

# Opterećenje njegovatelja osoba oboljelih od Alzheimerove bolesti

## */ Difficulties of Caregivers of Individuals Suffering from Alzheimer's Disease*

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U današnjem društvu postoji jasan trend porasta broja osoba starije životne dobi pa time i sve veća statistička značajnost broja osoba oboljelih od Alzheimerove bolesti što generira povećanu potrebu adekvatne skrbi za oboljele. Uz formalne oblike skrbi (pružene od profesionalaca iz sustava zdravstvene i socijalne skrbi), neformalna njega značajan je resurs u pružanju skrbi osobama s demencijom. Neformalni njegovatelji su pojedinci koji se dobrovoljno brinu za člana obitelji ili prijatelja koji se suočava sa bolešću, invaliditetom ili bilo kojim drugim stanjem koje zahtijeva posebnu pažnju. S obzirom na tijek i duljinu trajanja Alzheimerove bolesti i sama skrb za oboljelog je dugotrajna i iscrpljuća, a uključuje sve razine funkcioniranja njegovatelja pa ju je potrebno sagledavati u kontekstu kako ekonomskog, tako i emocionalnog, mentalnog i fizičkog stanja njegovatelja. Iako može imati i neke blagotvorne aspekte, skrb za oboljeloga je obično vrlo stresna i može u značajnoj mjesti utjecati na zdravlje i dobrobit njegovatelja te je stoga potrebno razmotriti probleme i opterećenja s kojima se susreću njegovatelji osoba oboljelih od Alzheimerove bolesti.

*/ In modern society, the number of elderly individuals is higher and so is the statistical significance of people living with Alzheimer's disease. This trend results in a higher demand for adequate care for such patients. Along with formal care (provided by social workers and other health care professionals), informal care has become a significant resource in the nursing of individuals with dementia. Informal caregivers are individuals who voluntarily attend to the needs of a family member or a friend living with illness, handicap, or any other condition that requires special needs. Considering the course and duration of Alzheimer's disease, the nursing of patients can also be lengthy and exhausting. Moreover, all aspects of a caregiver's job must be taken into consideration starting the mental, emotional, and physical health to nursing expenses. Although there are positive aspects, nursing an individual with dementia is extremely stressful and significantly affect the health and wellbeing of the caregiver, and therefore it is necessary to take into consideration all difficulties and problems caregivers of people living with Alzheimer's disease may encounter.*

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### **KLJUČNE RIJEČI / KEY WORDS:**

Alzheimerova bolest / *Alzheimer's Disease*  
Njegovatelj / *Caregiver*  
Opterećenje / *Burden*

### **TO LINK TO THIS ARTICLE:**

Alzheimerova bolest (AB) je neurodegenerativna, progresivna i neizlječiva bolest heterogene etiologije koju klinički prominentno obilježava deterioracija kognitivno-mnestičkih funkcija, a potom i gubitak sposobnosti izvođenja svakodnevnih aktivnosti te ovisnost o tuđoj njezi i pomoći. Sindrom demencije ima visoku godišnju incidenciju u Europi te se procjenjuje da premašuje incidenciju moždanog udara, dijabetesa i raka dojke (1). Svake godine se bilježi 7,7 milijuna novih slučajeva demencije u svijetu ili slikovito – jedan novi slučaj svake četiri sekunde (1). Epidemiološkim studijama je pokazano da svjetska prevalencija demencije iznosi oko 6,1 % u populaciji starijoj od 65 godina (0,5 % svjetske populacije) od čega je 59 % žena (2). Prema Europskoj federaciji neuroloških društava, demencija zahvaća 5,4 % osoba starijih od 65 godina te njena prevalencija raste s povećanjem dobi (2). AB je sveukupno najčešći (60-70 %) oblik demencije, a nakon dobi od 65 godina AB je uzrokom demencije u više od 80 % dementnih bolesnika. Smatra se da od demencije boluje više od 85 000 osoba (3). Također, smatra se da na području glavnog grada Hrvatske, Zagreba, ima više od 15 000 osoba oboljelih od demencije (3). Neurodegenerativne bolesti koje dovode do demencije po zdravstvenim (morbiditet i mortalitet su im odmah iza kardiovaskularnih i malignih tumorskih bolesti), socijalnim (onemogućavaju kvalitetan život oboljele osobe u zajednici) i ekonomskim pokazateljima (troškovi uzdržavanja i liječenja oboljelih od AB u zapadnom će svijetu uskoro biti jednaki kao zajednički troškovi za kardiovaskularne bolesti, rak i moždani udar zajedno) imaju danas ogromno značenje. Zbog porasta udjela starije populacije u budućnosti se očekuje daljnje povećanje broja oboljelih (4,5).

