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# **Jutarnjost-večernjost i umor u adolescenciji**

## **/ Morningness-eveningness and Fatigue in Adolescence**

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Obrasci spavanja u adolescenciji povezani su s brojnim biološkim i psihosocijalnim promjenama koje sa sobom nosi pubertalno sazrijevanje, a koje utječu na veću sklonost večernjosti u tom razdoblju života. Kako taj novonastali ritam i učestalije deprivacije spavanja često nisu u skladu sa svakodnevnim školskim i vanškolskim obvezama, adolescenti mogu doživljavati izražene simptome umora.

Cilj provedenog istraživanja bio je ispitati obrasce spavanja i umor s obzirom na spol, kronološku dob i pubertalnu zrelost adolescenata, a pritom su korištene Ljestvica pubertalnog razvoja, Ljestvica jutarnjosti-večernjosti i Multidimenzionalna ljestvica umora. Ispitivanje je provedeno u uzorku od 233 adolescenta i 206 adolescentica u dobi od 10 do 18 godina.

Rezultati su pokazali da veću sklonost večernjosti i više simptoma umora imaju stariji i pubertalno zreliji ispitanici te da adolescentice imaju veći stupanj pubertalne zrelosti, veću sklonost večernjosti i doživljavaju više simptoma umora. Rezultati regresijske analize pokazuju da je starija kronološka dob značajni prediktor sklonosti večernjosti, a ženski spol i starija kronološka dob prediktori su doživljavanja simptoma umora. Pubertalna zrelost nije se pokazala značajnom za jutarnjost-večernjost i doživljavanje umora. Naposljetku je naglašena potreba analize dobivenih obrazaca povezanosti između jutarnjosti-večernjosti i umora s obzirom na biološke i psihosocijalne čimbenike razvojnih promjena u adolescenciji.

*/ Sleep patterns in adolescence are associated with biological and psychosocial changes as a part of pubertal development, which leads to greater preference towards eveningness. This newly formed rhythm and frequent sleep deprivation are not coordinated with school and extracurricular activities and can lead to greater fatigue symptoms. The aim of this study was to asses sleep patterns and symptoms of fatigue with regards to sex, chronological age, and pubertal maturity of adolescents. A group of 233 adolescent boys and 206 girls aged between 10 and 18 years participated in the study and were assessed using the Pubertal Development Scale, Morningness-Eveningness Scale for Children, and Multidimensional Fatigue Scale. Results indicated that older and pubertally matured adolescents had greater preference towards eveningness and fatigue symptoms. Furthermore, girls were more evening oriented, more pubertally mature, and reported more fatigue symptoms. Results of regression analysis indicated older chronological age as a significant predictor of greater eveningness. Also, female sex and older chronological age were predictors of fatigue symptoms. Pubertal maturity was not a predictor of morningness-eveningness and fatigue. Finally, we emphasize the need to include biological and psychosocial aspects of developmental changes in adolescence with regard to morningness-eveningness and fatigue in this period of life.*

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## UVOD

U posljednja dva desetljeća sve više mladih u razdoblju adolescencije izvještava o kroničnom nedostatku spavanja i umoru. Saxena, Koreti i Gaur (1) navode da se u istraživanjima, kao i u intervjuiima s adolescentima i njihovim roditeljima, uočava tendencija među mladima da kasno-večernje sate provode u budnom stanju, najčešće na socijalnim mrežama na internetu. Radi se o trendovima u navikama spavanja i povećanom umoru koji nisu rezultat samo bioloških promjena u pubertetu, već isto tako promjena u životnom stilu. U longitudinalnom istraživanju koje su u razdoblju od 1984. do 2011. godine proveli Kronholm i sur. (2) praćeni su odnosi između simptoma nesanice, umora i školskog uspjeha adolescenata. Uočeno je gotovo dvostruko povećanje broja simptoma nesanice i umora od sredine devedesetih do 2008. godine, i to podjednako u svim dobnim i spolnim skupinama ispitanih. Očekivano, umor i nesanica bili su značajno povezani sa školskim neuspjehom. Pokazalo se da je školsko postignuće kronično umornih učenika iz generacije u generaciju sve lošije, a više je i komorbidnih problema nego prije. Loša kvaliteta spavanja značajna je za pojavu klinički značajnih simptoma anksioznosti, poremećaja raspoloženja, poremećaja spavanja i drugih psihijatrijskih poremećaja kasnije u životu. Brojni čimbenici mogu negativno utjecati na kvalitetu i kvantitetu spavanja u adolescenciji, podjednako

## INTRODUCTION

In the last two decades, an increasing number of adolescents has been suffering from chronic sleep deprivation and fatigue. Saxen, Koreti, and Gaur (1) stated that studies and interviews with adolescents and their parents showed a tendency among young people to spend late night hours awake, most commonly on social networks and the Internet. These are trends in sleep habits and increased fatigue that are not only the result of biological changes during puberty, but also lifestyle changes. In the longitudinal study carried out by Kronholm *et al.* (2) in the period from 1984 to 2011, the relationship between insomnia symptoms, fatigue, and school performance among adolescents was investigated. A twofold increasing trend in insomnia symptoms and fatigue was found in the period from the mid-1990s to the end of the 2000s, and the increase was evident in all age groups and in both sexes. As expected, fatigue and insomnia were significantly associated with poor school performance. The study showed that school performance of chronically fatigued students worsened from generation to generation and there were more comorbid problems than before. Poor quality of sleep is significant for the occurrence of clinically significant symptoms of anxiety, mood disorders, sleep disorders, and other psychiatric disorders later in life. Numerous factors can negatively

internalni (pubertalni status, osobine ličnosti) kao i eksternalni čimbenici (raspored školskih i izvanškolskih aktivnosti, druženje s vršnjacima i noćni izlasci, aktivnosti na internetu i sl.).

Najuočljivije promjene povezane sa spavanjem u adolescenciji vide se u preferenciji kasnijeg odlaska na spavanje i u razlikama u rasporedu spavanja i buđenja između radnog tjedna i vikenda (3-7). Ispitivanja pokazuju da samo 15 % adolescenata spava oko 8 sati tijekom radnih dana kada moraju ići u školu, a oko 26 % adolescenata izjavljuje da spava oko 6 sati ili manje, te da nedostatak spavanja nastoje kompenzirati spavajući duže vikendom (8). Wolfson i Carskadon (9) navode da adolescenti u dobi između dešet i četrnaest godina vikendom spavaju 30 do 60 minuta duže nego tijekom radnih dana, te da se te razlike povećaju za čak dva sata do njihove osamnaeste godine. Preferencije vremena buđenja i vremena odlaska na spavanje opisuju se na dimenziji jutarnjosti-večernjosti. Za jutarnje je tipove karakteristično da ujutro lako ustaju, alertniji su u jutarnjim satima, teško im pada kasni odlazak na spavanje i brzo usnivaju. Suprotno vrijedi za večernje tipove, tj. ujutro mogu dugo spavati, alertniji su navečer, potrebno im je duže vremena da bi navečer zaspali, te se češće žale da se nisu dovoljno naspavali (10). Sklonost jutarnjosti uglavnom je više povezana s emocionalnom stabilnosti, zdravijim životnim stilom, te s manjim brojem psiholoških i psihosomatskih poteškoća. Večernost je više povezana s depresivnim tendencijama, bulimičnim ponašanjem i manjim zadovoljstvom životom (10,11).

Razlike između jutarnjih i večernjih tipova potvrđene su u mnogim dosadašnjim ispitivanjima, te se pokazalo da su djelomično naslijedene i da osobito dob, spol, kulturni i socijalni čimbenici pridonose kronotipologiji (12,13). Promjene u jutarnjosti-večernjosti događaju se tijekom cijelog života: u mlađoj dobi djeca pokazuju veću preferenciju prema jutarnjosti, u adolescenciji, osobito u dobi između dvanaeste i četrnaeste godine uočava se promjena prema

affect the quality and quantity of sleep, both internal (pubertal status, personality traits) as well as external factors (schedule of curricular and extracurricular activities, socializing with peers and nights out, Internet activities, etc.).

The most obvious changes associated with sleeping in adolescence are seen in the preference for late bedtimes and in the differences of the sleep-wake schedule between the weekdays and weekends (3-7). Studies show that only 15% of adolescents sleep as long as eight and a half hours on school nights, and 26% say they usually sleep six and a half hours or less. They try to compensate on the weekends by sleeping longer (8). Wolfson and Carskadon (9) reported that adolescents aged 10 to 14 sleep 30 to 60 minutes more during weekends than on school nights, and those differences increase by two hours until they are 18. Morning types awaken early and are more alert in the morning, and have a hard time with late bedtimes and fall asleep quickly. The opposite is true for evening types: they wake up later and are more alert in the evening, it takes them more time to fall asleep, and they often complain of being sleep deprived (10). Morningness preference is more associated with emotional stability, a healthy lifestyle, and a smaller number of psychological and psychosomatic problems. Eveningness is more associated with depressive tendencies, bulimic behavior, and lower life satisfaction (10,11).

The differences between morning and evening types have been confirmed in many previous studies, and have proved to be partially hereditary, and that age, sex, cultural, and social factors contribute to chronotyping (12,13). Changes in morningness-eveningness occur throughout life: at a younger age, children show a greater morningness preference; in adolescence, especially between ages twelve and fourteen, the change toward eveningness is observed, which will revert to a morningness preference in adulthood (10,13). In this respect,

večernjosti, da bi se u odrasloj dobi ponovno vratila preferencija jutarnjosti (10,13). U tom smislu, adolescenti su u svojevrsnom tranzicijskom razdoblju između obrasca spavanja tijekom djetinjstva i odrasle dobi. Nadalje, u većini istraživanja dobiva se veća preferencija večernjosti kod djevojčica, premda nalazimo istraživanja u kojima je dobivena veća preferencija večernjosti u dječaka (7), kao i istraživanja u kojima ta razlika nije potvrđena (3,14). Djevojke također izvještavaju o više problema sa spavanjem, a k tome se ti problemi u njih manifestiraju u ranijoj dobi nego u dječaka. Razlike između adolescenata i adolescentica u obrascima spavanja i problemima sa spavanjem najčešće se pripisuju fiziološkim i psihosocijalnim promjenama povezanim s pubertetom (15). Naime, u većine dječaka pubertet započinje oko dvanaest godine, a kod djevojčica dvije godine ranije, tako da je većina djevojčica u dobi od četrnaest godine bliže završnim fazama puberteta, dok dječaci tek tada pokazuju prve znakove puberteta (3). Početak puberteta je ujedno početak fizioloških i psiholoških čimbenika koji djeluju na spavanje (16). Proces spavanje-budnost u adolescenciji prolazi u procesu reorganizacije i to se najčešće uočava u odgođenom spavanju prema večernjosti, skraćenom ukupnom vremenu spavanja, razvoju neredovitih obrazaca spavanja, te pojavi razlike u obrascima spavanja između radnih dana i vikenda. Malobrojna longitudinalna istraživanja daju neke nove uvide u rezultate na tom području. Tako su Sadeh i sur. (16) utvrdili da promjene u spavanju tipične za pubertet (odgođeno spavanje prema večernjim satima i spavanje s prekidima) ustvari prethode tjelesnim promjenama povezanim s pubertetom. To znači da se promjene u obrascu spavanja javljaju prije pubertalnih tjelesnih promjena. Autori smatraju da je dobivene rezultate potrebno promatrati u svjetlu neurobioloških promjena povezanih sa spolnim hormonima, koje mogu biti prepoznate u mjerama organizacije spavanja prije nego što se manifestiraju u tjelesnim promjenama povezanim s pubertetom.

adolescents are in a certain transitional period between sleeping patterns during childhood and adulthood. Furthermore, in most studies, a greater morningness preference is found in girls, although there are studies where greater morningness preference is found in boys (7) as well as studies where there were no significant differences (3,14). Girls also report more on sleep problems, and these problems also manifest at an earlier age than in boys. Differences in sleep patterns between adolescent boys and girls are most often attributed to the physiological and psychosocial changes associated with puberty (15). In fact, puberty in most boys begins around the age of twelve and two years earlier in girls, so most girls are approaching the end stages of puberty at the age of fourteen, while boys are only showing the first signs of puberty (3). The onset of puberty is also the beginning of the physiological and psychological factors that affect sleep (16). In adolescence, the process of sleep and wakefulness undergoes reorganization, and this is most commonly observed in sleep delayed toward eveningness, development of irregular sleep patterns, and differences in sleep patterns between weekdays and weekends. A few longitudinal studies give some insight into results from this field of study. Sadeh *et al.* (16) found that sleep changes typical for puberty (sleep delayed toward evening and interrupted sleep) actually precede the physical changes associated with puberty. This means that changes in sleep patterns occur before the physical changes of puberty. The authors believe that the obtained results should be observed in the light of neurobiological changes associated with sex hormones which can be recognized in sleep organization before they are manifested in body-related changes associated with puberty.

Whether or not the changes in sleep patterns and sleep difficulties are a result of biological changes, overloaded daily schedule, or adolescent lifestyle, they usually result in fatigue and

Promjene u obrascu spavanja i teškoće sa spavanjem, bez obzira jesu li rezultat bioloških promjena, pretrpanog dnevnog rasporeda, ili životnog stila adolescenta, najčešće za posljedicu imaju umor i oslabljeno svakodnevno funkcioniranje (9,17). Umor označava osjećaj abnormalne iscrpljenosti nakon inače uobičajenih aktivnosti. Ako umor potraje dulje od šest mjeseci može se govoriti o sindromu kroničnog umora koji može biti povezan s drugim somatskim simptomima. Procjenjuje se da u općoj populaciji 15 % do 30 % adolescenata često doživljava simptome umora, a 0,5 do 2 % ispunjava kriterije za kronični umor (18). Umor može nastati zbog već spomenutih promjena u obrascu i arhitekturi spavanja i njihove neusklađenosti sa školskim i drugim obvezama tijekom radnih dana i vikendom. Budući da se cirkadiurni sustav sporo adaptira na ove promjene produženo spavanje tijekom vikenda može uzrokovati simptome *jet lag-a* u početku radnog tjedna, osobito ako je nastava u jutarnjoj smjeni (19). Očekivano je da mnogi adolescenti tada osjeće izražene simptome umora jer se nastoje probuditi u vrijeme kada njihovo tijelo nije spremno za buđenje i aktivnost, tj. kada je temperatura njihova tijela najniža. Općenito, zanemareni signali umora tijekom adolescencije mogu imati brojne dugoročne negativne posljedice na zdravlje i kvalitetu života.

Unatoč naprijed navedenim nalazima uočava se da obrasci spavanja i umor u adolescenciji nisu istraživani u mjeri u kojoj bi to bilo očekivano (20). Stoga smo ovim istraživanjem nastojali ispitati preferenciju jutarnjosti-večernjosti i doživljavanje umora u adolescenciji u odnosu na spol, dob i pubertalni status ispitanika. Zbog brojnih interindividualnih razlika u početku i trajanju pubertalnih promjena u ovom istraživanju je uz kronološku dob u obzir uzeta i mjera pubertalne zrelosti. Naime, Keresteš, Brković i Kuterovac Jagodić (21,22) navode da stručnjaci na području psihologije adolescencije upozoravaju da zbog velikih razlika u vremenu

impaired daily functioning (9,17). Fatigue is indicated by a feeling of abnormal exhaustion after otherwise normal activities. If fatigue lasts for longer than six months, chronic fatigue syndrome that may be related to other somatic symptoms should be considered. It is estimated that around 15 to 30% of adolescents in the general population often experience symptoms of fatigue, and 0.5 to 2% meet the criteria of chronic fatigue (18). Fatigue may arise due to the already mentioned changes in the pattern and architecture of sleep and inconsistency of school and other responsibilities during weekdays and weekends. Since the circadian system adapts to these changes slowly, extended sleep over the weekend may cause jet lag symptoms at the beginning of the work week, especially if classes are in the morning shift (19). It is expected that many adolescents experience pronounced fatigue symptoms as they try to wake up on time and their bodies are not prepared for waking and activity, i.e. their body temperature is at its lowest level. In general, neglected fatigue symptoms during adolescence may have long-term negative consequences on health and quality of life.

Despite the above findings, it has been noticed that sleep patterns and fatigue in adolescence have not been investigated to the expected extent (20). With this study we have therefore tried to investigate the morningness-eveningness preference and experience of fatigue in adolescence in relation to sex, age, and the pubertal status of the respondents. Due to the numerous interindividual differences and the duration of pubertal changes, measures of pubertal maturity besides chronological age were taken into account in this study. In fact, Keresteš, Brković, and Kuterovac Jagodić (21,22) state that experts in the field of adolescent psychology warn that because of large variations in the onset of puberty and the rate of change and maturation, chronological age is not a sufficient indicator of the degree of phys-

početka puberteta, te brzine promjena i sazrijevanja, kronološka dob nije dovoljan pokazatelj stupnja tjelesne zrelosti. To je osobito izraženo u razdoblju rane adolescencije kada su promjene povezane s pubertetom najizraženije. Iako je stupanj pubertalne zrelosti u korelaciji s kronološkom dobi, povezanost je umjerene veličine te autori smatraju da je to nedovoljno da bi se opravdalo korištenje kronološke dobi kao pokazatelja pubertalne zrelosti adolescenata.

U skladu s navedenim, glavni cilj ovoga istraživanja je ispitati povezanost između spola, kronološke dobi, pubertalnog statusa, te jutarnjosti večernjosti i simptoma umora. Pri tome se pošlo od pretpostavke da će pubertalno zreliji adolescenti pokazivati veću tendenciju ka večernjosti, te da će doživljavati veće razine umora. Također, provjero je postoji li razlika između adolescenata i adolescentica u pubertalnoj zrelosti, obrascu spavanja i doživljavanju simptoma umora, jer podatci iz dosadašnjih istraživanja uglavnom pokazuju da su djevojke pubertalno zrelije i sklonije večernjosti, te shodno tome izvještavaju o više simptoma umora. Na kraju, ispitano je u kojoj mjeri kronološka dob i pubertalni status mogu objasniti jutarnost-večernost i umor kada se kontrolira varijabla spola ispitanika. S obzirom da se u dosadašnjim istraživanjima dobivaju značajne pozitivne korelacije između kronološke dobi i pubertalne zrelosti, bilo je zanimljivo ispitati koliki je sa mostalni doprinos svake varijable u objašnjenju jutarnjosti-večernjosti i umora u adolescenciji.

## METODA

### Ispitanici

Ispitivanje je provedeno u osnovnoj školi i dvije gimnazije u Zadru. U istraživanju je sudjelovalo 439 učenika u dobi od 10 do 18 godina, od toga 233 adolescenta i 206 adolescentica. U osnovnoj su školi ispitani učenici 5., 6., 7. i 8. razreda ( $N=248$ ), a u srednjim školama 1., 2. i 3. razre-

ical maturity. This is particularly visible in early adolescence when pubertal changes are most pronounced. Although the degree of pubertal maturity is in correlation with chronological age, the relationship is moderate in size and the authors consider that it is insufficient to justify the use of chronological age as an indicator of pubertal maturity in adolescents.

Accordingly, the main objective of this study was to examine the correlation between sex, chronological age, pubertal status, as well as the morningness-eveningness and symptoms of fatigue. We started from the hypothesis that adolescents with higher pubertal maturity will show a greater tendency toward eveningness and will experience higher levels of fatigue. It was also ascertained whether there was a difference between adolescent boys and girls in pubertal maturity, sleep patterns, and fatigue symptoms experience, as data from previous studies showed that girls are more mature and prone to eveningness and therefore have more fatigue symptoms. Finally, we examined to what extent chronological age and pubertal status can explain the morningness-eveningness preference and fatigue when the sex variable of the respondents is controlled. Given that significant positive correlations between chronological age and pubertal maturity were found in previous studies, it was interesting to examine the individual share of each variable in the explanation of the morningness-eveningness and fatigue in adolescence.

## METHOD

### Respondents

The study was conducted at an elementary school and two grammar schools in Zadar. The study included 439 students 10-18 years old, of which 233 were adolescent boys and 206 adolescent girls. The respondents from elementary school were 5<sup>th</sup>, 6<sup>th</sup>, 7<sup>th</sup>, and 8<sup>th</sup> grade students

da ( $N=188$ ). Prosječna dob ispitanika u ovom uzorku iznosila je  $M=14,33$  godine ( $SD=1,97$ ), a adolescentice i adolescenti nisu se razlikovali s obzirom na kronološku dob ( $M_M=14,29$ ;  $SD_M=1,95$ ;  $M_Z=14,38$ ;  $SD_Z=1,99$ ).

## Mjerni instrumenti

*Ljestvica pubertalnog razvoja* (*Pubertal Development Scale*, PDS, Petersen i sur., 1988; 21,22) je samoizvještajna metoda koja se sastoji od pet čestica kojima su opisane tjelesne promjene koje se događaju u pubertetu. Tri su čestice zajedničke i adolescenticama i adolescentima, dok su dvije čestice specifične za pojedini spol. Na pitanja se odgovara na ljestvici od 4 stupnja: 1 „označava to mi se još nije počelo događati“, 2 „to mi se počelo događati“, 3 „to mi se već neko vrijeme događa“, i 4 „to je kod mene već završeno“. U upitniku je bio ponuđen i odgovor 5 koji je označavao „ne znam“ i koji se nije bodovalo. Ukupni rezultat na PDS-u određuje se kao prosječan rezultat na pet čestica upitnika, a na temelju tog rezultata određene su kategorije pubertalnog statusa: prepubertet (rezultat 0 – 1,7), početak puberteta (rezultat 1,8 – 2,4), sredina puberteta (rezultat 2,5 – 3), poodmakli pubertet (rezultat 3,1 – 3,6) i postpubertet (rezultat 3,7 – 4). Za primjenu u našoj populaciji ljestvicu su prilagodile Keresteš i suradnici (21,22), a rezultati pokazuju kako je riječ o pouzdanoj i valjanoj mjeri pubertalnog razvoja koja značajno korelira s liječničkim procjenama Tannerovih stadija pubertalnog razvoja.

*Ljestvica jutarnjosti-večernjosti* (*Morningness-Eveningness Scale for Children*, MESC; 4,12) namijenjena je ispitivanju jutarnjosti-večernjosti u djece osnovnoškolske i srednjoškolske dobi. Sastoji se od 10 pitanja, a zadatak ispitanika je označiti onaj odgovor koji se najviše odnosi na njega. Bodovanje je u rasponu od 1 do 4 ili 5, ovisno o broju ponuđenih odgovora, a ukupni se rezultat na ljestvici dobije zbrajanjem bodova na pojedinim česticama. Raspon rezultata

( $N=248$ ), and in grammar schools they were 1<sup>st</sup>, 2<sup>nd</sup>, and 3<sup>rd</sup> grade students ( $N=188$ ). The average age of the respondents in this sample was  $M=14.33$  years ( $SD=1.97$ ), and there were no differences in terms of the chronological age of adolescent boys and girls ( $MM = 14.29$ ,  $SDM = 1.95$ ,  $M = 14.38$ ;  $SDF = 1.99$ ).

## Measuring instruments

*Pubertal Development Scale* (PDS, Petersen et.al., 1988; 21,22) is a self-report instrument, and it consists of five items that describe the physical changes in puberty. Three items are shared by both adolescent boys and girls, while two are specific to each sex. Questions are answered by a four-degree scale: 1 indicates “this has not yet happened to me”, 2 “this started to happen to me”, 3 “this has been happening to me for some time”, 4 “this already ended for me”. The questionnaire also offered a 5<sup>th</sup> option, “I do not know”, which was not scored. The total result on the PDS was determined as an average result on the five items of the questionnaire, and five categories identifying different the pubertal status were labeled on the basis of that result: pre-puberty (score 0-1.7), onset of puberty (score 1.8-2.4), mid-puberty (score 2.5-3), advanced puberty (3.1-3.6) and post-puberty (score 3.7-4). Keresteš et.al. (21,22) adjusted the scale for the application on our population, and the results show that it is a reliable and valid measure of pubertal development that significantly correlates with medial assessment of the Tanner scale of physical development.

*Morningness-eveningness Scale for Children* (MESC; 4,12) is used to assess morningness-eveningness in children of elementary and secondary school age. It is composed of 10 questions, and the respondents were asked to mark the answer that relates to them. Scoring was in the range from 1 to 4 or 5, depending on the number of offered answers, and the final

se kreće od 10 do 43 pri čemu veći rezultat na ljestvici ukazuje na veću jutarnost. U prvoj primjeni ove ljestvice na našoj populaciji dobiven je Cronbachov alfa  $\alpha = .74$  (3).

*Multidimenijska ljestvica umora (Multidimensional Fatigue Scale, MFS, Varni i sur., 2002; 23)* sastoji se od 18 čestica, a služi za samoprocjenu umora (za dob od 5 do 18 godina). Ispitanici na ljestvici od 5 stupnjeva procjenjuju koliko ih često muče određeni simptomi povezani s umorom. Raspon odgovora kreće se od *nikad* (koje se budi kao 100) do *gotovo uvijek* (koje se budi kao 0). Rezultati u ljestvici MFS mogu se analizirati na razini ukupnog rezulta ta i/ili na razini 3 podljestvice: umora, spavanja i kognitivnog umora. Za potrebe ovog rada, kao pokazatelj doživljavanja umora, korišten je samo ukupni rezultat. Veći rezultat na ljestvici ukazuje na bolju kvalitetu života povezanu sa zdravljem i manje simptoma umora. Psihometrijskom evaluacijom ljestvice uglavnom se dobivaju pokazatelji pouzdanosti u rasponu od 0.77 do 0.93 (23).

Prema deskriptivnim parametrima i koeficijentima pouzdanosti (tablica 1) sva tri instrumenata imaju zadovoljavajuće psihometrijske kvalitete, a dobiveni pokazatelji u skladu su s nalazima u dosadašnjim primjenama.

## Postupak

Upitnici su primjenjeni skupno u vrijeme održavanja redovite nastave. Sudjelovanje u istraživanju bilo je dobrovoljno i anonimno, a provedeno je uz dozvolu ravnatelja škola. Upitnike su primjenili školski psiholog i apsolvent psihologije. Prije primjene upitnika svim je

rezultat na skali dobit dobit po dodavanju poena svakog od predstavljenih predmeta. Rezultat je bio u rasponu od 10 do 43, gdje je veći rezultat označavao veću jutarnost. U prvom primjenjivanju na našoj populaciji dobit je Cronbachov alfa  $\alpha = .74$  (3).

*Multidimensional Fatigue Scale (MFS, Varni et.al. 2002; 23)* sastoji se od 18 predmeta i mjeri umor (starost 5-18). Na skali od 1 do 5, respondenti ocjenjuju koliko često određeni simptomi povezani s umorom su im učinak. Raspon odgovora kreće se od *never* (100 poena) do *nearly always* (0 poena). Rezultati na MF skali mogu se analizirati na ukupnom rezultatu i/ili na 3 podskali: General Fatigue, Sleep/Rest Fatigue, i Cognitive Fatigue. Veći rezultat na skali označava bolju kvalitetu života povezanu sa zdravljem i manje simptoma umora. Indeks pouzdanosti rangira od 0.77 do 0.93 (23) i obično se dobiva putem psihometrijske evaluacije skale.

Po podacima o opisnim parametrima i indeksima pouzdanosti (Tablica 1), svi tri instrumenti imaju zadovoljavajuće psihometrijske kvalitete, a dobiveni indeksi su u skladu s rezultatima prethodnih primjena.

## Procedure

Upitnici su primjenjeni skupno u vrijeme održavanja redovite nastave. Sudjelovanje u istraživanju bilo je dobrovoljno i anonimno, a provedeno je uz dozvolu ravnatelja škola. Upitnike su primjenili školski psiholog i apsolvent psihologije. Prije primjene upitnika svim je

**TABLE 1.** Descriptive indexes of the applied measuring instruments (N=439)

Scale		Number of items	Range	Arithmetic mean (M)	Standard deviation (SD)	Cronbach alpha	Average $r_{it}$
MESC	Morningness-eveningness Scale for Children	10	10-43	26.46	5.42	.80	.28
PDS	Pubertal Development Scale	5	0-4	2.75	.75	.83	.50
MFS	Multidimensional Fatigue Scale	18	0-100	69.19	15.60	.89	.31

ispitanicima objašnjen cilj ispitivanja, a zatim im je pročitana uputa o načinu popunjavanja upitnika. Zadatak ispitanika bio je da nakon što pročitaju svaku tvrdnju zaokruže odgovarajući broj s desne strane. Vrijeme rješavanja nije bilo ograničeno, a u prosjeku je trajalo oko 15 minuta.

## Statistička analiza

Kako bi se odgovorilo na postavljene ciljeve, u obradi rezultata primijenjeni su t-testovi, korelacije i regresijske analize. T-testovi su primijenjeni u ispitivanju razlika u kronološkoj dobi adolescenata i adolescentica u pojedinim kategorijama pubertalnog statusa te u ispitivanju razlika u ispitivanim varijablama između adolescenata i adolescentica. Pearsonovim koeficijentima korelacija određen je stupanj povezanosti između varijabli korištenih u istraživanju.

Kako bismo odgovorili na treći cilj ovoga istraživanja primijenjena je hijerarhijska regresijska analiza te smo provjerili u kojoj mjeri spol, kronološka dob i pubertalni status mogu objasniti jutarnjost-večernjost i doživljavanje umora u adolescenciji. U prediktorski skup varijabli uključeni su spol, kronološka dob i stupanj pubertalne zrelosti, a kriterijska varijabla u prvoj analizi bila je jutarnjost-večernjost, a u drugoj doživljavanje umora. Provedene su po dvije hijerarhijske regresijske analize za svaki kriterij s ciljem provjere razlika u samostalnom doprinosu kronološke dobi i pubertalnog statusa (varianjem redoslijeda unošenja tih dviju varijabli u regresijsku jednadžbu) objašnjenju varijance jutarnjosti-večernjosti, odnosno doživljavanja umora.

## REZULTATI

Prije naprijed navedenih statističkih analiza provjeren je pubertalni status ispitanika u ovom uzorku. Pet kategorija pubertalnog sta-

right side. There was no time limit, and it took an average of 15 minutes.

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## Statistical analysis

T-tests, correlations, and regression analyses were used for data processing in order to verify the set objectives. T-tests were used to test the differences in the chronological age of adolescent boys and girls in certain categories of the pubertal status and differences in the tested variables between adolescent boys and girls. The Pearson correlation coefficient determined the relationship between the variables used in the study.

In order to fulfill the third objective of the study, a hierarchy regression analysis was applied, and we were able to ascertain to what degree sex, chronological age, and pubertal status can explain morningness-eveningness and experience of fatigue in adolescence. The predictor variables included sex, chronological age, and the degree of pubertal maturity, and the criterion variable in the first analysis was morningness-eveningness while it was the experience of fatigue in the second analysis. Two hierarchy regression analyses were conducted for each criterion to ascertain the differences in the independent contribution of the chronological age and pubertal status (variance of the entry order of these two variables in the regression equation) in explaining the variance of the morningness-eveningness and experience of fatigue.

## RESULTS

The pubertal status of the respondents in this sample was verified before the abovementioned statistical analysis. Five categories of pubertal status were determined according to the criterions described in the chapter on measuring instruments: pre-puberty, onset of puberty, mid-puberty, advanced puberty, and

tusa određeno je prema kriterijima opisanima u poglavlju o mjernim instrumentima: prepubertet, početak puberteta, sredina puberteta, poodmakli pubertet i postpubertet. Deskriptivni pokazatelji za tih pet kategorija, te pripadajući podatci o kronološkoj dobi ispitanika u svakoj kategoriji prikazani su u tablici 2.

Rezultati t-testa pokazali su da se adolescenti i adolescentice značajno razlikuju s obzirom na prosječnu kronološku dob u četiri od pet ispitivanih kategorija pubertalne zrelosti. Premda se radi o vrlo malim razlikama u prosječnoj kronološkoj dobi, one su značajne i pokazuju da su u svim kategorijama adolescenti nešto stariji od adolescentica, tj. da su pubertalno nezreliji od adolescentica. Rezultati prikazani na sl. 1. daju precizniji uvid u dobivene razlike. Prikazan je postotak ispitanika u svakoj kategoriji pubertalnog statusa. Kao što se moglo i očekivati, u usporedbi sa svojim muškim vršnjacima, adolescentice su uglavnom pubertalno zrelijе. Npr. u prve tri kategorije (prepubertet, početak puberteta i sredina puberteta) nalazi se 75,53 % adolescenata i 43,21 % adolescentica, dok se u zadnje dvije kategorije (poodmakli pubertet i postpubertet) nalazi 24,46 % adolescenata i čak 56,8 % adolescentica. Treba podsjetiti da se adolescenti i adolescentice u ovom istraživanju nisu značajno razlikovali s obzirom na prosječnu kronološku dob.

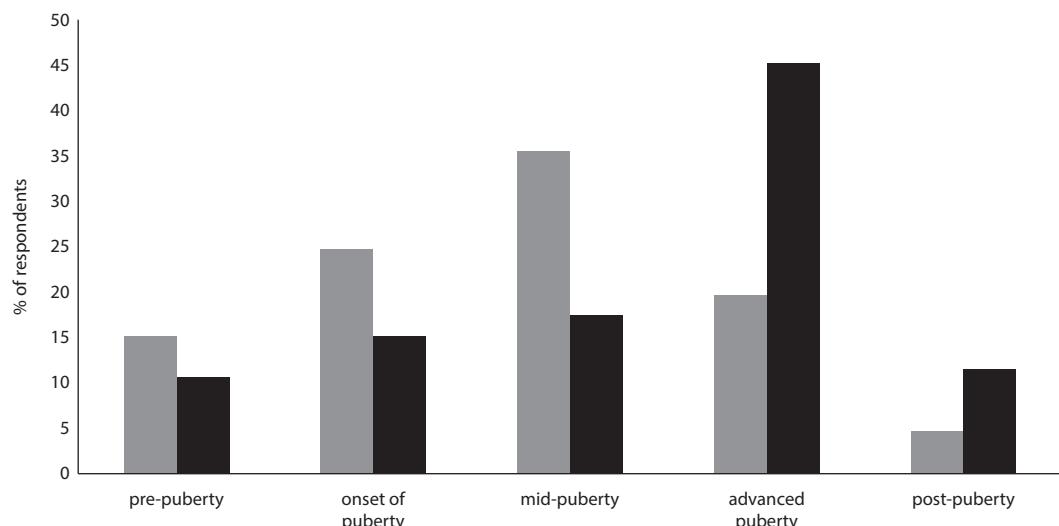
post-puberty. Descriptive indexes for these five categories and the associated results on the chronological age of the respondents in each category are shown in Table 2.

The results of the t-test showed significant differences between adolescent boys and girls with respect to chronological age in four out of five tested categories of pubertal maturity. Although the differences were very small in average chronological age, they were significant and showed that adolescent boys were slightly older than adolescent girls in all categories, i.e. they had a lower pubertal maturity than adolescent girls. The results shown in Figure 1 offer a more precise insight of the obtained differences. The percentage of the respondents for each category of the pubertal status is shown in Figure 1. As expected, when compared to their male peers, adolescent girls had a higher pubertal maturity. For example, in the first three categories (pre-puberty, onset of puberty, and mid-puberty) there were 75.53% of adolescent boys and 43.21% of adolescent girls, while in the last two categories (advanced puberty and post-puberty) there were 24.46% of adolescent boys and 56.8% of adolescent girls. It should be mentioned that there were no significant differences in regard to average chronological age between adolescent boys and girls.

**TABLE 2.** Arithmetic means, standard deviations, t-values, and statistical significance in chronological age of adolescent boys and girls in each category of the pubertal status

Categories of pubertal status	Chronological age						
	Adolescent boys (N=233)			Adolescent girls (N=206)			
	M	SD	N	M	SD	N	t-test
Pre-puberty	11.96	0.86	35	11.78	0.77	22	.81
Onset of puberty	13.26	1.45	58	12.31	0.96	31	3.29**
Mid-puberty	14.64	1.48	83	13.60	1.40	36	3.58**
Advanced puberty	16.04	1.12	46	15.43	1.34	93	2.68**
Post-puberty	17.24	0.45	11	16.50	1.09	24	2.16*

\*p<0.5, \*\*p<0.1



**FIGURE 1.** Percentage of adolescent boys (light grey) and percentage of adolescent girls (dark grey) in each category of the pubertal status (N=439)

## Povezanosti između ispitivanih varijabli

Provjerom stupnja povezanosti između ispitivanih varijabli utvrđene su statistički značajne korelacije između gotovo svih ispitivanih varijabli ( $p < .05$ ).

Iz tablice 3 je vidljivo da su najniže korelacije dobivene između spola i ispitivanih varijabli. Očekivano, najviša korelacija utvrđena je između kronološke dobi i pubertalnog statusa ( $r = .76$ ). Rezultati na ljestvici jutarnjosti-večernjosti bili su podjednako povezani s kronološkom dobi ( $r = -.34$ ) i pubertalnim statusom ( $r = -.36$ ). Slične relacije dobivene su između doživljavanja umora i kronološke dobi ( $r = -.37$ ), te umora i pubertalnog statusa ( $r = -.33$ ). Umjereni visoka korelacija dobivena je između rezul-

## Relationship between examined variables

Statistically significant correlations between virtually all examined variables were established after the verification of the relationships between them ( $p < .05$ ).

Table 3 shows the lowest correlations are between sex and the examined variables. As expected, the highest correlation was between chronological age and pubertal status ( $r = .76$ ). The results on the Morningness-eveningness Scale were equally associated with chronological age ( $r = -.34$ ) and pubertal status ( $r = -.36$ ). Similar relationships were obtained between the experience of fatigue and chronological age ( $r = -.37$ ) and fatigue and pubertal status ( $r = -.33$ ). A moderately high correlation was

**TABLE 3.** Pearson correlation coefficient between examined variables (N=439)

	Sex	Chronological age	PDS	MESC
Sex				
Chronological age	.02			
PDS      Pubertal Development Scale	.24*	.76*		
MESC      Morningness-eveningness Scale for Children	-.09*	-.34*	-.36*	
MFS      Multidimensional Fatigue Scale	-.13*	-.37*	-.33*	.51*

tata na ljestvici jutarnjosti-večernjosti i ljestvici umora i iznosila je  $r=.51$ .

found between the results on the Morningness-eveningness Scale and Fatigue scale,  $r=.51$ .

## Razlike u ispitivanim varijablama s obzirom na spol ispitanika

Adolescenti i adolescentice u ovom istraživanju bili su gotovo identične prosječne dobi, ali su se statistički značajno razlikovali u rezultatima na ljestvici pubertalnog razvoja, ljestvici jutarnjosti-večernjosti i multidimenzionalnoj ljestvici umora (tablica 4).

Uvidom u dobivene pokazatelje može se uočiti da su adolescentice bile pubertalno zrelije, imale su veću sklonost večernjosti i osjećale su se umornije od adolescenata.

## Rezultati hijerarhijske regresijske analize

U tablici 5 prikazani su rezultati provedenih analiza za kriterijsku varijablu jutarnjost-večernjost. Analiza je provedena u tri koraka, a redoslijed uvrštavanja pojedinih prediktorskih varijabli u regresijsku jednadžbu bio je sljedeći: u prvom koraku uvrštena je varijabla spola, u drugom je dodana varijabla pubertalnog statusa i u trećem varijabla kronološke dobi. Nakon toga, provedena je hijerarhijska analiza s istom kriterijskom varijablom (jutarnjost-večernjost) s promijenjenim redoslijedom uvrštavanja prediktorskih varijabli u regresijsku jednadžbu: u prvom koraku opet je uvrštena varijabla spola, a zatim je u drugom dodana

## Differences in examined variables with regard to the sex of the respondents

Adolescent boys and girls in this study had almost identical average age, but statistically significant differences were found in results on the Pubertal Development Scale, Morningness-eveningness Scale, and Multidimensional Fatigue Scale (Table 4).

After examining the obtained indicators, it can be observed that adolescent girls had a higher score of pubertal maturity, a higher eveningness preference, and were more fatigued than adolescent boys.

## Results of hierarchy regression analysis

Table 5 shows results of the analysis for the criterion variable of morningness-eveningness. The analysis was carried out in three steps, and the order of inclusion of certain predictor variables into the regression equation was the following: in the first step, the sex variable was included, the variable of pubertal status in the second step, and the variable of chronological age in the third step. After this, a hierarchy analysis was conducted, with the same criterion variable (morningness-eveningness) but a different order of inclusion of predictor varia-

**TABLE 4.** Arithmetic means, standard deviations, t-values, and statistical significance of the examined variables between adolescent boys and girls

		Adolescent boys (N=233)		Adolescent girls (N=206)		
		M	SD	M	SD	t-test
PDS	Pubertal Development Scale	2.74	1.08	3.32	1.18	5.34**
MESC	Morningness-eveningness Scale for Children	26.94	5.26	25.91	5.57	-1.99*
MFS	Multidimensional Fatigue Scale	71.03	15.09	67.11	15.93	-2.64**

\* $p<.05$ , \*\* $p<.01$

**TABLE 5.** Results of the hierarchy regression analysis for the morningness-eveningness criterion with the variables of sex, chronological age, and pubertal status as predictor variables (N=439)

Morningness-eveningness				
Step	Predictors	$\beta$	R <sup>2</sup>	$\Delta R^2$
1st Step	Sex	-.094*	.009	-
2nd Step	Sex Chronological age	-.088 -.341**	.125**	.116**
3rd Step	Sex Chronological age Pubertal status	-.069 -.280** -.083	.128**	.003
Morningness-eveningness				
Step	Predictors	$\beta$	R <sup>2</sup>	$\Delta R^2$
1st Step	Sex	-.094*	.009*	-
2nd Step	Sex Pubertal status	-.019 -.304**	.096	.086**
3rd Step	Sex Pubertal status Chronological age	-.069 -.083 -.280**	.128**	.032**

\*p<.05, \*\*p<.01

kronološka dob i u trećem varijabla pubertalnog statusa.

Rezultati hijerarhijske regresijske analize pokazuju da se opisanim setom prediktora (spol, kronološka dob i pubertalni status) može objasniti 12,8 % varijance jutarnjosti-večernjosti, pri čemu se pubertalni status nije pokazao značajnim prediktorom. Spol je bio značajni prediktor u prvom koraku obje analize, a rezultat ukazuje da su adolescentice značajno sklonije večernjosti od adolescenata. No, kada se u drugom koraku analize kontrolira doprinos spola objašnjenju varijance jutarnjosti-večernjosti i doda kronološka dob, spol više nije značajan prediktor, a samostalni dodatni doprinos kronološke dobi u tom drugom koraku iznosi 11,6 %. Nakon kontrole doprinosa spola i kronološke dobi u trećem koraku provjeren je samostalni doprinos varijable pubertalni status. Pokazalo se da taj doprinos nije statistički značajan.

U drugom slučaju hijerarhijske regresijske analize promijenjen je redoslijed dodavanja prediktora u regresijsku jednadžbu. Kao što se može vidjeti u tablici 5, u drugom koraku, kada je kontroliran doprinos varijable spola, pubertal-

bles into the regression equation: the sex variable was included again in the first step, after which chronological age in the second step and the variable of pubertal status in the third step.

The results of the hierarchy regression analysis show that the described set of predictors (sex, chronological age, and the pubertal status) can explain 12.8% of the variance in the morningness-eveningness, where the pubertal status was not a significant predictor. Sex was a significant predictor in the first step in both of the analyses, and the results indicated that adolescent girls had a higher eveningness preference than adolescent boys. However, when, in the second step of the analysis, the contribution of sex was controlled in the explanation of the morningness-eveningness and chronological age, then sex was no longer a significant predictor, and the independent contribution of chronological age in the second step was 11.6%. After control of the contribution of sex and chronological age in the third step, the independent contribution of the pubertal status variable was ascertained. The contribution of the pubertal status was not statistically significant.

