Alzheimerova bolest – utjecaj na život i psihičko zdravlje njegovateljica

/ *Alzheimer's Disease – Influence on Female Caregivers' Living and Mental Health*

Suzana Uzun[1,2], Ninoslav Mimica[1,3], Oliver Kozumplik[1,2], Marija Kušan Jukić[4], Ivana Todorić Laidlaw[1], Dubravka Kalinić[3], Nela Pivac[5], Trpimir Glavina[6,7], Ivan Požgain[2,8]

[1]Klinika za psihijatriju Vrapče, Zagreb, Hrvatska, [2]Sveučilište Josipa Jurja Strossmayera u Osijeku, Medicinski fakultet Osijek, Osijek, [3]Medicinski fakultet Sveučilišta u Zagrebu, Zagreb, [4]Centar za mentalno zdravlje i prevenciju ovisnosti Nastavnog zavoda za javno zdravstvo «Dr. Andrija Štampar», Zagreb, [5]Institut Ruđer Bošković, Zagreb, [6]Klinika za psihijatriju, Klinički bolnički centar Split, Split, Hrvatska, [7]Medicinski fakultet Sveučilišta u Splitu, Split, Hrvatska, [8]Klinika za psihijatriju, Klinički bolnički centar Osijek, Osijek, Hrvatska

[1]University Psychiatric Hospital Vrapče, Zagreb, Croatia, [2]Josip Juraj StrossmayerUniversity of Osijek, Faculty of Medicine in Osijek, Osijek, [3]University of Zagreb, School of Medicine, Zagreb, Croatia, [4]Andrija Štampar Teaching Institute of Public Health, Zagreb, Croatia, [5]Ruđer Bošković Institute, Zagreb, Croatia, [6]Clinic for Psychiatry, Clinical Hospital Center Split, Split, Croatia, [7]University of Split, School of Medicine, Split, Croatia, [8]Clinic for Psychiatry, Clinical Hospital Center Osijek, Osijek, Croatia

Demencija je javnozdravstveni problem koji će postati sve vidljiviji kako stanovništvo stari. Danas u svijetu živi 50 milijuna ljudi oboljelih od demencije, a procjenjuje se da će do 2030. broj oboljelih narasti na 65,7 milijuna, odnosno na 115,4 milijuna oboljelih do 2050. godine. Danas kada demenciju nastojimo dijagnosticirati što ranije, bitno je oboljelima i njihovim obiteljima ponuditi kontinuirani i što kvalitetniji program liječenja i skrbi. U ovom radu željeli smo pokazati koji su glavni problemi vezani uz Alzheimerovu bolest i druge demencije u suvremenom svijetu, a bitno utječu na život žena njegovatelja. Opisan je utjecaj na žene koje skrbe za ljude s demencijom u ulozi profesionalnog njegovatelja i na žene koje preuzimaju ulogu neformalnog njegovatelja osobe oboljele od demencije. Rano prepoznavanje emocionalnog stresa kod njegovatelja nužno je kako bi se uspjelo preventivno djelovati (savjetovanje, suportivna psihoterapija, kognitivno-bihevioralni tretman), te spriječiti razvoj ili pogoršanje već postojećih tjelesnih bolesti (npr. kardiovaskularnih), odnosno mentalnih poremećaja od kojih su, osim nesanice, najčešći anksioznost i depresivnost.

/ Dementia is a public health problem that will become more obvious as the population grows older. There are 50 million people with dementia in the world, and it is estimated that the number of people with dementia will rise to 65.7 million by 2030, and 115.4 million by 2050. At present, we are trying to diagnose dementia as early as possible, and it is important to offer patients and their families a continuous and high-quality program of treatment and care. In this article, we wanted to show the main problems connected with Alzheimer's disease and other dementias in the modern world which influence the lives of female caregivers. The influence on women who take care of people with dementia as professional caregivers, as well as women who take the role of an informal caregiver of a person with dementia has been described. Early recognition of emotional stress in caregivers is necessary for successful preventive actions (counselling, supportive psychotherapy, cognitive-behavioural treatment) and for preventing the development or worsening of already existing somatic diseases (e.g. cardiovascular), as well as mental disorders, among which, apart from insomnia, anxiety and depression are the most common forms.

