja u kontekstu hranjenja  Poremećaj odnosa između deteta i staratelja koji se povezuje sa hranjenjem

B) Odsustvo kognitivnih procesa u skladu sa poremećajima hranjenja i modelom oralnog unosa hrane nije posledica nedostatka hrane ili kulturoloških normi

duženim ispoljavanjem negativnih emocija stvaraju osećaj krivice kod deteta, usled njegove nesposobnosti tokom hranjenja (16). S druge strane, narušen kvalitet života u drugim stanjima (transplantacija bubrega ili akutna insuficijencija jetre) može biti kratkotrajne prirode, sa kolebanjima psihosocijalnog stanja, što će nakon intervencije podstaći nastanak pozitivnih emocija i motivacije da nastavi rehabilitaciju sa verom u bolje dane za porodicu (14-16).

*Fracchia* i saradnici (17) su u svojoj studiji, na uzorku od 35 dece, uzrasta od 5 do 79 meseci, analizirali kvaliteta života dece godinu dana nakon hirurške intervencije rascapa larinksa. Kod sve dece je došlo do blagog poboljšanja kvaliteta života, ali je njihov kvalitet života bio lošiji u odnosu na njihove vršnjake. Nezadovoljstvo koje osećaju stvara stres i razočarenje kod roditelja, koji obično očekuju trajno rešenje posle hirurške intervencije. Druge kvalitativne studije, takođe, pokazuju da deca sa disfagijom i članovi njihovih porodica u velikoj meri imaju redukovano učešće u društvenom životu (18,19).

*Rama* i saradnici (20) su, u svojoj međunarodnoj studiji sprovedenoj u Brazilu i Portugalu, te-

stirali kvalitet života roditelja/negovatelja dece sa disfagijom. Uzorak je činilo 95 roditelja dece sa različitim stepenom disfagije. Rezultati njihovog istraživanja pokazali su da kvalitet života porodice dodatno narušava nedostatak neophodne podrške zdravstvenog sistema i nedostupnost obučanih stručnjaka u ovoj oblasti.

*Estem* i saradnici (21) su anketirali 12 roditelja dece sa disfagijom i zaključili da porodice dece sa disfagijom nailaze na mnoge prepreke i beskorisne savete kada traže pomoć. Roditelji često ističu da je put do pronalaženja specijaliste koji poznaje i razume problem sa kojim se njihovo dete suočava veoma dug i naporan. Ističu i da bez samoinicijative za dalju analizu zdravstvenog stanja svog deteta ne bi mogli da poprave njegovo stanje. Nešto kasnije, *Estem* i saradnici (22) su, u svom preglednom radu, analizirali rezultate istraživanja pre 2000. i posle 2000. godine. Upoređivanjem rezultata ranijih i sadašnjih studija došli su do zaključka da roditelji, posebno majke, krive sebe za probleme u hranjenju svog deteta. Ističu da nedostatak neophodne podrške stručnjaka adekvatnog profila i zdravstvenog sistema uopšte predstavljaju dugogodišnje probleme koji do danas nisu rešeni.

**Table 1.** Proposed diagnostic criteria for pediatric feeding disorder (adapted according to reference 2)

A) A disturbance in oral intake of nutrients, inappropriate for age, lasting at least 2 weeks and associated with 1 or more of the following:

Medical dysfunction, as evidenced by any of the following:	Nutritional dysfunction, as evidenced by any of the following:	Feeding skill dysfunction, as evidenced by any of the following:	Psychosocial dysfunction, as evidenced by any of the following:
Cardiorespiratory compromise during oral feeding	Malnutrition	Need for texture modification of liquid or food	Active or passive avoidance behaviors by child when feeding or being fed
Aspiration or recurrent aspiration pneumonitis	Specific nutrient deficiency or significantly restricted intake of one or more nutrients resulting from decreased dietary diversity	Use of modified feeding position or equipment	Inappropriate caregiver management of child's feeding and/or nutrition needs
	Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration	Use of modified feeding strategies	Disruption of social functioning within a feeding context
			Disruption of caregiver-child relationship associated with feeding

B) Absence of the cognitive processes consistent with eating disorders and pattern of oral intake is not due to a lack of food or congruent with cultural norms.

children and parents in early childhood. Any disturbance of this function creates a sense of fear and disappointment in parents. During everyday activities parents unconsciously project their negative emotions onto the child. The prolonged expression of negative emotions creates a sense of guilt in the child, due to his inability during feeding (16). On the other hand, impaired quality of life in other conditions (kidney transplantation or acute liver failure) can be short-term, with fluctuations in the psychosocial state, which will encourage positive emotions after the intervention and motivation to continue rehabilitation with faith in better days for the family (14-16).

Fracchia and associates (17) in their study, which included the sample of 35 children, aged 5 to 79 months, analyzed the quality of life of children one year after surgical intervention due to laryngeal cleft. All children had a slight improvement in their quality of life, but their quality of life was worse in comparison to their peers. The dissatisfaction they felt created stress and disappointment of their parents, who usually expected a permanent solution after the surgical intervention. Other qualitative studies also showed that children with dysphagia and their parents reduced their participation in social life to a large extent (18,19).