In the second hierarchy analysis, the order of inclusion of predictor variables into the regres-

ni status je imao značajan dodatni samostalni doprinos varijanci jutarnjosti-večernjosti i iznosi je 8,6 %. No, u trećem koraku, kada je dodana kronološka dob, pubertalni status više nije bio značajan, a samostalni doprinos kronološke dobi objašnjenu varijance jutarnjosti-večernjosti bio je 3,2 %. Na temelju provedenih analiza može se zaključiti da je kronološka dob „jači“ prediktor jutarnjosti-večernjosti od pubertalnog statusa.

Isti postupak ponovljen je i za kriterijsku varijablu umora. Rezultati (tablica 6) upućuju na to da se setom prediktora (spol, kronološka dob i pubertalni status) može objasniti 14,9 % varijance umora, a pubertalni status ni u ovoj analizi nije bio značajni prediktor.

Spol je značajni prediktor u sva tri koraka analize, a rezultat ukazuje da su adolescentice značajno sklonije doživljavanju simptoma umora od adolescenata. Kada se u drugom koraku analize kontrolira doprinos spola objašnjenu varijance umora, samostalni dodatni doprinos kronološke dobi iznosi 13,4 %. Nakon kontrole doprinosa spola i kronološke dobi u trećem koraku, samostalni doprinos varijable pubertalni status nije se pokazao statistički značajnim. U nastavku, promijenjen je redoslijed dodavanja prediktora u regresijsku jednadžbu (drugi dio tablice 6). Uz kontrolu spola, u drugom koraku analize, pubertalni status je imao značajan dodatni samostalni doprinos varijanci doživljavanja umora i iznosi je 7,6 %. No, u trećem koraku, kada je dodana kronološka dob, pubertalni status više nije bio značajan, a kronološka dob samostalno je doprinijela objašnjenu varijance umora za dodatnih 5,7 %.

Zaključno, može se reći da se opisanim setom prediktorskih varijabli (spol, kronološka dob, pubertalni status) može objasniti 12,8 % ukupne varijance jutarnjosti-večernjosti i 14,9 % ukupne varijance umora. Treba napomenuti da uvođenjem varijable kronološke dobi varijabla pubertalne zrelosti postaje statistički neznačajna. Na temelju dobivenih rezultata može se

sion equation was altered. As we can see in Table 5, in the second step, when the contribution of the sex variable was controlled, the pubertal status had a significant additional contribution in the morningness-eveningness variance, 8.6%. However, in the third step, when chronological age was added, the pubertal status was no longer significant and the independent contribution of the chronological age in the morningness-eveningness variance was 3.2%. Based on the analysis, we can conclude that chronological age was a “stronger” predictor of the morningness-eveningness than pubertal status.

The same procedure was repeated for the fatigue criterion. Results (Table 6) show that the set of predictors (sex, chronological age, pubertal status) can explain the 14.9% fatigue variance and that the pubertal status was not a significant predictor in this analysis. Sex was a significant predictor in all three steps of the analysis, and the results indicate that adolescent girls were significantly more prone to the experience of fatigue than adolescent boys. When, in the second step, the contribution of sex in the explanation of the fatigue variance was controlled, the additional independent contribution of the chronological age was 13.4%. After controlling of the contribution of sex and chronological age in the third step, the independent contribution of the pubertal status variable did not prove statistically significant. Furthermore, the order of inclusion of predictors into the regression equation was altered (part two of Table 6). With the control of sex in the second step of the analysis, pubertal status had a significant independent contribution in the experience of fatigue variance and was 7.6%. However, in the third step, when chronological age was added, the contribution of pubertal status was no longer significant, and chronological age independently contributed to the explanation of the fatigue variance by 5.7%.

In conclusion, we can say that the described set of predictor variables (sex, chronological age, and pubertal status) can explain the 12.8%

**TABLE 6.** Results of hierarchy regression analysis for the fatigue criterion with variables of sex, chronological age, and the pubertal status with predictor variables (N=439)

Fatigue					
Step	Predictors	$\beta$	R <sup>2</sup>	$\Delta R^2$	
1st Step	Sex	-.125**	.016		
2nd Step	Sex Chronological age	-.118** -.366**	.149	.134**	
3rd Step	Sex Chronological age Pubertal status	-.120** -.372** .009	.149	.000	
Fatigue					
Step	Predictors	$\beta$	R <sup>2</sup>	$\Delta R^2$	
1st Step	Sex	-.125	.016		
2nd Step	Sex Pubertal status	-.055 -.286**	.092	.076**	
3rd Step	Sex Pubertal status Chronological age	-.120** .008 -.372**	.149	.057**	

\*p<.05, \*\*p<.01

zaključiti da su u ovom uzorku ispitanika jutarnjost-večernjost i umor povezani s pubertalnim statusom preko varijable kronološke dobi.

## RASPRAVA

Dobiveni rezultati provjere odnosa pubertalnog statusa, kronološke dobi i spola u skladu su s očekivanjima: u usporedbi s adolescentima, adolescentice su uglavnom pubertalno zrelijе. Na to ukazuju dva pokazatelja: 1) adolescentice u svim kategorijama pubertalne zrelosti su kronološki mlađe od adolescentata i 2) u kategorijama veće pubertalne zrelosti više je adolescentica. Dobiveni rezultati u skladu su s dosadašnjim nalazima prema kojima pubertalne promjene kod djevojčica najčešće započinju ranije nego kod dječaka. Nadalje, pokazalo se da kronološka dob i pubertalna zrelost visoko koreliraju i značajno su povezane sa sklonosti večernjosti i doživljavanjem umora. Adolescenti i adolescentice s dobi razvijaju večernji obrazac spavanja i doživljjavaju sve više simptoma umora. Sve tri ispitivane varijable (ženski spol, starija kronološka dob i veća pubertalna zrelost) zajedno objašnjavaju 12,8 % varijan-

overall morningness-eveningness variance and 14.9% overall fatigue variance. It should be noted that by introducing the chronological age variable, the pubertal maturity became statistically insignificant. Based on the obtained results, we can conclude that morningness-eveningness and fatigue were associated with pubertal status through the variable of chronological age in the respondents from this sample.

## DISCUSSION

The results from the relationship of the pubertal status, chronological age, and sex are in line with the expectations: when compared to adolescent boys, adolescent girls have higher pubertal maturity. Two indicators point to this: 1) in all of the categories of pubertal maturity, adolescent girls are chronology younger than adolescent boys, and 2) there are more adolescent girls in categories of higher pubertal maturity. The obtained results are in concordance with other findings so far, according to which the pubertal changes in girls start earlier than in boys. Furthermore, it has been shown that the chronological age and pubertal maturity are highly

ce jutarnjosti-večernjosti i 14,9 % varijance umora. Biološki čimbenici koji u adolescenciji pridonose pomaku k večernjosti vezani su za pomak u fazi endogenih cirkadiurnih ritmova i sporiju akumulaciju homeostatskog pritiska spavanja (12). No, biološki uvjetovane promjene u stalnoj su interakciji s brojnim psihosocijalnim čimbenicima. Ulaskom u pubertet adolescenti su skloniji u večernjim satima baviti se aktivnostima svojstvenim odraslima (kasniji izlasci, druženja s prijateljima, gledanje televizije), za razliku od ranijih razdoblja života. Nadalje, roditeljski nadzor se smanjuje u brojnim aspektima života mlade osobe, pa tako i nad vremenom odlaska na spavanje i načinom provođenja vremena prije spavanja (5,7). Nemali broj adolescenata do kasnih noćnih sati provodi vrijeme na internetu ili čak ostavljaju tijekom noći uključen mobitel kako bi u svakom trenutku bili dostupni vršnjacima (12), a istraživači naglašavaju da upravo gledanje TV-a i socijalno druženje na internetu neposredno prije spavanja može povećati fiziološku pobuđenost i otežati uspavljanje (24).

Dok je progresivna tendencija večernjosti u funkciji dobi potvrđena gotovo u svim dosadašnjim istraživanjima, nalazi o razlikama s obzirom na spol manje su konzistentni (4,25-27). Najčešće se veća sklonost večernjosti utvrđuje u adolescentica, premda u nekim istraživanjima nisu dobivene razlike u cirkadiurnim preferencijama s obzirom na spol. U ovom istraživanju utvrđene su značajne razlike: adolescentice su bile značajno sklonije večernjosti od adolescenata. Dobiveni nalazi najčešće se tumače ranijim početkom puberteta kod djevojčica i njihovim ranijim doživljavanjem bioloških promjena koje sudjeluju u cirkadiurnoj regulaciji (3,6,7,27). Adolescentice općenito radnim danom idu kasnije na spavanje i ustaju ranije, ali to onda nadoknađuju vikendom kada je duže spavanje više u skladu s njihovim cirkadiurnim preferencijama (26). Zanimljivi rezultati u vezi nadoknade spavanja vikendom

correlated and are significantly associated with the eveningness preference and experience of fatigue. Adolescent boys and girls develop an evening sleep pattern and experience more symptoms of fatigue. The three tested variables (female sex, older chronological age, and higher pubertal maturity) jointly explain the 12.8% of the morningness-eveningness variance and 14.9% of the fatigue variance. Biological factors in adolescence that contribute to the shift towards eveningness are associated with the shift in the endogenous circadian rhythm phases and the slower accumulation of homeostatic sleep pressure (12). However, the biologically driven changes are in constant interaction with numerous psychosocial factors. With the onset of puberty, adolescents are more likely to engage in adult activities (late nights out, socializing with friends, watching television) as opposed to their previous periods of life. Furthermore, parental supervision is reduced in many aspects of life of the young person and thus also in the control of bedtime and the time spent before it (5,7). A large number of adolescents spend late night hours on the Internet or even leave their cell phones turned on during the night to be available at all times (12), and researchers point out that watching television and socializing on the Internet before bed can increase psychological arousal and cause sleep difficulties (24).

While the progressive tendency toward eveningness as a function of age was confirmed in almost all of the previous studies, findings on sex differences are less consistent (4,25-27). A higher eveningness preference is found in adolescent girls, although in some studies, differences in the circadian preferences with regard to sex were not found. In this study, significant differences were found: adolescent girls had a higher eveningness preference compared with adolescent boys. The acquired results are most often interpreted as a consequence of the earlier onset of puberty in girls and earlier biological changes involved in the regulation of the

dobiveni su ispitivanju Wolfsona i Carskadon (9). U njihovom istraživanju nisu utvrđene razlike u jutarnjosti-večernjosti između adolescentica i adolescenata, no pokazalo se da su tijekom vikenda, kada nema nastave i kada su svi slobodni prilagođavati se vlastitom ritmu i potrebama za spavanjem, adolescentice ipak kasnije odlazile na spavanje i kasnije ujutro ustajale. Osim bioloških, brojni psihosocijalni čimbenici također mogu objasniti dio ovih spolnih razlika. Tako, na primjer, autori Gaina i sur. (28) ističu razlike u provođenju slobodnog vremena i smatraju da su adolescenti skloniji jutarnjosti, jer se općenito više bave sportskim aktivnostima i više vremena provode izloženi danjem svjetlu. Nadalje, nalaz dobiven u ovom istraživanju, da se s dobi i pubertalnim sazrevanjem adolescenti osjećaju sve umornijima, te da adolescentice doživljavaju više simptoma umora od adolescenata, očekivan je i konzistentan s rezultatima u drugim istraživanjima (29-31). U istraživanju provedenom u Hrvatskoj, ispitivana je učestalost doživljavanja somatskih simptoma u uzorku adolescenata u dobi od 10 do 25 godina. Pokazalo se da 69,5 % mladića i 83,4 % djevojaka izvještava o doživljavanju simptoma umora u posljednja 3 mjeseca, te da je s dobi umor sve učestaliji (32). Slični rezultati dobiveni su na širem dobnom uzorku od 14 do 92 godine s gotovo linearnim rastom doživljavanja umora kod ispitanika (33). Zajednički zaključak je da su žene općenito sklonije doživljavati i izvještavati o psihološkim i somatskim simptomima, pa tako i o simptomima umora (31,34,35). Longitudinalne studije pokazuju da se povećanje broja psiholoških i somatskih simptoma kod žena događa upravo tijekom adolescencije (31). U interpretacijama dobivenih razlika najčešće se koriste dva tumačenja: jedno, prema kojem raniji ulazak djevojaka u pubertet realno povećava broj tjelesnih simptoma općenito, pa tako i umora, i drugo, prema kojem djevojke imaju općenito veću interoceptivnu osjetljivost na tjelesne simptome, pa tako i simptome umora. Ovo drugo tumačenje

circadian rhythm (3,6,7,27). Adolescent girls have later bedtimes and rise earlier on weekdays, but they have longer sleep lengths on weekends that are in accordance with their circadian preferences (26). A study by Wolfson and Carskadon (9) reveled some interesting results regarding sleep compensation on weekends. In their study, adolescent boys and girls did not differ in morningness-eveningness preference, but on weekends when there was no school and everyone was free to adjust to their own rhythm and sleeping needs, girls had later bedtimes and rise times. In addition to biological factors, psychosocial factors can also explain some of the sex differences. Thus, for example, Gaina *et al.* (28) point to differences in leisure time and believe that adolescent boys have a greater tendency towards morningness because they are generally more engaged in sports and spend more time exposed to daylight. Furthermore, the finding in this study that adolescents feel more fatigue with age and pubertal maturity and that girls experience more fatigue symptoms than boys is expected and consistent with findings from other studies (29-31). In the study conducted in Croatia, the frequency of somatic symptoms was investigated in a sample of adolescents between ages 10 and 25. The study showed that 69.5% of adolescent boys and 83.4% of adolescent girls experienced fatigue symptoms in the last three months and that fatigue increased with age (33). Similar results were obtained in a broader age sample, ages 14 to 92, with almost a linear rise in experience of fatigue in respondents (33). A common conclusion is that women are generally more prone to experience fatigue and report on psychologic and somatic symptoms, including symptoms of fatigue (31,34,35). Longitudinal studies show that an increase in the number of psychological and somatic symptoms in women occurs during adolescence (31). Two interpretations are most commonly used to explain these differences: first, earlier onset of puberty in girls realistically increases the number of physical symptoms in general, including fatigue, second,

nalazi svoje uporište u *teoriji percepcije simptoma* (36,37) koja uzrok razlika u percepciji simptoma vidi u socijalnim utjecajima i očekivanjima koja se stavljuju pred žene, te općenito u većoj tendenciji žena da internaliziraju svoje psihološke i socijalne probleme. Wolbeek i sur. (31) smatraju da vrlo slični procesi dovode do umora u adolescenata i adolescentica, ali su adolescentice osjetljivije na tjelesne simptome, pa ih stoga procjenjuju intenzivnijima. Nadalje, dobiveni rezultati mogu se povezati s već spomenutom značajnom razlikom između adolescentica i adolescenata na dimenziji jutarnjosti-večernjosti. Moguće je da se umor općenito češće javlja u adolescentica kao posljedica češće deprivacije spavanja zbog veće sklonosti večernjosti. Također, kao i u slučaju jutarnjosti-večernjosti, i na te biološki uvjetovane promjene značajno utječu brojni psihosocijalni čimbenici. Moguće je da se u danima kada je nastava u jutarnjoj smjeni adolescentice ustaju ranije od adolescenata zbog jutarnjih rutina povezanih s njihovom rodnom ulogom (npr. više vremena provode u oblaženju i dotjerivanju).

Naposljetku, u ovom istraživanju dobiven je neočekivan nalaz o ulozi pubertalne zrelosti u objašnjenju varijance jutarnjosti-večernjosti kao i varijance umora. Naime, u većini dosadašnjih istraživanja naglašava se specifična povezanost spavanja i umora s pubertalnim sazrijevanjem. Još od prvih istraživanja autrice Carskadon i sur. (4) smatra se da javljanje puberteta ima snažniji učinak na promjene u cirkadiurnim preferencijama od psihosocijalnih čimbenika. Tome u prilog idu brojni nalazi o pomaku prema večernjosti 12 mjeseci nakon javljanja prve menstruacije u djevojčica (38), kao i nalazi o povećanim razinama umora u sklopu premenstrualnog sindroma. Premda je pubertalno sazrijevanje povezano sa smanjivanjem ukupnog vremena spavanja kod ispitanika oba spola, samo je u djevojaka to bilo povećani rizik za javljanje insomnije i umora čak i u onim situacijama kada postoji nadoknada

girls have a generally higher interoceptive sensitivity to physical symptoms, including fatigue. This second interpretation is grounded in the *symptom perception theory* (36,37) which sees the cause of differences in the perception of symptoms due to the social influences and expectations that are placed on women, and in the generally higher tendency of women to internalize their psychological and social problems. Wolbeek *et al.* (31) believe that very similar processes lead to fatigue in both boys and girls, but that girls are more sensitive to physical symptoms and therefore assess them as more intense. Furthermore, the obtained results could be associated to the already mentioned significant difference between adolescent boys and girls in the morningness-eveningness dimension. It is possible that fatigue is more common in girls as a consequence of a higher level of sleep deprivation due to their greater tendency toward eveningness. Additionally, as in the case of morningness-eveningness, numerous psychosocial factors significantly influence these biologically conditioned changes. It is possible that girls rise earlier than boys on school days because of morning routines associated with their gender (for example, they spend more time on dressing and getting ready).

Finally, this study obtained an unexpected finding on the role of pubertal maturity in the explanation of the morningness-eveningness and fatigue variance. Namely, most of the studies so far empathize the specific association of sleep and fatigue with pubertal maturation. Since the first study by Carskadon *et al.* (4), it was thought that puberty has a stronger effect on the changes in the circadian preferences than psychosocial factors. In addition to this, there are numerous findings about the shift toward eveningness in girls 12 months after their first period (38), as well as findings on increased levels of fatigue as a part of the premenstrual syndrome. Although pubertal maturation is associated with a reduction in the overall sleep time in both sexes, only in girls was there an

sna. Taj nalaz se povezuje i s većom učestalostu depresije u djevojaka pri čemu poremećaji spavanja i umor prethode prvim epizodama velikog depresivnog poremećaja (38).

Iako su navedena istraživanja pokazala nesumnjivu povezanost pubertalnog statusa i umora, te pubertalnog statusa i jutarnjosti-večernjosti, rezultati našeg istraživanja upozoravaju da je prigodom istraživanja na ovom području potrebno voditi računa da brojne varijable, poput kronološke dobi i pubertalnog statusa u ovom slučaju, uključuju niz tjelesnih pokazatelja koji se međusobno preklapaju, a da su istovremeno odvojeni biološki procesi. K tome, za razumevanje odnosa obrazaca spavanja i umora neophodno je uzimati u obzir s njima povezane biološke i psihosocijalne čimbenike, te njihovu međusobnu interakciju. Svi ti čimbenici međusobno su snažno povezani - biološke promjene tijekom puberteta u stalnoj su interakciji s promjenama na planu ponašanja, kao i s kognitivnim i socijalnim sazrijevanjem. U tom smislu, pubertalni status daje važnu, ali nedovoljnu informaciju o promjenama u obrascu spavanja ili doživljavanju umora. Kronološka dob je, s druge strane, puno sveobuhvatniji pokazatelj jer određuje psihološko i socijalno funkcioniranje vezano za neku dobnu skupinu, a psihosocijalni čimbenici su možda više povezani sa samom kronološkom dobi adolescenata. Kronološka dob određuje neke ključne normativne promjene (npr. prijelaz iz osnovne u srednju školu) koje se uvelike mogu odraziti na psihološko i socijalno funkcioniranje adolescenata, a time i na pojačano doživljavanje umora kod njih. Velik broj istraživanja upozorava na zdravstvene tegobe koje se javljaju zbog neusklađenosti razvojnih potreba učenika i karakteristika socijalne okoline vezane za obrazovno okruženje (39).

S obzirom na utvrđenu povezanost umora i sklonosti večernjosti otvara se mogućnost preventivnog djelovanja u školskom kontekstu na način da se napravi vremenski pomak u početku nastave u jutarnjem terminu. Naime,

increased risk for insomnia and fatigue, even in situations where there was sleep compensation. This finding is also associated with a greater incidence of depression in girls, where sleep disorders and fatigue precede the first stages of the major depressive disorder (38).

Although the abovementioned studies have shown an unquestionable association between pubertal status and fatigue and pubertal status and morningness-eveningness, the results of our study show that it is important in this research field to bear in mind that numerous variables, such as the chronological age and pubertal status, include a number of physical indicators that mutually overlap but are at the same time separate biological process. Additionally, in order to understand the relationship between sleep patterns and fatigue, it is necessary to take into account biological and psychosocial factors related to them and their interaction. All of these factors are strongly related – biological changes in puberty are in constant interaction with the behavioral changes as well as with cognitive and social maturation. In this regard, pubertal status provides important but insufficient information on the changes in sleep patterns or experience of fatigue. Chronological age, on the other hand, is a more comprehensive indicator because it determines the psychological and social function of a certain age group, and psychosocial factors may be more related to the chronological age of the adolescents. Chronological age determines some key normative changes (for example transition from elementary to secondary school) that can greatly affect the psychological and social functioning of adolescents and thus increase the experience of fatigue among them. Numerous studies warn of health problems that manifest due to the incompatibility between developmental needs of students and characteristics of the social environment related to the educational environment (39).

Given the established association of fatigue and eveningness preference, there is a possibility for

Bregers, Gable i Owens (40) su u svom istraživanju potvrdili da pomak u početku nastave (i onda kada se radi o samo 25 minuta) dovodi do smanjenja depravacije spavanja, dnevnog umora i pospanosti, poboljšanja raspoloženja, te smanjenog unosa kofeina. Seriju istraživanja o toj temi u Hrvatskoj su proveli autori Košćec, Radošević-Vidaček i Bakotić (12,41-44). Rezultati pokazuju da su i u dvosmjenskom sustavu nastave večernje preferencije povezane s nepravilnostima u rasporedu spavanja i s kraćim spavanjem adolescenata u jutarnjoj smjeni. Također navode da su kod starijih adolescenata razlike u spavanju između radnog tjedna i vikenda bile veće, osobito u tjednu kada se nastava održavala u jutarnjoj smjeni te je akumulacija duga u spavanju bila veća za taj tjedan. Nadalje, neregularnost u vremenu odlaska na spavanje u jutarnjoj smjeni bila je povezana s pospanošću, a pospanost je također bila povezana i s izraženijim večernjim preferencijama. Dobiveni rezultati pokazuju da se prilagođavanjem školskog rasporeda obrascu spavanja u adolescenciji mogu postići višestruki pozitivni utjecaji na kvalitetu života adolescenata.

Provedeno istraživanje ima i određena ograničenja. Kao prvo, radi se o transverzalnom nacrtu istraživanja pa se ne mogu donositi zaključci o vremenu kada se točno događaju promjene na dimenziji jutarnjosti-večernjosti. Nadalje, u ovom istraživanju nisu uzeti u obzir vanjski čimbenici koji su presudni za bolje razumijevanje relacija između ispitivanih varijabli. Na primjer, u ispitivanjima na ovom području svakako je potrebno uključiti informacije o kasnonoćnom korištenju raznih zabavnih medija i socijalnih mreža na internetu, kako bi se kontrolirao njihov utjecaj na psihološku pobuđenost i kvalitetu spavanja. I pored toga, istraživanje umora u adolescenciji može biti težak zadatak jer se radi o procesu koji je pod utjecajem različitih čimbenika karakterističnih za tu dobnu skupinu: tjelesnih (hormonske i pubertalne promjene u tjelesnom izgledu i

preventive action in schools, which is to delay school starting time in morning shifts. Bregers, Gable, and Owens (40) confirmed in their study that such a shift in the beginning of classes (even when it is only 25 minutes) leads to a reduction of sleep deprivation, daytime fatigue and drowsiness, mood improvement, and reduction of caffeine intake. Košćec, Radošević-Vidaček, and Bakotić (12,41-44) conducted a series of studies on this topic in Croatia. The results show that in the two-shift school system, eveningness preferences are associated with inconsistencies in the sleeping schedule and shorter sleep patterns of adolescents in morning shifts. The results also show that sleep differences in older adolescents were higher between weekdays and weekends, especially during the week when classes were held in the morning shift and the accumulation of sleep "debt" was higher during that week. Furthermore, irregularities in bedtime in the morning shift were associated with drowsiness, and drowsiness was also associated with a greater preference toward eveningness. The obtained results show that adjustment of the school schedule to the sleep pattern in adolescence can have multiple positive effects on the quality of life of adolescents.

The present study has certain limitations. First, this is a transversal outline of the study, so no conclusions can be drawn about the exact time of the changes in the morningness-eveningness dimension. Furthermore, the external factors that are crucial for a better understanding of the relationship between the examined variables were not taken into account. For example, in studies in this area it is essential to include information on late-night use of various entertainment media and social networks on the Internet in order to control their impact on the psychological arousal and quality of sleep. In addition, the study of fatigue in adolescence can be a difficult assignment because it is a process that is influenced by various factors specific for that age group: physical (hormonal and puber-

funkcioniranju), emocionalnih (npr. pojačan osjećaj neovisnosti) i socijalnih faktora (utjecaj vršnjaka, obiteljske interakcije, školski raspored i sl.) (46).

## ZAKLJUČAK

Može se zaključiti da su prva i druga hipoteza u ovom istraživanju potvrđene: pubertalno zrelji adolescenti pokazuju veću sklonost večernjosti i izvještavaju o više simptoma umora. Adolescentice su pubertalno zrelje, pa u skladu s prethodno rečenim, pokazuju veću sklonost večernjosti i izraženiji umor u odnosu na muške vršnjake. Neочекivan nalaz u ovom istraživanju odnosio se na treći cilj istraživanja. Kronološka dob i pubertalni status su visoko međusobno korelirani, no razlikuju se s obzirom na njihov doprinos objašnjenju jutarnjosti-večernjosti i umora. Pokazalo se da pubertalna zrelost nije značajan prediktor jutarnjosti-večernjosti i umora već su u ovom uzorku te varijable povezane s pubertalnim statusom preko varijable kronološke dobi. Taj nalaz upućuje da je oba pokazatelja potrebno uzeti u obzir kako bi se dobio bolji uvid u promjene tijekom adolescencije.

Naposljeku treba napomenuti da istraživanje spavanja i umora u adolescenciji ima veliku važnost jer može izravno pridonijeti znanjima o unutarnjim utjecajima na obrasce spavanja i doživljavanje umora tijekom razvoja, a također bi se u budućim istraživanjima pažnja trebala usmjeriti na sveobuhvatnu interakciju kako unutarnjih tako i vanjskih utjecaja na spavanje u ovom razdoblju života (45).

tal changes in physical appearance and functioning), emotional (for example an increased feeling of independence), and social (influence of peers, family interactions, school schedule, etc.) (46).

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## CONCLUSION

It can be concluded that the first and second hypothesis of this study were confirmed: adolescents with a higher pubertal maturity show a greater tendency toward eveningness and report more symptoms of fatigue. Adolescent girls have a higher pubertal maturity, and in accordance with abovementioned data, show a greater tendency toward eveningness and report more symptoms of fatigue than their male peers. An unexpected finding in this study was related to the third objective. The chronological age and pubertal status were significantly correlated but differed in their contribution to the explanation of morningness-eveningness and fatigue. It has been shown that pubertal maturity is not a significant predictor of morningness-eveningness and fatigue, but in this sample these variables were related to the pubertal status through the variable of chronological age. This finding suggests that both indicators need to be taken into account in order to gain a better insight into the changes during adolescence. Finally, it should be noted that the study of sleep and fatigue in adolescence is of great importance and can directly contribute to the knowledge about internal factors on sleep patterns and experience of fatigue during development, and future studies should focus their attention on the comprehensive interaction of internal and external factors on sleep in this period of life (45).

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# **Iskustvo stresa i mentalno zdravlje osoba s tjelesnim invaliditetom: Perspektiva manjinskog stresa**

## **/ The Stress Experience and Mental Health among Persons with Physical Disabilities: A Minority Stress Perspective**

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Osobe s tjelesnim invaliditetom često doživljavaju različite oblike diskriminacije te imaju povećan rizik za višu razinu stresa i negativnih ishoda mentalnog zdravlja. Do sada je stresno iskustvo osoba s invaliditetom u Hrvatskoj bilo slabo istraženo. Korištenjem manjinskog stresa kao konceptualnog okvira ovog istraživanja, cilj je bio istražiti iskustvo stresa kod osoba s tjelesnim invaliditetom i ispitati ulogu diskriminacije u oblikovanju tog iskustva te posljedične povezanosti s mentalnim zdravljem. U ovom su istraživanju provedeni individualni intervjuji sa šest odraslih osoba s tjelesnim invaliditetom. Transkribirani intervjuji analizirani su induktivno koristeći konstantan usporedni pristup. Sudionici su izvijestili kako su različiti stresori povezani s njihovim iskustvom življenja s tjelesnim invaliditetom negativno utjecali na njihov osobni osjećaj dobrobiti. Nadalje, sudionici su opisali brojna iskustva u kojima su posljedice diskriminacije, uključujući fizičku nepristupačnost, socijalnu izolaciju i ograničene mogućnosti zapošljavanja, izravno utjecali na njihovo iskustvo stresa. Preliminarna analiza ukazuje da manjinski stres pruža koristan okvir kroz koji se može dodatno ispitati i bolje razumjeti jedinstvene stresore koje doživljavaju osobe s tjelesnim invaliditetom i ulogu koju ima diskriminacija u njihovom iskustvu stresa.

*I Persons with physical disabilities often experience various forms of discrimination and are at increased risk for greater levels of stress and negative mental health outcomes. To date, however, the stress experience of persons with disabilities has not been studied extensively. Using minority stress as a conceptual framework, the aim of this study was to explore the experience of stress among people with physical disabilities and the consequences of stress for mental health, as well as to examine the role of discrimination in shaping this experience. In this study, individual interviews were conducted with 6 adults with physical disabilities. Transcribed interviews were analysed inductively using a constant comparative approach. Participants reported how various stressors specific to the lived experience of having a physical disability negatively influenced their emotional well-being. They also described numerous experiences in which the consequences of discrimination, including physical inaccessibility, social isolation, and limited employment opportunities, had a direct impact on their experience of stress. Preliminary analysis suggests that minority stress offers a useful framework from which to further examine and better understand the unique stressors experienced by persons with physical disabilities and the role played by discrimination on their experience of stress.*

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Stres označava stanje narušene psihičke i tjelesne ravnoteže pojedinca koje nastaje pri osjećaju ugroženosti ili subjektivnom doživljaju nemogućnosti suočavanja i prilagodbe zahtjevima okoline. Izvori stresa (stresori) u svakodnevnom životu mogu proizlaziti iz situacija vezanih uz pojedinca (individualni stresori) ili iz samog društva (socijalni stresori), a stres se prepoznaće kao univerzalno iskustvo (1,2). Istraživanja pokazuju da su osobe s invaliditetom kao skupina i pojedinačno izložene širem rasponu stresora od onih kojima su izložene osobe bez invaliditeta (3). Dodatni stres s kojim se suočavaju članovi određene manjinske skupine (u ovom slučaju, osobe s invaliditetom) nazvan je manjinskim stresom (4).

### Koncept manjinskog stresa

Prema Meyer (4), manjinski stres je pretjerani stres koji doživljavaju pojedinci iz stigmatiziranih društvenih kategorija, koji je rezultat njihovog manjinskog položaja. Manjinski stres je kroničan (odnosi se na relativno stabilne društvene i kulturne strukture) i društveno je utemeljen (proizlazi iz društvenih procesa i struktura izvan pojedinca) (4). Meyer (4) navodi da se među manjinskim skupinama različiti procesi stresa povezani s pripadnošću tim skupinama pridodaju općim ili univerzalnim stresorima te na taj način zahtijevaju dodatnu prilagodbu te proizvode negativne ishode povezane s mentalnim zdravljem. Meyer se u objašnjavanju koncepta manjinskog stresa posebno usmjerava na teoriju socijalnog stresa, odnosno na okolnosti koje proizlaze iz stava ili ponašanja okoline koji posljedično djeluju na usvajanje manjinskog identiteta te na mentalno zdravlje. Stresne procese koji su povezani s manjinskim statusom dijeli na distalne i proksimalne. Distalni se odnose na objektivne vanjske socijalne uvjete ili događaje u kojima predrasude postaju vidljive (kao što su diskriminacija, na-

### INTRODUCTION

Stress represents a state of disrupted psychological and physical balance created when an individual feels under threat or has the subjective experience of being unable to face and adapt to the demands of the environment. While the sources of stress in our everyday lives can arise in situations related to the individual (individual stressors) or society itself (social stressors), stress is widely recognized as a universal experience (1,2). Research suggests that persons with disabilities, as a group and as individuals, are exposed to a wider range of stressors than those experienced by persons without disabilities (3). This additive stress faced by members of a specific minority group (in this case, persons with disabilities) has been termed *minority stress* (4).

### Minority stress

According to Meyer (4), minority stress is the excess stress experienced by individuals from stigmatized social categories as a result of their minority position. Minority stress is both chronic (related to relatively stable social and cultural structures) and socially based (stems from social processes and structures beyond the individual) (4). Meyer (4) purports that, among minority groups, a variety of minority stress processes converge with the general stressors experienced by all of us and, in this way, demand additional adaptation and produce negative mental health outcomes. In his explanation of the minority stress concept, Meyer places special emphasis on social stress, or the stress processes that arise from the attitudes or behaviours of others in one's social environment, which consequently influence the individual's mental health and minority identity. In this model, stress processes associated with minority status are divided into distal and proximal processes. Distal processes are related to objective external social conditions or events in which prejudices become apparent (through

silje i izolacija), dok se proksimalni odnose na subjektivne procese koji ovise o pojedinčevim doživljajima i atribuciji (povezuju se s internalizacijom manjinskog statusa te prikrivanjem ili očekivanjem odbacivanja).

Iako se koncept manjinskog stresa u izvornom Meyerovom modelu primjenjivao za razumevanje narušenosti mentalnog zdravlja osoba različitih seksualnih orijentacija, čini se potencijalno korisnim okvirom iz kojeg se može istražiti iskustvo stresa u manjinskoj skupini osoba s invaliditetom (u modelu nazvan: manjinski status). Osobe s invaliditetom doživljavaju različita negativna iskustva kao rezultat pogrešne javne percepcije i stereotipa temeljenih na kulturi (5). Ovo, pak, može djelovati kao društveno izvedeni izvor potencijalnog stresa i čimbenik koji pridonosi ishodima povezanim s mentalnim zdravljem (4).

## Diskriminacija, stres i mentalno zdravlje

Istraživanja su pokazala da su osobe s invaliditetom ipak u većem riziku od opće populacije kada se govori o narušenom mentalnom zdravlju (6-10). Međutim, pitanje povezanosti stresa uvjetovanog invaliditetom i mentalnog zdravlja ostaje nedovoljno istraženo i slabo poznato. Istraživanja pokazuju da su jedinstveni stresori osoba s invaliditetom kronični i višestruki. Oni mogu biti fizičke, psihološke, socijalne, ekonomске ili političke prirode (11-15). Ne iznenađuje da ovaj oblik stresa negativno utječe na zdravlje, dobrobit i kvalitetu života (13). Mali broj istraživanja bavio se ulogom stresa u mentalnom zdravlju osoba s invaliditetom, no ona koja su dostupna upućuju na to da stres doprinosi različitim negativnim ponašajnim i kognitivnim ishodima u životima osoba s invaliditetom (15) te djeluje kao ključna zapreka psihološkom blagostanju (16).

Čini se razumnim pretpostaviti da brojne varijable imaju ulogu u odnosu između invaliditeta

discrimination, violence, and isolation), while proximal processes are related to subjective processes that depend on individual experiences and attribution (linked to the internalization of one's minority status, concealment or expectations of rejection).

Although the concept of minority stress in Meyer's original model has been primarily applied to understanding mental health outcomes for persons of various sexual orientations, it seems a potentially useful framework from which to explore the experience of stress among persons with disabilities. As a minority group, persons with disabilities have various negative experiences as a result of misinformed public perceptions and culturally-based stereotypes (5). This, in turn, can act as a socially-derived source of potential stress and a contributing factor in mental health outcomes (4).

## Discrimination, stress and mental health

Research has suggested that people with disabilities are at greater risk of mental health problems than the general population (6-10). However, the nature of the relationship between disability and mental health is not yet fully understood. Similarly, an emerging body of research has suggested that the unique stressors experienced by persons with disabilities are both chronic and multifaceted. They can be physical, psychological, social, economic, or political in nature (11-15). Unsurprisingly, this stress has negative implications for health, well-being and quality of life (13). The role of stress in the mental health of individuals with disabilities has been explored in a small number of studies, suggesting that stress contributes to various negative behavioural and cognitive outcomes in the lives of people with disabilities (15) and acts as a key obstacle to psychological well-being (16).

While it seems reasonable to assume that a number of variables play a role in the relation-

i mentalnog zdravlja. Od posebnog je interesa za ovo istraživanje ideja da bi sam invaliditet mogao pridonijeti teškoćama u mentalnom zdravlju, kao rezultat (pro)življenog iskustva osobe s invaliditetom (9). Život s ozljedama, kroničnom bolešću ili dugotrajnim onesposobljenjem može značiti niz dodatnih opterećenja uključujući rizik od pogoršanja zdravlja, promjene u načinu života, stigmu, smanjenu socijalnu podršku i sudjelovanje te socijalnu izolaciju (17). Životne se okolnosti (kao što je invaliditet, op.a.) mogu prenositi na socijalne procese isključivanja posredovane stavovima unutar skupina i voditi do diskriminacije i manjka pristupa resursima (18). Osobe s invaliditetom imaju veću vjerojatnost da će doživjeti socijalne zapreke i smanjenu društvenu mobilnost zbog isključenosti s tržišta rada i dodatnih troškova povezanih s invaliditetom (19-21). Ovi socijalni čimbenici također povezuju se sa slabijim mentalnim zdravljem (22-24) i nesumnjivo djeluju kao značajni stresori za osobe s invaliditetom.

Stanovište da socijalni procesi kao što su diskriminacija i socijalno isključivanje imaju važnu ulogu u ishodima mentalnog zdravlja osoba s invaliditetom je u skladu s modelom manjinskog stresa i ukazuje da socijalna isključenost može biti koristan okvir iz kojeg se može ispitati odnos stresa i ishoda mentalnog zdravlja osoba s invaliditetom. Dok konceptualizacija socijalne isključenosti ostaje predmetom tekuće rasprave u literaturi, čini se da trenutni konsenzus podržava mišljenje da je socijalna isključenost zbirka procesa koje doživljava određena skupina, a koji odražavaju stereotipe (kognitivne reakcije), predrasude (emocionalne reakcije) i diskriminaciju (ponašajne reakcije) dominantne većinske naspram stigmatizirane skupine (5,9,25,26). Korištenjem ovog okvira socijalna isključenost se može objasniti kao strukture i procesi nejednakosti unutar društva koje zauzvrat određuju kvalitetu pripadnosti pojedinca ili skupine u društvo (27,28).

ship between disability and mental health, of particular interest to the present study is the idea that disability might contribute to mental health problems as a result of the lived experience of having a disability (9). Living with injury, chronic disease, or long-term disability can mean a number of additional burdens, including the threat of declining health, lifestyle changes, stigma, reduced social support and participation, breakdown of relationships, and isolation (17). Life circumstances (such as disability) can translate into a social processes of exclusion mediated by intergroup attitudes and lead to discrimination and a lack of access to resources. (18). Persons with disabilities are more likely to experience social disadvantage, inadequate social support, and downward social mobility due to exclusion from the labour market and additional costs associated with disability (19-21). These social factors have also been linked to poorer mental health (22-24) and undoubtedly represent significant sources of stress for persons with disabilities.

The view that social processes such as discrimination and social exclusion play an important role in mental health outcomes among persons with disabilities is consistent with the minority stress model and suggests that social exclusion might be a useful framework from which to examine stress and mental health outcomes in this population. While the conceptualization of social exclusion remains a subject of debate in the literature, the current consensus seems to support the view that social exclusion is a collection of processes experienced by a particular group that reflect the stereotypes (cognitive reactions), prejudices (emotional reactions) and discrimination (behavioural reactions) of the dominant majority towards the stigmatized group (5,9,25,26). Under this framework, social exclusion includes structures and processes of inequality within society that in turn determine the quality of membership of an individual or group in society (27,28). This

To podrazumijeva isključenost s tržišta rada, ekonomsku, institucionalnu i kulturnu marginalizaciju (siromaštvo, nemogućnost pristupa javnim i privatnim službama, smanjeno političko sudjelovanje), socijalnu izolaciju i prostorne zapreke (loši uvjeti stanovanja, nedostatak fizičkog pristupa) (18,29,30).

U kvalitativnom istraživanju Iwasaki i Mactavish (12) su koristili socijalnu isključenost kao konceptualni okvir za istraživanje perspektiva stresa među osobama s tjelesnim invaliditetom. Sudionici ovog istraživanja izvjestili su o brojnim izvorima ili uzrocima stresa, grupiranim u dvije tematske skupine: pojedinačni i sustavni/okolinski. Pojedinačni su stresori uključivali izvore stresa koji se odnose na invaliditet, zdravlje, međuljudske odnose i samopoštovanje. Sustavni su stresori uključivali stresore povezane sa širim strukturnim razinama društva, a uključeni su čimbenici povezani s isključivim društvenim sustavima, fizičkom (ne)pristupačnosti i ekonomskom marginalizacijom. Autori zaključuju da izvori stresa o kojima su izvještavali njihovi sudionici odražavaju različite elemente socijalne isključenosti, a obje navedene skupine stresora, kao i proces socijalnog isključivanja međusobno su povezani i potencijalno pogoršavaju stresno iskustvo (12).

Trenutačno razumijevanje odnosa stresa i mentalnog zdravlja među osobama s invaliditetom podupire stanovište da se osobe s invaliditetom suočavaju s izraženijom količinom stresora i većim rizikom za negativne ishode u mentalnom zdravlju. Međutim, jedinstvena priroda iskustva stresa za osobe s invaliditetom te odnos stresa i ishoda mentalnog zdravlja tek treba biti u potpunosti shvaćena. Od dodatnog interesa je uloga diskriminacije koju ima u iskustvu stresa i mentalnoj dobrobiti osoba s invaliditetom. Prepoznavanje i razumijevanje stresora i rizičnih čimbenika koji doprinose stresu ključno je za pružanje učinkovite i prikladne potpore pri ublažavanju ili smanjenju takvih čimbenika

includes labour, economic, institutional, and cultural marginalization (poverty, lack of access to public and private service institutions, reduced political and civil participation), social isolation, and spatial exclusion (poor housing, lack of physical access) (18,29,30).

In a qualitative study, Iwasaki & Mactavish (12) used social exclusion as a conceptual framework to explore perspectives on stress among persons with physical disabilities. Participants in this study reported numerous sources or causes of stress, grouped by the researchers into two theme clusters: individual and systemic/environmental. Individual stressors included sources of stress related to disability, health, interpersonal relationships, and self-esteem. Systemic stressors included those stressors related to broader structural levels of society and included factors related to exclusionary social systems, physical (in)accessibility, employment (in)accessibility, and economic marginality. The authors argued that the sources of stress reported by their participants reflect various elements of social exclusion (economic, institutional, cultural) and both stressors and the social exclusion process mutually influence and potentially exacerbate the stress experience (12).

The current understanding concerning stress and mental health outcomes among persons with disabilities supports the notion that persons with disabilities experience greater levels of stress and are at higher risk for negative mental health outcomes. However, the unique nature of the stress experience for persons with disabilities and the relationship between stress and mental health outcomes is yet to be fully understood. Of additional interest is the role discrimination plays in the stress experience and mental well-being of persons with disabilities. Identifying and understanding stressors and stress-related risk factors is essential for providing effective and appropriate support in alleviating or reducing such factors and thus

te na taj način promicanju zdravlja i dobrobiti osoba s invaliditetom (11,12).