Uz formalnu skrb za pacijenta neformalna njega značajan je resurs u pružanju skrbi osobama s demencijom (4-6). Neformalni njegovatelji

Alzheimer's disease (AD) is a neurodegenerative, progressive, and incurable disease of heterogeneous etiology, clinically prominently characterized by a deterioration of cognitive-mnesic functions, and later by the loss of ability to carry out daily activities and by being dependent on other people's nursing and help. Dementia is a syndrome with a high yearly incidence in Europe, and it has been estimated that it is even higher than stroke, diabetes, and breast cancer (1). Every year around 7.7 million new cases of dementia are recorded worldwide, which means one new case every four seconds, on average (1).

Epidemiological studies have found that the prevalence of dementia is 6.1% in the average population above 65 years of age (0.5% of the world population), 59% of whom are women (2). According to the European Federation of Neurological Societies, dementia affects 5.4% of the population of 65 years of age and its prevalence grows along with age (2). AD is overall the most frequent form of dementia (60–70%), whereas in the population of above 65 years of age AD is regarded as the cause of dementia in 80% of cases. It has been recorded that over 85.000 people suffer from dementia (3). Also, in the area of Zagreb, the capital city of Croatia, there are 15.000 people suffering from dementia (3). Neurodegenerative diseases that lead to dementia according to health (moridity and mortality are immediately behind cardiovascular and malignant tumours), social (they prevent quality lifestyle of patients within their community), and economic parameters (support and medical expenses for AD patients in the western world will soon be equal to expenses of cardiovascular diseases, cancer, and stroke together) all have an enormous significance. Due to the growing percentage of the older population, we can expect an even higher number of patients in the future (4,5).

Along with formal care, informal care has become a significant resource in the nursing of

su pojedinci koji se dobrovoljno brinu za člana obitelji ili prijatelja koji se suočava s bolešću, invaliditetom ili bilo kojim drugim stanjem koje zahtijeva posebnu pažnju (7). Osobe oboljele od Alzheimerove bolesti tijekom same bolesti postaju u sve većem opsegu ovisne o okolini u svim aspektima života tako da neformalni njevogatelj zauzima ključnu ulogu u brizi za oboljelog. Samim tim se povećava mogućnost ekonomskog, emocionalnog, mentalnog i fizičkog opterećenja njevogatelja što generalno ostaje neprepoznato od strane države, tj. sustava socijalne i zdravstvene skrbi.

## EKONOMSKA OPTEREĆENJA NJEVOGATELJA

Istraživanje koje su objavili Bakker i sur. 2013. ukazuje da je omjer neformalne i formalne zdravstvene skrbi za osobe s demencijom 3:1 (8), dok prema Gustavssonu i sur. troškovi neformalne njege čine 82 – 86 % ukupnih troškova njege za osobe s demencijom (9,10). Prema Gustavssonu i sur. godišnji trošak njege po pacijentu je 7820 eura, od čega 54 % čine troškovi neformalne njege (9,10). U troškove neformalne skrbi spadaju lijekovi (porazna je činjenica da u Republici Hrvatskoj ne postoji nijedan antidementiv na osnovnoj listi lijekova Hrvatskog zavoda za zdravstveno osiguranje), pomoćna sredstva za njegu oboljeloga (npr. pelene za odrasle, specijalizirani medicinski kreveti i dekubitalni madraci, druga medicinska pomagala i sl.), dodatne prehrambene potrebe oboljeloga, prijevoz (mimo onog plaćenog preko osiguranja), izvaninstitucijska stručna pomoć medicinskog osoblja u kući (mreža patronažne skrbi u nekim slučajevima nije dostatna), održavanje kućanstva, ali i njevogateljevi izostanci s radnog mjesta, smanjena učinkovitost na radnom mjestu pa i potpuno napuštanje radnog mjesta (davanje otkaza) zbog skrbi za oboljeloga. S obzirom na starenje stanovništva, ali i aktualne sociološke

individuals suffering from dementia (4-6). Informal caregivers are individuals who voluntarily attend to the needs of a family member or a friend suffering from an illness, handicap, or any other condition that requires special needs (7). Throughout the duration of their illness, persons affected by Alzheimer's disease become more and more heavily reliant on their environment in all aspects of their life. Therefore, informal caregivers assume a fundamental role in the nursing of patients. Consequently, there is an increase in the risk of economic, emotional, mental, and physical distress for caregivers, who generally remain unrecognized by authorities such as social security and health service.