ADRESA ZA DOPISIVANJE /
***CORRESPONDENCE*:**
Doc. prim. dr. sc. Suzana Uzun, dr. med.
Klinika za psihijatriju Vrapče
Bolnička cesta 32
10090 Zagreb, Hrvatska
E-pošta: suzana.uzun@bolnica-vrapce.hr

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UVOD

Demencija je javno zdravstveni problem koji će postati sve vidljiviji kako stanovništvo stari. Danas u svijetu živi 50 milijuna ljudi oboljelih od demencije, a procjenjuje se da će do 2030. broj oboljelih narasti na 65,7 milijuna, odnosno na 115,4 milijuna oboljelih do 2050. godine (1,2). U dobi od 65 godina Alzheimerova bolest (AB) pojavljuje se u 0,6 % muškaraca i 0,8 % žena. Učestalost raste s dobi pa se procjenjuje da je incidencija oko 0,5 % za svaku godinu između 65. i 69. godine života, oko 1 % za svaku godinu od 70. do 74. godine; 2 % za svaku godinu od 75. do 79. godine; 3 % godišnje od 80. do 84. godine i 8 % godišnje nakon 85. godine (3). U dobi od 85 godina prisutna je u 14 % žena i 11 % muškaraca, u dobi od 90 godina taj je odnos 25 % i 21 %, a u dobi od 95 godina 41 % i 36 %. Od ukupno oboljelih bolesnika od demencije 50-60 % imaju najčešći tip demencije, tj. AB. Učestalost i incidencija AB povećavaju se eksponencijalno sa životnom dobi (3-5). Demografski trend trajno ubrzano rastućeg starijeg hrvatskog pučanstva, koje po procjeni u 2014. godini iznosi čak 18,62 % udjela 65-godišnjaka, posljedično donosi sve veću razliku između osobitosti zdravstvenih potreba starijih osoba i njihovog zadovoljenja. Najveće dostignuće, a time i izazov 21. stoljeća je veličina pojavnosti udjela stogodišnjaka odnosno dugovječnih osoba starijih od 95 godina. Tako je u Hrvatskoj broj stogodišnjaka, odnosno dugovječnih osoba starijih od 95 go-

INTRODUCTION

Dementia is a public health problem that will become increasingly obvious as the population ages. Today, 50 million of people with dementia live in the world and it is estimated that the number of affected people will rise to 65.7 million by 2030, and 115.4 million by 2050 (1,2). At the age of 65, Alzheimer's disease (AD) occurs in 0.6% men and 0.8% women. The frequency increases with age and it is estimated that the incidence is 0.5% for every year between 65 and 69 years of age, 1% for every year between 70 and 74, 2% for every year between 75 and 79, 3% for every year between 80 and 84, and 8% after 80 (3). At the age of 85 it is present in 14% of women and 11% of men; at the age of 90 it is present in 25% of women and 21% of men; at the age of 95 it is present in 41% of women and 36% of men. Of the total number of people with dementia, 50-60% have the most frequent type of dementia, that is, AD. The frequency and incidence of AD increase exponentially with age (3-5). Regarding the demographic trend in Croatian population whose aging is permanently accelerated it is estimated that in 2014 18.62% of people aged 65 will consequently experience more and more difference between the specificity of their health needs of and their fulfilment. Both the greatest achievement the greatest challenge of the 21st century is the size of incidence of proportion of 100-year-olds, that is, people over 95 years of age. The number of 100-year-olds, that is, people over 95 years of age in Crodina, 2001. godine iznosio 1.455 (1.132 starije žene i 323 starije muške osobe). U usporedbi s popisom 2011. godine, broj dugovječnih osoba starijih od 95 godina, iznosio je 2.201 (1.719 starijih žena i 482 starijih muških osoba), što ukazuje na povećanje od 51,21 % (34,15 % starijih žena i 49,23 % starijih muških osoba) u desetogodišnjem razdoblju (6). Hrvatska, kao zemlja čije je prosječno stanovništvo jedno od najstarijih u Europi, treba napraviti akcijski plan za borbu s AB, tj. znatno ozbiljnije se pripremati za nadolazeću epidemiju te bolesti u skoroj budućnosti (7,8). Trošak liječenja demencije je 600 milijardi godišnje na svjetskoj razini; troškovi se odnose na medicinsku, socijalnu, formalnu i neformalnu skrb. U razvijenim zemljama na neformalnu skrb troši se 45 % sredstava, na socijalnu skrb 40 %, a 15 % na medicinsku skrb. U siromašnijim zemljama većina sredstava odlazi na neformalne načine skrbi (9). Sukladno Globalnoj povelji o Alzheimerovoj bolesti koju je usvojilo Međunarodno udruženje za Alzheimerovu bolest u rujnu 2008. godine, a na hrvatski jezik prevela i poduprla Hrvatska udruga za Alzheimerovu bolest, navodi se da demencija utječe na mnoge aspekte života oboljele osobe kao i osoba koje ju okružuju, a posebice onih koji ih iz dana u dan njeguju (10). Raspon potencijalnih izvora socijalne podrške pokazao se kao jedan od najznačajnijih medijatora stresa i uspješnijeg suočavanja s AB (11,12). Danas kada demenciju nastojimo dijagnosticirati što ranije bitno je oboljelima i njihovim obiteljima ponuditi kontinuirani i što kvalitetniji program liječenja i skrbi (7,8). Skrb za osobu oboljelu od AB ili druge demencije, u našim je uvjetima najčešće na članovima obitelji, a oni obično nisu stručne osobe. Takva skrb zahtijeva barem mali stupanj znanja o problemima oboljele osobe. Zato su informiranje, podučavanje i savjetovanje obitelji osobe s demencijom sastavni dio cjelovitog procesa dijagnosticiranja, liječenja i skrbi za oboljelu osobu (12). Skrb za nemoćnoga člana obitelji jedan