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## CILJ RADA

Cilj je ovog rada dobiti bolji uvid u iskustvo stresa osoba s tjelesnim invaliditetom, osobito njihov doživljaj izvora i posljedica stresa. Od posebnog je interesa uloga društvenih čimbenika, osobito diskriminacije i socijalnog isključivanja u iskustvu stresa ove skupine. Ovo istraživanje je jedino dostupno istraživanje koje se do sada bavilo ovom temom, stoga mu je opći cilj generirati preliminarno teorijsko razumijevanje. Kao takvo, očekivanja smo da će teorija u nastajanju otkriti novo razumijevanje koje možda nije sasvim u skladu s postojećim referentnim okvirima. Na taj način, iako je prethodno opisan model manjinskog stresa korišten kao konceptualni okvir iz kojeg se može istražiti stresno iskustvo osoba s tjelesnim invaliditetom, također je moguće da će istraživanje otkriti jedinstvene elemente u stresnom iskustvu ove skupine. U istraživanju su postavljena tri pitanja:

- Koje izvore stresa u vlastitom životu prepoznaju osobe s tjelesnim invaliditetom?
- Kakvu ulogu ima diskriminacija u stresnim iskustvima osoba s tjelesnim invaliditetom?
- Povezuju li osobe s invaliditetom svoje iskustvo (manjinskog) stresa s vlastitim mentalnim zdravljem?

## METODOLOGIJA

U skladu s postavljenim ciljevima ovog istraživanja, u kojima se istražuje životno iskustvo i osobna percepcija sudionika, primjeren je primijeniti kvalitativnu istraživačku metodologiju. U radu je korištena metoda individualnog polustrukturiranog intervjua za prikupljanje podataka o pojedinačnim perspektivama stresa. S obzirom na slabo proučavanu temu

promoting health and well-being among persons with disabilities (11,12).

## AIM OF THE STUDY

The aim of this study was to shed further insight into the stress experience of persons with physical disabilities. Using a qualitative approach, it aimed to explore the individual perspectives of persons with disabilities on the sources and consequences of stress. Of particular interest was the role of social factors, and discrimination and social exclusion in particular, in the stress experience of this group. As one of the only known studies to examine this topic to date, the aim of this study was to generate preliminary theoretical understanding. As such, it was expected that emerging theory would reveal new understanding that is perhaps not entirely consistent with existing frames of reference. In this way, while the previously described minority stress model has been used as a conceptual framework from which to explore the stress experience of persons with physical disabilities, it is also expected that the study will reveal unique elements in the stress experience of this group. The study posed three research questions:

- What are the reported sources of stress among persons with physical disabilities?
- What role does discrimination play in the stress experience of persons with physical disabilities?
- Do persons with disabilities associate the (minority) stress experience with their own mental health?

## METHODOLOGY

Because the aim of this study was to investigate the life experiences and individual perspectives of participants, a qualitative research methodology was deemed most appropriate. The pres-

istraživanja, upotreba intervjeta omogućila je fleksibilan, otvoren pristup koji bi, umjesto da bude usmjeren predodređenim hipotezama, omogućio istraživanje perspektiva sudionika koju iskazuju svojim riječima (31).

## Sudionici

U istraživanju je sudjelovalo šest odraslih osoba s tjelesnim invaliditetom. Jedinstveni kriterij sudjelovanja u istraživanju je da su sudionici odrasle osobe s dugotrajnim iskustvom tjelesnog invaliditeta koji značajno utječe na samostalno kretanje. S obzirom na ciljeve istraživanja u regrutiranju sudionika korišteno je namjerno uzorkovanje. Dva su člana regrutirana preko udruga osoba s invaliditetom u kojima su sudionici članovi ili volonteri. Ostali su sudionici regrutirani preporukom o kvalitetnim informatorima, odnosno metodom snježne grude. Poziv za sudjelovanjem upućen je putem elektroničke pošte, a u pozivu je naglašena svrha i postupak istraživanja te dobrovoljna i anonimna priroda sudjelovanja. Nakon pristanka na sudjelovanje u istraživanju dogovoreno je vrijeme razgovora sa svakim sudionikom.

Svi pojedinci pozvani na sudjelovanje u istraživanju dali su svoj informirani pristanak. U svjetlu cjelokupnog cilja istraživanja, veličina uzorka namjerno je bila malena. Naime, provedbom preliminarnog istraživanja koje se bavi trenutno nedovoljno istraženom temom, autori su željeli najprije istražiti potvrđuje li se jedinstveno iskustvo stresa među osobama s tjelesnim invaliditetom ili se razlikuje od postojećeg konceptualnog okvira manjinskog stresa. Nadalje, kao prvi pokušaj ispitivanja ove teme u Hrvatskoj, bilo je potrebno prvo pilotirati metodu intervjeta i protokol kojim se istražuju ove ideje. Koristeći preliminarne rezultate izvedene iz ovog probnog istraživanja, planirano je proširenje istraživanja uključivanjem većeg uzorka.

ent study used semi-structured interviews to collect data regarding individual perspectives on stress. As a relatively under-studied topic of investigation, the use of interviews allowed for a flexible, open-ended approach that, rather than being directed by predetermined hypotheses, enabled the exploration of participant perspectives in their own words (31).

## Participants

Six adults with physical disabilities participated in the study. The single criterion for participation in the study was that participants were adults with long-term experience with physical disability that significantly affected mobility. In light of the aims of the study, participants were recruited using a purposive sampling method. Two participants were recruited via societies for persons with disabilities in which they were members or volunteers. All remaining participants were recruited using the snowball method via the recommendation of quality informants. An invitation to participate was extended via email, in which the purpose of the research and the voluntary and anonymous nature of participation was emphasized. Upon agreeing to participate in the research, an interview time was arranged with each participant.

All those invited to be part of the study agreed to participate. In light of the overall aim of the research, the size of the sample was purposefully kept small. Namely, as a preliminary study examining a currently under-researched topic, the authors wished to first explore the manner in which the unique experience of stress among persons with physical disabilities confirms or differs from the existing conceptual framework of minority stress. As a first attempt in examining this topic in Croatia, it was necessary to first pilot the interview method and protocol used to explore these ideas. Using the preliminary findings derived from this pilot study, further research is planned using a larger sample.

Od ukupno šest sudionika, tri su osobe s cerebralnom paralizom i tri osobe s ozljedom leđne moždine. Četiri sudionice su žene. Dob sudionika kretala se od 20 do 65 godina i svi su doživjeli značajne teškoće u kretanju kao rezultat njihove ozljede ili stanja<sup>1</sup>. Svi sudionici završili su najmanje srednjoškolski stupanj obrazovanja, troje ih živi s partnerom, dvoje samostalno i jedan u primarnoj obitelji. Većina volontira u udrugama, jedna je osoba zaposlena i jedan sudionik je student.

## Postupak intervjuiranja

Intervjui su provedeni individualno, a voditeljica svih intervjeta je druga autorica rada. Intervjui su provedeni u vrijeme i na mjestu pogodnom za sudionike. Svi intervjeti su zabilježeni snimačem glasa za što je svaki sudionik pojedinačno dao suglasnost. Intervjui su trajali između 30 i 60 minuta, a provedeni su korištenjem protokola intervjeta razvijenog za potrebe ovog istraživanja. Ovaj je protokol omogućio fleksibilnu strukturu koja je uključivala smjernice za otvaranje intervjeta, opće teme istraživanja (značenje stresa, upravljanje stresom, izvori stresa) te okvirne podteme koje su poslužile kao potencijalna pitanja za poticanje sudionika na proširenje odgovora, kao i smjernice za zaključivanje intervjeta. Otvorena struktura intervjeta planirano je omogućila istraživanje tema od važnosti i interesa samih sudionika te osiguravanje točne zastupljenosti perspektiva sudionika. Protokol intervjeta nalazi se u Prilogu 1 u kojem su predviđene faze intervjeta, osnovna pitanja i pitanja za poticanje i proširenje teme razgovora. Tijekom polustrukturiranih intervjeta, intervjuer je slijedio opću strukturu protokola i primijenio primarna pitanja kako bi pokrenuo raspravu oko središnjih tema. Po-

Of the six participants, three were persons with cerebral palsy and three were individuals with spinal cord injuries. Four participants were women. The age of participants ranged between 20 and 65 years and all participants experienced significantly impaired mobility as a result of their injury or condition<sup>1</sup>. All participants had completed at least a secondary level of education, three live with their partner, two live on their own, and one is living with family. While the majority of participants are volunteers in societies for persons with disabilities, one participant is employed full-time and another participant is a student.

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## Interview procedure

Interviews were conducted individually by the second author of this study, at a time and location convenient to the participants. All interviews were audio recorded, for which each participant gave consent. Interviews were between 30 and 60 minutes in length and were conducted using an interview framework developed for the purposes of this study. This framework offered a flexible structure that included guidelines for opening the interview, general study themes (meaning of stress, managing stress, sources of stress) and sub-themes that served as potential probing questions, as well as guidelines for concluding the interview. The interview structure was intentionally kept open-ended so as to allow the exploration of topics of relevance and interest to the participants themselves and to ensure that the perspectives of participants were accurately represented. The interview protocol is presented in Appendix 1, where interview phases, primary questions, and probe questions for expanding the discussion are presented. During semi-structured interviews, the interviewer followed the general structure of the protocol and used primary questions to initiate discussion around central

<sup>1</sup> Osobe s cerebralnom paralizom imaju cjeloživotno iskustvo, dok svi sudionici s ozljedom leđne moždine imaju najmanje deset godina iskustva života sa svojim stanjem.

<sup>1</sup> Participants with cerebral palsy have life-long experience with reduced mobility, while participants with spinal cord injury sustained their injuries at least 10 years prior to the study.

ticajna pitanja su postavljena kao smjernice za olakšavanje detaljnije rasprave, ali nisu bila obvezna sastavnica intervjuja. U skladu s time, intervjuer je imao fleksibilnost postavljanja novih pitanja koja su proistekla iz odgovora sudionika.

themes. Probe questions were provided as guidelines for facilitating more detailed discussion, but were not mandatory elements of the interview. Accordingly, the interviewer had the flexibility of posing follow-up questions that arose from the responses of the participant.

#### APPENDIX 1. Interview protocol

Interview Phase: purpose	Primary questions	Probe questions
Opening comments: Open the interview, consent	<i>Introduce theme of interview Use of audio recording (consent)</i>	<b>Thank you for agreeing to participate in our research and talk about this theme with me. Our discussion should take about half an hour.</b> <b>Before we begin, I would like to ask your permission to record our conversation. Everything you say is important and I would not like anything to be forgotten, left out or misunderstood. For this reason, recording is a good solution that will allow us to have a normal conversation without the pressure of having to quickly note everything on paper. Also, I would like to immediately emphasize that all information will be used only for the purposes of this research and all identifying information (your name, where you live, etc.) will be kept strictly confidential. Is it OK with you that I record this conversation?</b> <b>As I previously mentioned, in this discussion I would like to hear your perspectives on stress, whether you have experience with stress and how this makes you feel. I would also like to learn about what you think are the main causes or sources of stress in your life.</b>
Introductory questions: Engage participants in the topic	<b>Tell me about yourself.</b>  <b>What do you think of when you hear the word 'stress'?</b>  <b>Is stress always negative? Can it be positive?</b>	Probe questions: <b>living circumstances, participation in work/study, family...</b>
Transition questions: Personal discussion about stress	<b>How would you describe your experience with stress?</b>  <b>How do you manage/deal with stress?</b>	<b>How do you feel when you are stressed? Do you experience physical symptoms? Do you think that stress affects your physical/mental health? In what way? Have you ever sought support (example: family/friends, health/social care professionals) for difficulties you have experienced related to stress?</b>  <b>Can stress be avoided? Do you use any coping strategies for managing stress? What are they? Are they effective?</b>
Key questions: Examining causes/ sources of stress  Signal transition to new topic: Now I'd like to hear your thoughts on the things that make you stressed...	<b>What causes you stress? (What are the things that make you stressed?)</b>  <i>Probing questions for individual factors (disability, health, relationships...)</i>  <i>Probing questions for systemic/environmental factors (physical accessibility, employment/education access, attitudes (stigma/discrimination), institutional systems)</i>	<b>In your day-to-day life, what are things that make you stressed? Do you have any health concerns that contribute to your feelings of stress? Describe. Do you experience stress in work/study settings? Social situations? Family life?</b>  <b>What factors from the context (community, city, society) in which you live do you think contribute to stress?</b>
	<b>Note:</b> Participants should not be led to identify the listed factors, but when they are mentioned, interviewer should use probing questions to gain individual perspectives/personal experiences about these factors.	
Final questions, conclusion: Summarizing discussion, confirm main ideas	<i>Summarize discussion, confirming the main factors identified by participants as causes of stress</i>	<b>Our conversation is nearing the end. From what we have discussed, I have learned... Do you have anything else you would like to add? Ask? Thank you very much for your time and participation!</b>



Analiza podataka dobivenih intervjuiama provedena je pomoću stalnog komparativnog pristupa pri čemu se provodi otvoreni proces ispitanja, uspoređivanja, konceptualizacije i kategorizacije podataka za prepoznavanje i istraživanje novog ili slabo razumljivog fenomena (32). Stalna komparativna metoda ili Metoda konstantne usporedbe (engl. *constant comparative method*), kao analitički pristup za stvaranje nove teorije ili nove znanstvene spoznaje spominje se kao metoda izbora prigodom primjene utemeljene teorije. Općenito se provodi nizom stadija koji se događaju istodobno i neprekidno sve do završetka analize. U prvoj fazi, izdvajaju se „pojave“ u podatcima (pojedinačne, identificirajuće jedinice informacija koje se pojavljuju unutar transkriptata intervjua) koji se kodiraju (dodjeljuje im se oznaka) prema određenoj kategoriji ili konstrukciji od interesa. Novo-kodirane pojave kontinuirano se uspoređuju s prethodnim pojavama u istim ili različitim kategorijama u procesu u kojem se grupiraju prema sličnosti ili razlikama između kodiranih pojava te se postupno stvaraju teorijske značajke pojedine kategorije (32). Primjerice, u ovom istraživanju izvješća sudionika o specifičnoj reakciji ili izvoru stresa kodirani su kao pojave. Ove opće „kategorije“ kodova (npr. izvori stresa, učinci stresa) početno su formulirane korištenjem nekih temeljnih elemenata modela manjinskog stresa (4). Međutim, specifični kodovi generiraju se izravno putem analize samih podataka u kojima su kodovi povezani s emocionalnim utjecajem stresa, načinima suočavanja sa stresom i izvorima stresa postupno identificirani i prošireni tijekom konstantnog kodiranja i usporedbe.

U kasnijim fazama ove metode proces usporedbe se mijenja iz one između pojedinih pojava do međusobne usporedbe pojava sa svojstvima određene kategorije. Ova stalna usporedba (komparacija) omogućava reviziju i postupnu integraciju akumuliranih informacija vezanih

## Data analysis

Analysis of the interview data was conducted using a constant comparative approach, whereby an open process of examining, comparing, conceptualizing, and categorizing data was used to identify and explore a new or little understood phenomenon (32). As an analytical approach for generating new theory, the constant comparative method generally occurs in a series of stages that operate simultaneously and continuously until analysis is terminated. In the first stage, “incidents” in the data (single, identifiable units of information within interview transcripts) are coded (assigned a label) according to a given category or construct of interest. Newly-coded incidents are continuously compared with previous incidents in the same or different categories in a process in which similarities or conflicts between coded incidents are gathered, and theoretical properties of a given category are gradually generated (32). For example, in the present study, participants’ reports of a specific reaction to or source of stress were coded as incidents. These general “categories” of codes (e.g. sources of stress, effects of stress) were initially formulated using some of the fundamental elements of the minority stress model (4). However, specific identifiers or codes were generated directly via analysis of the data itself, in which codes related to the emotional impact of stress, ways of coping with stress, and sources of stress were gradually identified and expanded upon as coding and comparison continued.

In later stages of this method, the comparison process changes from one between individual incidents to a comparison of incidents with the properties of a given category. This “constant comparison” allows accumulated knowledge relating to a certain category to be revised and gradually integrated (32). For example, a code for “exclusionary institutional systems” was included in the code category “sources of stress”, which in turn encompassed several sub-codes (e.g. political, social, or health systems). This frame-

uz određenu kategoriju (32). Primjerice, unutar kategorije „izvori stresa“, određeni broj pojava označen je korištenjem koda „isključujući institucionalni sustavi“, što je zauzvrat obuhvaćalo nekoliko podkodova (npr. politički, društveni ili zdravstveni sustavi). Taj je okvir tada primijenjen na dubinski pregled podataka (transkripti intervjeta), u kojima su izjave identificirane i označene prema jedinstvenom identifikatoru koda na koji su primijenjene. Tijekom procesa kodiranja okvir za kodiranje je revidiran i ažuriran, budući da su nove teme ili teme koje nisu prethodno uključene u okvir proizašle iz odgovora sudionika.

Kako se kategorije sve više integriraju, postupno se razvija organizirana znanstvena spoznaja (ili teorija), modifikacije kategorija postaju manje te dolazi do točke teorijske zasićenosti (drugim riječima, daljnje kodiranje pojave ne otkriva nove kodove/kategorije, već potvrđuje samo postojeće kategorije). U ovom istraživanju faza zasićenosti postignuta je u kasnijim fazama analize, pri čemu se tijekom pregleda završnih transkripata nisu pojavili novi kodovi / kategorije. Koristeći ovu metodu razvijena teorija je utemeljena u samim podatcima ili je izvedena izravno iz perspektive sudionika. Kao takvo, novo razumijevanje proizašlo iz analize podataka ovog istraživanja, iako se temelji na konceptualnom okviru koji vodi istraživanje, istodobno je točan prikaz perspektiva sudionika i stoga nudi jedinstvenu perspektivu iz koje se dalje istražuje tema.

Svi intervjeti su pregledani i analizirani drugi put korištenjem ažuriranog okvira za kodiranje kako bi se potvrdio dogovor između konačnog okvira za kodiranje i kodova dodijeljenih odgovorima sudionika. Inicijalno kodiranje provela je prva autorica rada, a kontrolno kodiranje druge autorice. Obje autorice su zbog intenzivne interakcije s podatcima zadovoljile kriterij teorijske osjetljivosti (engl. *theoretical sensitivity*) (33). Sudioinci su u tekstu označeni šifrom koja označava spol (Ž/M), dob i dijagnozu (CP, OLM).

work was then applied to an in-depth review of the data (interview transcripts), in which statements were identified and denoted according to the unique code identifier to which they applied. During the coding process, the coding framework was revised and updated as new themes or topics not previously included in the framework arose from the responses of the participants.

As categories become increasingly integrated, theory develops gradually, modifications to categories become fewer, and a point of theoretical saturation is reached (i.e. further coding of incidents reveals no new codes/categories but only confirms existing categories). In the present study, this stage of saturation was reached in later analytical stages, where no new codes/categories arose during a review of the final interview transcripts. Using this method, the theory developed is “grounded” in the data itself or is derived directly from the perspectives of the participants. In this way, new understanding derived from the analysis, although based on the conceptual framework guiding the study, was also an accurate representation of participants’ perspectives and therefore offers a unique perspective from which this topic can be further explored.

All interviews were reviewed and analysed a second time using the updated coding framework to confirm agreement between the final coding framework and the codes assigned to the responses of the participants. Initial coding was carried out by the first author and control coding by the second author. Due to their intense interaction with the data, both authors met the criterion of theoretical sensitivity (33). In this paper, participants are identified with a code that indicates participants’ sex, age, and diagnosis. All identifying information that risked revealing the identity of a participant has been removed from the text. The research was conducted in line with all recommendations for the ethical conduct of research with human participants.

Using the framework and coded interviews, participant statements were clustered into

Iz teksta su uklonjeni svi identificirajući podatci koji bi mogli otkriti identitet sudionika. Istraživanje je slijedilo sve preporuke o etičnom provođenju istraživanja u kojem su sudionici ljudi.

Korištenjem okvira i kodiranih intervjeta izjave sudionika grupirane su u smislene cjeline koje predstavljaju različite teme od interesa za ovo istraživanje.

## REZULTATI

Prethodno opisana analiza omogućila je opisnu interpretaciju različitih učinaka stresa na emocijonalnu dobrobit sudionika, njihovo korištenje strategija suočavanja sa stresom i socijalne podrške, kao i različitih izvora stresa o kojima su izvještavali sudionici. O ovim temama će se raspravljati u narednim poglavljima.

### Učinci stresa

Korištenje otvorenih pitanja tijekom intervjeta omogućilo je sudionicima slobodu da iznesu svoje stavove o stresu i opisuju svoje osobno iskustvo stresa. Na pitanje o svojim općim stavovima o stresu, više sudionika prepoznalo je pozitivnu vrijednost stresa u svakodnevnom životu. Naime, sudionici su identificirali stres kao potencijalni izvor svrhe i motivacije:

*Pozitivan je u smjeru da te uvijek... čini pripravnim. Da ti zapravo pomaže da se osjećaš živ. Mislim da ljudi koji onako, dobro balansiraju između stresnih i nestresnih situacija, su oni koji...su proaktivni, veseli i vedri. 1.33.1*

Slično tome, sudionici su promatrali stres kao iskustvo koje ih priprema za buduće izazove u životu:

*Stres očvršćuje. Očvrstilo me na način da me više u životu ništa ne može razočarati. 2.20.1*

Međutim, najvećim dijelom, sudionici su pretežno izvjestili da je za njih stres uglavnom

meaningful units representing the various themes of interest to the present study.

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## FINDINGS

The analysis described above allowed for a descriptive interpretation of the various effects of stress on the emotional well-being of participants, participants' use of coping strategies and social support, as well as the various sources of stress reported by our participants. The findings related to each of these themes will be presented in the following sections.

### Effects of stress

The use of open-ended questions during the interview allowed participants the freedom to express their own views regarding stress and to describe their personal stress experience. When asked about their general views on stress, a number of participants recognized the positive value of stress in everyday life. Namely, participants identified stress as a potential source of purpose and motivation:

*It is positive in the sense that it always... keeps you prepared. It helps you to feel alive. I think people who are good at balancing between stressful and nonstressful situations, they are the ones who are... proactive, joyful, and happy. 1.33.1*

Similarly, participants viewed stress as an experience that prepares oneself for future challenges in life:

*Stress hardens you. It has strengthened me in a way so that nothing in life can disappoint me anymore. 2.20.1*

However, participants predominantly reported stress to be a negative experience. When asked to describe the effect of stress in their everyday lives, participants used a wide range of descriptors, such as "tension", "annoyance", "anger" and "discomfort". Many participants also described the bodily effects of stress:

negativan doživljaj. Na pitanje o opisivanju učinka stresa u svakodnevnom životu sudionici su koristili širok spektar opisa, kao što su 'napetost', 'uzravanost', 'ljutitost' i 'nelagoda'. Više sudionika je opisalo tjelesne manifestacije stresa:

*Da, čovjek se zacrveni, da bi ono pukla.  
Osjećam da ... srce počne ovako lupati,  
uglavnom osjeća se i fizički definitivno -*  
1.65.2

Doista, gotovo svi sudionici prepoznali su fizičke odgovore svojih tijela na stres. Ovo mišljenje sažeto je u izjavi sudionika s ozljedom kralježnične moždine:

*Nelagoda. Osjećaj nelagode uzrokovani nekim unutarnjim ili vanjskim faktorom, a koji... ustanovimo u sebi, ... ne isključivo psihičke nego čak i fizičke manifestacije. Kao što su ... nespavanje, pa onda i zbog zdravstvenog stanja u kojem jesam ... pojačavanje spazama, možda čak i smanjenje imuniteta.* 2.32.2

O teškoćama sa spavanjem ovog sudionika također su izvijestili i drugi, a često su bili povezani s poteškoćama kao što su umor i smanjena razina energije:

*Kod mene se stres manifestira u tom ne-kakov osjećaju umora ... na kraju dana.*  
1.33.1

Osim negativnih fizičkih učinaka stresa sudionici su također opisali svoje iskustvo stresa u smislu njihove emocionalne reakcije na stresne događaje. Specifično, na različite načine su opisivali osjećaje napetosti, agitacije i frustracije:

*Ja to zovem 'puknem'. Jednostavno moram to izbaciti iz sebe van. Koliko mi se god se činilo da sam ja izvana miran, iznutra me ipak nešto kopka.* 2.20.1

*Ne možeš čovjeku objasniti u čemu je problem jer ti si već lud od svega, ti si već mili-junti kojem to objašnjavam i lud si.* 1.33.2

*Yes, one gets red in the face, like I might burst. I feel like... my heart starts to pound like this, in general I feel stress physically, definitely.* 1.65.2

Indeed, nearly all participants recognized the physical responses of their bodies to stress. This sentiment is summarized by a statement from a participant with spinal cord injury:

*Discomfort. A feeling of discomfort caused by some internal or external factor that we establish in ourselves... not just mental but even physical manifestations. Such as problems with sleep, and then, because of the health condition which I am in, stronger spasms, maybe even reduced immunity.* 2.32.2

The difficulties with sleep experienced by this participant were also reported by others and were often related to difficulties with fatigue and decreased energy level:

*For me, stress manifests in some kind of feeling of weariness at the end of the day.*  
1.33.1

In addition to the negative physical effects of stress, participants also described their stress experience in terms of emotional reactions to stressful events. Specifically, feelings of tension, agitation, and frustration were described by participants in different ways:

*I describe it like I'm going to "burst". I just have to get it out of my system. No matter how much it seems from the outside that I am calm, inside something still digs at me.* 2.20.1

*You can't explain to someone what the problem is because you already feel crazy from it all, you have already explained it a million times and you feel crazy.* 1.33.2

Together, participant responses provide insight into the negative effects of stress on physical, mental, and emotional well-being. As a source of frustration, anxiety, worry, and anger, stress represented a mediator of overall health for our par-

Sveukupno, izvješća o odgovorima sudionika pružaju uvid u negativne učinke stresa na cjelokupnu mentalnu, tjelesnu i emocionalnu dobrobit. Kao izvor frustracije, tjeskobe, brige i ljutnje, stres je za naše sudionike posredni čimbenik cjelokupnog zdravlja. U nekim slučajevima, iskustvo stresa utjecalo je na mentalno zdravlje na značajnije načine:

*Osjećam anksioznost, nervozu, plačljivost... znam pasti i u depresiju zbog stresa.* 1.44.1

U jednom slučaju, vrlo ozbiljni, negativni učinci stresa na mentalno zdravlje zabilježeni su izjavom o suicidalnim mislima:

*Ja sam bio doslovno na rubu, ja sam bio doslovno smrt ili život. ... s obzirom da sam visokotlakaš, ... ja sam sve isplanirao: popijem tablete – sve - i nema šanse da ostaneš živ... ali u tom trenutku jednostavno mi ruka nije dala da uzmem čašu i to napravim.* 2.20.1

Iz prethodnih promjera vidljivo je da je stres bio univerzalni fenomen koji su svi sudionici prepoznali kao iskustvo s različitim negativnim utjecajima na tjelesno i duševno zdravlje te dobrobit. Svi sudionici izvjestili su o prisutnosti stresa u životu, no prijavljeni učinci stresnog iskustva su se razlikovali. Kod nekih je stres izazvao privremene ili blage tjelesne ili emocionalne reakcije dok je za druge kronično ili ponovljeno iskustvo stresa doprinijelo značajnijim teškoćama mentalnog zdravlja.

## Strategije suočavanja i podrška

Sudionici su prepoznali različite strategije i metode upravljanja i rješavanja vlastitog stresa. Za mnoge je sudjelovanje u različitim aktivnostima – slušanju glazbe i plesu, provođenju vremena u prirodnom okruženju, igranju video igara, usredotočujući se na rad – nudilo opuštanje ili odvlačenje pažnje od stresnog iskustva. Za jednu sudionicu, rad je predstavljao okružje

ticipants. In some cases, the stress experience influenced mental health in more significant ways:

*I feel anxious, nervous, weepy... I have a tendency to fall into depression because of stress.* 1.44.1

In a more serious case, the negative effects of stress on mental health led to thoughts of suicide:

*I was literally on the edge, I was literally between death and life. Because I have high blood pressure... I had everything planned – take the pills, everything, and no way I would survive... but at that moment my hand simply wouldn't take the glass and do it.* 2.20.1

Clearly, stress was a universal phenomenon recognized by all participants as an experience with varying negative influences on physical and mental health and well-being. While all participants reported feeling stress in their lives, the reported effects of the stress experience differed. For some, stress produced temporary or mild physical or emotional reactions while, for others, chronic or repeated experience of stress contributed to more significant mental health issues.

## Coping strategies and support

Participants identified a variety of strategies for managing and dealing with their own stress. For many, participation in various activities – listening to music and dance, spending time in nature, playing video games, focusing on work – offered a form of relief or distraction from experienced stress. For one participant, work represented a setting in which she was able to forget about stressors in other parts of her life:

*... when I am personally under stress, I actually escape to work. Because work is a kind of safe zone where I feel competent and then those banal things that cause me stress, and that are not work, I actually ignore. No, I stop thinking about them.* 1.33.1

For our participants, participating in preferred activities represented a way to be engaged in

u kojem je uspjela zaboraviti na stresove u drugim segmentima svoga života:

*...kad sam ja osobno pod stresom, zapravo pobjegnem u posao. Jer posao je nekakva moja sigurna zona, gdje se osjećam kompetentno i onda one stvari banalne koje mi uzrokuju stres, a nisu posao, zapravo zanemarim. Ne, prestanem razmišljat' o tome.* 1.33.1

Za naše sudionike, sudjelovanje u odabranim, željenim aktivnostima predstavljalo je način da uključivanjem u smislenu aktivnost smanjuju stres u drugim područjima svakodnevnog života, stvarajući tako osjećaj sposobnosti, kontrole i opuštanja.

Druga dominantna tema tijekom rasprave o suočavanju sa stresom bila je uporaba raznih samoupravljačkih ili samoregulacijskih strategija. To uključuje razne oblike djelovanja ili misli koje sam pojedinac odabire s ciljem otpuštanja stresa, smirivanja i kretanja naprijed. Ova vrsta pristupa odražava se u sljedećim izjavama sudionika:

*Pa pokušava sam samoj sebi reći – ok, to moraš prevazići i smiriti se...i riješiti to na najbolji mogući način.* 1.44.1

*Kad sam pod stresom onda često znam reći: Ma, nikad ništa od toga. Daleko si ti od toga. I to me u nekim trenutcima zna stopirat' onako kao da, znam što hoću, al' ostanem zabetonirana na jednoj točci.* 1.33.1

*Pa pokušam se smiriti, pokušam par puta udahnuti, dat si vremena da ne reagiram na prvu.* 1.65.2

Korištenje strategija suočavanja sa stresom svi su sudionici prepoznali kao važnu vještina za upravljanje neizbjegnim iskustvom stresa. Za neke je to također uključivalo identificiranje i razlikovanje situacija u životu na koje se može djelovati i onih koji su izvan vlastite kontrole:

*Kad se neke stvari dogode, ako ih mogu promijeniti onda ih krenem mijenjati. Ako ih ne mogu promijeniti, zašto se brinuti oko toga?* 2.32.2

meaningful activity and, as such, lessened stress in other domains of everyday life by providing feelings of competence, control, and relaxation.

Another dominant theme during the discussion about coping with stress was the use of various self-management or self-regulatory strategies. This included various actions or tasks conducted by the individuals themselves with the aim of relieving stress, calming down, and moving forward. This type of approach is reflected in the following statements from participants:

*So I tried to tell myself – OK, you have to overcome this and calm down... and solve it in the best possible way.* 1.44.1

*When I'm under stress, I often say, "OK, that's not going to happen. You're so far from reaching that." And sometimes, this can hold me back, as if I know what I want, but I stay fixed on a single point.* 1.33.1

*I try to calm down, I try to take a few breaths, give myself some time so that I don't react too quickly.* 1.65.2

The use of coping strategies was recognized by all participants as an important skill for managing the inevitable experience of stress. For some, this also involved identifying situations in life in which you can exert change and those which are beyond your own control:

*Sometimes, when things happen and if I can change them, then I work to change them. If I can't change them, why worry about it?* 2.32.2

Indeed, most participants agreed that stress was an unavoidable part of everyday life and, for this reason, effective coping and self-management was an important and necessary part of maintaining health. This sentiment is reflected in the words of one participant:

*The first phase of solving or dealing with stress... first, it needs to be recognized and then somehow controlled. And then*

Doista, većina sudionika složila se da je stres nezaobilazan dio svakodnevnog života i zbog toga je učinkovito suočavanje i upravljanje vlastitim reakcijama važan i neophodan dio održavanja zdravlja. Taj se dojam odražava u riječima jednog sudionika:

*Prva faza rješavanja ili nošenja sa stresom... kao prvo treba ga prepoznati i onda ga nekako kontrolirati. I onda kad ga možete kontrolirati, utvrditi što ga uzrokuje i ... onda se nositi s njime i u konačnici smanjiti ga.* 2.32.2

Unatoč širokom rasponu učinkovitih strategija za upravljanje stresom i samoregulacijom sudionici su također prepoznali važnu ulogu socijalne podrške u smanjenju i upravljanju stresom. Svi sudionici su izvjestili kako su različiti izvori socijalne podrške, uključujući roditelje, braću i sestre, partnera, kolege i prijatelje, bili važan čimbenik u posredovanju i upravljanju učincima stresa u svakodnevnom životu. Neki sudionici također su identificirali više organizirane (institucionalne) oblike podrške, poput osobnog asistenta ili udruge za osobe s invaliditetom, kao važne resurse za smanjenje utjecaja stresa. Za sudionike potpora osobnog asistenta tijekom potencijalno stresnih situacija identificirana je kao čimbenik snižavanja razine zabrinutosti i višeg osjećanja samopouzdanja:

*Imam asistenta u nastavi preko faksa pa mi je lakše. Da je čisto netko kraj mene lakše je to... čisto osjećaj sigurnost da je netko kraj mene ako padnem slučajno, da me se brzo podigne da nastavim dalje, a ne da ostanem dolje ležat.* 2.20.1

*Ako idem s nekom pratnjom koja je dovoljno informirana što treba, onda gotovo da ne brinem.* 2.32.2

Dvoje sudionika izvjestili su o traženju stručne podrške za upravljanje stresom i rješavanje negativnih emocionalnih posljedica stresnog iskustva. Prema riječima jednog sudionika, ta je strategija bila izbor kada postojeći mehanizmi suo-

*when you can control it, determine what causes it and then deal with it and ultimately reduce it.* 2.32.2

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Despite a wide range of effective strategies for stress management, participants also recognized the important role played by social support in minimizing and managing stress. All participants reported how various sources of social support, including parents, siblings, partners, colleagues, and friends, represented an important factor in mediating and managing the effects of stress in their everyday lives. Some participants also identified more organized (institutional) forms of support, such as a personal assistant or associations for persons with disabilities, as important resources for reducing the impact of stress. For participants, the support of a personal assistant during potentially stressful situations was identified as a factor for reducing worry and feeling more confident:

*All through university I had an assistant so it's easier for me. Just to have someone near me is easier... to have a sense of security that someone is near me so if I accidentally fall, that someone will help me up and I can carry on, and that I won't stay lying on the ground.* 2.20.1

*If I go with a companion who is sufficiently informed about what they need to do, then I basically don't have to worry.*  
2.32.2

Two participants also reported seeking professional support for managing stress and addressing the negative emotional consequences of experienced stress. In the words of one participant, this strategy represented a choice when existing coping mechanisms were insufficient to address emotional difficulties:

*I sought out professional support because in my private life I came to a period when I didn't know how to deal with things, with the amount of pressure I felt, I didn't know how to move left or right.* 1.33.1

čavanja nisu bili dovoljni za nošenje s pritiskom i posljedičnim emocionalnim poteškoćama:

*Tražila (sam) podršku stručnu neku, zato što sam u privatnom životu došla do jednog perioda kada više nisam znala zapravo kako se nositi s tim, količinom pritiska koju sam osjećala, nisam znala kako se maknuti lijevo ili desno.* 1.33.1

Ova je sudionica dalje naglašava kako je nijezina odluka o traženju profesionalne podrške bila potaknuta osjećajem da ju stres preplavljuje i potrebom da netko izvan njenog svakodnevnog konteksta sasluša ili joj promijeni perspektivu:

*Jednostavno mi je trebao ne'ko da se izventiliram, ... da zapravo svu onu silinu emocija koju imam da nekom kažem... Treba mi ne'ko zapravo samo da me sasluša i da mi kaže: „Ok, opcije koje biraš su dobre, nisu dobre, odnosno, ja vidim ono što ti želiš i kreni u tom smjeru“.* 1.33.1

U cjelini sudionici su prepoznali stres kao univerzalno iskustvo u svakodnevnom životu, na mnoge načine, opisujući negativne učinke stresa na zdravlje i dobrobit, uporabu vlastitih mehanizama i strategija suočavanja te ulogu socijalne podrške pri upravljanju stresom. Razumljivo, ove ideje o stresu ne razlikuju se od onoga što bismo očekivali od opće populacije. Na taj je način iskustvo stresa osoba s tjelesnim invaliditetom slično kao i kod ostatka populacije (s iznimkom određenih fizičkih reakcija na stres koje su povezane s teškoćama pri samostalnom kretanju). No, postoje li specifičnosti koje bi razlikovale stresno iskustvo osoba s tjelesnim invaliditetom? Za naše sudionike, jedinstvena priroda stresa bila je povezana s različitim izvorima stresa u njihovom životu. Ova će tema biti istražena u nastavku.

### Izvori stresa u životu sudionika

Svi su sudionici izvijestili o različitim svakodnevnim stresorima od kojih se neki mogu identificirati kao zajednički općoj populaciji.

This participant further related how her decision to seek professional support was spurred by a feeling of being overwhelmed by stress in her life and a need for someone outside of her everyday context to act as a voice of reason or perspective:

*Basically, I needed someone to vent to... to tell someone all that bottled up emotion I have inside. I need someone that will just listen and tell me: “Ok, the options you choose are good or not good, that is, I see what you want and you should go in that direction.”* 1.33.1

On the whole, participants identified stress to be a universal experience in everyday life. In many ways, their description of the negative influence of stress on health and well-being, their use of coping mechanisms, and the role of social support in managing stress were not different from what we might expect in the general population. In this way, the stress experience of persons with physical disabilities was similar to that of other adults (with the exception of the physical reactions to stress that are related to physical impairment). So what makes the stress experience of persons with physical disabilities different? For our participants, the unique nature of stress was related to the various sources of stress in their lives. This topic will be examined in the following section.

### Sources of stress in the lives of participants

All participants reported various everyday stressors, some of which were those that could be identified as common to the general population. This included stress related to the demands of life, stress in everyday work, and in family contexts and interpersonal relationships. Taken together, they confirm that the stress experience among persons with disabilities is in part shaped by common everyday stressors. A second group of stressors reported by all participants were those associated direct-

To uključuje stres nastao zbog zahtjeva svakodnevnog života; u svakodnevnom radu i vlastitim obiteljima te u međuljudskim odnosima. Zajedno oni potvrđuju da je iskustvo stresa među osobama s invaliditetom dijelom oblikovano uobičajenim svakodnevnim stresorima. Druga skupina stresora odnosi se na one koji su povezani sa samim invaliditetom te će ta skupina stresora biti podrobniye prikazana u radu. Slično kao u istraživanju Iwasaki i Mactavish (12), analiza u ovom istraživanju dala je dva opća klastera stresora: individualne i one nastale u interakciji s okolinom.

**INDIVIDUALNI STRESORI POVEZANI S INVALIDITETOM.** Mnogi sudionici govore o osjećaju stresa kao posljedici dodatnih zahtjeva u svakodnevnom životu koji nastaju zbog onesposobljenosti. Naime, dodatno vrijeme, napor, trošak i briga potrebni za obavljanje različitih zadataka bili su dodatni teret u dnevnoj rutini i doživljeni su kao značajan izvor stresa. Sudionici izvješćuju o širokom rasponu aktivnosti, od rutinskih aktivnosti obavljanja higijene do putovanja na posao:

*Određene stvari obavljaš na drugačiji način nego drugi i, da, moj dan ne započinje ustajanjem i izlaskom nakon pola sata, nego sigurno ustajanjem i dva sata, dva i pol prije, da bi mogla funkcirati cjełodnevno. A tako isto navečer imam dosta posla oko sebe 1.65.2*

*Jedino što meni kao osobi s invaliditetom predstavlja stres je ... niz tehničkih stvari na koje ne mogu utjecat' svaki dan moram nekako ishendlat'. Od toga koliko će mi taj dan trebat' vremena da se obučem, kako će zapravo doći na posao, hoće li padat' kiša ili neće ... 1.33.1*

Povezano s dodatnim zahtjevima svakodnevnog života sudionici navode stres koji je nastao u situacijama u kojima nisu bili u stanju samostalno obaviti zadatak. U takvim slučajevima,

ly with having a disability. Consistent with the work of Iwasaki i Mactavish (12), the analysis of these stressors in the present study yielded two general clusters: individual stressors related to having a disability and those that arise in interaction with one's surrounding environment.

**INDIVIDUAL STRESSORS RELATED TO DISABILITY.** In addition to general stressors, in the reports of our participants there were a number of unique individual stressors stemming directly from the lived experience of having a disability. Many of our participants reported feeling stressed as a result of the added demands on everyday life that arise as a result of having a disability. Namely, the extra time, effort, cost, and care required to carry out a range of tasks posed an additional burden on daily routines and was perceived as a significant source of stress. This was reported by participants for a wide range of activities, including self-care routines and commuting to work:

*Some things you do in a different way than others and, yes, my day doesn't start with getting up and leaving the house after half an hour, I need at least 2, 2.5 hours so that I can function the whole day. And it's the same in the evening, I have lots of work in self-care. 1.65.2*

*The one thing that for me, as a person with a disability, causes stress is all the technical things that I can't influence but that each day I need to somehow handle. From how much time it takes me to get dressed, to how I will actually get to work, will it rain or not... 1.33.1*

Related to these added demands on everyday life was stress arising in situations in which participants were unable to complete a task independently. In these instances, participants reported feeling stressed when they were required to ask someone for help:

*I needed to seek help to get into the tram. This also makes me stressed – asking for*

sudionici izvješćuju o osjećaju stresa kad im je potrebno tražiti nekoga za pomoć:

*Trebala sam zatražiti pomoć pri ulasku u tramvaj. To isto doživljavam kao stres... zamoliti pomoć stranca...nikad ne znaš kako će ljudi reagirati.* 1.44.1

Doživljeni stres uzrokovan smanjenjem neovisnosti posebno naglašavaju sudionici kod kojih je invaliditet nastao kao posljedica traume, ozljede ili bolesti, odnosno koji su imali pretходno iskustvo življenja bez invaliditeta. Za te pojedince važan izvor stresa bila je nužna prilagodba smanjenoj pokretljivosti ili sposobnosti. To je vidljivo u riječima sudionika koji je u adolescentnoj dobi stekao ozljedu leđne moždine:

*Većinu vremena sam se bavio sportom i sad sam jednostavno u toj poziciji u kojoj jesam u konačnici. Sviđalo mi se to druženje na takav način, putovanja po određenim turnirima, ta neka sloboda da ne moram biti, ne znam, na jednom mjestu... bio sam znači u potpunosti samostalan, a sad nisam... To me sad muči i to jako.... fali mi ta neka... lakoća postojanja.* 2.32.2

Za sudionike je nemogućnost uključivanja u značajne životne aktivnosti ili ispunjavanja ranije ostvarenih uloga povezanih s tim aktivnostima kao rezultata invaliditeta doživljena kao stresna jer je zapreka smislenom sudjelovanju u okolnostima u kojima su prije živjeli. To se ogleda u riječima jedne sudionice koja govori o osjećajima izolacije odnosno važnosti uključivanja u život zajednice:

*Čovjek je napravljen kao društveno biće, tako da ne možeš stalno biti doma... jer rad te, zapravo, stvarno te iščupa. Svi trebaju taj osjećaj koristi, ali nije samo osjećaj koristi, nego nekako osjećaš se, kao da si u nekakvoj zajednici....kao da smo nekakav kotačić...* 1.33.2

Razumljivo, prepoznati stresori vezani uz (pro)življeno iskustvo osobe s invaliditetom su značajni izvori stresa zbog povećanog oslanjanja

*help from strangers. You never know how people will react.* 1.44.1

The stress experienced by a reduction in independence was especially emphasized by participants who had acquired a disability as a result of trauma, injury, or illness or, in other words, had previously experienced life without a disability. For these individuals, an important source of stress and psychological distress was the necessary adjustment to reduced mobility or capability. This was reflected in the words of a young participant who suffered a spinal cord injury as a teenager:

*I used to spend most of my time playing sports and now I'm simply in the position that I am. I liked socializing in that way, travelling to tournaments, having that freedom that I don't have to be, I don't know, in one place. Before I was totally independent and now I'm not. That bothers me – it bothers me a lot. I miss that... "lightness of being".* 2.32.2

For our participants, the inability to engage in meaningful activities or to fulfil previously held roles associated with these activities as a result of a disability was stressful because it represented a barrier to meaningful participation in the contexts in which they lived. This is reflected in the words of one participant, who talks about feelings of isolation and the importance of being fully engaged in community life:

*People are social beings, no one can always be home alone. Work is, actually, something that really roots you. Everyone needs that feeling of being useful, but not just feeling useful but that you are part of a community, like we are all some kind of cog (in a system, author's note).* 1.33.2

Understandably, the reported stressors associated with the lived experience of having a disability are significant sources of stress because they represent an increased reliance on others that, in turn, contributed to feelings of reduced independence and social participation.

na druge ili nerazumijevanja od strane drugih (zbog specifičnosti pri artikulaciji govora) doprinose osjećajima smanjene neovisnosti i društvenog sudjelovanja.