## CAREGIVERS' ECONOMIC DIFFICULTIES

According to a paper by Bakker et al. from 2013, there is a 3 to 1 ratio between informal and formal nursing of persons suffering from dementia (8). Moreover, Gustavsson et al. found that the costs of informal nursing of patients with dementia amount up to 82–86% of the overall nursing expenses (9,10). According to Gustavsson et al., yearly nursing expenses per patient amount up to 7.820 EUR, 54% of which are informal nursing expenses (9,10). Informal nursing costs include medications (it is a frustrating that there are no antidementives on the basic medication list issued by the Croatian Health Insurance Fund), medical and general equipment (adult diapers, specially designed medical beds and anti-decubitus mattresses, or other essential equipment), additional nutritional needs of patients, transportation (other than what is covered by insurance), professional medical help at home (the patronage network is in some cases insufficient), household maintenance; but also it is important to take into account the caregivers' frequent absences from work, reduction of efficiency at work or even job loss or quitting in order to be at the patient's disposal at all

trendove (izostanak klasičnog obiteljskog nukleusa, poglavito u urbanim područjima), broj kreveta u državnim/gradskim domovima za starije i nemoćne je daleko ispod potreba stanovništva te se pribjegava smještaju oboljeloga u privatne domove (pogotovo u terminalnoj fazi bolesti) što je također značajno financijsko opterećenje.

## EMOCIONALNO I MENTALNO OPTEREĆENJE NJEGOVATELJA

Briga za osobe oboljele od Alzheimerove bolesti je dugotrajna i emocionalno vrlo iscrpljujuća tako da i sami negovatelji osjećaju patnju prolazeći kroz sve zahtjeve koji su stavljeni pred njih kao i sam proces bolesti koja je još uvijek neizlječiva i završava smrtnim ishodom. U usporedbi s negovateljima bolesnika koji boluju od drugih kroničnih bolesti, negovatelji bolesnika s demencijom češće se suočavaju s depresijom, doživljavaju veće opterećenje i pokazalo se da su lošijeg općeg zdravstvenog stanja (11,12). Negovatelji su često osjećaju nepripremljenima uz neadekvatna znanja i vještine za pružanje skrbi za oboljeloga. Kao rezultat i akutnog (poglavito u bihevioralnoj simptomatiki AB kao što je agresivno ponašanje, lutanje i sl.) i kroničnog stresa zbog nepredvidive prirode simptoma AB te sve većih zahtjeva vezanih uz njegu oboljeloga, negovatelji mogu doživjeti ozbiljne negativne psihološke posljedice (poput depresije, anksioznosti, nesanice) te često izražavaju osjećaje ljutnje, iscrpljenosti, socijalne izolacije/usamljenosti, krivnje ili nemoći.

Postoje brojni mjerni instrumenti kako bi se objektivizirala problematika s kojom se susreću negovatelji. Valjalo bi istaknuti Zarit upitnik (*Zarit Burden Interview*, ZBI), samocjensku ljestvicu procjene opterećenja negovatelja osoba oboljelih od Alzheimerove bolesti koja je jedna od najčešće korištenih i u kliničkoj praksi i u istraživanjima te se sma-

times. Having in mind the rapid ageing of the population, as well as current social trends (the disappearance of nuclear families, especially in urban areas), the number of beds in public facilities for the elderly is far below the required number, which is why many are forced to seek help in private institutions (especially at the terminal phase of the disease), which also significantly leads to financial difficulties.