Rama and associates (20) tested the quality of life in parents/caregivers of children with dysphagia in the international study, which was conducted in Brazil and Portugal. The sample consisted of 95 parents of children with different degrees of dysphagia. The results of their study showed that the quality of family life was further impaired by the lack of necessary support of the health care system and the unavailability of trained experts in this field.

Estem et al. (21) surveyed 12 parents of children with dysphagia and concluded that families of children with dysphagia encounter many obstacles and useless advice when they seek help. Parents often emphasize that the way to finding a specialist who knows and understands the problem their child is facing is very long and arduous. They also point out that without self-initiative for further analysis of their child's health condition, they would not be able to improve his condition. Later, Estem et. al (22), in their review article, analyzed the results of studies before and after 2000. By comparing the results of previous and current studies, they came to the conclusion that parents, especially mothers, blame themselves for problems related to feeding their child. They point out that the lack of necessary support from profession-

Izrada smernica u radu navodi se kao optimalno rešenje za podsticanje poboljšanja kvaliteta života dece i porodice.

S obzirom da je disfagija često hronično zdravstveno stanje i da dugotrajni problemi sa kojima se suočavaju pojedinci utiču na njihovo opšte funkcionisanje i dobrobit ljudi sa kojima su u stalnom kontaktu, *Leeman* i saradnici (23) su u metaanalizi, koja je uključila 54 studije koje analiziraju funkcionalnost i dobrobit dece i porodice, primenili četiri skale: skalu za procenu prilagodljivosti i kohezije, skalu porodičnog okruženja, indeks porodičnih odnosa ili procene porodice. Rezultati ovog istraživanja su pokazali značajnu vezu između mentalnog zdravlja dece i opšteg funkcionisanja porodice. Utvrđene su i značajne uzročno-posledične veze između porodične disfunkcije i poremećaja ponašanja kod dece, njihove socijalne kompetencije i kvaliteta života.

Simeon i saradnici (14) su sproveli studiju preseka, u oblasti Velikog Bostona, u periodu od 2017. do 2018. godine, tako što su analizirali uticaj poremećaja u ishrani na kvalitet života pedesetero dece uzrasta od 2 do 5 godina i uporedili ga sa kvalitetom života dece sa drugim stanjima. Roditelji su popunjavali generičku skalu kvaliteta života dece 4.0 (engl. *Pediatric Quality of Life Generic Core Scales 4.0* - PedsQL) i Upitnik o uticaju na hranjenje/gutanje (engl. *Feeding/Swallowing Impact Survey* - FS-IS). Upitnik o uticaju na hranjenje/gutanje predstavlja subjektivnu skalu ocenjivanja koja se koristi za procenu kvaliteta života u vezi sa zdravljem (HRQoL) staratelja čija dece imaju poremećaj hranjenja/gutanja. Rezultati ove studije su pokazali da deca sa poremećajima u ishrani (deca su imala heterogene medicinske dijagnoze) imaju loš kvalitet života ( $72,82 \pm 19,21$ ), kao i njihovi staratelji ( $2,33 \pm 0,89$ ). Brojna istraživanja pokazuju da roditelji doživljavaju visok nivo stresa zbog problema sa ishranom njihove dece (24-26).

## Smernice za rad sa decom koja imaju disfagiju

Do danas nisu osmišljene osnovne smernice za rad sa decom koja imaju disfagiju u smislu poboljšanja kvaliteta njihovog života. Naime, studije fokusiraju svoja istraživanja na ublažavanje primarnih zdravstvenih problema ove dece, zane-marujući njihove psihosocijalne potrebe i podršku okoline koja im je potrebna. S obzirom na to da

je disfagija višedimenzionalni poremećaj, ona se mora tretirati kao takva – multidisciplinarnim pristupom. Zato je veoma važno svakom detetu pristupiti holistički, uz angažovanje stručnjaka različitih profila (otolaringolog, stomatolog, nutricionista, alergolog, psihijatar, psiholog i logoped) (27).

Osnovne smernice koje se mogu koristiti u radu sa ovom decom, a koje se pre svega odnose na poboljšanje njihovog kvaliteta života, uključuju sledeće: roditelje treba posmatrati kao koterapeute u radu, jer oni najviše vremena provode sa decom i prvi se uključuju u njihovo hranjenje; neophodan je individualni plan rehabilitacije u cilju poboljšanja ishrane, jer je svako dete individua za sebe; treba razdvojiti šta dete dobro radi, kako bi bilo motivisano za dalji rad; treba omogućiti obuku za pružanje usluga od strane više negovatelja, kako bi bilo izbegnuto sagorevanje primarnog negovatelja; neophodno je obezbediti resurse za socijalne programe, koji mogu pomoći roditeljima i deci da se suoče sa problemima; organizovati edukacije o rizicima i komplikacijam povezanim sa aspiracijom starateljima dece sa disfagijom u cilju eliminisanja/minimiziranja aspiracije i omogućavanja kvalitetne ishrane, zdravlja i kvaliteta života; obezbediti obuku starateljima o vrstama i metodama vežbi orofacijalne regije koje mogu primenjivati u kućnoj atmosferi.