**OKOLINSKI STRESORI – FIZIČKE I INSTITUCIONALNE BARIJERE.** Osim jedinstvenih, pojedinačnih stresora koji su izravno nastali kao posljedica invaliditeta, svi sudionici su izvijestili o različitim čimbenicima iz okoline koje su prepoznali kao značajne izvore stresa.

Budući da su svi sudionici pojedinci sa značajnim teškoćama u kretanju, od kojih pet za kretanje koriste invalidska kolica i jedan štak, nepristupačnost fizičkih prostora u kojima žive je značajna zapreka sudjelovanju u društvenom, kulturnom i gospodarskom životu. Ovaj stresor su sudionici iskusili u širokom rasponu javnih prostora, od restorana i trgovina do rekreacijskih prostora i javnih ustanova. Primjerom se može ilustrirati frustracijom jedne sudionice pri čekanju pristupačnog tramvaja:

*...prodru tri stara (nepristupačna, op.a.) tramvaja, mogu otic' tražit' neku drugu liniiju i ne čekat' da dođe četvrti stari tramvaj.* 1.33.1

Za sudionike pitanje nepristupačnosti nije samo pitanje nemogućnosti fizičkog pristupa određenom prostoru, već je smanjenje mogućnosti samostalnog sudjelovanja u svakodnevnom životu. Doista, fizička nepristupačnost pokazala se snažnim stresorom jer je izvor socijalne isključenosti:

*Živciram se kad poželim nekud ići i onda vidim stepenice ovako koje idu u polukrug, koje su željezne i onda još nemaju rukohvat. Onda se naživciram žeće... jer ako ima nešto gore, na primjer, nešto fenomenalno se dešava što me zanima, a ne mogu pristupiti tome.* 2.20.1

*Ne možeš na WC, u pola prostora ne možeš ući, pola restorana, pola kafića, pola butika...kaj ču ja? Mene moj grad ne želi!* 1.33.2

ENVIRONMENTAL SOURCES OF STRESS – PHYSICAL AND INSTITUTIONAL BARRIERS. In addition to the unique individual stressors that arose directly as a result of having a disability, all participants reported issues related to various environmental factors as significant sources of stress.

Because all participants were individuals with significant mobility impairments, of which five used a wheelchair and one used walking sticks, the inaccessibility of the physical spaces in which they lived represented a significant barrier to participation in social, cultural, and economic life. This stressor was experienced by participants in a wide range of public spaces, from restaurants and stores to recreational spaces, theatres, and public institutions. This source of stress is reflected in the frustration of one participant when waiting for an accessible tram:

*... three old (inaccessible, author's note) trams pass, I could go and search for another line rather than wait for the fourth old tram to come.* 1.33.1

For participants, the issue of inaccessibility was not only a matter of being unable to physically access a particular space, but rather represented a reduction in opportunities for participating in everyday life. Indeed, physical inaccessibility was a powerful stressor because it represented a source of social exclusion:

*I get annoyed when I want to go somewhere and then I see stairs that go like this, in a semicircle, which are made of iron and don't even have a handrail. Then I really get annoyed... because if there is something at the top, for example, something phenomenal is going on that I'm interested in, and I can't get to it.* 2.20.1

*You can't get to the (public) toilet, half the places you can't get into – restaurants, cafes, stores... what will I do?! My own city doesn't want me!* 1.33.2

The words of these participants reflect a feeling that the society in which they live, by failing to

Riječi ovih sudionika odražavaju osjećaj da je društvo u kojem žive, ne osiguravajući pristupačne javne usluge i prostore, pokazalo nespremnost da u potpunosti integrira osobe s invaliditetom u život zajednice. To se na sličan način odražava u priči jedne sudionice o iskustvu u lokalnom kinu gdje je „dostupan“ prostor rezerviran za pojedince u invalidskim kolicima smješten na dnu kazališta neposredno ispred ekrana. Za sudionike ovaj je osjećaj segregacije značajan izvor stresa:

*Ali recimo u kinu, imate mjesto za osobe s invaliditetom koje je odvojeno od svih... Ja ne želim sjedit sama dva sata, odvojeno od svih, i gledati film. Kao: 'da, imamo mjesto za osobe s invaliditetom'. Ne! Imaš neki prostor gdje ćeš me stavit i gdje će svi prolaziti pored mene. Mi ne tražimo nikakvo izdvajanje, nikakvu posebnost. Mi se želimo uklopiti, da se uklopimo u društvo, a ne da imamo takve slučajeve, da nas izdvajaju u potpunosti 1.33.2*

U svim primjerima slučajevi fizičke nepristupačnosti uzrokovali su stres jer su stvorili prepreke smislenom sudjelovanju u svakodnevnom društvenom, kulturnom i profesionalnom životu, a zauzvrat su proizveli osjećaj isključivanja ili marginalizacije. Slično su iskušto sudionici iskazivali u odnosu na različite institucionalne strukture uključujući sustave zdravstvene i socijalne skrbi i tržište rada. Pritom je stres nastao kao rezultat iskustava u javnim ustanovama u kojima pojedinci ili sustavi nisu bili spremni ili voljni prilagoditi se specifičnim potrebama osoba s invaliditetom. O takvom doživljaju izvještava sudionica kada opisuje dolazak na sastanak u državnu instituciju kako bi raspravljala o pravima osoba s invaliditetom, a pritom nije mogla pristupiti zgradi:

*Gdje god kreneš, je li ministarstvo, je li poljavarstvo... Ne jednom smo došli, pa nije radio lift... A idemo kod ljudi koji surađuju s udružama za osobe s invaliditetom i koji*

provide accessible public services and spaces, demonstrates an unwillingness to fully integrate persons with disabilities into community life. This was similarly reflected in a story from one participant about an experience at a local movie theatre, where the “accessible” space reserved for individuals in a wheelchair was placed at the bottom of the theatre immediately in front of the screen. For participants, this feeling of segregation represented a significant source of stress:

*But let's say in the cinema, you have a place for people with disabilities that is separated from everyone else ... I don't want to sit alone for two hours, apart from everyone, and watch the movie. Like "Yes, we have a place for people with disabilities". No! You have some space where you'll put me and where everyone else will pass by me... We're not looking for segregation, any special treatment. We want to integrate, that we fit into society and not that we have this kind of situation, where we are completely segregated. 1.33.2*

In all cases, instances of physical inaccessibility were stressful because they created barriers to meaningful participation in everyday social, cultural, and professional life and, in turn, produced a sense of exclusion or marginalization. These issues were also reported in relation to various institutional structures, including health and social care systems and the labour market. Specifically, many participants reported stress arising from experiences in public institutions in which individuals or systems were unwilling or unprepared to address the specific needs of persons with disabilities. One such experience was reported by a participant when she arrived for a meeting at a government ministry to discuss disability rights and was unable to gain access to the building:

*Wherever you go, to a government ministry, a municipal agency... On several occasions, we came to an agency and the lift wasn't working. And we were going to meet with people who work with associations for*

*bi trebali bit upućeni... Ne poštuješ nas, al ono, ni malo. I sad očekuješ da imamo nekakvu suradnju... 1.33.2*

Bez sumnje, takva iskustva bila su ponižavajuća i iznimno stresna. Za naše sudionike, ova su događanja bila nedostatak osjetljivosti ili svjesnosti o osobama s invaliditetom što je zauzvrat često rezultiralo neugodnim, sramotnim i nedvojbeno stresnim situacijama. Možda najčešće citirano područje u kojem je institucionalna struktura izvor stresa je isključivo tržište rada. Jedna sudionica je izvjestila da su joj, unatoč postignutoj razini obrazovanja, mogućnosti za smisleno zapošljenje bile slabije samo zato što je riječ o osobama s invaliditetom:

*Recimo da mi je stres i neki taj što ja znam da sam jako kompetentna za područje za koje sam se školovala i da sam sposobna, a da imam osjećaj da u Hrvatskoj neću zapravo dobiti priliku da se to pokaže .. i da mislim da sam zapravo zapela na poslu koji je jako ispod onoga što ja mogu. 1.33.1*

Takve zapreke za osiguravanje i zadržavanje zaposlenosti bile su značajan izvor stresa ne samo zbog financijskih posljedica, već i zbog toga što odražavaju sustav u kojem su osobe s invaliditetom isključene. Prema jednom sudioniku ova marginalizacija je također vidljiva na strukturnoj razini pri čemu su velike tvrtke spremnije platiti kaznu umjesto zapošljavanja zakonom propisane kvote osoba s invaliditetom:

*Lakše ti je davat sav taj novac mjesечно, 40-50,000 kuna nego da zaposlji jednu osobu koju ćeš plaćat recimo 5,000 kuna. 1.33.2*

Isključivost ovih struktura sudionici su doživjeli kao nedostatak spremnosti da se u potpunosti angažiraju osobe s invaliditetom, razumiju njihove specifične potrebe i prava te da učinkovito zajednički rade kako bi se osigurala puna participacija u društvu. Kada se razma-

*people with disabilities, who should be better informed... You do not respect us, not even a little. And now you expect us to have some kind of collaboration. 1.33.2*

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Undoubtedly, these experiences were both humiliating and extremely stressful. For our participants, these events were representative of the lack of sensitivity or awareness about persons with disabilities that, in turn, often resulted in unpleasant, embarrassing, and undoubtedly stressful situations. Perhaps the most commonly cited area in which an institutional structure represented a source of stress was an exclusionary labour market. One participant reported feeling that, despite her achieved level of education, opportunities for meaningful employment were lower merely because she was a person with a disability:

*For me stress is knowing that I am very competent in the field in which I studied and I am capable, but I have the feeling that in Croatia I won't get the opportunity to show it... and that I am actually stuck in a job that is well below what I can do. 1.33.1*

Such barriers to securing and maintaining employment represented a significant source of stress not only because of the financial consequences, but again because it reflected a system in which persons with disabilities were excluded. According to one participant, this marginalization was also evident at a structural level, where large companies were more willing to pay a penalty instead of employing the necessary quota of persons with disabilities that is required by law:

*It's easier to pay all that money monthly, 40-50,000 kuna, than to employ one person whose salary you will pay around 5,000 kuna. 1.33.2*

The exclusionary nature of these structures were experienced by our participants as a lack of readiness or unwillingness to engage fully with persons with disabilities, to understand their specific needs and rights and to effectively work together to ensure full participation in society.

traju zajedno, individualni i stresori iz okoline koje spominju sudionici dijelom odražavaju sudionikovo iskustvo diskriminacije.

**SOCIJALNI IZVORI STRESA – DISKRIMINACIJA.** Za sve sudionike značajan dio stresa proizašao je iz iskustva implicitne diskriminacije prema osobama s invaliditetom, koji se pojavljuje u različitim oblicima i potiče iz više različitih izvora. Za mnoge je ova diskriminacija doživljena u međuljudskim interakcijama u njihovim svakodnevnim životima - s obitelji, prijateljima, kolegama i članovima zajednice. Za naše sudionike ova iskustva su doprinijela osjećaju da drugi imaju negativne stavove prema njima:

*Gdje god dodjete zapravo nisu ljudi spremni niti pripremljeni na vaše stanje i svagdje ste malo čudo i uvijek ste čuđenje u svijetu. 1.33.2*

*Iako čak zna vaše kvalitete, traži čak vaše nekakve savjete, ona još uvijek ne smatra vas ravnopravnom osobom sebi. 1.65.2*

Prepoznavanje da ih drugi nisu vidjeli kao podjednako sposobnog člana društva ili su izbjegavali interakcije s njima, bilo je značajan izvor stresa. Jedan sudionik izvještava o isključenosti iz društvenih situacija kao posljedice njegovog stanja:

*Ako ja nekog ne pozovem na kavu, nema sanse da će mene ikad pozvat na kavu.*

*Kao i svaki normalan čovjek zasluzujem da se i mene pozove. 2.20.1*

Za sve su sudionike eksplisitni i implicitni izrazi diskriminacije prema osobama s invaliditetom značajan izvor stresa koji se odrazio ne samo u izravnim interakcijama s drugima, već i u prethodno opisanim iskustvima isključivanja: diskriminacijske prakse zapošljavanja, isključivanje iz života zajednice te ograničavanje participacije zbog fizičke nepristupačnosti. Doista, čini se razumnim tvrditi da su ti izvori stresa kolektivno odraz implicitnih negativnih stavova koje javnost nastavlja odr-

When considered together, the various individual and contextual stressors reported by participants in part reflect their experience of discrimination.

**SOCIAL SOURCES OF STRESS – DISCRIMINATION.** For all participants, a significant proportion of stress stemmed from experiences of implicit discrimination towards persons with disabilities, which arose in various forms and stemmed from a number of different sources. For many, this discrimination was experienced in the interpersonal interactions in which participants engaged in their everyday lives – with family, friends, colleagues, and community members. For our participants, these experiences contributed to a feeling that others hold negative attitudes towards them:

*Wherever you go, people are not really ready nor prepared for your condition and everywhere you are a source of wonder and always perceived with a sense of bewilderment in the world. 1.33.2*

*Even though she understands your worth and she seeks your advice, she still doesn't consider you to be an equal person to herself. 1.65.2*

For participants, the recognition that others did not perceive them as an equally capable member of society or avoided interactions with them represented a significant source of stress. One participant reported feeling excluded from social situations as a result of his disability:

*If I didn't invite someone for coffee, there's no chance that someone would ever extend such an invitation. Like every normal person, I deserve to be invited for coffee too. 2.20.1*

For all participants, explicit and implicit expressions of discrimination towards persons with disabilities represented a significant source of stress that was reflected not only in direct interactions, but also in the exclusionary experiences described previously: discriminatory hiring practices, exclusion from social and community life, and reduced participation due to physical

žavati prema osobama s invaliditetom. Stres vezan uz ovakvo iskustvo pojačan je u situacijama u kojima su sudionici bili izravne žrtve predrasuda:

*Stala sam pred crkvom da pričekam da netko naiđe i otvori mi vrata. Naišla je jedna žena i ja sam htjela reći: Oprostite možete li mi otvoriti vrata? Ona je rekla: Oprostite, nisam uzela novčanik... Strašno... ja uđem u crkvu i jedva sam se smirila....predrasude su mi velik uzrok stresa... 1.44.1*

Sagledavajući prethodno, izvješća naših sudionika potvrđuju da se diskriminacija prema osobama s invaliditetom odražava ograničavanjem participacije, socijalnom izolacijom i kulturološkom, političkom i ekonomskom isključenostu koja i dalje postoji u mnogim područjima života. Takva su iskustva našim sudionicima bila odraz stalne prisutnosti negativnih stavova prema osobama s invaliditetom i ostavljala su im dojam da ih drugi smatraju manje sposobnim ili manje vrijednim članovima društva. Naš najmlađi sudionik opisao je situaciju u kojoj su članovi obitelji bez njegova znanja iskoristili pristup finansijskoj pomoći koju prima i koristili ju za svoje osobne potrebe. Za njega je ovo iskustvo bilo odraz implicitnih negativnih stavova njegove obitelji, uvjerenja da je on manje sposoban, i, po njegovim riječima, *budala koju se može iskoristiti*. Ne iznenaduje da je ovo iskustvo stvorilo značajan stres, ljutnju i obiteljski sukob:

*Ako ja sad ne reagiram, pokazujem - budala sam, možete raditi sa mnom što god hoćete, ono, što god vam padne na pamet. Ja sam budala. 2.20.1*

Negativni stavovi koje izražavaju drugi su u izrazitoj suprotnosti sa slikom o sebi samih sudionika, koji sebe doživljavaju kao potpuno sposobne pojedince koji zaslužuju biti u potpunosti aktivni i integrirani članovi društva u kojem žive:

inaccessibility. Indeed, it seems reasonable to argue that these sources of stress are a collective reflection of the implicit negative attitudes the general public continues to hold towards persons with disabilities. The stress related to this experience was amplified in situations in which participants were direct targets of prejudice:

*I stopped in front of the church to wait for someone to come and open the door. A women arrived and I wanted to say "Excuse me, can you open the door for me?" She said "I'm sorry, I didn't bring my wallet". Horrible! I went into the church and I could barely calm down. Prejudice is a great source of stress. 1.44.1*

Taken together, the reports of our participants confirm that discrimination towards persons with disabilities, reflected through reduced participation, social isolation, and cultural, political and economic exclusion, continue to exist in many spheres of life. For our participants, this experience was a reflection of the ongoing presence of negative attitudes towards persons with disabilities that left participants with the impression that others considered them less capable or less valuable members of society. Our youngest participant reported a situation in which family members took advantage of their access to the financial support he received and used these funds for their own personal means, leaving the participant without sufficient funds to cover his everyday needs. For him, this experience was a reflection of the implicit negative attitudes held by his family that he was less competent and, in his words, *a fool to be taken advantage of*. Unsurprisingly, this experience generated significant stress, anger, and family conflict:

*If I don't react now, than I show them I am a fool, that they can do whatever they want to me, whatever comes to mind, that I am just a fool. 2.20.1*

The negative attitudes expressed by others are in stark contrast to the images participants hold of themselves, who view themselves as fully capable individuals that deserve to be ac-

*Nerazumijevanje mog govora. Dokazivanje da, iako sam osoba s invaliditetom ne vrijedim manje od drugih. To me najviše muči.* 1.44.1

## RASPRAVA

Rezultati ovog istraživanja ukazuju da se niz jedinstvenih stresora javlja kao dio (pro)življennog iskustva tjelesnog ograničenja. Ovi izvori stresa bili su pridodani općim stresorima o kojima su također izvijestili sudionici. Međutim, najznačajniji izvori stresa za sve sudionike proizlazili su iz različitih čimbenika izravno povezanih s invaliditetom. Te su čimbenike iskusili u kontekstu individualnih situacija, kao i na sustavnijim, društvenim razinama. Glavna komponenta koja je prožimala stresore za sve sudionike je diskriminacija, pri čemu su se stresne situacije i događaji u svakodnevnom životu sudionika često smatrali izravnim posljedica implicitnih negativnih stavova i neuvažavanja od strane drugih.

Rezultati ovog istraživanja podupiru hipotezu da su osobe s tjelesnim invaliditetom izložene brojnim specifičnim stresorima, različitim od onih koji se obično susreću u široj javnosti (3,11,12,34). Nadalje, vrste stresora također su u skladu s nalazima drugih istraživanja koje ispituju stres kod osoba s invaliditetom. To uključuje istraživanja koja ukazuju na jedinstveno iskustvo stresa povezano s obavljanjem svakodnevnih aktivnosti (15), socijalnom izolacijom (34), stigmom i stereotipima (14), neinkluzivnim mogućnostima zapošljavanja (35) i nedostatkom svijesti o invaliditetu (16). Rezultati ovog istraživanja također su u skladu s glavnim upozorenjem modela manjinskih stresova (4), koji tvrdi da su stigmatizirane skupine osjetljive na kronične i jedinstvene stresore kao rezultat njihovog pripadanja određenoj manjinskoj skupini. Slično tome, ti stresori proizlaze iz društvenih procesa, institucija i struktura izvan pojedinca (4). Iz gore prikazanih nalaza

tive and integrated members of the society in which they live:

*When someone doesn't understand my speech. Proving myself is stressful... that although I am a person with a disability, I am no less valuable than others. This upsets me the most.* 1.44.1

## DISCUSSION

The results of the present study indicate that a number of unique stressors arise as part of the lived experience of having a physical disability. These sources of stress were additive to the general stressors also reported by our participants. Indeed, the most significant sources of stress for all participants stemmed entirely from various factors directly related to having a disability. These factors were experienced in the context of individual situations as well as at more systemic, social levels. A major element that pervaded the stressors for all participants was discrimination, where the stressful situations and events in the everyday lives of participants were frequently perceived to be a direct result of the implicit negative attitudes held by others.

The findings in the present study support the notion that persons with physical disabilities are exposed to a number of specific stressors over and above those typically encountered by the general public (3,11,12,34). Furthermore, the types of stressors are also consistent with the findings of studies examining stress among persons with disabilities. This includes research demonstrating the unique experience of stress associated with completing daily activities (15), social isolation (34), stigma and stereotypes (14), non-inclusive employment opportunities (35), and a lack of disability awareness (16). Our findings are also consistent with the main caveats of the minority stress model (4), which purports that stigmatized groups are susceptible to chronic and unique stressors as a result of their membership in a specific minority group.

čini se da je slično istinito i za iskustvo stresa sudionika ovog istraživanja.

Analiza perspektiva sudionika podržala je i tvrdnju da različiti oblici diskriminacije imaju važnu ulogu u stresnom iskustvu osoba s tjelesnim invaliditetom (12). Za naše sudionike, različiti izvori stresa, uključujući fizičku nepristupačnost, isključujuće institucionalne i društvene strukture te neposredna iskustva s predrasudama i diskriminacijom, smatrani su stresnim jer predstavljaju prepreku punom sudjelovanju i smislenom angažmanu u društvenom, kulturnom, ekonomskom i političkom životu. Opisani izvori stresa mogli bi se svrstati u Meyerovu kategoriju distalnih stresnih procesa u konceptualizaciji manjinskog stresa te su u skladu s okvirom koji su predložili Iwasaki i Mactavish (12), pri čemu su izvori stresa koji nastaju interakcijom s okolinom prikazani u uzajamnom odnosu s različitim oblicima isključenosti, odnosno diskriminacije.

U raspravi o iskustvu stresa, naši sudionici su također govorili o individualnim perspektivama koje, u skladu s Meyerovim modelom (4), mogu biti karakterizirane kao proksimalni stresni procesi. U skladu s ovim modelom, ovi unutarnji iskustveni stresni procesi, kao što su osjećaj nesposobnosti ili ovisnosti o drugima, osjećaj manje korisnosti u društvu, gubitak uloga, kao i potreba za „samodokazivanjem“ bili su pod utjecajem različitih distalnih stresnih procesa koje su doživjeli naši sudionici. Prema Meyeru (4), ti se proksimalni stresni procesi mogu pojaviti i kao posljedica percepcije pojedinca o sebi kao članu stigmatizirane manjinske skupine ili usvajanju manjinskog identiteta. To je vidljivo i u doživljajima naših sudionika pri čemu izvještavaju o potrebi da se svojoj okolini potvrde ili dokažu kao ravnopravni članovi društva.

Što ovaj proces znači za mentalnu dobrobit osoba s tjelesnim invaliditetom? Bez sumnje je stres ključni čimbenik rizika u određivanju ishoda mentalnog zdravlja (36). Stoga se čini

Similarly, these stressors stem from the social processes, institutions, and structures beyond the individual (4). From the findings presented above, it seems clear that this is similarly true for the stress experiences of our participants.

The analysis of participant perspectives also supported the notion that various forms of discrimination play an important role in the stress experience of persons with physical disabilities (12). For our participants, various sources of stress, including physical inaccessibility, exclusionary institutional and social structures, and direct experiences of prejudice and discrimination, were perceived as stressful because they represented a barrier to full participation and meaningful engagement in social, cultural, economic, and political life. The stressors described by our participants might be characterized as distal stress processes, as described by Meyer (4) in his conceptualization of minority stress. Similarly, the findings in the present study are consistent with the framework proposed by Iwasaki and Mactavish (12), in which stressors that arise through an individual's interaction with their environment are inter-related with various forms of exclusion or discrimination.

In their discussion of the stress experience, our participants also discussed individual perspectives that, in accordance with Meyer's (4) model, might be characterized as proximal stress processes. Consistent with the minority stress model, these internally experienced stress processes, such as feelings of incompetence, dependence on others, inability to contribute to society, role loss, and the need to “prove oneself”, were influenced by the various distal stress processes experienced by our participants. According to Meyer (4), these proximal stress processes can arise as a result of the individual's perception of oneself as a stigmatized minority, or the internalization of one's minority identity. This notion was similarly reflected in the reported experiences of our participants, in which they felt it was necessary to validate or prove themselves as equal members of society.

razumnim pretpostaviti da skupine koje doživljavaju dodatni stres kao rezultat manjinskog statusa mogu biti osjetljivije na negativne učinke stresa te osjećati posljedice u mentalnom zdravlju. Svi sudionici su izvijestili o emocionalnim učincima različitih stresnih iskustava koje su opisali kao uznenimirujuće, frustrirajuće i depresivne. Dok se kod pojedinih sudionika ozbiljnost tih učinaka razlikovala, sudionici su iskazali konsenzus o negativnom utjecaju stresa na emocionalnu dobrobit. Kao rezultat toga, svi su sudionici razvili različite metode upravljanja i suočavanja sa stresom te prepoznali ulogu socijalne podrške u posredovanju negativnim učincima stresa.

Sveukupno, ovdje prikazani nalazi omogućili su izgradnju pokusnog radnog modela koji ilustrira iskustvo stresa među našim sudionicima (sl. 1). Ovaj model, koji se temelji na modelu manjinskog stresa koji je predložio Meyer (4), smješta proces stresa unutar (pro) življenog iskustva pojedinca iz manjinske skupine (u ovom slučaju osobe s invaliditetom). Taj manjinski status uključen je u kontekst različitih okolnosti pojedinca i okoline, kao što su status zapošljavanja, razina obrazovanja i društveni kontekst. Zajedno, ovi čimbenici dovode do različitih procesa stresa. Sukladno Meyerovom modelu (4) stresori o kojima govore sudionici ovog istraživanja mogu se općenito razlikovati kao stresori zajednički općoj populaciji i jedinstveni stresori koji proizlaze kao posljedica manjinskog statusa. Procesi manjinskog stresa mogu se podijeliti na subjektivne (ili proksimalne) stresore, te objektivne (ili distalne) stresore. U skladu s našim rezultatima ovi su stresori u modelu prikazani kao preklapajući kako bi prikazali njihovu međuvisnost. Prema Meyerovom modelu (4) ti stresni čimbenici konvergiraju i utječu na eventualne ishode mentalnog zdravlja koji su pak posredovani prisutnošću društvene podrške i različitim strategijama suočavanja.

What does this process mean for the mental well-being of persons with physical disabilities? It is without a doubt that stress is a key risk factor in determining mental health outcomes (36). As such, it seems reasonable to assume that groups experiencing additive stress as a result of their minority status might be at greater risk of the negative effects of stress on mental health. In the present study, all participants discussed the emotional effects of various stress experiences using descriptors such as "disturbing", "frustrating", and "depressing". While the severity of these effects differed across participants, there was universal consensus regarding the negative impact of stress on emotional well-being. In response, all participants had developed methods of managing and dealing with stress and recognized the role of social support in mediating the negative effects of stress.

Taken together, the findings presented here have allowed for the construction of a tentative working model illustrating the experience of stress for our participants (Figure 1). The model, based on the minority stress model proposed by Meyer (4), locates the stress process within the lived experience of an individual from a minority group (i.e. person with a disability). This minority status is nested within the context of various individual and environmental circumstances, such as employment status, education level, and social context. Together, these elements give rise to various stress processes. Consistent with Meyer's (4) model, the stressors reported by our participants can generally be distinguished as stressors common to the general population and the unique stressors that arise as a consequence of one's minority status. These minority stress processes can be divided into subjective (proximal) stress processes and objective (distal) stress processes. Consistent with our results, these stressors are depicted in the model as overlapping in order to depict their interdependency. According to Meyer's (2004) model, these stress processes converge to influence eventual mental health outcomes

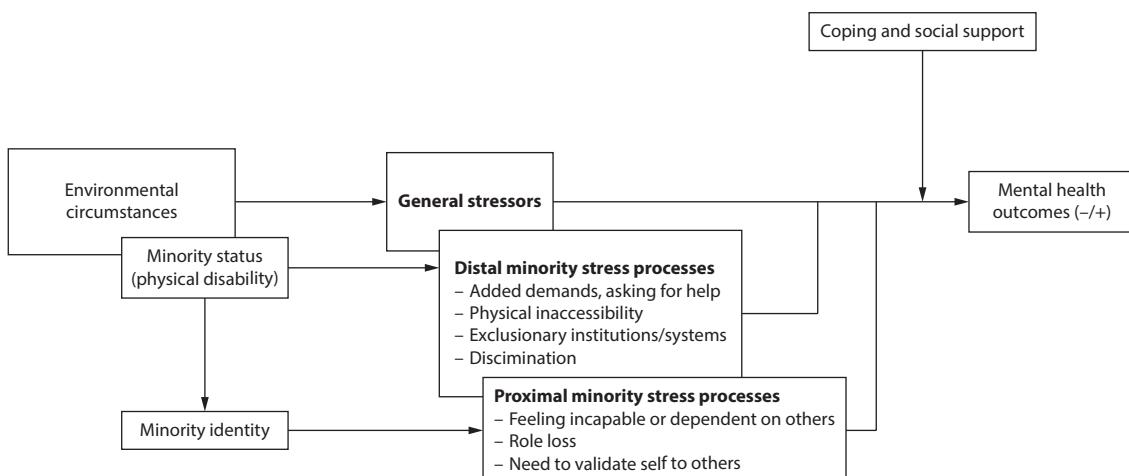
Na temelju rezultata ovog istraživanja čini se razumnim tvrditi da je značajan dio iskustva stresa osoba s invaliditetom oblikovan različitim oblicima diskriminacije. Međutim, kako je riječ o preliminarnom istraživanju koje se bavi do sada slabo istraženom temom, predloženi odnosi između koncepata predstavljenih u našem modelu su hipoteze koje zahtijevaju daljnje ispitivanje u budućim istraživanjima. Nadalje, implikacije ovog istraživanja ne mogu se u potpunosti uvažiti bez razmatranja nekih ograničenja, koja proizlaze iz prirode uzorka. Naime, uzorak je namjeran i sužen te je u svjetlu svrhovitog načina odabira sudionika relativno specifična podskupina populacije od interesa. Budući da je većina sudionika aktivno uključena u zajednicu osoba s invaliditetom te u šire društvo, našom smo analizom bili svjesni mogućnosti da njihove perspektive nisu univerzalan odraz iskustva stresa cijele populacije osoba s tjelesnim invaliditetom u Hrvatskoj. Odluka o ograničavanju raznolikosti i veličini uzorka potaknuta je istraživačkim ciljem te sukladno odabranom kvalitativnom metodologijom koja je proučavala slabo istraženu i razumljenu temu. Stoga je cilj bio dubinsko ispitivanje pojedinačnih perspektiva manjeg broja namjerno odabranih sudionika bez prethodno određenog okvira podataka koje očekujemo prikupiti. Time smo uspjeli stvoriti poticajan okvir za opis utjecaja stresa na mentalno zdravlje osoba s tjelesnim invaliditetom i stresora koje su iskusile osobe s tjelesnim invaliditetom. Kao takvo, ovo probno istraživanje ponudilo je novo razumijevanje stresnog iskustva osoba s tjelesnim invaliditetom u Hrvatskoj. Međutim, potrebno je poduzeti daljnja istraživanja s većim i raznolikijim uzorcima kako bi se dodatno istražili i potvrdili ovdje prikazani rezultati.

Specifično, potrebno je daljnje istraživanje povezanosti stresa i mentalnog zdravlja ove skupine kako bi se bolje razumjeli posljedice

that are, in turn, mediated by the presence of social support and various coping strategies.

Based on the results of this study, it seems reasonable to conclude that a significant part of the stress experience among persons with disabilities is shaped by various forms of discrimination. However, as a preliminary study examining a rarely studied topic, the proposed relationships between the concepts presented in our model are hypotheses that require further investigation in future studies. Furthermore, the implications of this study cannot be fully appreciated without considering a number of limitations that stem from the nature of the sample. Namely, the sample is both small and, in light of the purposive manner with which participants were selected, representative of a relatively specific sub-group of the population of interest. Because most of our participants were active and involved members of the disability community as well as the larger surrounding society, we were aware of the possibility that their perspectives are not a wholly accurate reflection of the stress experience of the larger population of persons with physical disabilities in Croatia. The decision to limit the diversity and size of the sample was prompted by the research aim and is consistent with the selection of a qualitative research methodology for examining a poorly researched and understood topic. Accordingly, our aim was to deeply probe the individual perspectives of purposefully selected participants without a pre-determined framework of the data we expected to collect. In doing so, we have been able to construct a tentative framework describing the effect of stress on the mental health of persons with physical disabilities and the unique stressors experienced by this population. In this way, this pilot study has offered new insight into the stress experience of persons with disabilities living in Croatia. However, further research should be undertaken with larger and more diverse samples in order to further explore and confirm the findings presented here.

Specifically, further research into the relationship between stress and mental health for this



stresa za osobe s tjelesnim invaliditetom i potvrdio način na koji je iskustvo stresa u ovoj populaciji u skladu s manjinskim modelom stresa. Kako bi se osobama s invaliditetom mogla pružiti učinkovitija podrška u upravljanju i suočavanju sa stresom, posebice je važno istražiti učinke distalnih procesa stresa (diskriminacije i socijalne isključenosti) na ishode mentalnog zdravlja, s obzirom da se na te uzroke može društveno djelovati. Iako su negativni učinci socijalne isključenosti na mentalno zdravlje započeli primati više pozornosti u literaturi, još uvijek je to relativno slabo istražen i razumljen proces. U malom broju istraživanja koja su se do sada bavila tom temom, rezultati su pokazali da socijalna isključenost može doprinijeti povećanom riziku za slabije mentalno zdravlje (37). Čini se razumnim tvrditi da različiti oblici diskriminacije o kojima su govorili naši sudionici na sličan način predstavljaju potencijalni čimbenik rizika za negativne ishode mentalnog zdravlja osoba s tjelesnim invaliditetom.

group is necessary to better understand the consequences of stress for persons with physical disabilities and confirm the manner in which the stress experience in this population is consistent with the minority stress model. In order to offer persons with disabilities more effective support in managing and coping with stress, the effects of distal stress processes related to discrimination and social exclusion on mental health outcomes is a theme of particular relevance for future research, especially when one considers the societal influence that can be exerted on these stress processes. Although the negative effects of social exclusion on mental health have begun to receive more attention in the literature, it remains a process that is under-researched and poorly understood. In the small number of studies examining this topic to date, findings have demonstrated that social exclusion increases the risk for poorer mental health (37). It seems reasonable to argue that the various forms of discrimination reported by our participants similarly represent a potential risk factor for negative mental health outcomes among persons with physical disabilities.

## ZAKLJUČAK

Rezultati ovog istraživanja omogućili su početno istraživanje jedinstvenih stresora kod osoba s tjelesnim oštećenjem koje žive u Hrvatskoj i načina na koji ti stresori utječu na

## CONCLUSION

The findings of the present study have allowed for an initial exploration of the unique stressors experienced by persons with physical disabilities

svakodnevni život. Time se pružio uvid u odnos između invaliditeta, stresa i diskriminacije, što je omogućilo izgradnju pokusnog modela koji se može koristiti za daljnje istraživanje kako se stres među osobama s invaliditetom oblikuje pripadnošću u često stigmatiziranoj manjinskoj skupini. Ipak, treba naglasiti hipotetsku prirodu ovog modela. Nadamo se da će ovdje prikazana analiza poslužiti kao platforma za provođenje istraživanja koja će dalje istraživati i potpunije razumjeti odnos stresa, diskriminacije, socijalne isključenosti i mentalnog zdravlja osoba s tjelesnim invaliditetom. Takva istraživanja neće samo omogućiti istraživanje tih ideja s većim i raznolijekim skupinama osoba s invaliditetom, nego će također istražiti kako se iskustvo stresa mijenja za osobe iz različitih skupina osoba s invaliditetom, kao što su osobe s oštećenjem sluha ili vida, osobe s intelektualnim ili razvojnim poteškoćama. Korištenjem ovog modela, buduća istraživanja trebala bi biti usmjerena i na daljnje istraživanje uloge socijalne isključenosti, kao važnog oblika diskriminacije koju doživljavaju osobe s invaliditetom, u stresnom iskustvu i na način na koji takvi procesi djeluju kao posrednici u oblikovanju ishoda mentalnog zdravlja među osobama s invaliditetom. Konačno, potrebno je daljnje istraživanje kako bi se ispitali potencijalni zaštitni čimbenici prevencije stresa za osobe s invaliditetom, kao što su društvena informiranost, aktivne inkluzivne socijalne politike, mehanizmi suočavanja i osjećaj samosvjesnosti u svojoj manjinskoj skupini.

Rezultati ovog istraživanja također nude niz praktičnih implikacija. Bez sumnje, povećano razumijevanje različitih izvora stresa za osobe s tjelesnim invaliditetom i utjecaj tih stresora u svakodnevnom životu omogućuju pružanje primjerenije i učinkovitije podrške u okruženju savjetovanja ili rehabilitacije. Nadalje, svijest o različitim čimbenicima koji doprinoсе stresnom iskustvu ove skupine, a osobito

living in Croatia and the manner in which these stressors influence their daily lives. In doing so, it has provided insight into the relationship between disability, stress, and discrimination. It has allowed for the construction of a tentative model that can be used to further examine how stress among persons with disabilities is shaped by membership in an often stigmatized minority group. However, the tentative and emergent nature of this model should be emphasized. It is the hope of the researchers that the analysis presented here will act as a platform from which to conduct research examining these notions further and to more fully understand processes of stress, discrimination, and social exclusion and mental health among persons with physical disabilities. Such research will not only allow for the exploration of these ideas with larger and more diverse groups of persons with disabilities, but might also explore how the stress experience varies for persons from different disability groups, such as persons with hearing/visual impairments or persons with intellectual or developmental disabilities. Using the model presented here, future studies should also be directed at further exploring the role of social exclusion in the stress experience as an important form of discrimination experienced by persons with disabilities and the manner in which processes of social exclusion act as mediators in shaping mental health outcomes among persons with disabilities. Finally, further research is necessary to examine the potential protective factors against stress for persons with disabilities, such as social awareness, active inclusion in social politics, coping mechanisms, and self-identity within one's minority group.

The findings of the present study also offer a number of practical implications. Undoubtedly, an increased understanding of the various sources of stress for persons with physical disabilities and the impact these stressors have in everyday life allows for the provision of more appropriate and effective support in counselling or rehabilitation settings. Furthermore, an awareness of

uloga diskriminacije, bit će korisni u razvoju inicijativa usmjerenih na ublažavanje i smanjenje potencijalnih posljedica takvih čimbenika. Naše je uvjerenje da će suradnjom s osobama s invaliditetom u razvoju učinkovitih struktura podrške, inicijative zagovaranja i podizanja svijesti temeljene na okviru društvenog sudjelovanja i inkluzije, omogućiti osobama s invaliditetom više zadovoljavajućih i manje stresnih iskustava te punopravnu uključenost u društvo u kojem žive.

the various factors contributing to the stress experience of this group, and the role of discrimination in particular, will be useful in developing initiatives aimed at alleviating and reducing the potential consequence of such factors. It is our hope that, by working together with persons with disabilities in the development of effective support structures, advocacy, and awareness-raising initiatives based on a framework of social participation and inclusion, persons with disabilities will be able to live more satisfactory and less stressful lives as fully participating members of the societies in which they live.

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# **Od demencije češće boluju žene**

## **/ Dementia is More Frequent in Women**

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Demencija je sindrom globalnog i progresivnog oštećenja stečenih kognitivnih sposobnosti pri očuvanoj svijesti prouzročen organskom bolešću središnjeg živčanog sustava u kojem su posebno oštećene sposobnosti pamćenja, učenja, apstraktnog mišljenja, orientacije te poimanja vidno-prostornih odnosa. Prevalencija i incidencija Alzheimerove bolesti (AB), najčešćeg uzroka demencije, znatno je veća kod žena nego kod muškaraca, a ta se razlika s dobi povećava. Dvostruko veća učestalost AB kod žena u odnosu na muškarce djelomično se može objasniti time što žene imaju očekivano dulji životni vijek. Žene imaju lošiju kognitivnu izvedbu na mnogim neuropsihologičkim testovima u odnosu na muškarce u istom stadiju bolesti, odnosno višestruke kognitivne funkcije kod žena teže su i šire zahvaćene nego kod muškaraca. Mogući razlozi za ovaku nepovoljnost naspram žena su redukcija estrogena u postmenopauzi, veće kognitivne rezerve muškaraca te utjecaj apolipoproteina E. Određeni biološki čimbenici također bi mogli objasniti različite kliničke manifestacije AB s obzirom na spol. Osim što prema prezentiranim podatcima žene češće obolijevaju od AB, žene su također te koje u bitno većoj mjeri pružaju neformalnu njegu ljudima s demencijom, te su oko dvije trećine neformalnih njegovatelja žene. Zaključno, u dalnjem istraživačkom i kliničkom radu s AB svakako bi trebalo obratiti pozornost na spoznaje o spolnim razlikama u razvoju i progresiji ove bolesti.

*/ Dementia is a syndrome of global and progressive impairment of acquired cognitive abilities with preserved consciousness caused by an organic illness of the central nervous system with especially pronounced damage to the ability to memorise, learn, think abstractly, orientate, and perceive spatial relations. The prevalence and incidence of Alzheimer's Disease (AD), the most common cause of dementia, is considerably greater in women than in men, and that difference increases with age. The fact that AD occurs twice as often in women than in men may be partially explained by a longer life expectancy among women. Women show worse cognitive performance on numerous neuropsychological tests in comparison to men during the same stage of the disease, meaning that multiple cognitive functions are more widely and severely impaired in women than in men. Possible reasons for such unfavourable results among women are a reduction of oestrogen during post-menopause, larger cognitive reserves in men, and the influence of apolipoprotein E. Certain biological factors may also explain various clinical manifestations of AD regarding sex. Apart from the fact that, according to presented data, women develop AD more often than men, women are also those who offer informal care to people with dementia in much greater numbers, and almost two thirds of informal caregivers are women. In conclusion, further research and clinical work with AD should certainly pay attention to insights about sex differences in the development and progression of this disease.*

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## UVOD

Demencija (lat. *de* – bez, *mens* – um) je sindrom globalnog i progresivnog oštećenja stečenih kognitivnih sposobnosti pri očuvanoj svijesti prouzročen organskom bolešću središnjeg živčanog sustava (SŽS), u kojem su posebno oštećene sposobnosti pamćenja, učenja, apstraktног mišljenja, orijentacije te poimanja vidno-prostornih odnosa. Demenciju se ne može promatrati kao jedinstvenu dijagnozu, već kao skup simptoma koji rezultiraju nemogućnošću obavljanja osnovnih društvenih, moralnih te radnih obaveza.