## EMOTIONAL AND MENTAL DISTRESS

Providing care to patients suffering from Alzheimer's disease is a lengthy and emotionally extremely exhausting experience. Apart from the patients, the caregivers themselves also go through suffering while meeting the demands and challenges their work requires, especially considering the nature of the disease which is incurable and ends in death. Compared to caregivers of other chronic patients, caregivers of patients with dementia more frequently suffer from depression, experience higher strain, and generally suffer from worse medical conditions (11,12). Caregivers often feel inadequate and believe they have insufficient knowledge and skills to provide the patients with the best possible care. As a result of both acute (especially in the case of behavioural symptoms of AD such as aggressive and wandering behaviour, etc.) and chronic distress caused by the unpredictable nature of AD symptoms, along with growing demands in the nursing of the sick, caregivers may experience significantly negative mental consequences (such as depression, anxiety, and insomnia) and often display feelings of anger, exhaustion, social isolation, loneliness, guilt, and powerlessness.

There are many measurement instruments for the objectification of problems caregivers face. It is important to mention the Zarit Burden Interview, ZBI – a self-evaluation scale that estimates the difficulties caregivers of AD patients encounter. ZBI is one of the most widely



tra da daje integrirane rezultate kod mjerenja subjektivnog opterećenja skrbi. U upitniku su opisane tri dimenzije opterećenja: utjecaj na društveni i osobni život njegovatelja, psihološko opterećenje te osjećaj krivnje. Neka istraživanja su pokazala da supružnici i djeca osoba oboljelih od Alzheimerove bolesti drugačije percipiraju opterećenje – dok supružnici naglašavaju deterioraciju njihovog osobnog i društvenog života, djeca, koja su načelno manje involvirana u svakodnevnu njegu, više su sklonija izražavati osjećaj krivnje da ne čine dovoljno za pacijenta (13). Također je dokazano da ne postoji značajna razlika u opterećenju njegovatelja u odnosu na dob, spol, uvjete života, bračni status ili status zaposlenja te da postoji snažnija povezanost između depresivnih simptoma kod njegovatelja i bihevioralnih problema pacijenta u odnosu na kognitivni i funkcionalni status pacijenta (14). Treba naglasiti da su Adelman i sur. u preglednom članku iz 2014. ukazali da čimbenici rizika za opterećenje njegovatelja uključuju ženski spol, nisko obrazovanje, življenje s oboljelim, veći broj sati provedenih u skrbi, depresiju, socijalnu izolaciju, financijski stres i nedostatak izbora da se bude njegovatelj (15) što upućuje na potrebu daljnjih istraživanja i klarifikacije ove problematike.

## FIZIČKO OPTEREĆENJE NJEGOVATELJA

Oboljeli od AB tijekom trajanja bolesti i po samoj njenoj prirodi (uzimajući u obzir i učestale somatske komorbiditete) postaju sve više fizički nemoćni i ovisni o okolini što dovodi i do većih fizičkih zahtjeva za njegovatelje. U usporedbi s drugim njegovateljima, supružnici oboljelih provode najviše vremena pružajući skrb (16) te mogu doživljavati značajno veće opterećenje ne samo zbog sve većih zahtjeva oko njege kako bolest napreduje (npr. podizanje oboljeloga ili pomoć u osnovnim potrebama),

used parameter in clinical practice and research and is considered to provide integrated results in measuring subjective difficulties in caregiving. The questionnaire describes three burden dimensions: impact of social and personal life, psychological burden, and the caregiver's feelings of guilt. Some studies have shown that spouses and children of AD patients experience their burden in different ways – while spouses stress the deterioration of their personal and social lives, children, who are generally less involved in daily caregiving, are more inclined to express feelings of guilt for not doing enough for the patient (13). Moreover, it has been proven that there are no significant differences in caregiver burden with respect to their age, gender, life conditions, marital status, or employment, and that there is a stronger correlation between the caregiver's symptoms of depression and the patient's behavioural problems in relation to the cognitive and functional state of the patient (14). It is important to mention that in a review article from 2014 Adelman et al. pointed out that risk factors for caregiver burden are female gender, lower education, living with the patient, long hours spent nursing them, depression, social isolation, financial distress, and being compelled to assume the role of the caregiver (15), which clearly shows the need for further research and clarification of the issue.