atia was 1455 in 2001 (1132 older women and 322 older men). In comparison with the register from 2011, the number of long-lived people older than 95 was 2201 (1719 older women and 482 older men), which suggests an enlargement of 51.21% (34.15% of older women and 49.23% of older men) in a 10 year period (6). Croatia as a country with an average age of population that places it among the oldest in Europe needs to make an action plan to combat AD, that is, to prepare much more seriously for the upcoming epidemic of this illness in the near future (7,8). The cost of treatment of dementia is $600 billion worldwide; the cost concerns medical, social, formal, and non-formal care. In developed countries 40% of resources are spent on non-formal care, 40% on social care and 15% on medical care. In poorer countries most resources are spent on non-formal care (9). In parallel with the Global Declaration of AD that was adopted by the Alzheimer’s Disease International in September 2008, and which was translated into Croatian and supported by the Alzheimer Croatia, it is stated that dementia influences many aspects of the affected person’s life as well as the lives of people surrounding the affected person, especially those who take care of them on a daily basis (10). The range of potential sources of social support has been proven to be one of the most important mediators of stress and more successful coping with AD (11,12). Today, when we try to diagnose dementia as early as possible, it is important to offer a continuous and high-quality program of treatment and care to the affected people and their families (7,8). In our environment, care for a person with AD or other dementias is most often provided by family members and they are most often not professionals. This kind of care requires at least a small degree of knowledge of problems of the affected person. Therefore, informing, teaching, and advising the family of the person with dementia are integral parts of the overall process of diagnosing, treating, and caring for the affected person (12). The care for the weak member of je od najstresnijih događaja u životu obitelji. Skrbnici su izloženi primarnim stresorima: događajima i aktivnostima izravno povezanima s pružanjem pomoći oboljeloj osobi, te sekundarnim stresorima: promjenama u životu nastalima zbog pružanja skrbi (13). Pearlin i sur. u svojem modelu procesa stresa u skrbnika osoba oboljelih od demencije opisuju kako usmjeriti pomoć (14). Psihološke intervencije za skrbnike uključuju: procjenu stanja i izloženosti skrbnika opisanim stresorima te procjenu izvora pomoći. U sklopu tretmana za skrbnike sljedeće su strategije: edukacija, kontrola stresa, pružanje potpore – individualno i grupno te savjetovanje skrbnika i savjetovanje obitelji (15).