Prevalencija demencije u Evropi kreće se u rasponu od 6 % do 18 % kod osoba starijih od 65 godina, a kod osoba starijih od 85 godina ona čak doseže 30 % (prema nekim podatcima i 50 %) (1). Ako se uzme u obzir činjenica da je stanovništvo sve starije, tj. da se prosječna životna dob stanovništva stalno produžuje, za očekivati je da će u vrlo skoroj budućnosti demencija postati jedan od vodećih medicinskih, društvenih, ali i ekonomskih problema modernog društva. Svjetska zdravstvena organizacija (*World Health Organization, WHO*) procjenjuje da trenutno na svijetu od demencije boluje oko 35,6 milijuna ljudi, a pretpostavka je da će se taj broj do 2030. godine udvostručiti, a do 2050. godine utrostručiti (2).

Demencija je sindrom s visokom incidencijom i Alzheimerova bolest (AB) je najčešći uzrok

## INTRODUCTION

Dementia (lat. *de* – without, *mens* – mind) is a syndrome of global and progressive impairment of acquired cognitive competences in a state of preserved consciousness, caused by an organic disease of the central nervous system with especially pronounced impairment of memory, learning, abstract thinking, orientation, and perception of visuospatial relations. Dementia cannot be viewed as a single diagnosis, but as a collection of symptoms which result in the inability to perform basic social, moral, and workplace duties. The prevalence of dementia in Europe is between 6% and 18% in people older than 65, and in people older than 85 it even reaches as high as 30% (even 50% according to some data) (1). If one considers the fact that the population is becoming older, or in other words that the average age of the population is continually being extended, it is to be expected that dementia will become one of the leading medical, social, and economic problems of modern society in the near future. The World Health Organization (WHO) estimates that there are currently around 35.6 million people suffering from dementia, and it is estimated that the number will double by 2030, and triple by 2050 (2).

Dementia is a syndrome with a high incidence, and Alzheimer's disease (AD) is the most common cause of dementia. New data show that the prevalence of dementia will almost double every 20 years, and it is believed that the cur-

demencije. Novi podatci pokazuju da će se prevalencija demencije gotovo udvostručiti svakih 20 godina i vjeruje se da je sadašnji procijenjeni broj osoba s demencijom u Hrvatskoj veći od 80.000 (3).

AB danas sve više i više dobiva na značenju kako unutar neurologije i psihijatrije tako i u segmentu obiteljske medicine odnosno javno-zdravstvene problematike. Najnoviji epidemiološki podatci pokazuju da trenutno na svijetu od AB boluje oko 47 milijuna ljudi, te da uz svaku oboljelu osobu još najmanje 3 osobe, najčešće kao neformalni njegovatelji, nose to teško breme. Kratkoročne i srednjoročne prognoze glede pojavnosti AB nažlost nisu nimalo optimistične, pa tako predviđaju pravu epidemiju ove bolesti, tj. do 2050. godine očekuje se da bi globalno na svijetu moglo biti i preko 115 milijuna oboljelih od AB (4). Danas kada demenciju nastojimo dijagnosticirati što ranije, bitno je oboljelima i njihovim obiteljima ponuditi kontinuirani i što kvalitetniji program liječenja i skrbi. AB odnosno demencija je stanje koje ne možemo izlječiti, ali upotreboom standardnog (simptomatskog) farmakološkog liječenja antidementivima i drugim psihofarmacima moguće je usporiti prirodni tijek bolesti, poboljšati kvalitetu života oboljelih i njihovih njegovatelja. U menedžmentu bolesti potrebno je rabiti i nefarmakološke intervencije jer su se i one pokazale učinkovitima. Hrvatska, kao zemlja čije je prosječno stanovništvo jedno od najstarijih u Europi, treba napraviti akcijski plan za borbu s AB, tj. znatno se ozbiljnije pripremati za nadolazeću epidemiju te bolesti u skoroj budućnosti (5).

## DIJAGNOZA DEMENCIJE

Demencija je karakterizirana pojavom kognitivnih smetnji i otežanog obavljanja svakodnevnih aktivnosti, ali je ona često popraćena i dodatnim neurološkim ili psihijatrijskim simptomima. Za dijagnozu demencije danas se

rent estimated number of people with dementia in Croatia is greater than 80,000 (3).

Today, AD is gaining more and more prominence within neurology and psychiatry but also within family medicine and public healthcare. The latest epidemiological data show that there are currently 47 million people suffering from AD in the world and that there are at least three people per each patient who carry this heavy burden, most commonly as informal caregivers. Short-term and long-term prognoses regarding the appearance of AD are unfortunately not at all optimistic, and a real epidemic of this disease has been predicted. In other words, over 115 million people in the world are expected to be suffering from AD by 2050 (4). Today, when we attempt to diagnose dementia as soon as possible, it is important to offer patients and their families a continued and high-quality program of treatment and care. AD, or dementia, is a condition we cannot cure, but the use of standard (symptomatic) pharmacological treatment using antidementives and other psychopharmacs can slow down the natural course of the disease and improve the quality of life for patients and their caregivers. Disease management also requires the use of non-pharmacological interventions because they too have shown to be effective. As a country whose population is among the oldest in Europe, Croatia must form an action plan to combat AD and seriously prepare for the upcoming epidemic of this disease in the near future (5).

## DIAGNOSING DEMENTIA

Dementia is characterised by the appearance of cognitive interruptions and difficulties in performing everyday activities but is also followed by additional neurological or psychiatric symptoms. In the diagnosis of dementia, the following criteria are used today: a combination of laboratory tests and a neurological examination in order to exclude all other potential causes of dementia; a combination of methods of

koriste: kombinacije laboratorijskih pretraga i neurološkog pregleda kako bi se isključili svi ostali potencijalni uzroci demencije; kombinacije metoda radiološke dijagnostike kao što su računalna tomografija (CT, engl. *Computed Tomography*) i magnetska rezonancija (MRI, engl. *Magnetic Resonance Imaging*), kako bi se detektirala atrofija entorinalnog kortexa ili hipokampa; kombinacije radionukleidnih metoda kao što su pozitronska emisijska tomografija (PET, engl. *Positron Emission Tomography*) i jedno-fotonska emisijska računalna tomografija (SPECT, engl. *Single-Photon Emission Computed Tomography*), kako bi se mogla pratiti snižena perfuzija ili snižena metabolička aktivnost u pojedinim moždanim regijama.

Za procjenu kognitivnog oštećenja koriste se različiti orijentacijski testovi koji moraju uključivati procjenu pažnje, orijentacije, dugoročne i kratkoročne memorije, govora, prakse, vizualno-prostornih sposobnosti, mogućnost donošenja odluke, itd.

Prema rezultatima istraživanja Mimice i sur. (6) rezultati na ljestvici *Mini Mental State-Examination* (MMSE) kada se upitnik standardizira i validira u nekoj populaciji mogu bolje doprinijeti prepoznavanju osoba pod rizikom koje treba uputiti na ambulantno liječenje u klinike za liječenje demencije (6).

Uz navedene metode koriste se i metode neuropsihologische dijagnostike, tj. psihometrijski testovi koji su posebno dizajnirani za bolesnike s demencijom jer demenciju često prate i drugi psihijatrijski simptomi (depresija, anksioznost, euforija, apatija, psihotični simptomi i dr.) (7). Depresivni simptomi se pojavljuju kod 50 % osoba oboljelih od demencije. Oštećenje mozga bez obzira na etiologiju demencije je čimbenik rizika za razvoj depresije. U oboljelih od AD depresija je povezana s degeneracijom neurona te povećanom gustoćom amiloidnih plakova i neurofibrilarnih snopića posebno u području jezgara moždanog debla (*locus ceruleus, raphe nuclei*). Diferencijalna dijagnoza između de-

radiological diagnostics such as computed tomography (CT) and magnetic resonance imaging (MRI) in order to detect entorhinal cortex atrophy or hippocampal atrophy; a combination of radionuclide methods such as positron emission tomography (PET) and single-photon emission computed tomography (SPECT) in order to follow lower perfusion or lower metabolic activity in certain regions of the brain.

Various orientation tests are used for the assessment of cognitive impairment, and they must include the assessment of focus, orientation, long-term and short-term memory, speech, practice, visual-spatial abilities, the ability to make decisions, etc.

According to the study conducted by Mimica *et al.* (6), the results of the Mini Mental State-Examination scale (MMSE) may, following the standardization and validation of the questionnaire in a certain population, improve the identification of people at risk who should be sent to receive outpatient treatment at a clinic for the treatment of dementia (6).

Along with the methods listed above, there are also the methods of neuropsychological diagnostics, or psychometric tests designed specifically for patients suffering from dementia, because dementia is often followed by other psychiatric symptoms (depression, anxiety, euphoria, apathy, psychotic symptoms, etc.) (7). Depressive symptoms occur in 50% of people suffering from dementia. Brain damage, regardless of the aetiology of dementia, is a risk factor in the development of depression. In patients with AD, depression relates to neuronal degeneration and an increased thickness of amyloid plaques and neurofibrillary bundles, especially in the area of brain stem nuclei (*locus ceruleus, raphe nuclei*). The differential diagnosis between dementia, depression, and dementia with depression is difficult due to the overlapping symptoms in the aforementioned entities such as apathy, agitation, social isolation, impaired cognitive abilities, loss of bodyweight, and insomnia (8). Research results

mencije, depresije i demencije s depresijom je teška zbog preklapanja simptoma kod navedenih entiteta poput apatije, agitacije, socijalne izolacije, oštećenja kognitivnih sposobnosti, gubitka tjelesne težine i nesanice (8). Rezultati istraživanja upućuju da je neuroticizam u srednjoj životnoj dobi povezan s povećanim rizikom od demencije u AB te da stres posreduje u ovoj povezanosti. Rezultati imaju kliničke implikacije jer je identificirana skupina žena pod rizikom za demenciju u AB (9). Osim kognitivnih sposobnosti vrlo je važno pratiti i promjene ličnosti – od početne anksioznosti i depresije do smanjene kontrole emocionalnih reakcija koja, uz potpunu nemogućnost uvida i nekriticnost, nastaje u krajnjoj fazi ove bolesti. Također je važno istaknuti i emocionalnu potporu obitelji, odnosno osoba koje se skrbe o bolesnicima oboljelima od demencije (10). Brojne studije upućuju da uporaba specifičnih antidementiva dovodi do usporavanja napredovanja AB te odgode institucionalizacije kao i opterećenja skrbnika. Navedeno je od izravnog značenja u ukupnim troškovima liječenja ovih bolesnika. Učinjene farmakoekonomske procjene služe kao podloga te opravdavaju buduću uporabu najčešće korištenih antidementiva (kolinesterazni inhibitori) s kliničkog, ali i farmakoekonomskog aspekta, a što će biti od značenja ne samo za bolesnike već i za njihove skrbnike te društvo u cijelini (11). Razvojem neuroznanosti došlo je do novih znanstvenih i kliničkih spoznaja iz područja AB koje su uklopljene u DSM-5. Nova kategorija „Neurokognitivni poremećaji“ u DSM-5 zamjenila je DSM-IV kategoriju „Delirij, demencija, amnestički i drugi kognitivni poremećaji“. Novi naziv obuhvaća poremećaje kojima je glavna karakteristika stečeni gubitak u kognitivnoj funkciji, a ne obuhvaća poremećaje u kojima je stečeno kognitivno oštećenje prisutno, ali nije glavna karakteristika samog poremećaja (npr. shizofrenija, velika depresivna epizoda). DSM-5 definira tri sindroma: delirij, veliki neurokognitivni poremećaj, blagi neurokognitiv-

suggest that neuroticism in middle age is associated with an increased risk of dementia in AD and that stress modulates this association. The results have clinical implications because a group of women at risk of dementia in AD has been identified (9). Apart from cognitive abilities, it is very important to follow changes in the personality – from initial anxiety and depression to reduced control over emotional reactions which, along with a complete lack of insight and self-reflection, appears in the last stage of this disease. It is also important to emphasise the emotional support of the family or the people who care for patients suffering from dementia (10). Numerous studies have suggested that the use of certain antidepressants leads to a slowdown in the progress of AD and a delay in institutionalisation, as well as an increase in the burden placed on the caregiver. All of the above is of direct importance for the overall cost of treatment of such patients. Performed pharmacoeconomic assessments serve as a basis and justify the use of commonly used antidementives (cholinesterase inhibitors) from both a clinical and pharmacoeconomic perspective, which is of importance not just for patients but also their caregivers and the society as a whole (11). Development of neuroscience has brought new scientific and clinical insights from the area of AD which have been integrated into DSM-5. The new category of DSM-5 called *Neurocognitive disorders* has replaced the DSM-IV category *Delirium, dementia, amnesia, and other cognitive disorders*. The new term encompasses disorders which share the main characteristic of acquired loss of cognitive function and does not encompass disorders in which acquired loss is present, but not the main characteristic of the disorder itself (e.g. schizophrenia, major depressive episodes). DSM-5 defines three syndromes: delirium, major neurocognitive impairment, and mild neurocognitive impairment. Major neurocognitive impairment implies the earlier term dementia, although that does not exclude the use of the term dementia within aetiological subtypes in which that term is the standard one,

ni poremećaj. Veliki neurokognitivni poremećaj podrazumijeva od ranije poznati naziv demencija, iako to ne isključuje korištenje izraza demencija unutar etioloških podtipova u kojih je taj izraz standardan, dok blagi neurokognitivni poremećaj označava manje tešku razinu kognitivnog poremećaja (12).

Uloga lipida u etiologiji i progresiji AB još je uvijek nejasna. Visoke razine lipida mogле bi biti jedan od rizičnih čimbenika za AB, ali također je pronađeno da nema povezanosti ili čak da visoke vrijednosti kolesterola mogu imati protektivni učinak na razvoj AB (13).

## ALZHEIMEROVA BOLEST

AB je najčešći oblik demencije i na nju otpada oko 60-70 % slučajeva demencije u Europi (14). Oko 15-20 % demencija otpada na vaskularnu demenciju, a 10-25 % na ostale oblike demencije (14).

Još uvijek nije poznat točan uzrok AB, ali je poznato da postoje određeni čimbenici rizika koji pridonose pojavi bolesti (15,16). Kao potencijalni čimbenici rizika za AB spominju se visoka životna dob, genetička predispozicija, spol, kardiovaskularni čimbenici i prisutnost blagog kognitivnog (spoznajnog) poremećaja (MCI, engl. *Mild Cognitive Impairment*) (17-20). Kao čimbenici rizika spominju se također način života (prehrana, tjelesna aktivnost, pušenje, konzumiranje alkohola, itd.) (21-23). Prema podatcima iz literature ulogu u razvoju AB imaju stres, trauma glave, upalni procesi, dijabetes, depresija te okolišni čimbenici (24-28). Postoji više različitih negenetičkih čimbenika rizika koji su do sada istraživani, a povezani su s povećanim rizikom za AB. Ovi negenetički čimbenici rizika odnose se na: pušenje, konzumaciju alkohola, prekomjernu tjelesnu težinu i pretilost, hipertenziju, hipercolesterolemiju, lošu prehranu, šećernu bolest, kardiovaskularne i cerebrovaskularne bolesti, razinu edukaci-

while mild neurocognitive impairment signifies a less severe level of cognitive impairment (12).

The role of lipids in the aetiology and progression of AD remains unclear. High levels of lipids may be one of the risk factors of AD, but some results have also found no association or that high values of cholesterol may even have a protective effect on the development of AD (13).

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## ALZHEIMER'S DISEASE

AD is the most common form of dementia and comprises approximately 60-70% of cases of dementia in Europe (14). Around 15-20% are cases of vascular dementia, and 10-25% of other forms of dementia (14).

The exact cause of AD is yet to be discovered, but it is known that there are certain risk factors which contribute to the onset of the disease (15,16). Such potential risk factors of AD are old age, genetic predisposition, sex, cardiovascular factors, and the presence of mild cognitive impairment (MCI) (17-20). Other risk factors are related to lifestyle (diet, physical activity, smoking, drinking alcohol, etc.) (21-23). According to data from existing literature, the development of AD is affected by stress, head trauma, inflammatory processes, diabetes, depression, and environmental factors (24-28). There are several non-genetic risk factors that have been studied and are connected to a higher risk of AD. Such non-genetic risk factors are: smoking, drinking alcohol, excess weight and obesity, hypertension, hypercholesterolemia, poor diet, diabetes, cardiovascular and cerebrovascular diseases, education level, socioeconomic status, and physical and mental activity (29). Age is considered the best-confirmed and most important risk factor in the development of the sporadic form of AD (7). Lower cardiac index is associated with a higher risk of developing AD (30). Smoking has proved to be a risk factor in the development of AD, especially in

je pojedinaca, socioekonomski status, fizičku i mentalnu aktivnost (29). Dob se smatra najbolje potvrđenim i najvažnijim čimbenikom rizika za razvoj sporadičnog oblika AB (7). Niži kardijalni indeks povezan je s povišenim rizikom za razvoj AB (30). Pušenje se pokazalo kao rizičan čimbenik za razvoj AB, posebice kod osoba koje nisu nositelji E4 alela (31-33), a isti je slučaj i s prekomjernom zloporabom alkohola. Poznata je činjenica da osobe s dijagnozom ovisnosti o alkoholu često pate i od demencije uzrokovane dugogodišnjom zloporabom alkohola. Osobe u srednjoj životnoj dobi, ovisne o alkoholu, imaju oko 3 puta veći rizik od razvoja demencije (34).

Dio studija je povezao povišeni krvni tlak s većim rizikom od razvoja AB kod osoba koje nisu primale adekvatnu terapiju (35,36). Kod osoba kod kojih je hipertenzija držana pod kontrolom pomoću antihipertenziva pokazano je da ovi lijekovi zapravo mogu imati protektivan učinak u slučaju razvoja demencije u kasnijoj životnoj dobi (37,38). Hiperkolesterolemija, tj. povišena razina kolesterola u serumu smatra se također jednim od rizičnih faktora za razvoj AB (39,40).

Od psihosocijalnih čimbenika važnih u razvoju demencije ističe se važnost razine obrazovanja kod pojedinaca. Pokazano je da osobe koje imaju višu razinu obrazovanja rjeđe obolijevaju od demencije (41,42). Također, smatra se da je i uključenost pojedinca u društvene obveze važan čimbenik kod razvoja demencije u kasnijoj dobi, tj. istraživanja pokazuju da osobe koje imaju slabije socijalne kontakte te žive više izoliranim životom imaju i veći rizik za razvoj AB (43,44). Fizička aktivnost mogla bi imati pozitivan učinak na kognitivne sposobnosti pojedinca, tj. redovita fizička aktivnost mogla bi odgoditi pojavu simptoma demencije u starosti (45), a isto vrijedi i za mentalnu aktivnost (46).

Prema rezultatima istraživanja Pivac i sur. (47) muški pacijenti bili su mlađi, imali su kraće trajanje bolesti, blažu demenciju i bolje kognitivne izvedbe nego žene s AB. Varijante gena

people without E4 allele (31-33), and the same is true for alcohol abuse. It is a known fact that people who have been diagnosed with alcohol addiction often suffer from dementia caused by years of alcohol abuse. Middle-aged people addicted to alcohol have an approximately three times greater risk of developing dementia (34).

Some studies have found an association between increased blood pressure and a higher risk of developing AD in people who did not receive appropriate therapy (35,36). It has been shown that in people whose hypertension was controlled using antihypertensives, such medications can have a protective effect in the case of the development of dementia in older age (37,38). Hypercholesterolemia, i.e. increased level of serum cholesterol, is considered as another risk factor in the development of AD (39,40).

Among psychosocial factors important in the development of dementia, the importance of education level stands out. It has been shown that people with higher education levels develop dementia less commonly (41,42). It is also believed that the inclusion of people in social obligations is an important factor in the development of dementia in old age. In other words, research has shown that people who have weaker social contacts and a more isolated lifestyle are also at a higher risk of developing AD (43,44). Physical activity may have a positive effect on the cognitive abilities of an individual, meaning that regular physical activity may postpone the onset of symptoms of dementia in old age (45), and the same is true of mental activity (46).

According to the study conducted by Pivac *et al.* (47), male patients were younger, had a shorter disease duration, milder dementia, and better cognitive performance than women suffering from AD. Gene variation of brain-derived neurotrophic factor (BDNF) and the presence of one or two Met allele with regards to BDFN Val-66Met polymorphism were significantly associated with the presence of psychotic symptoms in men, but not in women suffering from AD (47).

za moždani neurotrofni čimbenik (BDNF) i to prisustvo jednog ili dva Met alela s obzirom na BDNF Val66Met polimorfizam bile su značajno povezane s prisustvom psihotičnih simptoma u muškaraca, ali ne i u žena s AB (47).

## ALZHEIMEROVA BOLEST U POPULACIJI ŽENA

Prevalencija i incidencija AB, najčešćeg uzroka demencije, znatno je veća kod žena nego kod muškaraca a ta se razlika s dobi povećava (48). Meta-analiza 13 populacijskih studija diljem SAD-a, Europe i Azije upućuje na to kako žene imaju značajno veći rizik za razvoj AB, ali ne i drugih demencija. Dvostruko veća učestalost AB kod žena u odnosu na muškarce djelomično se može objasniti time što žene imaju očekivano dulji životni vijek. Dokazi na temelju oslikavanja mozga, postmortalna analiza, hormonalne terapije i genetika upućuju da AB pogoda različito muškarce i žene. Žene imaju lošiju kognitivnu izvedbu na mnogim neuropsihologijskim testovima u odnosu na muškarce u istom stadiju bolesti, odnosno višestruke kognitivne funkcije kod žena teže su i šire zahvaćene nego kod muškaraca. Muškarci značajno nadmašuju žene u nekoliko kognitivnih domena uključujući jezične i semantičke sposobnosti, vizuospatialne sposobnosti i epizodičko pamćenje. Ove se razlike ne mogu pripisati godinama, edukaciji ni težini demencije. Mogući razlozi za ovakvu nepovoljnju kognitivnu izvedbu u žena su redukcija estrogena u postmenopauzi kod žena, veće kognitivne rezerve muškaraca te utjecaj apolipoproteina E. Određeni drugi biološki čimbenici također bi mogli objasniti različite kliničke manifestacije AB s obzirom na spol. U odnosu na muškarce, žene imaju manji hipokampalni volumen i pokazuju veću atrofiju mozga i degeneraciju temporalnog režnja, a postmortalne analize pokazale su kako žene imaju više neuritskih plakova i neurofibrilarnih klupka u odnosu na muškarce.

## ALZHEIMER'S DISEASE IN WOMEN

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The prevalence and incidence of AD, the most frequent cause of dementia, is significantly greater among women than men, and the difference increases with age (48). A meta-analysis of 13 population studies across the US, Europe, and Asia suggests that women are at a significantly higher risk of developing AD, but not other types of dementia. The fact that AD occurs twice as much among women than men can be explained by a longer life expectancy in women. Evidence based on brain imaging, post-mortem analysis, hormonal therapy, and genetics suggests that AD affects men and women differently. Women show worse cognitive performance on numerous neuropsychological tests in comparison with men at the same stage of the disease, meaning that a number of cognitive functions are more severely and widely affected in women than in men. Men are significantly better than women in several cognitive areas, including linguistic and semantic abilities, visual-spatial abilities, and episodic memory. Such differences cannot be ascribed to age, education, or the level of dementia. Possible reasons for such unfavourable cognitive performance in women are the reduction of oestrogen during postmenopause in women, greater cognitive reserves in men, and the influence of apolipoprotein E. Certain other biological factors may also explain different clinical manifestations of AD regarding sex. In comparison with men, women have a lower hippocampal volume and show greater brain atrophy and temporal lobe degeneration, and post-mortem analyses have shown that women have higher levels of neuritic plaques and neurofibrillary bundles in comparison with men. Additionally, sexual steroid hormones following menopause may affect the risk of developing AD in women. Similarly, the reduction of testosterone levels with age may also increase the risk of developing AD in men. Despite the advancements in the understanding of the clinical aspect of sex differences in AD, the

Također, spolni steroidni hormoni nakon menopauze mogu utjecati na rizik za razvoj AB u žena. Slično, smanjenje razina testosterona s dobi također može povećati rizik za razvoj AB kod muškaraca. Usprkos napretku u razumijevanju kliničkog aspekta spolnih razlika u AB, mehanizmi u podlozi AB i pitanje zašto je ženski rod podložniji razvoju AB, zapravo ostaju nejasni (48).

Istraživanja pokazuju kako estrogeni moduliraju protok krvi i aktivnost u ključnim područjima mozga uključujući područje za pažnju te verbalno i prostorno pamćenje. Kako se razina estrogena nakon menopauze smanjuje, slabija je kognitivna funkcija (49). Žene zapažaju promjene u kognitivnoj funkciji osobito u vrijeme menopauze. Brojna istraživanja pokazala su kako estrogeni modeliraju protok krvi i aktivnost u ključnim područjima mozga, uključujući područje za pažnju, te verbalno i prostorno pamćenje. Naime, žene u razdoblju menopauze imaju teškoće s pamćenjem i koncentracijom što napisljektu može rezultirati svakodnevnim problemima s ponašanjem i sposobnošću nošenja s njima. Stručnjaci su suglasni kako na kognitivnu funkciju mogu utjecati brojni drugi čimbenici, no jasno je da je promjena u razini estrogena važna i značajno utječe na kognitivne čimbenike u žena. Također, istraživanja su ukazala na zaštitnu ulogu estrogena ne samo za kogniciju, već i za pojavu Alzheimerove demencije (50). U istraživanju *Seattle Midlife Women's Health Study* 62 % žena žalilo se na teškoće pamćenja i koncentracije u vrijeme oko menopauze, što je rezultiralo u svakodnevnim problemima s ponašanjem i sposobnošću nošenja s njima.

Istražujući pomoći hormonskog nadomjesnog liječenja (HNL) u borbi protiv smanjenja kognitivnih sposobnosti, u baltimorskoj je longitudinalnoj studiji starenja primijenjen niz ispitivanja u istraživanju učinka HNL na kognitivnu funkciju žena u postmenopauzi u dobi između 50 i 89 godina (51,52). Unatoč sličnostima

mechanisms underlying AD and the question of why women are more susceptible to developing AD remain unclear (48).

Research shows that oestrogens modulate blood flow and activity in key brain regions including the regions of attention and verbal and spatial memory. As the level of oestrogen following menopause decreases, cognitive function is also impaired (49). Women notice changes in cognitive function, especially during menopause. Numerous studies have shown that oestrogens modulate blood flow and activity in key brain regions, including the region of attention and verbal and spatial memory. During menopause women experience difficulties with memory and concentration, which may result in everyday problems with behaviour and the ability to cope with such problems. Experts agree that the cognitive function may be affected by numerous other factors, but it is clear that the change in oestrogen levels is important and significantly affects cognitive factors in women. Studies have also emphasized the protective role of oestrogen not just for cognition, but the onset of Alzheimer's dementia as well (50). In the study entitled *Seattle Midlife Women's Health Study*, 62% of women complained about memorization and concentration problems during menopause, which resulted in everyday problems with behaviour and the ability to cope with such problems.

While researching the benefits of hormone replacement therapy (HRT) in the struggle against impaired cognitive abilities, the *Baltimore Longitudinal Study of Aging* applied several tests in the investigation of the effect of HRT on the cognitive function in women during postmenopause at the age between 50 and 89 (51,52). Despite similarities between groups regarding health and other characteristics, women who received HRT exhibited different blood flow in brain regions responsible for memorization and different brain activity while performing tasks related to memory in comparison to women who received a placebo. Women who received HRT were sig-

skupina u zdravlju i ostalome, žene koje su primjenjivale HNL imale su različit protok krvi kroz područja mozga odgovorna za pamćenje te drukčiju moždanu aktivnost tijekom ispunjavanja zadaća u svezi s pamćenjem u odnosu na žene koje su uzimale placebo. Žene koje su primjenjivale HNL značajno su bolje verbalno učile i izvodile testove pamćenja uključujući i ispitivanje svježeg i kratkotrajnog pamćenja. Uz to, bolje su rezultate imale žene koje su primjenjivale kombinaciju estrogena i progestagena nego žene koje su primjenjivale samo estrogen (50). Jacob i sur. (53) uspoređivali su primjenu estrogena s kognitivnom funkcijom. Skupina koju je sačinjavalo 727 žena u postmenopauzi ispitivana je nakon dvije i nakon tri godine primjene liječenja. Žene koje su trenutno i pretходno primjenjivale HNL imale su mnogo više ishodišne vrijednosti kognitivne funkcije nego žene koje nisu nikada primjenjivale HNL. Također, u žena koje su primjenjivale HNL verbalno se pamćenje s vremenom poboljšalo (53). Yaffe i sur. 1998. proveli su meta-analizu deset studija ispitujući ulogu primjene estrogena u poboljšanju kognitivne funkcije, sprječavanja demencije ili smanjenja njezine težine u žena u postmenopauzi (54). Rezultati pokazuju 29-postotno smanjenje rizika za nastanak demencije u žena koje su primjenjivale estrogensko nadomjesno liječenje (ENL) (54). Prema rezultatima istraživanja Yaffe i sur. žene u postmenopauzi s višim koncentracijama nevezana estrogena manje su sklone padu kognitivne funkcije (54).

Uz pomoć testa MMSE 425 je žena u dobi od 65 godina ili starije ispitivano tijekom šest godina. Mjerene su im koncentracije bioraspoloživa estradiola i testosterona nevezana za bjelančevine u krvi. Usporedba je razine estrogena i kognitivne funkcije ukazala kako unatoč nepostojanju sveze između razine uku-pnoga estradiola i kognitivne funkcije postoji sveza između razine slobodnog estradiola i kognitivne funkcije (55). Žene s višim koncentracijama slobodnog estradiola imale su 70

nificantly better at verbal learning and performing memory tests, including tests of fresh and short-term memory. Also, women who received a combination of oestrogen and progestogen showed better results than women who received only oestrogen (50). Jacob *et al.* (53) compared the application of oestrogen to the cognitive function. A group comprised of 727 women in postmenopause was tested after two and three years of receiving therapy. Women who were currently receiving HRT and had previously done so showed a much greater starting value of the cognitive function than women who never received HRT. Additionally, women who received HRT showed an improvement in verbal memory over time (53). In 1998, Yaffe *et al.* conducted a meta-analysis of ten studies researching the role of the application of oestrogen in the improvement of the cognitive function, the prevention of dementia, or the reduction of its severity in women in postmenopause (54). The results showed a 29 percent reduction of risk of developing dementia in women who received oestrogen replacement therapy (ORT) (54). According to the results of the study conducted by Yaffe *et al.*, women in postmenopause with higher concentrations of unbound oestrogen are less prone to the impairment of the cognitive function (54).

With the aid of the MMSE test, 425 women at the age of 65 or older were followed over a period of six years. Measurements were taken of their concentrations of biodegradable oestradiol and testosterone not bound to blood proteins. The comparison of the levels of oestrogen and the cognitive function showed that despite the lack of association between the levels of total oestradiol and cognitive function there was an association between the level of free oestradiol and cognitive function (55). Women with higher concentrations of free oestradiol had a 70% lower risk of impaired cognitive function than women with lower concentrations of free oestradiol. This result suggests that oestrogen must be able to cross the blood-brain barrier in order to have a favoura-

posto manji rizik za pad kognitivne funkcije nego žene s niskom koncentracijom slobodnog estradiola. Taj nalaz upućuje kako estrogen mora biti sposoban prijeći krvno-moždanu barijeru da bi imao povoljan učinak. Budući da neki progestageni olakšavaju sposobnost slobodnog estrogena da prođe krvno-moždanu barijeru, neki kombinirani pripravci HNL mogu biti najučinkovitiji u sprječavanju kognitivnoga pada (55). LeBlanc i sur. (56) su na temelju provedenog istraživanja zaključili kako su žene s menopausalnim simptomima, koje su primjenjivale HNL, imale poboljšanja u verbalnom pamćenju, budnosti, prosuđivanju i motoričkoj brzini. Uz to su imale i manji rizik za demenciju (56). McEwen i sur. (57) u studiji također ukazuju kako HNL može spriječiti pogoršanje kognitivne funkcije u svezi sa starenjem, a nadomjestak estrogena možda štiti hipokampus i druga područja mozga povezana s demencijom (57). Opservacijske su studije pokazale kako estrogeni mogu odgoditi ili spriječiti pojavu AB ako je liječenje započeto u ranome razdoblju postmenopauze (50). Tang i sur. proučavali su 1124 starije žene prosječne životne dobi 74,2 godine tragajući za kognitivnim promjenama tijekom pet godina (58). Zaključili su kako je pojava AB bila značajno kasnija u žena koje su uzimale estrogene nego u onih koje ih nisu uzimale. U žena koje su koristile estrogene dulje od godine dana smanjenje je rizika za bolest bilo najveće (58). Randomizirano i placeboom kontrolirano ispitivanje *Alzheimer Disease Cooperative Study* istraživalo je prethodnu primjenu HNL u žena kojima je dijagnosticirana blaga do umjerena AB (59). Prema rezultatima istraživanja liječenje estrogenima nije usporilo napredovanje bolesti. U ispitivanju *Cache County Study* (59) koje je istražilo incidenciju AB u 135 muškaraca prosječne životne dobi 73,5 godina i 1889 žena prosječne životne dobi 73,2 godine tijekom tri godine, istraživači su zaključili kako nadomjestak estrogena može zaustaviti degeneraciju i zaštiti žene od pojave AB, no

ble effect. Since some progestogens help free oestrogen pass the blood-brain barrier, certain combined preparations of HRT may be most effective in the prevention of cognitive impairment (55). Based on conducted research, LeBlanc *et al.* (56) concluded that women with menopausal symptoms who received HRT showed improvement in verbal memorization, alertness, judgement, and rapid motor skills. They also showed a lower risk of dementia (56). In their study, McEwen *et al.* (57) also showed that HRT can prevent cognitive function impairment in connection with aging, and oestrogen replacement may protect the hippocampus and other brain regions tied to dementia (57). Observational studies have shown that oestrogens may delay or prevent the onset of AD if the therapy was started in an early stage of postmenopause (50). Tang *et al.* examined 1124 older women of an average age of 74.2 years in search of cognitive changes over a period of five years (58). They concluded that the onset of AD happened significantly later in women who received oestrogens than in those who did not. The greatest reduction of the risk of developing the disease was noted in women who used oestrogens for more than a year (58). The randomized and placebo-controlled *Alzheimer Disease Cooperative Study* studied prior application of HRT in women diagnosed with mild to moderate AD (59). According to the results of the research, the oestrogen therapy did not slow down the onset of the disease. In the *Cache County Study* (59), which investigated the incidence of AD in 135 men of the average age of 73.5 years and in 1889 women of the average age of 73.2 years over the period of three years, the researchers found that oestrogen replacement may stop the degeneration and protect women from the onset of AD, but that effect depends on the length of the therapy and on how soon the therapy was initiated. The oestrogen therapy did not improve the condition of participants who were already suffering from AD (59). In the third workshop in Pisa in 2003, the International Menopause Society concluded that "oestrogens may provide a better protection from

taj učinak ovisi o duljini trajanja liječenja te o tome kako je rano liječenje započeto. Liječenje estrogenima nije poboljšalo stanje sudionika studije koji su već imali AB (59). Na Trećoj radionicici (*Workshop*) u Pizi 2003. godine Internacionalno društvo za menopauzu ustvrdilo je kako „estrogeni mogu pružiti bolju zaštitu od AB mlađim ženama u postmenopauzi, a podatci novih opservacijskih studija upućuju kako najveću zaštitu od AB u tih žena može pružiti dulja primjena estrogena“ (50). Epidemiološki dokazi pokazuju smanjenje rizika za AB uz liječenje estrogenima, dok su kontrolirana ispitivanja pokazala izostanak bilo kojega pozitivnog učinka u žena s razvijenom AB (60). Barbara Sherwin zaključuje da s obzirom na prikupljene dokaze može postojati kritični „prozor“ u vremenu za započinjanje liječenja estrogenima, odmah nakon nastupa postmenopauze, koja može najviše povećati njegov potencijal protiv pada kognicije, kao i u smanjenju rizika za AB (60). Ranim započinjanjem i najmanjom učinkovitom dozom žene mogu računati na zaštitni učinak estrogena uz vrlo nizak rizik liječenja (50). Daljnja istraživanja potrebna su kako bi se objasnile razlike prema spolu, a i klinička istraživanja bi trebala rutinski pratiti razlike prema spolu (61). Hormonske promjene povezane s menopauzom i postmenopauzom imaju potencijal da utječu na procese povezane sa simptomima i patogenesom AB, ali učinci menopauze na rizik za AB mogu se povezati samo indirektno. Devet randomiziranih kliničkih ispitivanja terapije koja uključuje hormon estrogen u pacijenata s AB pronađeno je sistemskim pretraživanjem literature. Rezultati upućuju da hormonska terapija ne poboljšava kognitivne simptome žena s AB. Ni jedno kliničko ispitivanje hormonske terapije ne odnosi se na prevenciju AB, ali jedno kliničko ispitivanje daje umjerene dokaze da kontinuirana, kombinirana terapija estrogenom i progestogenom započeta u dobi od 65 godina ili starijoj povećava rizik za demenciju. Hipoteza kritičnog razdoblja ukazuje

AD to younger women in postmenopause, and the data from new observational studies suggest that in those women the best form of protection from AD is provided by prolonged application of oestrogen“ (50). Epidemiological evidence has shown a reduction of risk of developing AD while receiving oestrogen therapy, while controlled tests have shown a lack of any positive effects in women with developed AD (60). Barbara Sherwin has concluded that collected data shows there may be a critical “window” in time for starting oestrogen therapy immediately after the onset of postmenopause, which can significantly increase its potential in fighting against cognition impairment, as well as in the reduction of risk of developing AD (60). With an early start and the lowest effective dosage, women can count on the protective effect of oestrogen with a very low treatment risk (50). Further research is needed to explain the differences between sexes, and clinical research should routinely follow the differences between sexes (61). Hormonal changes tied to menopause and postmenopause have the potential of affecting processes associated with the symptoms and pathogenesis of AD, but the effects of menopause on the risk of developing AD can be associated only indirectly. A systematic search of literature uncovered nine randomized clinical studies of a therapy that included the hormone oestrogen in patients with AD. The results suggest that hormonal therapy does not improve cognitive symptoms in women with AD. None of the clinical studies of hormonal therapy refer to the prevention of AD, but one clinical study gives moderate evidence suggesting that continued, combined oestrogen and progesterone therapy begun at the age of 65 or later increases the risk of dementia. The hypothesis of a critical period suggests that a hormonal therapy started at a younger age closer to menopause may reduce the risk of developing AD (62).

Cardiac disease is an independent risk factor for mild neurocognitive impairment. The comparison between sexes has shown a stronger association with the female sex. The prevention

da hormonska terapija započeta u mlađoj dobi vremenski bliže menopauzi može reducirati rizik od AB (62).

Kardijalna bolest je neovisni rizični čimbenik za blagi neurokognitivni poremećaj. Usporedba prema spolu pokazala je jaču povezanost sa ženskim spolom. Prevencija i liječenje kardijalnih bolesti i čimbenika vaskularnog rizika može sniziti rizik za blagi neurokognitivni poremećaj (63). Hormonska terapija estrogenom započeta tijekom kasne postmenopauze ne poboljšava epizodično pamćenje (važan rani simptom AB) i povećava rizik za demenciju (64).

Kod žena koje razviju demenciju, prihvatanje promjene uloge i identiteta može biti vrlo teško za njih same i za druge. Promjena iz uloge primarnog njegovatelja u obitelji u osobu kojoj treba njega je vrlo velika i često joj se oboljela žena opire. Oboljele žene najviše muči pitanje identiteta te zadržavanje kontrole pri donošenju odluka kao i prelazak iz uloge pružatelja njege i stupa obitelji u status njegovane osobe. Istaknuta je važnost „ručne torbice“ i njenog nošenja kao znaka očuvanosti dostojanstva i identiteta (65). Gubitak neovisnosti u oboljelih žena rađa „zahvalnu krivnju“. Žene koje njeguju kćeri često ne iznose iskreno sve smetnje da bi što duže zadržale neovisnost. U tim bi slučajevima parcijalno uključivanje socijalne skrbi pomoglo premostiti ovaj problem. Žene oboljele od demencije zbog bolesti moraju napuštati svoje uloge njegovatelja, skrbitelja u obitelji te ih to dodatno hendikepira i tjera u naučenu bespomoćnost (66).

Diljem čitavog svijeta demencija neproporcionalno utječe na žene. Iako su istraživanja pokazala veću pojavnost demencije kod žena, nema puno razrađenih strategija i provođenja adekvatnih mjera kao odgovor na te rezultate (67).

Osim što prema prezentiranim podatcima žene češće obolijevaju od Alzheimerove demencije, žene su također te koje u bitno većoj mjeri pružaju neformalnu njegu ljudima s demencijom,

and treatment of cardiac diseases and factors of vascular risk may reduce the risk of mild neurocognitive impairment (63). Hormonal oestrogen therapy begun during late postmenopause does not improve episodic memory (an important early symptom of AD) and increases the risk of dementia (64).

In women who develop dementia, the acceptance of a change in role and identity may be very difficult for themselves and others. The shift of role from primary caregiver in the family to the person who requires care is significant, and women suffering from this disease often struggle against it. Such women are greatly troubled by the question of identity and maintaining control while making decisions, as well as the change from the role of the caregiver and pillar of the family to the person requiring care. There is great significance in the “purse” and carrying it as a symbol of maintained dignity and identity (65). The loss of independence in women suffering from the disease creates “gratitude guilt”. Women who are cared for by their daughters often do not express all their problems honestly in order to maintain their independence for as long as possible. In such cases, partial involvement of social care may help solve the problem. Women suffering from dementia are forced to leave their role of the caregiver in the family, and that additionally handicaps them, forcing them into learned helplessness (66).

Across the world, dementia affects women disproportionately. Although research has shown that dementia is more frequent in women, there are few developed strategies and adequate measures being put into action as a response to those results (67).

Apart from the fact that presented data shows that women develop Alzheimer's disease more frequently, most people offering informal care to those suffering from dementia are women, and approximately two thirds of informal caregivers are women. The proportion is much greater in countries with low and medium income, so

te su oko dvije trećine neformalnih njegovatelja žene. Taj omjer je puno veći u zemljama s niskim i srednjim prihodima, stoga je učinak pružanja njege na zdravlje i dobrobit, kao i finansijski učinak, veći za žene u zemljama s niskim prihodima. Žene čine većinu formalne njegovateljske radne snage, posebice u njezi osoba s demencijom te su one te koje pružaju većinu zdravstvene i socijalne skrbi u zajednici, bolnicama i domovima (67).

U neformalnoj skrbi se razlozi odabira uloge njegovatelja razlikuju i ovdje navodimo četiri glavna razloga. Često je ta uloga njegovatelja nametnuta zbog kulturoloških razloga i tradicije. Na primjer, na Cipru se smatra prirodnom ulogom žene, a sličnog su stava u obiteljima Latinoamerikanaca u SAD-u i domicilnoj Španjolskoj (68-70). Zatim, uloga njegovatelja je kulturološka i tradicijska u multigeneracijskim kućanstvima (Sri Lanka, azijske zemlje). Takva uloga je neupitna i altruistična. Kćeri i snahe su emotivna potpora, podrška u svakodnevnim aktivnostima, sinovi su finansijska potpora (70,71). U Sjedinjenim Američkim Državama, u latinoameričkim obiteljima 78 % njegovatelja su kćeri i nevjeste, u kineskim obiteljima 63 %, a ostalim obiteljima 49 % (72). U Nizozemskoj, u turskim i marokanskim obiteljima najstarija kćer ili supruga najstarijeg sina, tradicionalno je njegovatelj (73). Proširena bračna uloga također je razlogom zašto žena preuzima ulogu njegovatelja te na kraju, žena će preuzeti ulogu njegovatelja zbog osjećaja ponosa i zadovoljstva.

