

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 intervjui sa šest odraslih osoba s tjelesnim invaliditetom. Transkribirani intervjui 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.

/ 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 prepoznaje 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-

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 pojedinačnim 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 razumijevanje 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, ekonomske 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, stigmatu, 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 izvijestili 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).

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, primjereno 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).

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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 intervjuva 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 intervjuva 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 stanja¹. 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 intervjuja je druga autorica rada. Intervjui su provedeni u vrijeme i na mjestu pogodnom za sudionike. Svi intervjui 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 intervjuja razvijenog za potrebe ovog istraživanja. Ovaj je protokol omogućio fleksibilnu strukturu koja je uključivala smjernice za otvaranje intervjuja, opće teme istraživanja (značenje stresa, upravljanje stresom, izvori stresa) te okvirne pod teme koje su poslužile kao potencijalna pitanja za poticanje sudionika na proširenje odgovora, kao i smjernice za zaključivanje intervjuja. Otvorena struktura intervjuja planirano je omogućila istraživanje tema od važnosti i interesa samih sudionika te osiguravanje točne zastupljenosti perspektiva sudionika. Protokol intervjuja nalazi se u Prilogu 1 u kojem su predočene faze intervjuja, osnovna pitanja i pitanja za poticanje i proširenje teme razgovora. Tijekom polustrukturiranih intervjuja, intervjuer je slijedio opću strukturu protokola i primijenio primarna pitanja kako bi pokrenuo raspravu oko središnjih tema. Po-

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

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 condition¹. 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.

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

¹ 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 intervjua. 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</i> <i>Use of audio recording (consent)</i>	Thank you for agreeing to participate in our research and talk about this theme with me. Our discussion should take about half an hour. 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? 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.
Introductory questions: Engage participants in the topic	Tell me about yourself.	Probe questions: living circumstances, participation in work/study, family...
	What do you think of when you hear the word 'stress'?	
	Is stress always negative? Can it be positive?	
Transition questions: Personal discussion about stress	How would you describe your experience with stress?	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?
	How do you manage/deal with stress?	Can stress be avoided? Do you use any coping strategies for managing stress? What are they? Are they effective?
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...	What causes you stress? (What are the things that make you stressed?)	
	<i>Probing questions for individual factors (disability, health, relationships...)</i>	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?
	<i>Probing questions for systemic/environmental factors (physical accessibility, employment/education access, attitudes (stigma/discrimination), institutional systems)</i>	What factors from the context (community, city, society) in which you live do you think contribute to stress?
	Note: 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>	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!

Analiza podataka

Analiza podataka dobivenih intervjuima provedena je pomoću stalnog komparativnog pristupa pri čemu se provodi otvoreni proces ispitivanja, 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 podacima (pojedinačne, identificirajuće jedinice informacija koje se pojavljuju unutar transkripata 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 intervjua), 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 pojava 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 podacima ili je izvedena izravno iz perspektive sudionika. Kao takvo, novo razumijevanje proizašlo iz analize podataka ovog istraživanja, iako se temelji na konceptijskom okviru koji vodi istraživanje, istodobno je točan prikaz perspektiva sudionika i stoga nudi jedinstvenu perspektivu iz koje se dalje istražuje tema.

Svi intervjui 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 druga autorica. Obje autorice su zbog intenzivne interakcije s podacima zadovoljile kriterij teorijske osjetljivosti (engl. *theoretical sensitivity*) (33). Sudionici 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 intervjua 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 emocionalnu 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 intervjua 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 izvijestili da je za njih stres uglavnom

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

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', 'uzrujanost', '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 uzrokovan 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 nekakvom 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 milijunti 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 isplani-
rao: 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 izvijestili 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

participants. 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 samoupravljujućih 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 pokušavala 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 trenucima zna stopirat' onako kao da, znam što hoću, al' ostanem zabetonirana na jednoj točki. 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 vještinu za upravljanje neizbježnim 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 izvijestili kako su različiti izvori socijalne podrške, uključujući roditelje, braću i sestre, partnere, 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 izvijestili 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

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 njezina 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 detaljnije 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 funkcionirati cjelodnevno. 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 ću zapravo doć' 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 doživljam 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 prethodno 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 štace, 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:

...prođu tri stara (nepristupačna, op.a.) tramvaja, mogu otić' tražit' neku drugu liniju i ne čekat' da dođe četvrti stari tramvaj. 1.33.1

Za sudionike pitanje nepristupačnosti nije samo pitanje nemogućnosti fizičkog pristupanja 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 ruko-hvat. Onda se naživciram žešće... jer ako ima nešto gore, na primjer, nešto fenomenalno se dešava što me zanima, a ne mogu pristupit tome. 2.20.1

Ne možeš na WC, u pola prostora ne možeš ući, pola restorana, pola kafića, pola butika...kaj ću 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 staviti 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 iskustvo 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 poglavarstvo... Ne jednom smo došli, pa nije radio lift... A idemo kod ljudi koji surađuju s udrugama 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 izvijestila da su joj, unatoč postignutoj razini obrazovanja, mogućnosti za smislenu zaposlenje bile slabije samo zato što je riječ o osobi 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 mjesečno, 40-50,000 kuna nego da zaposliš 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

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 dođete 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 šanse da će mene ikad pozvat na kavu. Kao i svaki normalan čovjek zaslužujem da se i mene pozove. 2.20.1

Za sve su sudionike eksplicitni 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 isključenošću 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 financijskoj 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 iznenađuje 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 woman 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)življenog 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 smatrale izravnim posljedicama 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 uznemirujuće, 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 međuovisnost. 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 razumjele 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

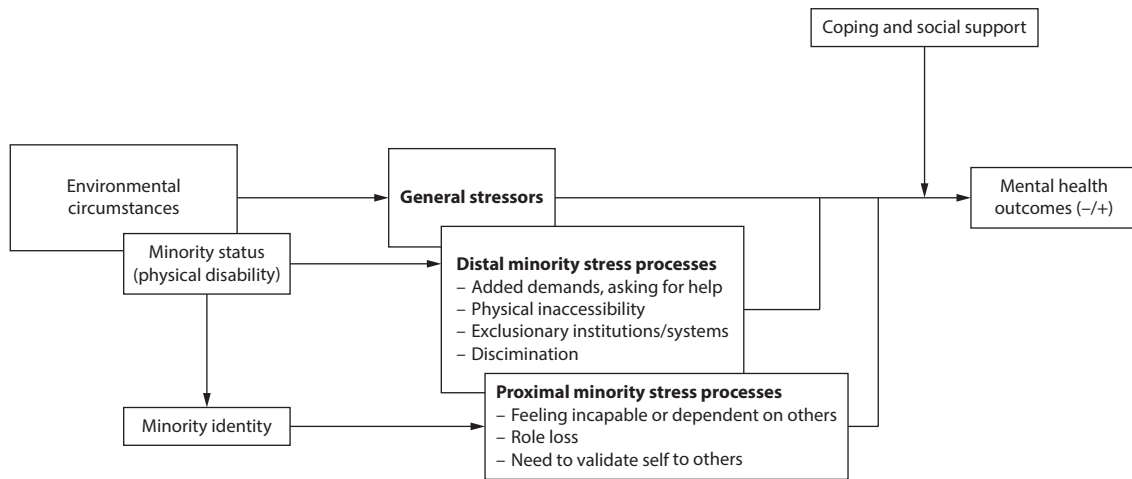


FIGURE 1. Working model of the stress experience among persons with disabilities, based on Meyer's minority stress model

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.

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

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.

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 raznolikijim 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 doprinose 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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