## Zaključak

Hranjenje se smatra osnovnom roditeljskom aktivnošću. Poremećaji gutanja kod dece mogu imati dalekosežne posledice po njihovo zdravlje i kvalitet života uopšte. Disfagija se smatra ozbiljnim problemom kod dece, jer je detinjstvo period brzog rasta i razvoja, a bilo kakve smetnje u pogledu ishrane mogu narušiti dalji razvoj deteta, a samim tim i kvalitet njegovog života.

Ranjivost funkcije hranjenja u detinjstvu, s jedne strane, i činjenica da deca ubrzano rastu i razvijaju se sa druge strane, postavlja zadatak da se pronađu najprihvatljiviji modeli rada sa ovom decom uz uvažavanje njihove individualnosti. Stoga, polazna tačka u radu uvek treba da bude razumevanje kako različita zdravstvena stanja mogu da naruše kvalitet života pojedinca s ciljem pronalazjenja adekvatnih smernica koje bi pomogle da se ova deca ostvare u funkcionalnom, emocionalnom i društvenom domenu. Takođe, paralelno treba raditi na unapređenju kvaliteta života njihovih staratelja.

als in different fields and the health care system, in general, represent long-standing problems that have not been solved so far. In the study, the development of guidelines is claimed to be the optimal solution for encouraging the improvement of the quality of life of children and families.

Considering the fact that dysphagia is a chronic health condition and that the long-standing problems faced by individuals affect their general functioning and the well-being of people, with whom they are in constant contact. Leeman et al. (23) in a meta-analysis, which included 54 studies that analyzed the functionality and well-being of children and families, applied four scales: the scale for the assessment of adaptability and cohesion, the scale of family environment, the index of family relations or family assessments. The results of this study showed a significant relationship between children's mental health and the general functioning of the family. Significant causal relationships between family dysfunction and behavioral disorders in children, their social competence and quality of life were also established.

Simione et al. (14) conducted a cross-sectional study, in the region of Greater Boston, from 2017 to 2018, by analyzing the impact of eating disorders on the quality of life of 50 children aged 2 to 5 years and comparing it with the quality of life of children with other conditions. Parents filled out the Pediatric Quality of Life Generic Core Scales 4.0 (PedsQL) and the Feeding/Swallowing Impact Survey (FS-IS). The Feeding/Swallowing Impact Survey is a subjective assessment scale that is used to assess the health-related quality of life (HRQoL) of caregivers, whose children have feeding/swallowing disorders. The results of this study showed that children with eating disorders (children had heterogeneous medical diagnoses) had a poor quality of life (72.82±19.21), as well as their caregivers (2.33±0.89). Numerous studies show that parents experience a high level of stress due to the eating problems of their children (24-26).

### Guidelines for working with children who have dysphagia

To date, no basic guidelines have been developed for working with children who have dysphagia in terms of improving their quality of life. Namely, studies focus their research efforts on alleviating the primary health problems of these

children, neglecting their psychosocial needs and the necessary support of the environment. Considering the fact that dysphagia is a multidimensional disorder, it must be treated as such – using a multidisciplinary approach. Therefore, it is very important to approach each child in a holistic way, and engage professionals in different fields (otolaryngologist, dentist, nutritionist, allergologist, psychiatrist and speech therapist) (27).

Basic guidelines, which can be used when working with these children, and which primarily relate to improving their quality of life, include the following: parents should be seen as co-therapists in the work, because they spend most time with their children and they are the first to be involved in their feeding; an individual rehabilitation plan is necessary aimed at improving nutrition because each child is an individual for himself; one should discern what the child does well, in order to motivate him for future work; training for the provision of services by several caregivers should be allowed, in order to avoid the burnout of the primary caregiver; it is necessary to provide resources for social programs, which can help parents and children to face problems; organize education about risks and complications associated with aspiration for the caregivers of children with dysphagia aimed at eliminating/minimizing aspiration and enabling quality nutrition, health and quality of life; provide training for caregivers about types and methods of orofacial exercises that can be implemented in the home environment.

### Conclusion

Feeding is deemed to be a basic parenting activity. Swallowing disorders in children can have far-reaching consequences for their health and quality of life. Dysphagia is considered to be a serious problem in children, because childhood is the period of fast growth and development, and any disturbances related to nutrition can impair further development of the child, and therefore, the quality of his life.

The vulnerability of the feeding function in childhood, on the one hand, and the fact that children grow and develop fast, on the other hand, set a task to find the most appropriate models of work with these children while respecting their individuality. Therefore, the starting point in the work should always imply understanding how different



## Konflikt interesa

Autori su izjavili da nema konflikta interesa.

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health conditions can impair the quality of life of an individual aimed at finding adequate guidelines that would help these children to accomplish their goals in the functional, emotional and social domain. Also, work should be done in parallel to improve the quality of life of their caregivers.

## Competing interests

The authors declared no competing interests.

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