## PHYSICAL DIFFICULTIES

During the time of their sickness and due to the nature of the disease (taking into account frequent somatic comorbidities), AD patients become more and more physically impaired and reliant on their environment, which causes growing physical strain for the caregivers. In comparison to other caregivers, spouses of AD patients are those who spend most of the time nursing (16) and more frequently experience significant strain, not only due to greater demands in nursing as the disease progresses (for instance, physically having

nego i zbog njihovih zdravstvenih tegoba povezanih sa starenjem. Nekoliko istraživanja je pokazalo da polovica njegovatelja pati od barem jednog kroničnog zdravstvenog stanja (17,18). Recentna demografska istraživanja pokazuju da je među onima koji se brinu za osobe starije od 65 godina prosječna dob 63 godine, a trećina tih njegovatelja je u lošem zdravstvenom stanju (19). Kod njegovatelja su zabilježeni pogoršanje tjelesnog zdravlja (pogotovo kako bolest pacijenta kojeg njeguju progredira) i prerana smrt pa tako stariji supružnici koji se susreću s vrlo stresogenim zahtjevima za oboljeloga imaju 63 % veću stopu smrtnosti nego njihovi vršnjaci koji nisu njegovatelji (20). Pogoršanje tjelesnog zdravlja njegovatelja je posebno povezano s njegovateljima koji sebe percipiraju opterećenima (20). Isto tako, pojačano opterećenje njegovatelja je povezano s njegovim lošim zdravstvenim stanjem, rizičnim zdravstvenim ponašanjem (poput pušenja) i većom uporabom lijekova na recept (21). Različita istraživanja su pokazala da kod njegovatelja postoji veći rizik od poremećaja spavanja, slabijeg funkcioniranja imunološkog sustava, promijenjenog odgovora na cjepiva protiv gripe, sporijeg zacjeljivanja rana, povišene razine inzulina i krvnog tlaka, izmijenjenog profila lipida te kardiovaskularnih bolesti (22).

## ZAKLJUČAK

Alzheimerova bolest po svom tijeku, trajanju i ishodu zahtijeva skrb cjelokupne zajednice, ne samo pojedinca i njegove najbliže okoline. Poznato je da briga o pacijentu s demencijom može negativno utjecati na psihičko, fizičko, socijalno i financijsko zdravlje (11). Društvo bi (sustavom socijalne skrbi i zdravstvene zaštite) trebalo jasno definirati i naglasiti potrebe njegovatelja osoba oboljelih od Alzheimerove bolesti te preuzeti aktivnu ulogu u pomoći oboljelima i njegovateljima uz sredstva kojima

to move the patient or help them in basic activities), but also due to their health problems related to ageing. Several studies have shown that half of the caregivers suffer from at least one chronic health condition (17,18). Recent demographic studies have shown that among those who provide nursing to persons over 65 are on average 63 years old, whereas a third of them suffer from some sort of health condition (19). It has been found that caregivers suffer from a deterioration of health (especially when the patient's disease progresses) and premature death. Elderly spouses who are confronted with extremely stressful demands in the nursing process have a 63% higher chance of premature death than their peers who are not caregivers (20). A deterioration of physical health in caregivers is particularly relevant in the case of caregivers who consider themselves burdened (20). Likewise, increased caregiver burden correlates with deterioration of health, high-risk health behaviours (such as smoking) and higher intake rate of prescribed medications (21). Several studies have shown that caregivers are at risk of sleeping disorders, weaker functioning of the immune system, alterations in the response to influenza vaccination, slower wound healing process, elevated insulin levels and blood pressure, altered lipids profile, and cardiovascular diseases (22).

## CONCLUSION

Alzheimer's disease, its course, duration, and outcome require an engagement of the entire community, and not only of individuals and a closer circle of people. It is known that the nursing of patients with dementia will most likely affect the mental, physical, social, and financial health of caregivers (11). Society (through health care and social security) should clearly define and stress the need for caregivers for people affected by Alzheimer's disease and assume an active role in helping patients and caregivers likewise through resources that can provide them with adequate

se može pružiti potrebna podrška. Ključan je dugoročni partnerski odnos pojedinca/njegovatelja i zajednice kako bi se prevenirali i reducirali multifaktorski štetni učinci na kvalitetu života i zdravlja koju treba sagledavati iz svih perspektiva. Važno je istaknuti i ulogu stručnih društava i građanskih udruga kao i ulogu osvještavanja javnosti o opisanim problemima i poteškoćama.

support. A long-term partnership between individuals/caregivers and the community is crucial in order to prevent and reduce multi-factor damaging effect on the quality of living and health, which should be examined from all perspectives. It is important to point out the role of professional associations and civil organizations, as well as the need to inform the public of the problems and difficulties described in this paper.

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