Svrha je ovog rada pokazati koji su glavni problemi vezani uz AB u suvremenom svijetu, a bitno utječu na život žena njegovatelja. Opisan je utjecaj na žene koje skrbe za ljude s demencijom u ulozi profesionalnog njegovatelja i žene koje preuzimaju ulogu neformalnog njegovatelja osobe oboljele od demencije. Poznato je da diljem svijeta demencija neproporcionalno utječe na žene. U mnogo zemalja postoji očekivanje da će se obitelj skrbiti za starije članove obitelji, uključujući i one s demencijom. To očekivanje se često proteže na očekivanje da će ženski članovi obitelji preuzeti ulogu izravnog njegovatelja. Posebice se u zemljama s niskim nacionalnim bruto dohotkom pokazalo važnim osigurati dostupnost usluga zajednice neobrazovanim ženama ili ženama s niskim stupnjem obrazovanja (16).

POLOŽAJ I ULOGA ŽENA NJEGOVATELJA U BRIZI O OBOLJELIMA OD ALZHEIMEROVE BOLESTI

Žene čine većinu starijeg stanovništva. Godine 2014. 62 % stanovništva starijeg od 80 godina bile su žene, a starenje stanovništva pogoto-

the family is one of the most stressful events in family life. Caregivers are exposed to primary stressors, events and activities directly connected with helping the affected person, and secondary stressors, changes in one’s life that occurred due to providing care (13). Pearlin et al. in their Stress process model for caregivers of individuals with dementia describe how to direct help (14). Psychological interventions for caregivers include the evaluation of condition and exposition of caregiver to the described stressors and the evaluation of the source of help. As part of treatment for caregivers, the strategies are the following: education, stress control, providing help – individually and in a group, and advising the caregiver and the family (15).

The aim of this article is to show which main problems are connected to AD in the modern world, which significantly influence the lives of women caregivers.

The influence on women that take care of people with dementia in the role of a professional caregiver and women who take the role of a non-formal caregiver of a person with dementia has been described. It is well known that all around the world dementia affects women disproportionally. In many countries there is an expectation that the family will take care of older family members, including those with dementia. It is often expected of female members of the family to directly take care of the affected member of the family. The importance of securing accessibility of social support for women without education or women with a low level of education has been shown, especially in the countries with low income (16).

STATUS AND ROLE OF WOMEN CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER'S DISEASE

Women are the majority of the older population. In 2014, 62% of population older than 80 years of age were women, and the aging of the vo je ubrzano u Africi, Latinskoj Americi, na Karibima i u Aziji (17). Međutim, učestalost demencije diljem svijeta je u porastu. Do 2050. godine 71 % ljudi s demencijom živjet će u zemljama s niskim nacionalnim bruto dohotkom. Učinak demencije na život žena značajniji je nego za muškarce. Žene su te koje u bitno većoj mjeri pružaju neformalnu njegu ljudima s demencijom pa su oko dvije trećine neformalnih njegovatelja žene. Taj omjer je puno veći u zemljama s niskim i srednjim bruto nacionalnim dohotkom, te je stoga učinak pružanja njege na zdravlje i dobrobit, kao i financijski učinak, veći za žene u zemljama s niskim bruto nacionalnim dohotkom (17). Žene također čine većinu formalne njegovateljske radne snage, posebice u njezi osoba s demencijom te su one te koje pružaju većinu zdravstvene i socijalne skrbi u zajednici, bolnicama i domovima (17).

Veliki broj istraživanja o utjecaju demencije na žene proveden je u zemljama s visokim bruto nacionalnim dohotkom, ali potrebno je i bolje razumijevanje problema s kojima se suočavaju žene u zemljama s niskim bruto nacionalnim dohotkom (16).

Kad se pojavi bolest članovi obitelji i okolina bolesnika kao i on sam prolaze kroz različite faze njenog prihvaćanja. Postoji ogromna potreba u cjelokupnoj zajednici za što boljim razumijevanjem bolesti, te načinima ophođenja prema bolesniku/obitelji, a sam bolesnik/obitelj ima potrebu što više saznati o svojoj bolesti i stanju, svojim mogućnostima, pravima i obvezama (17). Muški njegovatelji, supružnici, pomažu suprugama nanijeti *make-up*, obući se, kupuju im kozmetičke proizvode na koje su one prethodne naviknute. Supruge njegovateljice pak pomažu supružnicima obući se, obrijati se i počešljati (17). Poželjno je za oboljelog da što duže bude u obiteljskom okruženju uz kvalitetnu njegu. Od velike pomoći su tzv. dnevni boravci ili dnevne bolnice, gdje oboljeli tijekom dana imaju odgovarajuću njegu, tret-