Njegovatelji-članovi obitelji razvijaju psihičke tegobe poput velikog depresivnog poremećaja i anksioznih poremećaja (67,74). Žene njegovatelji se žale na osjećaj tereta, stres i depresivne simptome više od muških njegovatelja, i izvještaji su slični iz svih kultura i društava. Supruge-njegovateljice puno teže podnose ulogu njegovatelja. Taj teret je osobito vidljiv nakon dvije godine brige za oboljelog člana; javljaju se teži osjećaj stresa, gubitak bliskosti, anksiozni

the effect of caregiving on health and well-being, as well as finances, is greater for women in countries with low income. Women make up the greater part of the caregiving workforce, especially in care for people with dementia, and women also offer most medical and social care in communities, hospitals, and homes (67).

In informal care, the reasons for choosing the role of the caregiver vary, and the four main reasons are listed here. Very often the role of the caregiver is enforced by culture and tradition. For example, caregiving is considered the natural role for women on Cyprus, and a similar attitude is shared among Latino-American families in the US and in their domicile, Spain (68-70). The role of the caregiver is also part of culture and tradition in multigenerational households (Sri Lanka, Asian countries). Such a role is unquestionable and altruistic. Daughters and daughters-in-law provide emotional support and support in everyday activities, while sons are a financial support (70,71). In the United States of America, in Latino-American families 78% of caregivers are daughters and brides, while in Chinese families they make up 63%, and 49% in other families (72). In the Netherlands, in Turkish and Moroccan families the oldest daughter or the wife of the oldest son is traditionally the caregiver (73). The extended marital role is another reason why women take over the role of the caregiver, but also because of a sense of pride and pleasure.

Caregiving family members develop psychological problems such as major depressive disorder and anxiety disorders (67,74). Female caregivers complain of a sense of burden, stress, and symptoms of depression more than male caregivers, and reports from all cultures and societies are similar. Caregiving wives have a more difficult time coping with the role of the caregiver. The burden is especially visible after two years of caring for a sick member of the family; there is a greater feeling of stress, a loss of closeness, symptoms of anxiety and depression, and decreased family support (67,75). First, they

i depresivni simptomi, i manja je podrška okoline (67,75). Susreću se prvo s gubitkom kontrole, zbumjeno prihvaćaju novu ulogu, kvaliteta braka i bliskost stradava te se moraju naviknuti na nove uloge u kućanstvu. Muškarci supružnici njegovatelji se žale na gubitak kvalitetne komunikacije, kognitivne i bihevioralne simptome, gubitak društva i finansijski teret (76). Kćeri njegovatelji bolje podnose stres njegovanja, imaju također vlastitu ulogu majke, ali više puše, smanjene su tjelesne aktivnosti, više dobivaju na tjelesnoj težini, razvijaju hipertenziju i češće obolijevaju od kronične bolesti pluća od majki njegovateljica. Latinoamerikanke bolje podnose stres u odnosu na kineske imigrante te bijelu populaciju SAD-a (77).

Žene su najveći udio profesionalne njegovateljske radne snage u skrbi za demenciju te u pružanju formalne zdravstvene i socijalne skrbi i potpore osobi s demencijom i njenom ili njegovom njegovatelju. Mnoge žene koje rade kao njegovateljice skrbe i za svoju djecu i starije roditelje. To djeluje na njihovu sposobnost pružanja obiteljske skrbi i utječe na kvalitetu života cijele obitelji, uključujući i osobu koja živi s demencijom.

Žene čine 42 % radnog pučanstva, a u zdravstvenom sektoru u mnogim zemljama čine 75 % radne snage. Većina ih je zaposlena u skrbi za oboljele od demencije, kako u primarnoj, kućnoj njezi, socijalnoj skrbi, dobrotvornim organizacijama i udruženjima. U Velikoj Britaniji 87 % osoba koje rade u formalnoj skrbi su žene, ¾ su izravno uključene, a ¼ su zaposlene kod privatnih poslodavaca (78).

Sve zemlje moraju shvatiti trenutnu i predviđenu pojavnost i prepoznati da demencija neproporcionalno utječe na žene. Učinak na žene mora biti utvrđen u svakoj pojedinoj zemlji, kao i pregled trenutno dostupne potpore i što je potrebno da bi se zadovoljilo buduće potrebe. Žene treba upoznati s pomoći koja im je dostupna, putem podizanja svijesti i boljeg obavještavanja od strane organizacija zdravstvene

experience loss of control, confusion in accepting the new role, decreased quality of marriage and closeness, and the need to adjust to the new roles in the household. Caregiving husbands complain of a loss of quality communication, cognitive and behavioural symptoms, a loss of companionship, and financial burden (76). Caregiving daughters who are also mothers themselves, cope with the stress of caregiving better, but smoke more, show reduced physical activity, gain more weight, develop hypertension, and develop chronic lung disease more often than caregiving mothers. Latino-American women cope with stress better than Chinese immigrants and the white population of the US (77).

Women make up the largest segment of professional caregivers providing care for those suffering from dementia and the largest part of those offering formal medical and social care and support to people with dementia and their caregivers. Many women who work as caregivers also provide care to their own children and elderly parents. This affects their ability to provide family care and the quality of life of the entire family, including the person living with dementia.

Women make up 42% of the workforce, and in many countries they make up 75% of the workforce in the health sector. Most are employed as caregivers to people with dementia in primary care, home care, social care, and charities. In Great Britain, 87% of people employed in formal care are women, three-quarters are directly involved, and one quarter is employed in private practice (78).

All countries must understand the current and predicted incidence of dementia, and recognize the fact that dementia affects women disproportionately. Every country must identify the effect on women, as well as review currently available support and what is necessary to satisfy future demands. Women should be informed about the aid that is available to them by raising awareness and improving the way organizations providing health and social care

i socijalne skrbi o formalnim i neformalnim uslugama koje postoje i kako ih ostvariti.

Sve zdravstvene radnike koji rade u zajednici treba obučiti o demenciji kako bi se povećalo njihovo samopouzdanje u shvaćanju ponašanja ljudi s demencijom.

Nizak ekonomski status, financijske nagrade i nedostatna obuka i podrška za rad u njegovateljskoj struci utječe na žene, njihove obitelji i na ljude koji žive s demencijom. Postoji potreba za stručnim kompetencijama zdravstvenih i njegovateljskih radnika koji rade s ljudima koji žive s demencijom s kompleksnim potrebama i komorbiditetima.

Palijativna skrb je fokusirana na ublažavanje i olakšavanje simptoma koje ima osoba s AB pa iako postoje određene zakonitosti i faze kod AB karakteristične za većinu bolesnika, važno je osvijestiti postojanje velikih interindividualnih razlika. Stoga je od iznimne važnosti pristup usmjeren osobu, a naglasak u palijativnoj skrbi treba ležati na fleksibilnosti kako bi se udovoljilo jedinstvenim potrebama svakog bolesnika i njegove obitelji (5,79).

Komunikacija je medij kroz koji se odvija interpersonalna interakcija koja je od iznimne važnosti u palijativnoj skrbi za bolesnika s AB i članovima njegove obitelji (79,80).

## ZAKLJUČAK

Spol utječe na tri specifične skupine: žene koje žive s demencijom; žene koje skrbe za ljude s demencijom u ulozi profesionalnog njegovatelja; žene koje preuzimaju ulogu neformalnog njegovatelja osobe oboljele od demencije. Potrebno je napraviti ili poboljšati postojeće nacionalne programe za liječenje demencije te nglasiti jasnije ulogu žena i njihovu specifičnost povezanu s ovim entitetom. Istraživanja treba usredotočiti na pitanja što ljudima pomaže građiti izdržljivost kako bi se prilagodili i dugoročno nosili s problemom demencije.

share information on available formal and informal services and how to use them.

All medical workers working in the community should be educated about dementia in order to increase their confidence in understanding the behaviour of people with dementia.

Low economic status, financial rewards, and a lacking education and support for working in the caregiving profession affect women, their families, and people living with dementia. There is a need for professional competencies in medical and caregiving workers working with people with dementia with complex needs and comorbidities.

Palliative care is focused on mitigating and alleviating symptoms in people with AD, and although there are certain regularities and phases in AD which are characteristic for most patients, it is important to raise awareness about significant interindividual differences. Therefore, an approach focused on the individual person is very important, and the emphasis in palliative care should be on flexibility in order to satisfy the unique needs of every patient and their family (5,79).

Communication is a medium for developing interpersonal interaction, which is of great importance in palliative care for a patient with AD and the members of their family (79,80).

## CONCLUSION

Sex affects three specific groups: women living with dementia; women providing care for people with dementia in the role of a professional caregiver; women who are taking over the role of an informal caregiver for a person suffering from dementia. It is necessary to create or improve existing national programs for the treatment of dementia and emphasize the role of women and their specific connection to this entity. Studies should focus on the question what helps people build their resilience in order to adjust to the problem of dementia and cope with it in the long term.

U dalnjim translacijskim istraživanjima i kliničkom radu s osobama oboljelima od AB nužno je obratiti pozornost na spoznaje o spolnim razlikama u razvoju i progresiji ove bolesti, tj. na uočene značajne nepovoljnosti koje nosi ženski spol, a shodno tome prilagoditi i sam tretman bolesti ovisno o spolu.

Further translational research and clinical work with people suffering from AD must pay attention to insights about sex differences in the development and progression of this disease, i.e. in the observed disadvantages related to female sex, and therefore adjust the treatment itself according to the sex of the patient.

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# **Stigmatizacija i stereotipizacija oboljelih od epilepsije**

## **/ Stigmatization and Stereotypes in Patients with Epilepsy**

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Epilepsija je bolest mozga obilježena spontanim, nepredvidivim i prekomjernim električnim pražnjenjima određenih dijelova mozga ili cijelog mozga, koji se klinički manifestiraju epileptičkim napadajima. Epileptički napadaji mogu uključivati raznolike simptome i znakove, ovisno o zahvaćenom dijelu mozga. Napad je izrazito traumatičan za pacijenta i okolinu čak i kada se događa rijetko. Jedan od faktora s izrazitim utjecajem na oboljelog je stigmatizacija socijalne okoline. Na stigmatizaciju moramo utjecati kvalitetnjom edukacijom populacije. Cilj edukacije je olakšati život, smanjujući osjećaj nelagode koju napad može prouzročiti, ako se dogodi u javnom okruženju. *Svrha rada:* Dokazati kako je znanje o bolestima važan faktor za smanjenje predrasuda. *Metode:* U ispitivanju je sudjelovalo 80 ispitanika zdravstvenih struka (medicinske sestre/tehničari, farmaceutski tehničar) te 84 ispitanika nezdravstvenih struka (prodavač, frizer, kuhar, konobar). Prema mjestu stanovanja selo/grad raspodjela je 82 ispitanika sa sela i 82 ispitanika s mjestom stanovanja u gradu. Ispitivanje je provedeno anonimnom anketom. *Rezultati:* Za testiranje radnih hipoteza korišten je nezavisni T-test. Rezultati istraživanja pokazali su da veća razina znanja utječe na manju razinu stigmatizacije osoba oboljelih od epilepsije. Potrebno je dodatno educirati opću populaciju, jer to je najbolji način da se smanje predrasude prema većini bolesnika. Također, testirajući drugu radnu hipotezu utvrdili smo da nema značajne razlike između osoba koje žive u urbanim ili ruralnim sredinama. *Zaključak:* Treba naglasiti potrebu kvalitetnije edukacije zdravstvenih djelatnika i opće populacije. Stigmatizacija je povezana s razinom znanja i stoga možemo reći: „Znanjem protiv stigma!” kako za epilepsiju tako i za mnoge druge bolesti kod kojih neznanje uzrokuje socijalnu izolaciju i time produbljuje problematiku pacijentovog stanja.

*/ Epilepsy is a brain disease presenting with spontaneous, unpredictable and excessive electric discharges of parts of the brain or the whole brain which are clinically manifested by seizures. Epileptic seizures may include various symptoms and signs, depending on which part of the brain is affected. The seizure is highly traumatic for the patient and his surroundings even when a patient's seizures are rare. One of the major factors which affects patients is constant stigmatization by the society they live in. Stigmatization can only be affected by higher quality of education. The goal of high quality education is to make the life of patients easier by lowering the level of discomfort that the seizure brings if it happens in public. Goal: Demonstrate that knowledge about a disease is a major factor in reducing prejudice and stigmatization. Methods: The study was conducted on 80 medical professionals (nurses, pharmacists) and 84 other professional examinees (sellers, hairdressers, cooks, and waiters). 82 examinees lived in a rural and 82 lived in an urban area. The examination was performed with an anonymous questionnaire. Results: The independent T-test was used to test the hypothesis. The results of the study showed that a higher knowledge level decreases stigmatization, which confirms the necessity of additional education of the general population. This is the best way to lower prejudice towards people suffering from epilepsy. By testing our hypothesis about the effect of the living area on stigmatization we came to the conclusion that there is no significant difference between examinees living in urban and rural areas. Conclusion: It is important to improve the education of medical employees and the general population. Stigmatization is associated with the level of knowledge. That is why we should emphasize the motto: "Knowledge against stigma!" for epilepsy and other diseases which cause social discomfort due to lack of knowledge.*

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## UVOD

Epilepsija je bolest mozga obilježena spontanim, nepredvidivim i prekomjernim električnim pražnjenjima dijelova ili cijelog mozga, koji se klinički očituju napadajima koji mogu uključivati raznolike simptome i znakove, ovisno o zahvaćenom dijelu mozga (2). Postoji iznimno velik broj kliničkih oblika epilepsije, ali najjednostavnija podjela prema ICES klasifikaciji iz 1989. je na parcijalne i generalizirane epilepsije (1). Generaliziranu epilepsiju karakterizira široko rasprostranjeno, sinkronizirano izbijanje neurona obje hemisfere, dok se žarišna (parcijalna, fokalna) epilepsija odnosi na lokalno izbijanje neurona.

**Primarno generalizirane epilepsije** karakterizira potpuni gubitak svijesti različitog trajanja. Dijelimo ih na veliki i mali epileptički napadaj. **Veliki epileptički napadaj** (grand mal) karakteriziran je pojavom toničkih i/ili kloničkih grčeva, a uobičajeno ga prati i potpuni gubitak svijesti. Najčešće napadaj nastupa bez predznaka, no kod manjeg broja bolesnika samoj ataci prethodi neki predznak, tzv. aura (primjerice – trnci u nekom dijelu tijela, smetnje govora). Bolesnik se obično iznenada ruši, a zatim nastupa spazam svih mišića na tijelu. Nerijetko možemo čuti i krik koji nastupa zbog spazma laringealne muskulature. Zbog spazma muskulature dolazi do prestanka disanja te bolesnik postaje cijanotičan. Nerijetko dolazi i do inkontinencije urina ili stolice. Poslije toničke faze nastupa klonička faza. Prvo se javlja tremor kao posljedica umora mišića

## INTRODUCTION

Epilepsy is a brain disorder presenting with spontaneous, unpredictable, and excessive electric discharge of certain parts of the brain or the entire brain which clinically manifest in seizures that may include various symptoms and signs depending on the affected part of the brain (2). There is a large variety of clinical forms of epilepsy, but the simplest classification is by ICES from 1989 into partial and generalized epilepsy (1). Generalized epilepsy is characterized by a widespread, synchronized outbreak of neurons in both hemispheres, while partial (focal) epilepsy refers to a local outbreak of neurons.

**Primary generalized epilepsy** is characterized by a complete loss of consciousness of varying durations. This type of epilepsy has two basic types of seizures: tonic-clonic and absence.

**Tonic-clonic (grand mal) seizure** is characterized by a complete loss of consciousness and tonic and/or clonic muscle spasms. The seizure most commonly occurs without any signs, but in a small number of patients the seizure is preceded by a sign, the so-called aura (for example – tingling in some part of the body, speech difficulties). The patient suddenly collapses and then all muscles of the body go into a spasm. We can often hear a cry due to spasm of the laryngeal muscles. Respiratory failure occurs due to muscle spasm and the patient becomes cyanotic. Urine and stool incontinence often occur. The clonic phase occurs after the tonic phase. In the tonic phase, tremors first appear as a result of muscle fatigue, followed by clon-

u toničkoj fazi te nastupaju klonički grčevi (ritmične kontrakcije svih mišića tijela). Prigodom kloničkih grčeva prisutna je i hipersalivacija te se zbog kontrakcija masetera stvara pjena (primjesa krvi u slučaju ugriza jezika). Na kraju nastupa *postiktalna faza* tijekom koje se konvulzije smiruju i bolesnik zapada u duboku komu. Zatim se, postupno preko svih stupnjeva kvantitativnog poremećaja svijesti, budi. Najčešće se napadaju ne sjećaju, umorni su i zbumjeni te nakon nekog vremena utonu u normalan san (3).

**Mali epileptički napadaji** javljaju se ponajprije u djetinjstvu ili prije puberteta, a samo iznimno u odrasloj dobi. I ovdje je riječ o primarno generaliziranoj epilepsiji koju od početka prati gubitak svijesti (3). Najčešće se manifestiraju kao *odsutnost svijesti* (apsans) u kojima bolesnik nakratko gubi kontakt s okolinom, zagleda se u jednu točku, no nakon toga nastavlja započetu aktivnost. Napadaji traju 10 – 20 sekundi i dolaze u serijama tijekom dana. Ponekad su praćeni motornim fenomenima (treptanje), ali traju prekratko da bi za posljedicu imali gubitak mišićnog tonusa.

**Žarišna (parcijalna) epilepsija** posljedica je abnormalnih električnih izbijanja u lokaliziranom području mozga. Kliničke značajke ovih napadaja su varijabilne, ovisno o moždanoj regiji u kojoj se izbijanje javlja (3). Svest tokom parcijalnog napadaja može biti očuvana (jednostavni parcijalni napad) ili narušena (kompleksni parcijalni napad) (2). Parcijalni epileptički napadaji ponekad mogu poprimiti i karakteristike velikog epileptičkog napadaja i tada govorimo o sekundarno generaliziranom epileptičkom napadaju (3). **Jednostavni parcijalni napad** manifestira se najčešće u obliku motornih ili senzornih ataka, ovisno o zahvaćenoj regiji. Obično je riječ o izoliranim grčevima (klonizmima) neke mišićne skupine ili ponavljanim osjetnim sensacijama (trnjenje, bol) u nekom dijelu tijela. Kod **kompleksnog parcijalnog napadaja**,

ic cramps (rhythmic contractions of all body muscles). Hyper-alkalinization is also present during clonic cramps, and the contraction of the masseter causes foaming (blood in the case of tongue biting). The postpartum stage comes last, during which the convulsions calm down and the patient falls into a deep coma. Then, gradually, through all stages of quantitative disturbances of consciousness, the patient wakes up. Most often the patient does not remember the seizure, is tired and confused, and after some time falls into normal sleep (3).

**Absence (petit mal)** seizures occur primarily in childhood or before puberty and only exceptionally in adulthood. This type of seizure is also primary generalized epilepsy which is accompanied by the loss of consciousness from the beginning (3). The most common manifestations of this type are absences of consciousness in which the patient briefly loses contact with the environment, stares at one point, but then continues the activity. The seizures last from 10 to 20 seconds and come in a series during the day. Sometimes they are accompanied by motor phenomena (blinking) but are too short to result in a loss of muscle tone.

**Focal (partial) epilepsy** is a consequence of abnormal electrical activity in a localized part of the brain. Clinical features of these types of seizures are variable, depending on the cerebral region in which the discharge occurs (3). During partial seizures, consciousness can be preserved (simple partial seizures) or deteriorated (complex partial seizures) (2). Partial epileptic seizures can sometimes take on characteristics of a major epileptic seizure, and we refer to such cases as generalized epileptic seizures (3). Depending on the affected region, a **simple partial seizure** mostly presents in the form of motor or sensory attack. It generally involves isolated spasms (cloning) of some muscle group or a repeated sensation (tingling, pain) in some part of the body. In **complex partial seizures**, in addition to the altered state of conscious-

uz promjene stanja svijesti, često se opažaju i neki motorički fenomeni (automatizmi, nesvrhovite radnje) koji najčešće zahvaćaju mimično–žvačnu muskulaturu (mljackanje, žvakanje).

Prema Europskoj deklaraciji o epilepsiji iz 2011. godine smatra se da u Europi oko 6 milijuna ljudi ima epilepsiju, a novo dijagnosticiranih slučajeva svake godine ima oko 300 tisuća. Ako se primijene slični epidemiološki kriteriji, u Hrvatskoj epilepsiju ima oko 45 000 ljudi od kojih je 15 000 mlađe od 18 godina (5).

Sam epileptički napadaj izrazito je traumatičan za pacijenta i okolinu, čak i ako se rijetko događa, uzrokuje niz problema za oboljelog. Često se zaboravlja koliko osobe s epilepsijom pate i izvan napadaja. Jedan od faktora koji utječe na oboljelog je stigmatizacija socijalne okoline sa svim negativnim posljedicama. Najteži dio života s epilepsijom je nošenje s reakcijama okoline. Primarni cilj terapije pacijenta je stvoriti i pozitivno stajalište.

Stigma je negativan pogled društva prema pojedincu zbog krivog shvaćanja bolesti (10). Krivo shvaćanje bolesti nastaje iz neznanja i stvara predrasude. Društvena stigma je osjećaj manje vrijednosti koji se manifestira u kontaktu s drugima. Stigmatizacija može dovesti do poremećaja ponašanja kod kuće i u školi, razviti osjećaj manje vrijednosti te sklonost tjeskobi i depresiji (5).

U Hrvatskoj djeluje Hrvatska udruga za epilepsiju (HUE) čiji je cilj unaprjeđenje kvalitete života osoba s epilepsijom i njihovih bližnjih te omogućavanje boljeg razumijevanja prirode epilepsije i potreba osoba s epilepsijom. U svrhu navedenog HUE provodi djelatnosti:

- edukacije osoba s epilepsijom, članova njihovih obitelji i šire društvene zajednice o medicinskim i društvenim aspektima epilepsije
- poticanja druženja, razmjena znanja i iskustava osoba s epilepsijom

ness, some motor phenomena (automatisms, obstructive actions) that most often affect the masticatory and mimic muscles (munching, chewing) are commonly observed.

According to the European Declaration on Epilepsy from 2011, it is estimated that around 6 million people in Europe have epilepsy, and there are around 300, 000 newly diagnosed cases each year. If similar epidemiological criteria are applied, there are around 45,000 people with epilepsy in Croatia, of which 15,000 are under 18 years old (5).

The epileptic seizure itself is extremely traumatic for the patient and the environment, even if it is rare, and it causes a number of problems for the patient. It is often forgotten that people with epilepsy suffer from factors other than seizures. One factor that affects the patient is the stigmatization of the social environment with all its negative consequences. The hardest part of living with epilepsy is dealing with the reactions of the environment. The primary goal of patient therapy is to create a positive attitude.

Stigma is a negative attitude of society towards an individual due to the poor understanding of a disease. The poor understanding of a disease arises from ignorance and creates prejudice. Social stigma is a feeling of inferiority, which manifests itself in contact with others. Stigmatization can lead to behavioral disorders at home and in school, developing a sense of inferiority, and a tendency towards anxiety and depression (5).

The Croatian Epilepsy Association (HUE) aims to improve the quality of life of people with epilepsy and their families and facilitate a better understanding of the nature of this disorder and needs of people suffering from it. For this purpose, HUE carries out the following activities:

- Education of people with epilepsy, members of their families and the wider community on the medical and social aspects of epilepsy.
- Encouraging socialization, knowledge exchange, and experiences with patients with epilepsy.

- izdavanja knjiga i brošura, audiovizualnih i elektroničkih materijala koji se bave epilepsijom
- organizacije sastanaka i seminara o različitim medicinskim i socijalnim aspektima epilepsije
- razmjene informacija o društvenoj i medicinskoj skrbi osoba s epilepsijom sa sličnim udrugama u svijetu
- istraživanja socijalnih aspekata epilepsije i suradnje s Hrvatskom ligom protiv epilepsije i međunarodnom organizacijom *International Bureau for Epilepsy* (5).

- Publication of books and brochures, audiovisual and electronic materials on epilepsy.
- Organization of meetings and seminars on various medical and social aspects of epilepsy.
- Exchange of information on social and medical care of patients with epilepsy with similar associations internationally.
- Research on social aspects of epilepsy and cooperation with the Croatian League Against Epilepsy and the International Bureau for Epilepsy (5).

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## CILJ

Cilj istraživanja je utvrditi utječe li razina znanja u srednjoj školi Viktorovac na razinu predrasuda o osobama oboljelima od epilepsije između zdravstvenih i nezdravstvenih smjerova. Također, cilj je utvrditi utječe li i mjesto sticanja na razinu predrasuda.

## OBJECTIVE

The objective of this study was to determine whether the level of knowledge of medical students and students of other courses at the Viktorovac secondary school affects the level of prejudice toward people suffering from epilepsy. The objective was also to determine whether the place of residence affects the level of prejudice.

## ISPITANICI I METODE

Ispitivanje je provedeno u razdoblju od 1. travnja 2016. godine do 1. svibnja 2016. godine u srednjoj školi Viktorovac u Sisku. Korištena je anonimna anketa, a za istraživanje je dobivena suglasnost Etičkog povjerenstva srednje škole Viktorovac.

## PARTICIPANTS AND METHODS

The survey was conducted in the period from April 1<sup>st</sup>, 2016 to May 1<sup>st</sup>, 2016 at the Viktorovac Secondary School in Sisak. An anonymous questionnaire was used, and the study was conducted after the approval from the Ethics Committee of the Viktorovac Secondary School.

## Uzorak

U ispitivanju je sudjelovalo 80 ispitanika zdravstvenih struka (medicinske sestre/tehničari, farmaceutski tehničar) te 84 ispitanika nezdravstvenih struka (prodavač, frizer, kuhan, konobar). Prema mjestu stanovanja selo/grad raspodjela je bila 82 ispitanika sa sela i 82 ispitanika s mjestom stanovanja u gradu.

## Sample

The survey included 80 students of medical (nurses/technicians, pharmaceutical technicians) and 84 students of other courses (sales assistant, hairdresser, cook, waiter). According to the place of residence, 82 participants were from the rural area and 82 from the city.

## Instrument

Kao instrument istraživanja korištena je anketna koja se sastojala od 23 pitanja, a možemo ju podijeliti na 4 dijela prema vrsti prikupljenih podataka.

1. Opći sociodemografski podatci ispitanika
2. Pitanja 1-4 – susretanje s epilepsijom
3. Pitanja 5-10 – opća znanja i razumijevanje epilepsije. Pitanja su bodovana jednim bodom za točan odgovor, osim pitanja 8, gdje je bilo više točnih odgovora pa je postojala i mogućnost 0,5 boda. Maksimalan ostvaren broj bodova bio je 6.
4. Pitanja 11-18 – stavovi o oboljelima od epilepsije koji povremeno dožive epileptički napadaj.

Pitanja 12-17 korištena su u procjeni predrasuda o oboljelima od epilepsije – procjena društvenih predrasuda. U tim pitanjima se koristilo specifično bodovanje, odgovor A-1 bod, B-2 boda, C-3 boda, D-4 boda. Raspon bodova je 6-24 s tim da manja vrijednost označava i manju razinu predrasuda prema oboljelima od epilepsije. 6 bodova – bez predrasuda, 14 bodova – visoka razina predrasuda, 24 boda – maksimalna razina predrasuda.

Upitnik je preuzet iz članka „A Survey of Public Awareness, Understanding, and Attitudes toward Epilepsy in Greece“ (8) te je preveden i prilagođen potrebama ovog istraživanja. Pri odgovaranju na taj dio upitnika ispitanici su u svrhu istraživanja trebali uzeti u obzir da se radi o osobi, koja povremeno ima epileptički napad, no inače je zdrava.

## STATISTIČKA ANALIZA

Rezultati dobiveni ispitivanjem prikazani su kao apsolutni brojevi (N), aritmetičke sredine pojedinih bodovanja te kao postotci. Odnos između rezultata skupina utvrđivan je nezavistnim t-testom uz P vrijednost manju od 0.01.

## Instrument

The survey instrument was a questionnaire consisting of 23 questions, divided into four sections according to the type of data collected.

1. General sociodemographic data of the respondents
2. Questions 1-4 – contact with epilepsy
3. Questions 5-10 – general knowledge and understanding of epilepsy. Questions were scored with one point for the correct answer, except for question 8, where there were more correct answers so there was a possibility of scoring 0.5 points. The maximum number of points was 6.
4. Questions 11-18 – attitudes towards patients with epilepsy who occasionally experience epileptic seizures.

Questions 12-17 were used to assess the level of prejudice towards patients with epilepsy – an assessment of social prejudice. These questions used specific scoring, A-1 point, B-2 points, C-3 points, D-4 points. The range of points was 6 to 24, where the lower value indicated a lower level of prejudice toward patients with epilepsy. 6 points – no prejudice, 14 points – a high level of prejudice, 24 points – a very high level of prejudice.

The questionnaire was taken from the article “A Survey of Public Awareness, Understanding, and Attitudes toward Epilepsy in Greece” (8), translated and adapted for the purposes of this survey. When responding to this part of the questionnaire, the respondents were asked to take into account that it concerns a person who occasionally has an epileptic seizure, but is otherwise healthy.

## STATISTICAL ANALYSIS

The results of the survey are presented as absolute numbers (N), the arithmetic mean of individual scoring, and as percentages. The relationship between the groups was determined by an independent T-test with a P value of less than 0.01.



**Hipoteze:**

H1: Veća razina znanja utječe na smanjenje predrasuda prema oboljelima od epilepsije.

H1/a: Ispitanici medicinskih škola imaju više znanja o osobama oboljelim od epilepsije i stoga imaju manje predrasuda

H2: Ispitanici iz ruralnog područja imaju manje predrasuda prema oboljelima od epilepsije u odnosu na ispitanike iz urbanih sredina

**Hypotheses:**

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H1: A higher level of knowledge reduces the level of prejudice toward people with epilepsy.

H1/a: Medical school students have more knowledge about people with epilepsy and therefore have less prejudice.

H2: Participants from the rural area have less prejudice toward people with epilepsy in comparison with participants from the city.

**REZULTATI****Demografski podatci**

Anketi je prisustvovalo 164 ispitanika: 45 muškaraca i 119 žena; 82 ispitanika je iz ruralnih sredina, 82 iz urbanih. Raspon dobi varira od 15-20 godina (sl. 1). Ispitanici su iz 6 smjerova škole Viktorovac (sl. 2).

Iz sl. 1 možemo vidjeti da je najveći broj ispitanika u starosnoj dobi od 17 godina (49), potom 19 godina (46), a najmanji broj ispitanika imao je 16 godina (3).

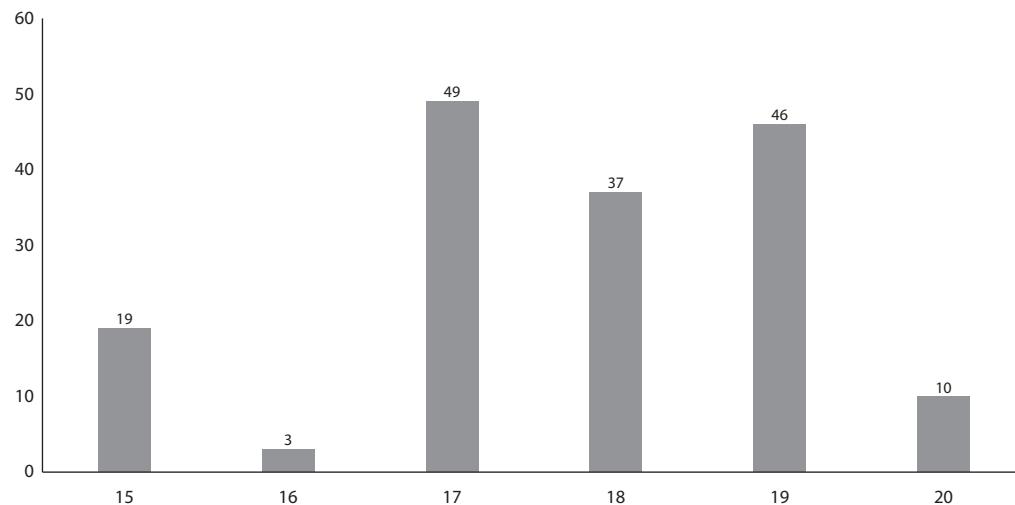
Iz sl. 2 možemo vidjeti da je najveći broj ispitanika iz medicinske škole (54), slijede farmaceutski tehničari (26), a najmanji broj je konobara (16).

**RESULTS****Demographic data**

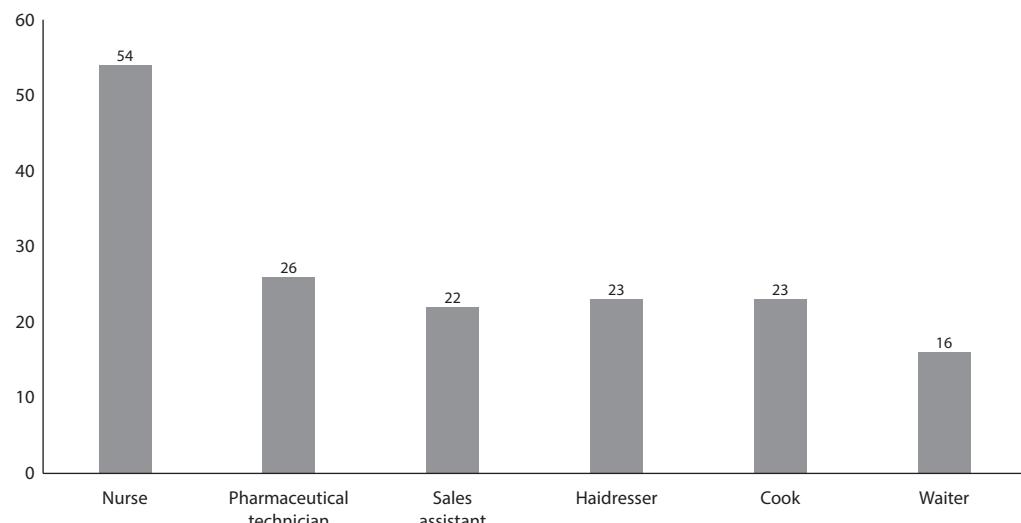
The survey included 164 participants, 45 men and 119 women. According to the place of residence, 82 of the participants were from the rural area and 82 from the city. The age range was 15-20 years (Fig. 1), and the participants were from 6 different courses at the Viktorovac secondary school.

Figure 1 shows that the largest number of participants was 17 years old (49), followed by participants who were 19 years old (46), and only three participants were 16 years old (3).

Figure 2 shows that the largest number of participants were nurses (54), followed by phar-



**FIGURE 1.** Distribution according to age



**FIGURE 2.** Distribution according to school/course

Iz sl. 3 vidimo prosječnu dob ispitanika koja je kod medicinskih struka 18,8 godina, a kod strukovnih nešto niža (16,7 godina) što je i za očekivati jer se radi i o trogodišnjim školama, dok je kod medicinara petogodišnje obrazovanje.

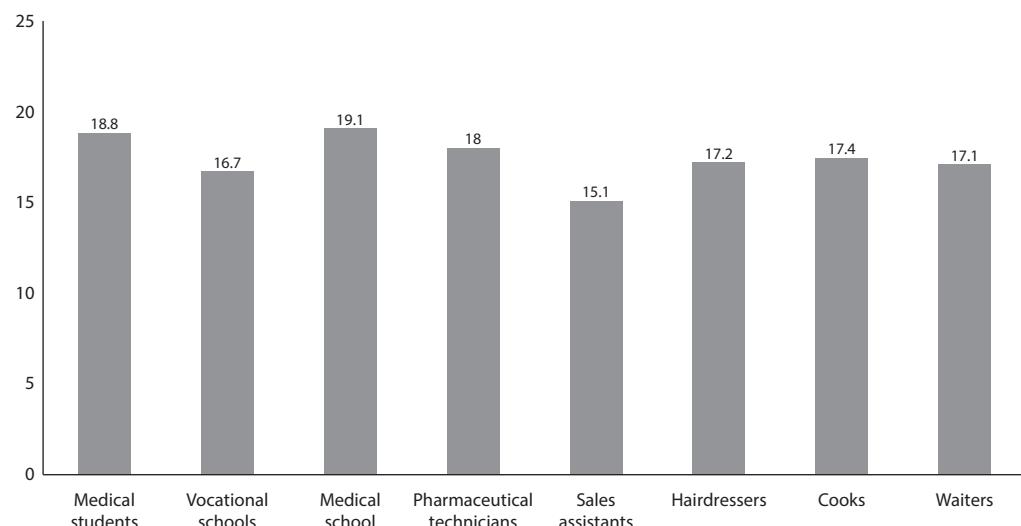
Susretanje s epilepsijom – pitanje 1-4. (tablica 1) Dio upitnika je formiran kako bismo ustavili koliko su se ispitanici susretali s epilepsijom do provođenja ovog upitnika.

Iz tablice 1 vidimo da je na prvo pitanje potvrđeno odgovorilo 78 ispitanika (97,5 %) za medi-

maceutical technicians (26), and the smallest number were waiters (16).

Figure 3 shows that the average age of medical school students was 18.8; in vocational students the number was slightly lower, 16.7, which is expected as vocational schools have three years of education as opposed to medical schools where the education lasts for five years.

Contact with epilepsy – Questions 1-4 (Table 1). Part of the questionnaire constructed to determine the participants' contact with epilepsy up until the survey.



**FIGURE 3.** Average age of participants by schools

cinske te 84 ispitanika (100 %) za strukovne škole. Međutim zanimljivim se pokazalo da 2 ispitanika (2,5 %) iz medicinskih usmjerjenja nisu čuli za epilepsiju. Iz drugog pitanja možemo vidjeti da većina ispitanika nema oboljelog od epilepsije u obitelji (93,75 % iz medicinskih te 78,54 iz strukovnih škola). U trećem pitanju vidimo da su podjednako distribuirani odgovori (48,75 %/58,31 %). Odgovori su podjednako distribuirani i u četvrtom pitanju (42,5 %/36,89 %).

Pitanja 5.-10. – razumijevanje epilepsije – na temelju idućih pitanja rađena je procjena znanja o epilepsiji. Svaki točan odgovor bio je bodoval jednim bodom osim pitanja osam gdje je postojala mogućnost 0,5 boda (tablica 1).

Na peto pitanje točno je odgovorilo 93,75 % iz medicinskih te 73,98 % strukovnih škola. Samo 2,38 % ispitanika iz strukovnih škola mislilo je da je epilepsija vrsta mentalne retardacije. Na pitanje broj 6 većina ispitanika je odgovorila da epilepsija nije psihijatrijska bolest (55,51 %), ali i velik broj ispitanika (21 %) odgovorio je potvrđno. Važan je podatak da su podjednako netočno odgovorili učenici medicinskih i strukovnih škola (21,25 %/20,23 %). Sedmo pitanje, odnosno da je epilepsija nepravilnost u radu mozga 82,5 % učenika medicinskih škola odgovorilo je točno, dok je iz strukovnih taj postotak samo 40,46 %. U osmom pitanju je bilo moguće zaokružiti više točnih odgovora. Od 247 ukupno zaokruženih odgovora o uzroku nastanka epilepsije 42,23 % odgovorilo je da je to poremećaj u funkcioniranju živčanog sustava, s time da su to bili većinom ispitanici medicinske struke (73/30 u broju zaokruženih odgovora pod „A“). Slijedi naslijedena bolest sa 29,28 %. 12,81 % ispitanika je odgovorilo da je uzrok mentalni ili psihološki poremećaj.

U devetom pitanju dominirao je odgovor A, koji je odabralo 56,25 % medicinara te 30,94 % učenika strukovnih škola; 22,5 % medicinara te 42,84 % učenika strukovnih škola nije znalo odgovor. U desetom pitanju dominiraju dva odgo-

Table 1 shows that 78 (97.5%) participants from medical and 84 (100%) from vocational school answered affirmatively to the first question. However, it is interesting that 2 participants (2.5%) from the medical school never heard of epilepsy. The replies to the second question show that most of the participants do not have any family members suffering from epilepsy (93.75% from medical and 78.54 from vocational schools). The responses are equally distributed in the third (48.75% / 58.31%) and the fourth (42.5% / 36.89%) question.

Questions 5-10 – understanding of epilepsy – the assessment of knowledge of epilepsy was based on these questions. Every correct answer was scored with one point apart from Question 8 where 0.5 points were a possible score (Table 1).

Question five was answered correctly by 93.75% of students from medical and 73.98% of students from vocational schools. Only 2.38% of participants from vocational schools thought that epilepsy was a type of mental retardation. When asked if epilepsy is a type of psychiatric illness (Q6), most of the participants (55.1%) answered negatively, but also a large number of participants answered affirmatively (21%). It is important to note that the students of medical and vocational schools were equally incorrect in their answers (21.25% / 20.23%). An affirmative answer was given by 82.5% of medical school students to Question 8 – epilepsy is a nervous system disorder, while the same answer was given by only 40.46% of students from vocational schools. In Question 8 it was possible to choose more than one correct answer. Out of the 247 circled answers on the causes of epilepsy, 42.23% of the participants answered that it is a nervous system disorder, provided that most of the respondents were from medical schools (73/30 ratio for answer “A”). This was followed by hereditary disease with 29.28%. The answer chose by 12.81% of the participants was that it is a mental or psychological disorder.

Question 9 was dominated by response A, which was chosen by 56.25% of students from

**TABLE 1.** Questions 1-10 – distribution of answers

QUESTION		MEDICAL SCHOOLS		VOCATIONAL SCHOOLS	
		N	%	N	%
1. Have you ever heard of a disease called epilepsy?	YES	78	97.5	84	100
	NO	2	2.5	0	0
	I DO NOT KNOW	0	0	0	0
2. Do you have a close relative with epilepsy?	YES	4	5	11	13.09
	NO	75	93.75	66	78.54
	I DO NOT KNOW	1	1.25	7	8.33
3. Do you personally know someone with epilepsy?	YES	39	48.75	49	58.31
	NO	38	47.5	27	32.13
	I DO NOT KNOW	3	3.75	8	9.52
4. Have you ever seen an epileptic seizure?	YES	34	42.5	31	36.89
	NO	44	55	49	58.31
	I DO NOT KNOW	2	2.5	4	4.76
5. Do you think epilepsy is a type of mental retardation?	YES	0	0	2	2.38
	NO	75	93.75	62	73.78
	I DO NOT KNOW	5	6.25	20	23.08
6. Do you think epilepsy is a type of psychiatric illness?	YES	17	21.25	17	20.23
	NO	53	66.25	38	45.22
	I DO NOT KNOW	10	12.5	29	34.51
7. Do you think epilepsy is a type of brain disorder or malfunction?	YES	66	82.5	34	40.46
	NO	3	3.75	14	16.66
	I DO NOT KNOW	11	13.75	36	42.84
8. What do you think is the cause(s) of epilepsy? (you may choose more than one answer).	A nervous system disorder.	73	53.29	30	27.3
	A congenital abnormality.	12	8.76	13	11.83
	A mental or psychological disorder.	13	9.49	8	7.28
	A hereditary disease.	32	23.36	16	14.56
	A blood disease.	1	0.73	3	2.73
	Some other cause.	3	2.19	6	5.46
	I do not know	3	2.19	34	30.94
9. An epileptic can be radically cured without taking any medications.	Never	45	56.25	26	30.94
	Rarely	16	20	19	22.61
	Often	0	0	1	1.19
	Usually yes	1	1.25	2	2.38
	I do not know	18	22.5	36	42.84
10. An epileptic person (man or woman) has children. What do you think is the risk of his/her children having the same problem?	No risk	7	8.75	4	4.76
	Low risk	12	15	7	8.33
	Moderate risk	34	42.5	27	32.13
	High risk	6	7.5	8	9.52
	I do not know	21	26.25	38	45.22

vora, „C“ i „E“, 37,29 % svih ispitanika misli da postoji srednji rizik za djecu da naslijede epilepsiju od roditelja, a 35,99 % nije znalo odgovoriti. Nema značajnih razlika u odgovorima na pitanje deset između medicinara i strukovnih škola.

Iz dobivenih vrijednosti izračunate su aritmetičke sredine. Aritmetička sredina ispitanika medicinskog smjera iznosi 3,42 boda, a za ispitanike strukovnog smjera 2 boda. Analiza dobivenih podataka izračunata je nezavisnim t-testom uz P vrijednost 0,01, kojom je utvrđeno da je razlika između dobivenih rezultata statistički značajna te da učenici medicinskih struka imaju veće znanje (sl. 4). Time smo djelomično potvrdili početnu hipotezu da učenici medicinskih škola imaju više znanja o epilepsiji od njihovih vršnjaka iz strukovnih škola.

Iz sl. 4 vidimo distribuciju bodovanja znanja. Kod medicinskih škola se 56 od 80 ispitanika nalazi u rasponu od 3 do 4,5 boda. Kod strukovnih škola 54 od 84 ispitanika nalazi se u rasponu od 0 do 2 boda od mogućih 6 maksimalnih bodova.

Pitanja 11-18 – stavovi o oboljelima od epilepsije, pitanje 11 (tablica 2). Pitanje br. 11 željeli smo vidjeti kako bi ispitanici reagirali kada bi oni sami bolovali od epilepsije i trebali nekoime reći za svoju bolest – razina samostigma-

medical and 30.94% of students from vocational schools; 22.5% of medical and 42.84% of vocational school students did not know the answer. Question 10 was dominated by two answers, C and E: 37.29% of participants thought that there is risk for children to inherit epilepsy from their parents, and 35.99% did not know the answer. There are no significant differences between medical and vocational school students in Question 10.

The arithmetic mean was calculated from the obtained values. The arithmetic mean for the medical school participants was 3.42 and 2 points for the vocational school. The analysis of obtained data was performed by an independent T-test with a P value of 0.01, which determined that the difference between obtained results as statistically significant and that students from medical schools have greater knowledge of epilepsy (Fig. 4). This partially confirms the initial hypothesis that medical school students have more knowledge of epilepsy than their peers from vocational schools.

Figure 4 presents the distribution of scores of knowledge on epilepsy. In medical schools, 56 out of 80 participants are in the range of 3 to 4.5 points. In vocational schools, 56 out of 84 participants are in the range of 0 to 2 out of the possible 6 points.

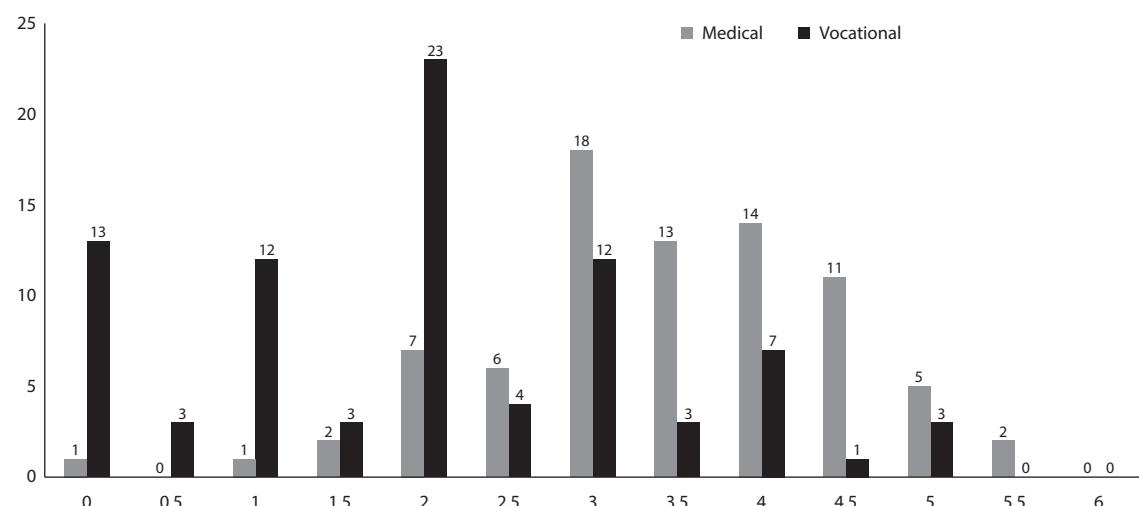


FIGURE 4. Comparison of knowledge between medical and vocational courses

tizacije. Od ukupnog broja ispitanika 51,85 % reklo bi bliskim osobama, a 34,77 % bi mogli svakome reći bez suzdržavanja.

Iz tablice 2 možemo vidjeti da se velika većina ispitanika slaže da bi rekli bliskim ljudima da imaju epilepsiju. Ispitanici medicinskih škola 47,5 %, a strukovne 55,93 %.

Pitanja 12-17 – stavovi o oboljelima od epilepsije koji povremeno dožive epileptički napadaj. Pitanja su korištena u procjeni predrasuda o oboljelima od epilepsije – procjena društvenih predrasuda.

U pitanju 12 dominira odgovor „A“ odnosno da bi se ponašali isto prema nekoj osobi i kada bi saznali da boluje od epilepsije (85,4 %); 87,23 % ispitanika bi se i dalje s njima družilo (išli na koncerте, kino...), a 95,16 % bi s oboljelim mogli biti dobar prijatelj; 22,57 % ispitanika malo bi okljevalo prilikom ulaska u brak s osobom koja ima epilepsiju, a 28,06 % bi malo okljevali prigodom zapošljavanja oboljelog u svojoj tvrtki; 90,28 % osoba bi pristalo da se njihova djeca igraju s djetetom koje ima epilepsiju.

Iz pitanja 12-17 (**tablica 3**) izračunali smo aritmetičke sredine dobivenih rezultata. Aritmetička sredina ispitanika medicinske škole iznosi 6,65 bodova, a strukovnih 8,56 boda. Utvrđena je vrlo niska razina stigmatizacije kod obje skupine. Analiza dobivenih podataka izračunata je nezavisnim t-testom uz P vrijednost 0,01, kojom je utvrđeno da je razlika između dobivenih rezultata statistički značajna te da učenici medicinskih struka imaju manju količinu predrasuda o osobama oboljelim od epilepsije od njihovih vršnjaka

Questions 11-18 – questions on attitudes toward patients with epilepsy, Question 11 (Table 2). With Question 11 we wanted to see how the participants reacted if they themselves were suffering from epilepsy and had to tell someone – the level of self-stigmatization. Out of the total number of participants, 51.85% would tell people close to them and 34.77% would talk about it freely with anyone.

Table 2 shows that the vast majority of participants would tell people close to them that they have epilepsy: 47.5% of medical school participants, 55.93% vocational school participants.

Question 12-17 – attitudes toward people with epilepsy who occasionally have seizures. Questions were used to assess the prejudice toward people with epilepsy – assessment of social prejudice.

Answer A dominates in Question 12, i.e. the participants would treat the person the same if they found out he/she suffered from epilepsy (85.4%); 87.23% of the participants would still socialize with them (go to concerts, cinema...), and 95.16% could be good friends with the patient; 22.57% would be a little hesitant before entering into marriage with someone with epilepsy, and 28.06% would be a little hesitant before hiring someone with epilepsy; 90.28% of participants would agree for their children to play with a child with epilepsy.

We calculated the arithmetic mean based on the data obtained from Questions 12-17 (Ta-

**TABLE 2.** Question 11 – question on attitudes toward patients with epilepsy

If you had epilepsy, how easily would you talk about it with other people?	MEDICAL SCHOOLS		VOCATIONAL SCHOOLS	
	N	%	N	%
I would never tell anyone.	1	1.25	2	2.38
I would only tell to people close to me.	38	47.5	47	55.93
I would talk about it freely with anyone.	34	42.5	23	27.37
I do not know.	7	8.75	12	14.28

TABLE 3. Question 12-17

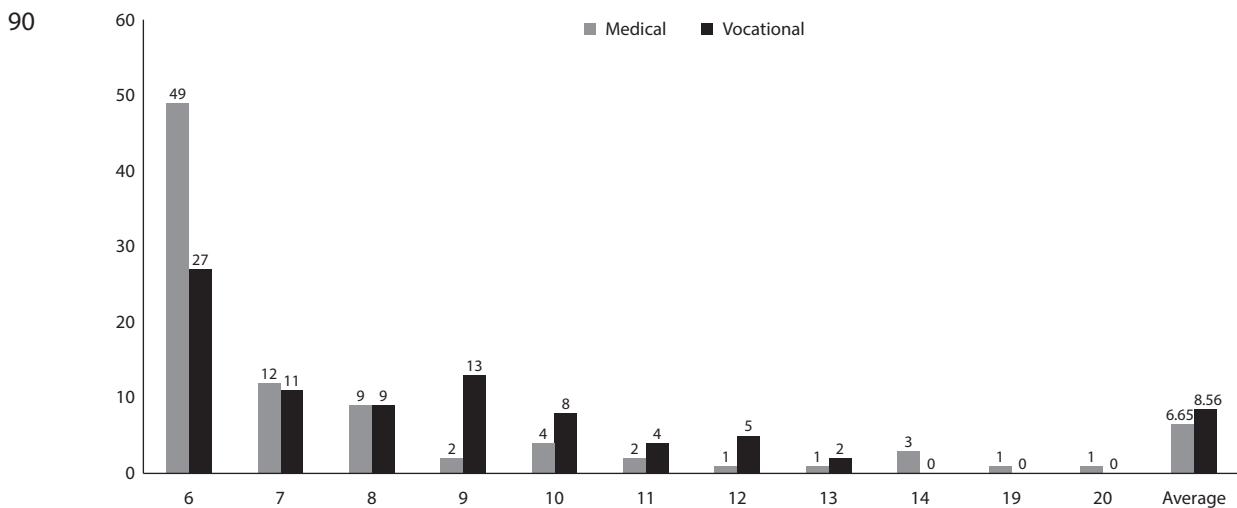
QUESTION		MEDICAL SCHOOLS		VOCATIONAL SCHOOLS	
		N	%	N	%
12. How would you react if you learned that someone you know has epilepsy?	I would act the same.	76	95	64	76,16
	I would feel a little awkward and afraid and I would rather avoid him/her.	1	1,25	2	2,38
	I would feel very awkward and afraid and I would stop contacting him/her.	0	0	0	0
	I do not know	3	3,75	18	21,42
13. Would you like to associate with him/her in social situations? (concert, cinema)	Yes, no problem.	69	86,25	74	88,06
	I would be a little hesitant about it.	11	13,75	9	10,71
	I would be very hesitant about it.	0	0	1	1,19
	No	0	0	0	0
14. Could you be a close friend with person with epilepsy?	Yes, no problem.	79	98,75	77	91,63
	I would be a little hesitant about it.	1	1,25	7	8,33
	. I would be very hesitant about it.	0	0	0	0
	No	0	0	0	0
15. Would you agree to marry him/her provided this person is otherwise acceptable?	Yes, no problem.	57	71,25	50	59,5
	I would be a little hesitant about it.	18	22,5	19	22,61
	I would be very hesitant about it.	2	2,5	2	2,38
	No	3	3,75	10	11,9
	Unanswered			3	3,5
16. Would you hire him/her in your own business provided he/she had the skills or qualifications for it?	Yes, no problem.	67	83,75	42	49,98
	I would be a little hesitant about it..	12	15	34	40,46
	I would be very hesitant about it.	0	0	0	0
	No	1	1,25	8	9,52
17. Would you agree your children to play and have as a friend another child with epilepsy?	Yes, no problem.	73	91,25	75	89,25
	I would be a little hesitant about it.	7	8,75	6	7,14
	I would be very hesitant about it.	0	0	0	0
	No	0	0	3	3,57

iz strukovnih škola (sl. 5). Time smo potvrdili našu hipotezu povezanosti stigmatizacije i znanja jer su učenici medicinskih škola pokazali veće znanje i manju razinu predrasuda (sl. 6).

Iz grafikona (sl. 4) vidimo da je većina ispitanika pokazala nisku razinu stigmatizacije prema oboljelima od epilepsije.

Iz sl. 6 vidimo distribuciju odgovora koje smo i očekivali. Veću razinu znanja, a manju razinu stigmatizacije pokazali su učenici medicinskih škola.

ble 3). The arithmetic mean of participants from medical schools was 6.65 and 8.56 points for vocational schools. The level of stigmatization was very low in both groups. Analysis of the obtained data was performed by an independent T-test with P value of 0.01, which determined that the difference between the obtained results was statistically significant and that students from medical schools have less prejudice toward people with epilepsy than their peers from vocational schools. This confirms our hypothesis on the association of



**FIGURE 5.** Questionnaire results – stigma scale

Pitanjem 18 (tablica 4) željeli smo saznati kako bi osobe kategorizirale navedene bolesti prema težini kada se radi o nekome tko im je blizak. Od 164 ispitanika na pitanje je odgovorilo 115 (sl. 6), većinom na pitanje nisu odgovarali učenici nezdravstvenih usmjerjenja (42 od 49 neodgovorenih), a čak 70 % odgovorenih se opredijelilo za dijabetes kao najlakšu bolest.

Tablica 4 pokazuje distribuciju svih odgovora. Velik postotak neodgovorenih pitanja (49,98 %) kod strukovnih pripisujemo nerazumjevanju pitanja.

Iz sl. 7 možemo vidjeti da je većina ispitanika koji su odgovorili na pitanje odabrala dijabetes (67 %) kao potencijalno najlakše oboljenje, a potom slijedi epilepsija (23 %).

Analizom rezultata utvrđeno je utječe li mjesto stanovanja na razinu predrasuda. Izračunom su dobivene aritmetičke sredine razine stigmati-

stigmatization and knowledge, since medical school students demonstrated more knowledge of people with epilepsy and therefore have less prejudice.

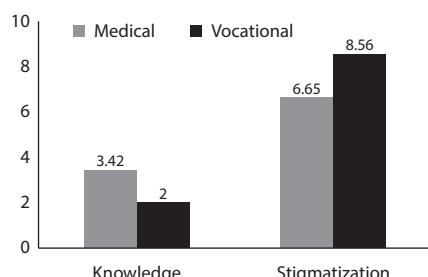
Figure 4 shows that most of the participants showed a low level of stigmatization toward patients with epilepsy.

Figure 6 presents the expected distribution of answers. Medical school students demonstrated a higher level of knowledge and a lower level of stigmatization.

With Question 18 (Table 4), we wanted to find out how people categorize these diseases according to severity when it comes to someone close to them. Out of the 164 participants, 115 answered the question (Figure 6); most of the participants from vocational schools did not answer the question (42 out of 49 unanswered), and 70% of the participants opted for diabetes as the disease they “prefer”.

Figure 7 shows that most of the participants chose diabetes (67%) as the preferred disease, followed by epilepsy (23%).

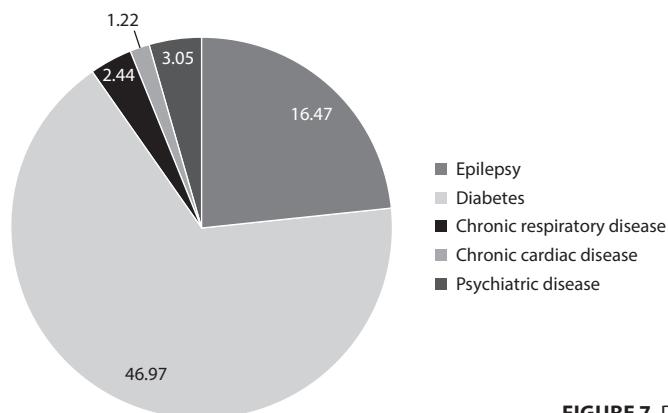
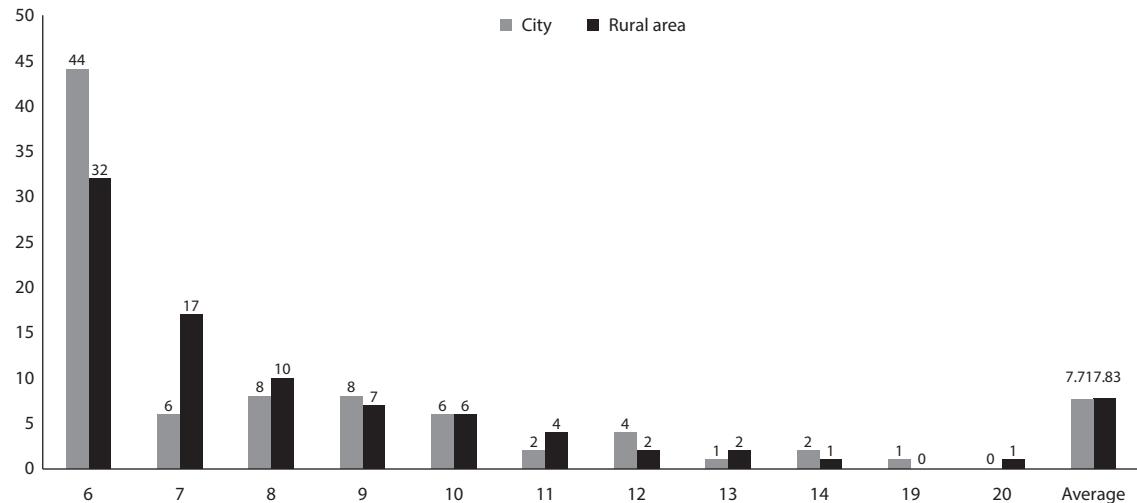
The analysis showed whether the place of residence influences the level of prejudice. The arithmetic mean for the rural area was 7.83 and 7.71 points for the city. The analysis using independent T-test identified that the differ-



**FIGURE 6.** Comparison of knowledge and stigmatization

**TABLE 4.** Question 18

If a person close to you was to have a disease, which one would you "prefer" it to be?	MEDICAL SCHOOLS		VOCATIONAL SCHOOLS	
	N	%	N	%
Epilepsy	16	20	11	13.09
Diabetes	52	65	25	29.75
Chronic respiratory disease	2	2.5	2	2.38
Chronic cardiac disease	1	1.25	1	1.19
Psychiatric disease	2	2.5	3	3.57
No answer	7	8.75	42	49.98

**FIGURE 7.** Distribution of participants who answered question 18**FIGURE 8.** Difference in stigmatization according to place of residence

zacijs od 7,83 za selo te 7,71 za grad. Analizom nezavisnim t-testom utvrđeno je da razlika nije statistički značajna i odbacujemo hipotezu da mjesto stanovanja utječe na razinu stigmatizacije (sl. 8).

Iz sl. 8 vidimo da razlika između stigmatizacije prema oboljelima od epilepsije prema mjestu stanovanja nije statistički značajna.

ence was not statistically significant, and we thus reject the hypothesis that the place of residence influences the level of stigmatization (Figure 8).

Figure 8 shows the difference between the level of stigmatization towards epilepsy patients according to place of residence is not statistically significant.

Danas je podložnost stigmatizaciji veća nego ikada, poglavito zbog visoko postavljenih standarda društvene prihvatljivosti. Od ljudi se danas očekuje da većini poslova pristupaju bez ikakvih ograničenja u funkciranju koja sa sobom nose pojedine bolesti kao što je epilepsija. Posvuda u svijetu stigmatizacija bolesnika je prepoznata kao veliki problem. Godine 2011. Europska unija je usvojila „Deklaraciju o epilepsiji“ kako bi se podigla svijest javnosti, ali i osigurao novac za istraživanje ove česte bolesti. Danas je u Hrvatskoj oko 45 000 oboljelih od epilepsije, a oko 30 % odnosno 15 000 oboljelih mlađe je od 18 godina. Mlađe osobe podložnije su utjecaju okoline i samim time osjetljivije na predrasude iz društva (6).

Nakon testiranja prve radne hipoteze „veća razina znanja ujedno utječe na smanjenje predrasuda prema oboljelima od epilepsije“ utvrdili smo pomoću nezavisnog t-testa da učenici medicinskih škola imaju veću razinu znanja te manju količinu predrasuda i da je ta razlika statistički značajna. Učenici medicinskih škola ostvarili su prosjek od 3,42 boda od mogućih 6, dok je kod učenika strukovnih škola prosjek bio 2 boda. Kod procjene stigme obje grupe su pokazale vrlo nisku razinu stigmatizacije. Prosjek kod medicinskih škola je bio 6,65 od mogućih 24, a kod strukovnih nešto viši, 8,56. Time potvrđujemo prvu radnu hipotezu.

Nakon testiranja druge radne hipoteze „Ispitanici iz ruralnog područja imaju manje predrasuda prema oboljelima od epilepsije u odnosu na ispitanike iz urbanih sredina“ utvrđeno je nezavisnim t-testom da razlika među rezultatima nije statistički značajna.

Godine 2007. provedeno je istraživanje među studentima zdravstvenih usmjerjenja u Brazilu (studenti četvrtog do sedmog semestra medicine, farmacije, radne terapije). Upitnik se

## DISCUSSION

Today, stigmatization is greater than ever, especially due to high standards of social acceptability. People are expected to perform most jobs without any restrictions, which may be present in disorders such as epilepsy. Patient stigmatization is recognized as a major problem all over the world. In 2011, the European Union adopted the “Declaration on Epilepsy” in order to raise public awareness, but also to provide money for research of this common disorder. There are around 45,000 people with epilepsy in Croatia today, and around 30%, i.e. 15,000, patients are younger than 18 years of age. Younger people are more susceptible to peer pressure and thus more vulnerable to societal prejudice (6).

After testing the first working hypothesis, “A higher level of knowledge reduces the level of prejudice towards people with epilepsy”, we used an independent T-test to determine that medical school students have a higher level of knowledge and a lower level of prejudice, and that this difference is statistically significant. Medical school students achieved an average of 3.42 out of the possible 6 points, while the average score of vocational school students was 2 points. In the assessment of stigma, both groups showed very low levels of stigmatization. Medical school students achieved an average of 6.65 out of the possible 24, and vocational school students had a slightly higher score of 8.56. This confirms the first working hypothesis.

After testing the second working hypothesis, “Participants from the rural area have less prejudice towards people with epilepsy in comparison with participants from the city”, the independent T-test determined that the difference between the results was not statistically significant. In 2007, a survey was conducted among medical students in Brazil (students of the fourth and seventh semesters of medicine, pharmacy, and occupational therapy). The questionnaire was based on knowledge, attitudes, and procedures of epileptic seizures. 32% of

osnivao na poznavanju, stavovima i postupcima kod epileptičkog napada. 32 % ispitanika odgovorilo je da epilepsiju nasljeđujemo, a 11 % da je epilepsija psihijatrijska bolest (9). U našem istraživanju ti podatci su drugačiji. 65 % ispitanika medicinskih škola smatra epilepsiju nasljednom, a 21,12 % da je epilepsija psihijatrijska bolest, što ukazuje na lošiju edukaciju te veću razinu stigmatizacije u našim školama.

Kada sumiramo cijelo istraživanje, neke od dobivenih podataka možemo usporediti s istraživanjem koje je provedeno 2007. godine pod nazivom „Epilepsije i stigma“, koje je provedeno u sklopu globalne kampanje „Izaći iz sjene“ (tablica 5). Većina pitanja koja se podudara u istraživanjima su odgovorena u sličnom postotku. U istraživanju „Izaći iz sjene“ dominantna predrasuda je svrstavanje epilepsije u psihičke bolesti (4). U našem istraživanju je postotak osjetno manji od 21 %, ali je i dalje vrlo visok, pogotovo kada uzmemu u obzir da je polovica naših ispitanika medicinske struke. Distribucija rezultata kod tog pitanja je neочекivana (tablica 1 – pitanje 6). Po 17 ispitanika iz obje skupine odgovorilo je potvrđno, tako da u slučaju tog pitanja (pitanje 6) razlika u znanju nije bila vidljiva. Pad u broju osoba koje misle da je epilepsija psihijatrijska bolest služi kao pokazatelj napretka. Za usporedbu, 2007. godine na isto pitanje u SAD-u je tek 5 % odgovorilo potvrđno, što pokazuje visoku razinu educiranosti populacije o epilepsiji (7). Nažalost, u Hrvatskoj takva razina znanja nije dosegnuta ni 10 godina kasnije. Kasnije ćemo usporediti i rezultate u drugim zemljama (**tablica 7**).

**TABLE 5.** Comparison with the survey conducted in Croatia in 2007 (2)

QUESTION	2007 (%)	2016 (%)
Have you heard of epilepsy?	91	99
Have you seen an epileptic seizure?	40	50
Do you know anyone with epilepsy?	54	57
Epilepsy is a psychiatric illness.	41	21

the participants answered that epilepsy is hereditary, and 11% that it is a psychiatric disease (9). Our study found different results. 65% of medical school participants consider epilepsy hereditary, and 21.12% consider it a psychiatric illness, indicating poor education and a higher level of stigmatization in our schools.

When we summarize the entire survey, some of the data obtained can be compared with the study “Epilepsy and Stigma” conducted in 2007 as a part of the global campaign “Out of the Shadows” (Table 5). The questions compatible between the two studies were answered at similar percentages. In “Out of the Shadows” research, the dominant prejudice was the classification of epilepsy as a psychiatric illness (4). In our survey, the percentage was significantly lower, 21%, but was still very high, especially when we consider that half of our participants were medical school students. The distribution of results for this question was unexpected (Table 1 – Question 6). 17 participants from each of the survey groups answered affirmatively, so in the case of this question (Question 6) the difference in the knowledge on epilepsy is not visible. The decline in the number of participants who think that epilepsy is a psychiatric illness serves as an indicator of progress. In comparison, only 5% of the participants in the United States survey (2017) answered affirmatively to the same question, indicating a higher level of education of the population on epilepsy (7). Unfortunately, even 10 years later, this level of knowledge is not present in Croatia. The results from other countries are compared below (Table 7).

The results of vocational school participants from questions 15 and 16 (Table 3) are interest-

**TABLE 6.** Comparison with research in Greece in 2006 (8)

QUESTION		2006 Greece		2016 Croatia	
		%	%		
12. How you would react if you learnt that someone you know has epilepsy?	I would act the same.	76.3		85.4	
	I would feel a little awkward and afraid and I would rather avoid him.	8.9		1.8	
	I would feel very awkward and afraid and I would stop contacting him.	6.5		0	
	I do not know.	6.9		12.8	
13. Would you like to associate with him/her in social situations? (concert, cinema)	Yes, no problem.	74.9		87.3	
	I would be a little hesitant about it.	14.5		12.2	
	I would be very hesitant about it.	4.9		0.6	
	No.	4.1		0	
14. Could you be a close friend with him/her?	Yes, no problem.	64.7		95.1	
	I would be a little hesitant about it.	17.8		4.9	
	I would be very hesitant about it.	7.8		0	
	No	8.2		0	
15. Would you agree to marry him/her provided this person is otherwise acceptable?	Yes, no problem.	9		65.3	
	I would be a little hesitant about it.	22.8		22.6	
	I would be very hesitant about it.	21		2.4	
	No	45.4		7.9	
	Unanswered			1.8	
16. Would you hire him/her in your own business provided he/she had the skills or qualifications for it?	Yes, no problem.	37.7		66.5	
	I would be a little hesitant about it.	35.7		28.1	
	I would be very hesitant about it.	12.1		0	
	No	12.8		5.4	
17. Would you agree your children to play and have as a friend another child with epilepsy?	Yes, no problem.	65.2		90.3	
	I would be a little hesitant about it.	18.9		7.9	
	I would be very hesitant about it.	6.5		0	
	No	7.9		1.8	

**TABLE 7.** Comparison with similar researches (8)

Research	I have heard of epilepsy	I know someone with epilepsy	Epilepsy is a psychiatric illness	Do not want their children to play with someone with epilepsy	Do not want to marry someone with epilepsy	Would you hire someone with epilepsy
SAD Cavennes 1974. (11)	95	63	3	6	18	79
Italy Canger 1985. (12)	73	61	8	21	-	70
Denmark Jensen 1992. (13)	97	60	-	7	-	93
Hungary Mirnics 1994. (14)	88	51	15	19	53	45
China Lai 1990. (15)	93	77	16	57	87	35
New Zealand Hills 2002. (16)	95	73	1	18	5	69
Austria Spatt 2005. (17)	89	40	11	11	15	84
Greece 2006. (8)	94	40	15	14	66	73
Croatia Breček 2016.	99	54	21	2	8	95

Interesantni su rezultati pitanja 15 i 16 (tablica 3) kod ispitanika iz strukovnih škola, gdje je 23 % reklo da bi malo okljevali prilikom ulaska u brak sa osobom koja boluje od epilepsije, a 41 % bi malo okljevalo u slučaju zapošljavanja osobe s epilepsijom. Možemo zaključiti iz tih rezultata da smatraju kako osobe s epilepsijom nisu jednako radno sposobne kao zdrave osobe. Puno lakše se odlučuju na suživot, nego na poslovnu suradnju.

Možemo usporediti i dobivene podatke sa sličnim istraživanjem koje je 2006. godine provedeno u Grčkoj. Obuhvaćalo je raznoliku populaciju (750 ispitanika) pa smo kao usporedbu u našem istraživanju uzeli ukupne rezultate bez obzira na usmjerjenje (8). U prva tri pitanja (12,13,14 – **tablica 6**) razlike su vrlo male. Ali kada gledamo iduća 3 pitanja (15, 16, 17), evidentna je razlika u razini predrasuda, kako je tih 6 pitanja i korišteno u procjeni stigmatizacije epilepsije. Na pitanje biste li ušli u brak s osobom koja ima epilepsiju u Grčkoj je čak 45,4 % ispitanika odgovorilo negativno, kod nas je taj postotak daleko manji, samo 7,9 %. Nadalje samo 37,7 % osoba bi bez okljevanja zaposlilo oboljelogu u svojoj firmi, naspram 66,5 % u Hrvatskoj. I na kraju 65,2 % ispitanika u Grčkoj bi bez okljevanja pristalo da se njihova djeca igraju s oboljelim, dok je kod našeg istraživanja i taj podatak pokazatelj manje razine predrasuda, 90,3 %.

Istraživanja o stigmatizaciji oboljelih od epilepsije provođena su i u drugim zemljama te ćemo priložiti odgovore na pitanja koja su se u našim istraživanjima podudarala. I u drugim istraživanjima se analizira mišljenje o epilepsiji kao psihijatrijskoj bolesti. Postotak je manji nego u našem istraživanju. U posljednjim godinama smo napredovali, ali i dalje je potrebno djelovati na stigmatizaciju u području znanja o bolestima.

Tablica 6 prikazuje pitanja iz sličnog istraživanja koje je provedeno u Grčkoj 2006 godine, a

ing: 23% of them answered that they would hesitate before entering into marriage with someone with epilepsy, and 41% would hesitate before hiring someone with epilepsy. These results allow us to conclude that they regard people with epilepsy less capable for work than healthy people. They chose cohabitation with people with epilepsy much more easily than business cooperation.

We can also compare the data obtained from a similar survey conducted in Greece in 2006. This survey included a diverse population (750 participants), and for the comparison with our results we used the overall results regardless of the profession (8). In the first three questions (12, 13, 14 – Table 6), the differences are very low. But when we look at the three following question (15, 16, 17), there is an obvious difference in the level of prejudice, as these six questions have been used in the assessment of stigmatization of patients with epilepsy. In Greece, 45.4% of the respondents answered negatively to the question: "Would you agree to marry him/her provided this person is otherwise acceptable?" In our survey this percentage is much lower, only 7.9%. In addition, only 37.7% of the participants would hesitate to hire a person with epilepsy to their company, compared with 66.5% in Croatia. Lastly, 65.2% of the participants in Greece would agree for their child to play with children with epilepsy, while in our survey these data are the indicator of a lower level of prejudice, 90.3%.

Studies on stigmatization of patients with epilepsy have been conducted in other countries, and we will supply the answers to questions which coincided those used in our study. Attitude towards epilepsy as a psychiatric illness was also analyzed in other studies. The percentage is lower than in our study. There has been progress in the last few years, but there is still a need to act on stigmatization in the education about this disorder.

Table 6 presents questions from a similar study conducted in Greece in 2006, from which we

iz kojeg smo preuzeли upitnik procjene stigme za naše istraživanje.

Tablica 7 prikazuje usporedbe pitanja koja se podudaraju s prijašnjim sličnim istraživanjima provedenim u drugim zemljama.

## ZAKLJUČAK

Ako krenemo od teorije da je stigma pogled društva ili osobno iskustvo povezano s osjećajem krivnje i manje vrijednosti nastalo kao posljedica krivog shvaćanja bolesti, iz te teorije možemo uvidjeti važnost edukacije, odnosno ulogu znanja u sprječavanju nastanka predsuda. Često se smatra da su osobe koje boluju od epilepsije znatno ograničenije u svojim životnim potrebama, a pri tome zaboravljamo na ljudе koji su bili uspješni usprkos epilepsiji (Alfred Nobel, Vincent Van Gogh, Napoleon Bonaparte...). Do danas je liječenje epilepsije bitno uznapredovalo i čak 80 % medikamенно tretiranih ne dožive ni jedan napad (18). Epilepsija, dakako, remeti sve aspekte života i lako može postati fizičko, psihičko i socijalno opterećenje/problem za pojedinca, no i s njom osoba može živjeti ispunjen i zadovoljavajući život. Često je najteži dio života s epilepsijom kako se nositi s reakcijama drugih.

U konačnici je važno staviti naglasak na edukaciju, kako zdravstvenih djelatnika, tako i opće populacije, jer kao što smo dokazali u ovom istraživanju stigmatizacija je povezana s razinom znanja i stoga možemo reći: „Znanjem protiv stigme!“, kako za epilepsiju, tako i za mnoge druge bolesti kod kojih neznanje uzrokuje socijalnu izolaciju i time produbljuje problematiku pacijentovog stanja.

have taken the questionnaire on the assessment of stigmatization for our research.

Table 7 presents the comparison between questions that are consistent with similar surveys conducted in other countries.

## CONCLUSION

If we start from the theory that stigma is the mindset of society or personal experience associated with the feeling of guilt and inferiority resulting from a misconception of an illness, we can see the importance of education and the role of knowledge in preventing the occurrence of prejudice. It is often thought that people with epilepsy are more limited in their needs, and we forget about those who have been successful despite epilepsy (Alfred Nobel, Vincent Van Gogh, Napoleon Bonaparte...). To date, the treatment of epilepsy has significantly improved, and as many as 80% of those medically treated do not experience a single seizure (18). Epilepsy clearly disrupts all aspects of life and can easily become a physical, psychological, and social burden or problem for the individual, but a person can also live a fulfilling and satisfying life with epilepsy. Often, the hardest part of living with epilepsy is dealing with the reactions of others.

Ultimately, it is important to focus on education of medical professionals and the general population, because, as we demonstrated in our research, stigmatization is associated with the level of knowledge, and we can therefore say: “Knowledge against stigma!” This applies to epilepsy and many other illnesses in which ignorance causes social isolation and thus deepens the problematics of the patient’s condition.

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## QUESTIONNAIRE

Dear,

Before you is a questionnaire for the purpose of research work on the topic: "**Stigmatization and Stereotypes in Patients with Epilepsy**". Please follow the instructions carefully and answer honestly to questions and offered statements. The data will be used solely for the purpose of research. We take responsibility for keeping your personal data.

We thank in advance all participants of the research!

**1. Sex (mark with X)**

- M
- Ž

**2. Age (write age in years)**

**3. Place of residence (mark with X)**

- City - A
- Rural area - B

**4. School /courses (mark with X)**

- Nurse / technician - A
- Pharmaceutical technician - B
- Sales assistant - C
- Hairdresser - D
- Cook - E
- Waiter - F
- Other (name): \_\_\_\_\_

1. Have you ever heard of a disease called epilepsy?
  - a) Yes
  - b) No
  - c) I do not know
  
2. Do you have a close relative with epilepsy?
  - a) Yes
  - b) No
  - c) I do not know
  
3. Do you know anyone with epilepsy?
  - a) Yes
  - b) No
  - c) I do not know
  
4. Have you ever seen an epileptic seizure?
  - a) Yes
  - b) No
  - c) I do not know
  
5. Do you think epilepsy is a type of mental retardation?
  - a) Yes
  - b) No
  - c) I do not know
  
6. Do you think epilepsy is a type of a psychiatric illness?
  - a) Yes
  - b) No
  - c) I do not know
  
7. Do you think epilepsy is a type of brain disorder or malfunction?
  - a) Yes
  - b) No
  - c) I do not know
  
8. What do you think is the cause(s) of epilepsy? (you may choose more than one answer).

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- a) A nervous system disorder
  - b) A congenital abnormality
  - c) A mental or psychological disorder
  - d) A hereditary disease
  - e) A blood disease
  - f) Some other cause
  - g) I do not know
9. An epileptic can be radically cured without taking any medications.
- a) Never
  - b) Rarely
  - c) Often
  - d) Usually yes
  - e) I do not know
10. An epileptic person (man or woman) has children. What do you think is the risk of his/her children having the same problem?
- a) No risk
  - b) Low risk
  - c) Moderate risk
  - d) High risk
  - e) I do not know

**Before answering the following questions please consider, for the purpose of this questionnaire, an epileptic as a person who occasionally has a seizure but is otherwise normal.**

11. If you had epilepsy, how easily would you talk about it with other people?
- a) I would never tell anyone
  - b) I would tell only to people close to me
  - c) I would talk about it freely with anyone
  - d) I do not know
12. How would you react if you learned that someone you know has epilepsy?
- a) I would act the same
  - b) I would feel a little awkward and afraid and I would rather avoid him/her
  - c) I would feel very awkward and afraid and I would stop contacting him/her
  - d) I do not know

13. Would you like to associate with him/her in social situations? (concert, cinema)

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- a) Yes, no problem
- b) I would be a little hesitant about it
- c) I would be very hesitant about it
- d) No

14. Could you be a close friend with person with epilepsy?

- a) Yes, no problem
- b) I would be a little hesitant about it
- c) I would be very hesitant about it
- d) No

15. Would you agree to marry him/her provided this person is otherwise acceptable?

- a) Yes, no problem
- b) I would be a little hesitant about it
- c) I would be very hesitant about it
- d) No

16. Would you hire him/her in your own business provided he-she had the skills or qualifications for it?

- a) Yes, no problem
- b) I would be a little hesitant about it
- c) I would be very hesitant about it
- d) No

17. Would you agree your children to play and have as a friend another child with epilepsy?

- a) Yes, no problem
- b) I would be a little hesitant about it
- c) I would be very hesitant about it
- d) No

18. If a person close to you was to have a disease, which one would you “prefer” it to be?

- a) Epilepsy
- b) Diabetes
- c) Chronic respiratory disease
- d) Chronic cardiac disease
- e) Psychiatric disease

# Život na Golom otoku kroz tetovaže

## / Life on Goli otok Through Tattoos

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Od početka vremena čovjek, kao misaono biće, ima potrebu ostavljati i odašiljati poruke drugim ljudima, bilo u obliku spiljskih crteža, kipova ili otisaka na svojoj koži. Kako će poruka koju prenosi izgledati u očima primaoca i hoće li je on htjeti prihvati kao takvu, u tom trenutku čovjek ne može znati. Čovjekova potreba za ostavljanjem traga nije stala na spiljskim slikarijama, već je svoje strahove, vjerovanja i ideale želio utkati u nešto više, nešto najvrjednije što postoji, a to je on sam. Otkrivači tehniku tetoviranja, njegovo tijelo postaje nositelj slike i teksta, a tetovaže svjedok načina života koji je živio. Tetoviranje, kao kulturna praksa i jedan od oblika tjelesnih modifikacija, zabilježeno je na svim stranama svijeta te datira još iz Brončanoga doba i nastavlja se sve do današnjice u raznim područjima ljudskoga djelovanja. Tetovaža je svjesna tjelesna modifikacija nastala pod utjecajem okoline i kulture u kojoj se individuum nalazi. U ovom radu opisan je bolesnik s brojnim tetovažama po tijelu njihovo značenje u bolesnikom životu te zatvorenički dani na Golom otoku. Možemo reći da su tetovaže način na koji neke osobe drugima dopuštaju da vide što oni misle, osjećaju ili kako doživljavaju sami sebe.

*/ Since the beginning of time, man has, as a thinking creature, felt the urge to leave and transmit messages to others, whether in the form of cave drawings, statues, or prints on his skin. At the moment of sending a message, one cannot know how the message will appear to the eyes of the recipient or whether they will want to accept it as such. Man's need to leave traces did not end with cave paintings, and he wished to weave his fears, beliefs, and ideals into something more, something of utmost value, which is man himself. Having discovered the technique of tattooing, his body became the bearer of image and text, and his tattoos evidence of the way he had lived his life. As a cultural practice and one of the forms of body modification, tattooing has been found in all parts of the world and dates from the Bronze Age, continuing until today in various fields of human activity. A tattoo is a conscious modification of the body created under the influence of an individual's surroundings and culture. This paper describes a patient with numerous tattoos, their meaning in the patient's life, and the days of imprisonment spent on Goli otok. We can say that tattoos are a way in which certain people allow others insight into what they think, feel, or how they perceive themselves.*

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### KLJUČNE RIJEČI / KEY WORDS:

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Od početka vremena čovjek, kao misaono biće, ima potrebu ostavljati i odašiljati poruke drugim ljudima, bilo u obliku spiljskih crteža, kipova ili otiska na svojoj koži. Kako će poruka koju prenosi izgledati u očima primaoca i hoće li je on htjeti prihvati kao takvu, u tom trenutku čovjek ne može znati. Upravo zbog toga, ljudska kultura, odnosno pojedinac sam se kasnije susreće s osuđivanjem prakse tjelesnih modifikacija, u ovom slučaju tetoviranja. Ukrašavajući svoje tijelo tetovažom, nositelj komunicira sa svijetom te jasno iskazuje svoje stavove, strahove i želje. Čovjekova potreba za ostavljanjem traga nije stala na spiljskim slikarijama, već je svoje strahove, vjerovanja i ideale želio utkati u nešto više, nešto najvrjednije što postoji, a to je on sam. Otkrivši tehniku tetoviranja, njegovo tijelo postaje nositelj slike i teksta, a tetovaže svjedok načina života koji je živio (1,2).

## Povijest tetoviranja

Riječ tetovaža, nastala je od engleske riječi „tattoo“, koja je anglikanizirana verzija tahičanske riječi „tatau“, što znači pisati ili označiti nešto, a u Europu ju je donio James Cook 1769. godine, kada se vratio sa svojeg putovanja na Tahiti i Novi Zeland (3).

Postojanje tetovaža na ljudskom tijelu dokumentirano je u povijesti mnogih kultura u cijelome svijetu, a najstarija, do danas pronađena tetovaža, nađena je na mumificiranom tijelu muškarca iz bakrenog doba otkrivenom u Ötzalskim Alpama u Austriji, popularno zvanom Ötzi (3). Ötzijeve tetovaže su nastale utrljavanjem ugljena u prethodno izbušenu kožu. Vjeruje se da su tetovaže imale za cilj ublažavanje bola jer su napravljene na točkama koje se i danas koriste u akupunkturi (4).

Tetoviranje, kao kulturna praksa i jedan od oblika tjelesnih modifikacija, zabilježeno je na svim stranama svijeta te datira još iz Brončanoga doba i nastavlja se sve do današnjice u

## INTRODUCTION

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Since the beginning of time, man has, as a thinking creature, felt the urge to leave and transmit messages to other people, whether in the form of cave drawings, statues, or prints on his skin. When sending a message, one cannot know how the message will appear to the eyes of the recipient or whether they will want to accept it as such. Precisely due to that, human culture and the individual himself has faced disapproval of the practice of body modification, in this case tattooing. Man's need to leave traces did not end with cave paintings, and he wished to weave his fears, beliefs, and ideals into something more, something of utmost value, which is himself. Having discovered the technique of tattooing, his body became the bearer of image and text, and his tattoos evidence of the way he had lived his life (1,2).

## The history of tattooing

The term tattoo comes from English, which is an anglicized version of the Tahitian word *tatau*, meaning to write or mark something, and was brought to Europe by James Cook in 1769 when returning from his trip to Tahiti and New Zealand (3).

The existence of tattoos on the human body has been documented in numerous cultures from around the world, and the oldest tattoo so far is one found on the mummified body of a man from the Copper Age discovered in the Ötztal Alps in Austria, known as Ötzi (3). Ötzi's tattoos were created by rubbing charcoal into previously punctured skin. It is believed that tattoos were supposed to reduce pain because they were located on points that are still used in acupuncture even today (4).

As a cultural practice and one of the forms of body modification, tattooing has been found in all parts of the world and dates from the Bronze Age, continuing until today in various

raznim područjima ljudskoga djelovanja (1). Tetoviranje je jedna od najčešćih i najpopularnijih vrsta tjelesnih modifikacija i *body-art-a* (5). Tetovaža je svjesna tjelesna modifikacija nastala pod utjecajem okoline i kulture u kojoj se individuum nalazi (5).

U našim krajevima se tetoviranje pojavilo za vrijeme turskih osvajanja, i to kod Hrvata katolika iz Bosne i Hercegovine koji su tetovirali djecu kako bi ih učinili odbojnima turskim osvajačima te ih tako spasili od otmice ili korištenja prava prve bračne noći (6). Migracijom stanovništva ovaj se običaj preselio i u Dalmatinsku zagoru, na područje između Šibenika i Sinja. Procjenjuje se da i danas postoji između 50 i 100 tetoviranih žena na tom prostoru, a tetovaže su najčešće smještene na člancima prstiju na šakama. Vjeruje se da je posljednja osoba tetovirana na ovaj, tradicionalan način, rođena 1969. godine, a tetovirana je oko 1984. godine (6).

U Guinnessovoj knjizi rekorda zabilježeno je da je čovjek s najviše tetovaža na svijetu Lucky Diamond Rich iz Australije čije tijelo je u potpunosti prekriveno tetovažama. Tetovirani su mu čak i kapci, desni te unutrašnjost ušnih školjaka (7).

Za razliku od arhitekture, kiparstva, slikarstva i sličnih oblika izražavanja, tetoviranje je teško precizno datirati, jer ostavlja malo arheoloških ostataka. Tetovaže žive i umiru zajedno sa svojim nositeljima, dok tetovirački alati zbog minaljaturnosti i razgradivosti rijetko bivaju pro-

fields of human activity (1). Tattooing is one of the most common and most popular forms of body modification and body-art (5). A tattoo is a conscious body modification created under the influence of an individual's environment and culture (5).

In these parts, tattooing appeared during Turkish conquests among Croatian Catholics from Bosnia and Herzegovina who tattooed children to make them unappealing to Turkish invaders and therefore save them from kidnapping or the use of the right of the first night (6). Migrations led to this custom spreading into the Dalmatian Hinterland, in the area between Šibenik and Sinj. It is estimated that nowadays there are between 50 and 100 tattooed women in that area, and the tattoos are most commonly found on the knuckles. It is believed that the last person tattooed in this way was born in 1969 and tattooed around 1984 (6).

According to the Guinness book of records, the man with the greatest number of tattoos in the world is Lucky Diamond Rich from Australia, whose body is almost entirely covered in tattoos. Even his eyelids, gums, and the insides of his ears have been tattooed (7).

Unlike architecture, sculpture, painting, and similar forms of expression, tattooing is difficult to date precisely because it leaves few archaeological traces. Tattoos live and die with their bearers, while tattooing tools are rarely found and their original use is rarely identified due to their miniature size and propensity to decompose. In addition to that, official archaeology often refuses to accept that ornamental surface decoration of statues of prehistorical cultures is in fact a depiction of tattoos. The beginning of the practice of tattooing is impossible to determine because it developed independently even in the remotest parts of the world (8). As Poon states, unlike antique pottery and cave paintings, tattooing is much more difficult to research be-



**FIGURE 1.**

nađeni i pravilno prepoznati u svojoj izvornoj namjeni. Također službena arheologija često odbija prihvatići da je ornamentalna površinska dekoracija kipova pretpovijesnih kultura u biti prikaz tetovaža. Početak tetoviranja je nemoguće odrediti, jer se neovisno razvijao i u svakom najzabačenijem kutku planete (8). Kako Poon navodi, za razliku od antičkog lončarstva i crteža u spiljama, tetoviranje je mnogo teže istraživati, jer je platno na kojem nastaju tetovaže upravo ljudska koža. Koža je kako znamo, jedan od artefakata koji se može najslabije očuvati, stoga ne možemo sa sigurnošću reći koja je godina ishodišna točka tetoviranja. Upravo zbog toga tetovaža je ujedno i stalni i nestalan trag identiteta. U svim kulturama plemstvo je, uz najbolje oružje, opremu, odjeću, hranu i nastambe posjedovalo najkvalitetnije i najskuplje tetovaže, u pravilu rad vrsnih, dobro plaćenih majstora. Često su postojali određeni simboli rezervirani isključivo za plemiće kao oznaka ranga i podrijetla. Povijest bilježi mnoge primjere tetoviranja heraldičkih simbola na pripadnicima europskih kraljevskih i plemićkih obitelji, kao i na plemenskoj aristokraciji Sjeverne Amerike, Azije, Afrike i Oceanije (pacifička regija) (8).

Neke kulture smatraju da su umjetnost i kultura tetoviranja namijenjene samo onima višeg staleža, odnosno plemstvu. Npr. u kulturama poput maorske, polinezijске i inuitske, tetovaža simbolizira prelazak u svijet odraslih, dok u nekim kulturama tetovažama tijelo oslikavaju oni ljudi koji su najčešće u sukobu s vlastima i zakonom, čime zapravo označavaju pripadnost određenoj kriminalnoj skupini (8). Tetovaže mogu imati različito značenje i različitu ulogu, ovisno o nositelju: magična uloga, talisman, zaštita od bolesti, katastrofa ili zlih duhova, svojevrsna potvrda za prijelaz duše na drugi svijet u različitim religijama i konačno način da se iskažu unutarnje želje, afiniteti i predanost nečemu (9).

DeMello navodi kako je francuski antropolog Claude Lévi-Strauss rekao da tetovaže transfor-

cause its canvas is human skin. Skin is known to be among the artefacts that are the most difficult to conserve, which is why we cannot identify its year of origin with any certainty. Due to that, tattoos are both a permanent and an impermanent trace of identity. Along with the best weapons, equipment, clothes, food, and dwellings, aristocracies of all cultures also possessed the best and most expensive tattoos, created by highly skilled and well-paid masters. Certain symbols were often reserved exclusively for the aristocracy as a sign of rank and background. History holds many examples of tattooing heraldic symbols among the members of European royal and aristocratic families, as well as among the members of tribal aristocracies of Northern America, Asia, Africa, and Oceania (the Pacific region) (8).

Some cultures believe the art and culture of tattooing to be primarily reserved for those of higher rank, or the aristocracy. For example, in cultures such as Maori, Polynesian, and Inuit, a tattoo symbolizes the entrance into adulthood, while in other cultures tattoos are found only among those in conflict with the authorities and the law, which means that they actually show that they belong to a certain criminal group (8). Tattoos can have a variety of meanings and roles, depending on the bearer of the tattoo: a magical role, a talisman, a protection from diseases, catastrophes, or evil spirits, a kind of confirmation of the passage of a soul into the other world in a variety of religions, and finally a way of expressing their wishes, affinities, or a dedication to something (9).

DeMello points out that French anthropologist Claude Lévi-Strauss claimed that tattoos transform a person from a *raw animal* into a being of culture. In many cultures, bodies without modifications or some form of markings are not considered truly human. Non-tattooed individuals were also sometimes marginalized

miraju čovjeka iz „sirove životinje“ u kulturno biće. U mnogim kulturama tijela koja nisu modificirana ili obilježena na neki se način ne smatraju uistinu ljudskim. Netetovirani pojedinci u mnogim kulturama bili su marginalizirani i odbačeni od tadašnjeg društva. Mnogim pripadnicima zapadne kulture je veoma neobično čuti kako u tradicionalnim kulturama žene koje posjeduju tetovažu ili neku drugu tjelesnu modifikaciju djeluju privlačnije (10).

Tetovaže također mogu biti prelazak u svijet odraslih. Često zadobivene tijekom rituala prelaska tetovaže kao i druge tjelesne modifikacije pomažu novim članovima pri ulasku u društvo (11). Muškim pripadnicima nekih plemena tetovaže su kao i drugi brojni bolni rituali poput skarifikacije i obrezivanja bili pokazatelj da su zaslužili da ih se tretira kao odraslog člana društva (12). Koliko je važno tetoviranje nekim kulturama pokazuje nam pleme Samoanaca, gdje se od muškarca očekuje nošenje cijelog *pe'a*, tetovaže koja prekriva dio torza, stražnjicu i natkoljenice. Onaj muškarac koji ne uspije dovršiti svoj *pe'a* ne smatra se muškarcem. Čak i danas pripadnici plemena Samoa ne mogu odati priznanje onom muškarцу koji ne nosi *pe'a* (13). DeMello navodi kako su tetovaže duboko utkane u tradicionalno društvo. Iako dekorativne,

and rejected by their societies. Many members of Western culture find it unusual that women with tattoos or some other body modifications are considered more attractive in traditional cultures (10).

Tattoos can also signify an entrance into adulthood. Often acquired during rituals of entering adulthood, such tattoos and other body modifications aid new members in the process of entering society (11). For male members of some tribes, tattoos and other numerous painful rituals such as scarification and circumcision served as a sign that they had earned the right to be treated as an adult member of society (12). Some cultures place great importance on tattooing, as is the case with the Samoan tribe, which expects the man to bear an entire *pe'a*, a tattoo that covers a part of the torso, buttocks, and thighs. If a man fails to complete his *pe'a*, he is not considered a man. Even today, members of Samoan tribes cannot honour a man who does not have a *pe'a* (13). DeMello claims that tattoos are deeply woven into traditional societies. Although decorative, they are a means of communication and a symbol of status, religious beliefs, marital status, significant achievements, and other matters of great importance (12).

FIGURE 2.



one su sredstvo komunikacije i pokazatelj položaja, vjerskog opredjeljenja, bračnog statusa, važnih postignuća i ostalih važnijih stvari (12).

Prisjećajući se starih civilizacija, točnije gledano Perzijanaca, DeMello navodi da su u njihovoј kulturi tetovaže upotrebljavane u svrhu dehumanizacije čovjeka i obilježavanja istoga kao roba, zatvorenika ili vojnika koji pripadaju nekome. Ovakvo institucionalizirano nametanje tetovaža kao objektivizacije ljudi kasnije se nastavilo u 20. stoljeću prigodom nacističke propagande protiv pripadnika židovske vjeroispovijesti i ostalih zatvorenika koncentracijskog logora u Auschwitzu. Ironično je to što su navedeni bili prisilno tetovirani ne bi li ih se obilježilo, dok zatvorenici europskih, ruskih i američkih zatvora često sami odabiru svoje tijelo ukrasiti tetovažama ne bi li pokazali svoj status naspram drugih zatvorenika (13). DeMello ističe kako je povjesna povezanost tetovaža s marginaliziranim pripadnicima društva jedan od većih razloga zašto su one u zapadnoj kulturi negativno percipirane od strane srednjeg i višeg staleža (13). Tetovaže pripadnica Li naroda označavaju njihov ulazak u svijet odraslih i spremnost za udaju. Li djevojke smatrale su kako njihove tetovaže nisu samo lijepi geometrijski uzorci, već i sredstvo prepoznavanja nakon smrti od strane njihovih predača (14). „Tvoja ogrlica se može slomiti, *frau* drvo se može raspuknuti, ali moje tetoviranje je neuništivo. Ono je svevremenski dragulj kojeg ćeš ponijeti sa sobom u grob.“ (stih iz tradicionalne polinezijiske pjesme, autor nepoznat) (2).

Afrička plemena osim po skarifikaciji poznata su po još jednoj vrsti tjelesne modifikacije, u ovom slučaju privremenog vida poput *body painting-a*. *Body painting* je uobičajena metoda ukrašavanja i modificiranja tijela pripadnika afričkih plemena pri izvođenju religijskih rituala, ceremonija slavlja i pokazivanja spolne zrelosti (15). Upotrebljavane boje su često, ako ne i uvijek, simboličke prirode: crvena boja simbolizira npr. krv, smrt ili plodnost (13).

Eskimi su vjerovali kako su njihova tijela stanista više duša te da svaka duša počiva u odre-

Thinking back to older civilizations, more precisely Persians, DeMello states that in their culture tattoos were used for dehumanizing people and marking them as slaves, prisoners, or soldiers who belonged to someone. Such institutionalized enforcement of tattoos as objectivization of people later continued in the twentieth century as part of Nazi propaganda against Jewish people and other prisoners of the Auschwitz concentration camp. It is ironic that they were forcibly tattooed in order to be marked, while prisoners of European, Russian, and American prisons often chose to decorate their bodies with tattoos in order to show their status was different than that of other prisoners (13). DeMello points out that the historical connection between tattoos and marginalized members of society is one of the reasons why tattoos are perceived as negative by members of the middle and upper class in Western culture (13). Tattoos among the Li women mark their entrance into adulthood and their readiness for marriage. Li girls believed their tattoos were not just beautiful geometric patterns, but also the means by which they would be recognized by their ancestors after death (14). “Your necklace may be broken, the *frau* tree may burst, but my tattoos are indestructible. This is the eternal jewel you shall carry to your grave” (a verse from a traditional Polynesian poem, author unknown) (2).

African tribes are known for scarification, but also for another type of body modification, in this case a temporary form like body painting. Body painting is a common method of decorating and modifying the bodies of members of African tribes during the performance of religious rituals, celebration ceremonies, and the display of sexual maturity (15). The colours they use are very often, if not always, of symbolic nature: red symbolizes blood, death, or fertility (13).

Eskimos believed their bodies were inhabited by multiple souls, and that each soul existed in

đenom zglobu. Zbog navedenog, tetovaže su imale veliku ulogu pri pogrebu u eskimskoj kulturi. Pogrebne tetovaže sastojale su se od malih točaka na različitim zglobovima (rame, lakat, zapešće, koljeno...) koje su svojim postojanjem na tijelu pokojnika omogućavale dušama da napuste tijelo i prijeđu na drugi svijet (16). Pripadnici naroda Ungan, Alutiiq i Chugach na području Aljaske kulturu tetoviranja i ostalih tjelesnih modifikacija povezuju sa svetim i kulturnim iskustvom (16). *Body art* za pripadnike navedenih naroda nije bio samo užitak, već je podizao socijalni status unutar plemena, duhovnu moć, ljepotu i obožavanost (16).

Krajem 19. stoljeća tetovaže su se preselile na karnevale i u cirkuse, gdje su pozornost plijenili potpuno tetovirani pojedinci, čija su tijela bila prekrivena tetovažama od glave do pete, a služila su im poput kostima. Identitet ovih cirkuskih dama i muškaraca nije bio povezan s oslobođenjem i poštovanjem, već s kapitalizmom i poslovnim ulaganjima (17).

DeMello navodi da su se razlozi tetoviranja uvelike promijenili, kao i njihova simbolika,

a different joint. Due to that, in Eskimo culture tattoos played an important role during burial. Burial tattoos consisted of small dots on various joints (shoulders, elbows, wrists, knees...) and their presence on the body of the deceased enabled the souls to leave the body and cross into the other world (16). The Uigan, Alutiiq, and Chugach people from the Alaskan area associate the culture of tattooing and other body modification with a holy and cultural experience (16). For those people, body art did not just represent pleasure, but also increased social status within the tribe, as well as spiritual power, beauty, and admiration (16).

At the end of the nineteenth century tattoos moved to carnivals and circuses, where completely tattooed individuals attracted attention because their bodies were covered with tattoos from head to toe and served as a costume. The identity of those men and women from the circus was not related to liberation or respect, but with capitalism and business investments (17).

DeMello claims that reasons for tattooing have largely changed, and so has the symbolism of tattoos, thus making them one great cultural mixture (13). In fact, *the body as a project* is one of the most significant expressions used to describe ways that individuals treat their own bodies (1).

As societies changed, so did beauty standards. What was the ideal of beauty for a man from antiquity is nowadays the complete opposite, so it is no wonder we find ourselves in times of increasing numbers of surgical interventions on the body which, of course, follow certain trends. In 2011, Adamović and Maskalan claimed that there were at least two dominant trends among aesthetic changes of the body, which depend on whether they are aimed at *standardization* or *grotesquization* (1).

Tattoos are initiators and mediators within symbolic communication. As Wilson claims, tattoos are active, and in moments during which



**FIGURE 3.**

čineći tetovaže uistinu jednom velikom kulturnom mješavinom (13). Upravo je „tijelo kao projekt“ jedna od značajnijih sintagmi kojom se opisuju načini na koje se individuumi odnose prema vlastitom tijelu (1).

S razvitkom društva mijenjaju se i standardi ljepote. Ono što je antičkom čovjeku bio ideal ljepote danas je upravo suprotno i obrnuto, stoga nije ni čudo da se nalazimo u vremenu kada svjedočimo sve većem porastu kirurških intervencija u tijelo pri čemu naravno pojedinač prati trendove. Godine 2011. Adamović i Maskalan navode kako postoje najmanje dva dominantna trenda estetskih promjena tijela ovisno jesu li navedene usmjerene ka „standarizaciji“ ili „groteskizaciji“ (1).

Tetovaža je pokretač, posrednik u komunikaciji simbola. Kako navodi Wilson, tetovaže su aktívne, u trenutcima izloženosti drugima one projiciraju simbole drugima. Pojedincima tetovaže nisu samo označka koja je u tom trenutku bila ideja ili želja, već dio identiteta njih samih (18).

Wilson navodi kako tetovaža započinje impresijom, konceptom u mislima umjetnika, odnosno njezina dizajnera. Moglo bi se čak reći da je tetovaža psihička formacija kako njen nositelj vidi samoga sebe (18). U kulturi gdje je vanjsčina veoma važna, koža, kao najveći ljudski organ, je platno na koje projiciramo naše najveće fantazije i najdublje strahove (19).

## Podjela tetovaža

Tetovaže možemo podijeliti u dvije skupine. Prvoj skupini pripadaju privremene tetovaže, odnosno one tetovaže koje traju od nekoliko dana do nekoliko tjedana, dok u drugu skupinu spadaju one tetovaže koje krase ljudsko tijelo zauvijek, izuzev „trajne šminke“ korištene u kozmetičke svrhe, čiji je vijek trajanja nekoliko godina (20).

Hustić navodi kako se u modernoj dermatologiji tetovaže, uz trajne i privremene, dijele još na one koje su zadobivene slučajnim umetanjem pigmenta u kožu (npr. ubod kemijskom

they are revealed to others they project symbols towards them. For some, tattoos are not simply a marking that was at a certain moment an idea or a wish, but a part of their own identity (18).

Wilson claims that a tattoo begins with an impression, a concept in the mind of the artist or its designer. One could say that a tattoo is a psychological image reflecting the way the bearer sees himself (18). In a culture in which appearance is very important, skin as the largest human organ functions as the canvas on which we project our greatest fantasies and deepest fears (19).

## Types of tattoos

Tattoos can be divided into two groups. The first one comprises temporary tattoos, meaning those tattoos that last from several days to several weeks, while the second group comprises tattoos that decorate the human body forever, apart from *permanent make-up*, which is used for cosmetic purposes and lasts for a few years (20).

Hustić claims that in modern dermatology tattoos are divided further into those gained through accidental insertion of pigment into skin (e.g. by being pricked by a pen), amateur and professional tattoos which include the drawing of various images on the body, cosmetic for permanent substitution of make-up (e.g. eyeliner), and medical ones used by doctors to mark parts of the body, most commonly for the purposes of radiation therapy (21).

As Poon claims, the first tattoo was probably the result of a pigment that accidentally remained in the body due to an injury, which later inspired people to modify their own physical appearance. Poon's dissertation also mentions four basic methods of inserting pigment into the skin recorded in ethnographic works: cutting and smearing, sewing, tapping, and pricking (8).

Like every other branch of human activity, tattooing is also not free of production that hap-

olovkom), amaterske i profesionalne tetovaže pri kojima se iscrtavaju raznoliki motivi na tijelo, kozmetičke za trajni nadomjestak šminke (npr. olovke za oči) i medicinske kojima liječnici označavaju dijelove tijela najčešće kod radijacijskog liječenja (21).

Kako Poon navodi, prva tetovaža je vjerojatno produkt slučajnog zaostajanja pigmenta u tijelu prigodom ozljede što je kasnije potaklo ljude na modifikaciju vlastitog tjelesnog izgleda. U svojoj disertaciji Poon također spominje četiri osnovna načina umetanja pigmenta u kožu zabilježena u etnografskim radovima: rezanje s premazivanjem, prošivanje, tapkanje i ubadanje (8).

Kao i svaka druga grana ljudskog djelovanja, tako i tetoviranje nije lišeno produkcije koja se odvija samo radi produkcije, a ne stvaranja nečeg umjetnički vrijednog. Nažalost, kako su se mijenjali trendovi u tetoviranju, tako su se pojavile i određene tetovaže koje i sami umjetnici, odnosno tetovirači, smatraju nisko vrijednim stvaralaštвом, odnosno kićem (16).

Tetovaže bivaju promovirane od strane mode i medija i postaju sve popularnije, osobito među mladima. Broj mladih osoba s nekom od tjelesnih modifikacija se u zadnjih desetak godina ubrzano povećava.

## Tetovaže i psihopatologija

D'Ambrosio i sur. navode kako različite studije pokazuju povezanost između tjelesnih modifikacija i sklonosti k samoozljđivanju (16). Prema navodima D'Ambrosia i sur. u praksi je zamijećeno da većina pacijenata s tjelesnim modifikacijama nije generalno bila dobrog mentalnog zdravlja (16). Različite studije u zadnjih desetak godina pokazuju kako tetovaže mogu indicirati unutarnji nemir i biti pokazatelj psihopatološke bolesti, uključujući i sklonost već navedenom samoozljđivanju (16).

Braitwaite i sur. u svojoj studiji iznose kako su ispitani subjekti s tjelesnim modifikacijama

pens purely for the purposes of production and not for the creation of something of artistic value. Unfortunately, as tattooing trends have changed, we have also witnessed the appearance of certain tattoos which the artists or tattooists consider to be of low artistic value, or kitsch (16).

Tattoos are promoted by fashion and the media, and are becoming more popular, especially among young people. The number of young people with some form of body modification has risen rapidly in the last ten years.

## Tattooing and psychopathology

D'Ambrosio *et al.* claim that different studies have shown the interconnection between body modifications and the tendency to self-harm (16). According to D'Ambrosio *et al.*, in practice it has been noted that most patients with body modifications were, generally speaking, not of good mental health (16). In the last ten years, a variety of studies have shown that tattoos may be an indication of inner unrest and a psychopathologic illness, including the tendency to self-harm (16).

In their study, Braitwaite *et al.* claim that the questioned subjects with body modifications (including tattoos) were most commonly exposed to marijuana and alcohol abuse and overuse of antidepressants and sedatives, which they used as evidence of an association between tattoos/piercing and harmful behaviour (5). Statistical analysis (ANOVA) conducted by D'Ambrosio *et al.* clearly showed a significant connection between piercing and tattoos and psychopathologic problems (13).

Dissocial personality disorder, borderline personality disorder, and alcohol and drug abuse are the most common psychiatric disorders associated with tattoos (22). An American study has shown that people with tattoos entering the American army are more prone to consuming large quantities of alcohol and smoking cigarettes, but also to engaging in risky behaviour

(koje uključuju u tetovaže) bili najčešće izloženi zloporabi marihuane i alkohola te pretjerenoj upotrebi antidepresiva i sedativa, čime su pružili dokaz o povezanosti između tetovaža/*piercing-a* i štetnog ponašanja (5). Statistička analiza (ANOVA) koji su proveli D'Ambrosio i sur. jasno pokazuje značajnu povezanost *piercing-a* i tetovaža i psihopatoloških smetnji (13).

Disocijalni poremećaj ličnosti, granični poremećaj ličnosti te zloporaba alkohola i droga najčešći su psihijatrijski poremećaji koji se povezuju s tetovažama (22). Američko istraživanje pokazalo je da su osobe s tetovažama koje stupaju američkoj vojsci sklonije konzumaciji većih količina alkohola, pušenju cigareta, ali i rizičnom ponašanju kao što je vožnja s vozačem pod utjecajem alkohola (23). Povišena impulzivnost i rizično ponašanje nađeni su u vojnika s tetovažama i u toj skupini više je bolesnika dijagnosticirano s antisocijalnim poremećajem ličnosti u usporedbi s vojnicima bez tetovaža (24,25).

Bender i sur. pokazali su da je impulzivnost indirektno povezana sa suicidalnim ponašanjem te da je ova povezanost posredovana bolnim i provokativnim događajima koji također uključuju i tetoviranje. S druge strane, ima istraživača koji pokazuju da je tetovira-

like riding in a car driven by a person under the influence of alcohol (23). Increased impulsiveness and risky behaviour have been identified in soldiers with tattoos, and the same group contained more patients diagnosed with anti-social personality disorder than the group of soldiers without tattoos (24, 25).

Bender *et al.* have shown that impulsiveness is indirectly tied to suicidal behaviour and that this association is mediated through painful and provocative events that also include tattooing. On the other hand, there are researchers who have shown that tattooing is nowadays merely a fashion statement and not associated with a higher rate of risky behaviour and differences in personality (26-28). Based on their research, Zrno *et al.* have concluded that, despite being popular and no longer stigmatized, tattooing still carries some risky behaviour and potential behavioural risk factors (29).

Over the last ten years, various studies have shown that tattoos and piercing can be indicators of negative emotions and a potential psychopathologic indicator of illness, including self-harming types of behaviour (13). Results gained through analysing the risk of behaviour have shown that 99% of tattooed subjects abused alcohol, 92% often drove carelessly, 90% used



**FIGURE 4.**

nje u današnje vrijeme samo izraz mode i nije povezano s višom stopom rizičnog ponašanja i razlika u osobnosti (26-28). Zrno i sur. zaključuju da tetoviranje, prema rezultatima istraživanja, iako popularno i nije više stigmatizirajuće za osobe kao ranije, ipak nosi neka rizična ponašanja i moguće rizične čimbenike u ponašanju (29).

Različita istraživanja tijekom zadnjih deset godina rasvjetlila su da tetovaže i *piercing* mogu biti pokazatelji unutarnjeg lošeg osjećanja i mogu biti mogući psihopatološki pokazatelj bolesti uključujući samoozljedujuća ponašanja (13). Rezultati dobiveni analizom rizika ponašanja ispitanika pokazali su da je 99 % onih s tetovažama imalo zlorabu alkohola, 92 % često nemarno vozilo, 90 % je koristilo psihoaktivne tvari, 45 % je imalo seksualne interakcije različite od uobičajenog, dok je 35 % ispitanika imalo povremene izvještaje o rizičnom ponašanju; 25 % odnosno 26 % ispitanika preveniralo je cijeljenje svojih rana i zanemarivalo terapijske upute, dok je 33 % pokazalo samoozljedujuća ponašanja (13).

Swami ukazuje da, kada se mjeri kao pojedinačna psihološka razlika, a nasuprot aktualnom (ili samoprocijenjenom) ponašanju, nema značajne razlike u stavovima prema autoritetu kod tetoviranih i netetoviranih pojedinaca (30). Štoviše, Swami i sur. našli su da nije bilo značajnih razlika u pogledu tetoviranja s obzirom na spol, obrazovanje, maritalni status i nacionalnost (31). Najveća razlika između skupina tetoviranih i netetoviranih osoba bila je u pogledu impulzivnosti što ukazuje na tendenciju djelovanja trenutnim osjećanjem (32).

De Mello u svojoj knjizi „Bodies of Inscription“ navodi kako je tetovaža, kao umjetnički izraz identiteta, glavni razlog zašto se sve više pojedinaca u zadnjih nekoliko desetljeća odlučuje na ovakav oblik ukrašavanja tijela. Tetovaže se na prvi pogled mogu doimati površnim, čisto dekorativnim ukrašavanjem tijela, ali kada

psychoactive substances, 45% had out-of-the-ordinary sexual encounters, while 35% occasionally reported on risky behaviour; 25% prevented their wounds from healing, 26% neglected instructions regarding therapy, while 33% exhibited self-harming types of behaviour (13).

Swami points out that, when measured as individual psychological difference, and in contrast to current (or self-estimated) behaviour, there is no significant difference in attitudes toward authority in tattooed and non-tattooed individuals (30). Furthermore, Swami *et al.* found that there were no significant differences regarding tattoos when it comes to sex, education, marital status, or nationality (31). The most significant difference between groups of tattooed and non-tattooed subjects was regarding impulsiveness, which indicates a tendency to act according to current emotions (32).

In her book *Bodies of Inscription*, DeMello claims that tattoos are an artistic expression of identity, which is the main reason why increasing numbers of people over the past few decades have been choosing this type of body decoration. At

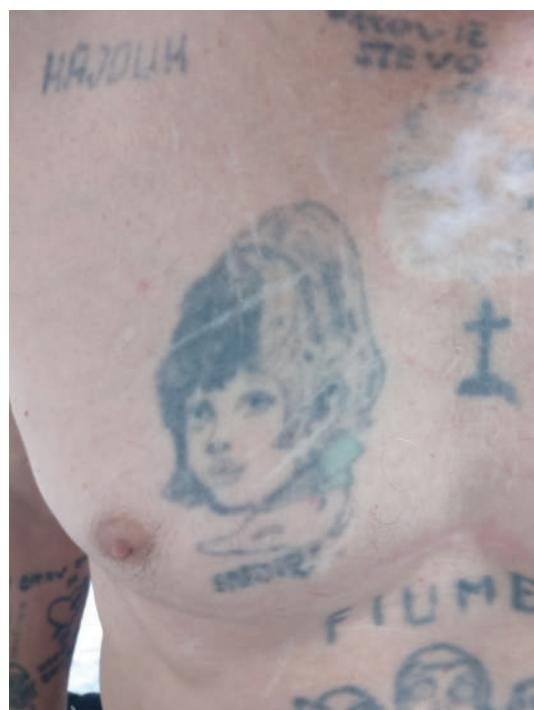


FIGURE 5.

pobliže razmotrimo svijet tetovaža, možemo zaključiti da su one više nego površna maska (10).

Ako je čovjek sam refleksija onoga što se događa oko njega, možemo reći da je njegova koža ogledalo u njegov unutarnji svijet. Tetovaže su način na koji drugima dopuštamo da vide što mislimo, osjećamo ili kako doživljavamo sami sebe. Može se reći da je koža tzv. prijenosnik svog iskustva koje je pojedinac doživio tijekom svojeg života (2).

## PRIKAZ BOLESNIKA S TETOVAŽAMA I NJEGOVA PRIČA

Pacijent XY primljen je 2. 7. 2017. godine na liječenje u Zavod za biologisku psihiatriju i psihogerijatriju Klinike za psihiatriju Vrapče. Na prijam je dovezen vozilom Hitne medicinske pomoći zbog suicidalnih promišljanja koja su oscilirala u intenzitetu i spram kojih je bolesnik bio kritičan. Uz primijenjenu psihofarmakoterapiju te suport u protektivnom bolničkom okruženju, pacijent je kritičniji prema događajima koji su prethodili hospitalizaciji, jasno otklanja suicidalne i heteroagresivne pulzije te ga se 5. 9. 2017. godina otpušta s bolničkog liječenja uz preporuke nastavka liječenja u ambulantnom tretmanu.

Bolesnik je dao pisano dopuštenje da se objavi ovaj prikaz s fotografijama.

Za vrijeme hospitalizacije u našoj ustanovi provedeno je psihološko testiranje pacijenta. Prema rezultatima procjene ličnosti MMPI-2 inventarom postigao je sljedeće: na svim ljestvicama kontrole urednih rezultata, izuzev rezultata na Fb ljestvici koji upućuje na dekoncentriranost u odgovaranju na pitanja u posljednjem dijelu ispitne knjižice. Stoga ćemo se ograničiti na interpretaciju temeljnih kliničkih ljestvica i restrukturiranih kliničkih ljestvica. Na temeljnim kliničkim ljestvicama intenziteti na većini ljestvica nalaze se u

first sight, tattoos may appear superficial, or pure decoration of the body, but when we take a closer look at the world of tattoos, we can conclude that they are more than a superficial mask (10).

If man is a reflection of what happens around him, then we can say that his skin is a mirror of his inner world. By using tattoos, we allow others an insight into our thoughts, feelings, or the way we perceive ourselves. It can be said that skin is, in a way, a transmitter of the entirety of experience gained over an individual's lifetime (2).

## CASE PRESENTATION OF A PATIENT WITH TATTOOS AND HIS STORY

On the 2<sup>nd</sup> of July 2017, patient XY was admitted to the Institute of Biological Psychiatry at the Vrapče Psychiatric Hospital. He was brought by ambulance due to suicidal thoughts which oscillated in intensity, but patient showed insight into his condition. With psychopharmacotherapy and support in a protective hospital environment, the patient became more critically aware of events prior to hospitalization, clearly rejected suicidal and hetero-aggressive compulsions, and on the 5<sup>th</sup> of September 2017 was released from hospital care with a recommendation to seek outpatient treatment.

The patient signed a permission to publish this case presentation with photographs.

During his stay in our hospital, a psychological test was carried out on the patient. According to the MMPI-2 personality assessment, the patient showed the following results: the results were normal on all control scales apart from the Fb scale results, which indicated a lack of concentration while answering the questions in the final part of the questionnaire. Therefore, we shall limit ourselves to the interpretation of basic clinical scales and restructured clinical scales. On most of the basic clinical scales, the intensities were within the normative boundaries. There

okvirima koje toleriraju norme. Aktualno se ističu, i to blago, ljestvica paranoidnosti (Pa) koja ukazuje situacijsku paranoidnost, osjećaj da ga drugi ne razumiju i s njim ne postupaju pošteno. Naglašena je i Sc ljestvica u blažim intenzitetima povišenja koji upućuju na neke shizoidne karakteristike ličnosti kao što su prisutnost neobičnih vjerovanja, mogućnost ekscentričnog ponašanja uz sklonost pretjeranom oslanjanju na maštu/imaginaciju. Sumnjičav je, može imati osjećaj da se s njim loše postupa, osjetljiv na potencijalnu kritiku od strane drugih, na koju može pretjerano reagirati. Sklon projekciji, generalno povišeno hostilan, može biti sarkastičan, iritabilan, općenito zazoran, emocionalno labilan. Bazično se radi o poremećaju ličnosti (dosta crta ličnosti u okviru Pd ljestvice). Društveno je hladnokrvan, osjeća se sigurno i lišeno anksioznosti u različitim socijalnim situacijama, ima izražene stavove o nizu društvenih situacija koje je spremam žestoko braniti. Opisuje svoju obitelj kao obitelj bez podrške i ljubavi. Osobe ovih kodova rezultata često u svojoj povijesti imaju poteškoće sa zakonom i zloporabu alkohola. Restrukturirane kliničke ljestvice aktualno upućuju na dominaciju Rc1 ljestvice koja opisuje prisutnost somatskih tegoba. Zaključno, procjena ličnosti upućuje na bazični poremećaj ličnosti, a sada prevaliraju blaža situacijska paranoidnost i višestruki somatski simptomi.

„Tetovaža je bila dosadna igra, ali ako si bio tetoviran, nešto si značio...“ – tim riječima šezdesetčetverogodišnji pacijent Klinike za psihijatriju Vrapče započinje svoju priču o tetovažama nastalim na Golom otoku. Tijekom dviju godina, koliko je boravio na Otoku, napravio je na svojem tijelu 128 tetovaža. Dok je odjeven, većina ih se ne vidi, ali odmah za oko zapadnu hrvatski grb i križ na vratu te tekst „AKO LAŽEM TU ME SJECI“ (sl. 1.). Sve tetovaže su mu nacrtali drugi kažnjenici, a crtanje su otopljenom gumom s potplata cipela.

was mild irregularity on the paranoia scale (Pa), which indicated situational paranoia, a feeling of being misunderstood and treated unfairly by others. There was an increase on the Sc scale as well, with mild intensities, which points to certain schizoid personality characteristics such as unusual beliefs and the possibility of eccentric behaviour with a tendency to excessively rely on imagination or fantasy. The patient was suspicious, sometimes felt that he was being treated badly, and was sensitive to potential criticism received from others to which he may react in an exaggerated way. He was prone to projection, generally highly hostile, could be sarcastic, irritable, generally wary, and emotionally unstable. Basically, this is a case of personality disorder (numerous personality traits are within the limits of the Pd scale). The patient was socially cold, felt secure and free of anxiety in a variety of social situations, had distinct attitudes on several social situations, which he is prepared to vigorously defend. He described his family as a family without support and love. People with such results have often had previous problems with law and alcohol abuse. Restructured clinical scales currently indicate a dominant Rc1 scale, which describes the presence of somatic difficulties. To conclude, the personality assessment indicated a basic personality disorder, with a currently prevailing mild situational paranoia and numerous somatic symptoms.

“Tattooing was just an boring game, but if you had a tattoo, you meant something...” – these are the words the sixty-four-year-old patient of the University Psychiatric Hospital Vrapče used to begin his story of tattoos created on Goli otok. Over two years, which is how long he spent on the island, he made 128 tattoos on his body. Most cannot be seen while dressed, but the ones immediately noticeable are the tattoos of a Croatian coat of arms and a cross on his neck, along with the inscription “IF I'M LYING, CUT ME HERE” (Fig. 1). All the tattoos were created by other inmates using melted rubber from the

Svaka tetovaža, na neki način, predstavlja crticu iz njegovog života. 21 tetovaža su imena drugih kažnjenika s kojima je u određenom razdoblju zajedno izdržavao kaznu. Kaže kako ne zna gdje su danas i jesu li uopće živi. Osim tri koje su na desnom bedru, sve ostale tetovaže se nalaze na gornjem dijelu tijela. S ponosom pokazuje veliku tetovažu preko trbuha za koju kaže da je grb Golog otoka te da je on jedini koji ima tu tetovažu. Napravljena je iz više dijelova, a sastoji se od tri „mrtvačke glave“, mača zabodenog u otvorenu knjigu u kojoj piše „Bio sam rob“, pera te natpisa „Goli otok“ (sl. 2.). Najdraža tetovaža mu je na desnoj šaci gdje je podvučena riječ „SMRT“, a ispod toga piše „VOLIM TE MAMA“ (sl. 3.). Ne sjeća se kako je nastala ni zašto je to napisao, ali ju svakodnevno gleda i za njega ima posebnu vrijednost. Tetovaže erotskog karaktera nisu bile osobito popularne, ali on ima dvije takve na ledima. Navodi da je to bila šala od strane drugog zatvorenika te da on nije znao što će mu nacrtati. Jedna tetovaža prikazuje muškarca koji gura kolica u kojima nosi svoje veliko spolovilo, a na drugoj su prikazane dvije gole žene u trenutku intimnosti (sl. 4.). Zatvorenici su si relativno često tetovirali lica dragih osoba i djevojaka. Jednu takvu tetovažu nam prikazuje i naš pacijent na desnoj strani svojih prsiju (sl. 5.). Kaže da je to lice njegove velike ljubavi iz mladosti te da je on nacrtao sliku po kojoj je nastala tetovaža. Navodi da je ta slika ubrzo postala popularna pa je kasnije veći broj kažnjenika imao jako sličnu tetovažu na svojem tijelu. Ni prije ni poslije boravka na Golom otoku nije napravio nijednu tetovažu. Na Otoku su mu one bile zaštita: „Ako si bio tetoviran, ljudi su ti se micali, drugi robičaši nisu ulazili u konflikt s tobom. Što si ih više imao, to bolje.“ Zbog brojnih tetovaža, kroz život je imao više problema nego koristi. Da može vratiti vrijeme u nazad, kaže, nikada se ne bi tetovirao, no tada nije razmišljao o posljedicama. Kasnije je primijetio da mu ljudi pristupaju s predra-

soles of shoes. In a way, each tattoo represents an event from his life. Twenty-one tattoos are names of other prisoners with whom he served time during a certain period. He claims he does not know where they are today or whether they are even alive. Apart from three on his right thigh, all other tattoos are on the upper part of his body. He shows a large tattoo on his stomach with pride, saying it is the emblem of Goli otok, and adding that he is the only one who has it. It is made of several parts, and consists of three death's heads, a sword impaled on an open book with the text "I was a slave", a feather, and an inscription saying "Goli otok" (Fig. 2). His favourite tattoo is on his right fist, and consists of the underlined word "DEATH", under which there is an inscription saying, "I LOVE YOU MOM" (Fig. 3). He does not remember how it was created or why he wrote that, but he looks at it every day and it carries a special value for him. Tattoos with erotic content were not especially popular, but he has two such tattoos on his back. He claims that it was a joke by another prisoner, and that he did not know what the prisoner was going to draw. One tattoo shows a man pushing a cart with his large penis, and the other shows two naked women in a moment of intimacy (Fig. 4). Prisoners would relatively often tattoo faces of their loved ones and their girlfriends. Our patient showed us one such tattoo on the right side of his chest (Fig. 5). He said it was the face of his great love from his youth and that he drew the picture that the tattoo is based on. He says that the picture soon became popular, so a great number of prisoners later had a very similar tattoo on their bodies. He did not make any tattoos before or after his stay on Goli otok. On the island, they served as his protection: "If you were tattooed, people stepped out of your way, other prisoners didn't get into fights with you. The more you had, the better." His numerous tattoos have caused him more harm than good in his life. If he could turn back time, he says, he would never get a tattoo, but back then he did not think of the consequences. Later he noticed that people

sudama, samo na temelju njegovog izgleda. Često je imao i neugodnosti s policijom, ali i s mladićima koji su se htjeli dokazivati izazivajući ga. Tek kada bi ga malo bolje upoznali, osjećao je da ga gledaju kao osobu, a ne samo kao tetoviranog čovjeka.

were prejudiced against him merely based on his appearance. He often had problems with the police, and with young men who wanted to prove themselves by teasing him. Once they got to know him better, he felt they perceived him as a person, and not just as a tattooed man.

## ZAKLJUČAK

U ovom radu opisan je bolesnik s brojnim tetovažama po tijelu te je opisano njihovo značenje kroz bolesnikov život i zatvoreničke dane na Golom otoku. Možemo reći da su tetovaže način na koji neke osobe drugima dopuštaju da vide što oni misle, osjećaju ili kako doživljavaju sami sebe (2). Naš bolesnik je rekao: „Tetovaža je bila dosadna igra, ali ako si bio tetoviran, nešto si značio...“ – i time najbolje objasnio značenje tetovaža u njegovom životu.

Zaključno možemo reći da kulturu tetoviranja pronalazimo na svim stranama svijeta u različitim razdobljima ljudskog bivanja. Ovakvi trajni tragovi, ponekad jednostavnii, a ponekad složeni od više dijelova s jakom pozadinskom pričom, služili su kroz povijest kao statusni simboli, srećnošće, prikazi ljubavi, simboli vjeronaučanja, pa čak i oblici kazne (2). Ako je čovjek sam refleksija onoga što se događa oko njega, možemo reći da je njegova koža ogledalo u njegov unutarnji svijet, što je potvrdio i bolesnik opisan u ovom radu.

## CONCLUSION

This study describes a patient with numerous tattoos on his body and their significance throughout the patient's life and days of imprisonment spent on Goli otok. We can say that for some people tattoos serve as a way of allowing others to see what they think, feel, or how they perceive themselves (2). Our patient said: "Tattooing was just an boring game, but if you had tattoos, you meant something..." – and thus gave the best explanation of the importance of tattoos for his life.

To conclude, we can say that the culture of tattoos can be found in all corners of the world in a variety of periods during human history. Such permanent markings, sometimes simple, and sometimes composed of several parts with a strong background story, have served throughout history as status symbols, good luck charms, depictions of love, symbols of beliefs, and even forms of punishment (2). If man reflects what takes place around him, then we can say that his skin is a mirror of his inner world, which was confirmed by the patient described in this study.

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Zahvaljujemo našem bolesniku što se spremno odazvao pozivu da ispriča svoju priču o nastanku njegovih tetovaža i dopustio da isto objavimo.

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