population is especially accelerated in Africa, Latin America, in the Caribbean and in Asia (17). Nevertheless, the frequency of dementia is growing worldwide. By 2050, 71% of people with dementia will live in countries with low national income. The effect of dementia on the lives of women is more significant in comparison with men. Women are the ones who to a higher degree provide non-formal care of people with dementia; two thirds of non-formal caregivers are women. This ratio is much higher in countries with low and middle national income, and therefore the effect of caregiving on health and wellbeing, as well as the financial effect, is higher for women in countries with low national income (17). Women also make up the majority of formal caregivers, especially in the care of individuals with dementia, and they are the ones who provide the majority of health and social care in the community, hospitals, and nursing homes (17).

A large number of investigations of the influence of dementia on women has been performed in countries with high national income, but there is a necessity for a better understanding of the problem women face in countries with low national income (16).

When illness occurs, family members and the patient’s environment, as well as the patient, go through different stages of its acceptance. There is an immense necessity in the whole community for a good understanding of the illness and ways of communicating with the patient through families, and the patient/family have the need to learn as much as possible about the illness and the condition, options, rights, and obligations (17). Male caregivers, husbands, help their wives to dress and put on make-up; they buy them cosmetic products which they were previously used to. Wives caregivers help their husbands dress, shave, and comb their hair (17). It is advisable for the affected person to be in a family surrounding with quality care. Day hospitals are of great help, where patients manske aktivnosti i druženja, a za to vrijeme član obitelji može obavljati druge poslove ili se jednostavno odmoriti. Dnevni boravci dolaze u obzir samo u početnoj fazi bolesti, dok je još moguć transport oboljelog i primjerena terapijska aktivnost (18). Dostupnost socijalne podrške pomaže kod prilagodbe na bolest, dok njena odsutnost dovodi do pogoršanja ishoda skrbi (depresivnosti i njegovateljskog stresa) kako za oboljelu osobu tako i za njegovatelja (19,20). Koji će oblik socijalne podrške pojedinom njegovatelju biti važniji ovisi svakako i o stadiju bolesti pa će tako instrumentalna podrška biti iznimno značajna u akutnoj fazi bolesti kada su kapaciteti oboljele osobe ograničeni u izvršavanju svakodnevnih aktivnosti. Emocionalna podrška u svim fazama bolesti može također unaprijediti suočavanje s izazovima skrbi (21). Socijalna podrška označava dostupne resurse u socijalnoj okolini koji pridonose dobrobiti njegovatelja i pomažu mu u obnošenju njegove uloge (22-24). Postoji distinkcija između „povezujuće“ podrške i „nepovezane“ podrške, koja se temelji na percepciji njegovatelja oboljelih od demencije u primanju pomoći, tj. podrške. „Povezujuća“ podrška označava interakciju koju njegovatelj percipira kao pomažuću u bavljenju njegovim/njezinim potrebama. „Nepovezana“ podrška označava interakcije/u koja pojačava otuđenost njegovatelja, jer podrška nije kongruentna s potrebama koje percipira njegovatelj (2,25). Rezultati istraživanja Kovačić Petrović i Repovečki (26) upućuju na simptome sagorijevanja i kod obiteljskih i profesionalnih djelatnika, te na nedostatnu skrb za osobe koje se brinu o oboljelima od AB koja je kronična bolest i uzrokuje stresne odgovore i kod članova obitelji koji su najčešći njegovatelji. Važno bi bilo razviti specifične suportivne programe za obiteljske njegovatelje kakvi već postoje u mnogim zemljama (26). Otprilike dvije trećine ljudi s demencijom u zemljama s višim bruto nacionalnim dohotkom živi u vlastitim domovima. Njega osoba s demencijom ponaj-

have adequate care during the day, treatment activities, and a chance to socialize; during that time, a member of the family can do other activities or simply relax. Day care becomes an option only during the initial stage of the illness when it is still possible to transport the patient and provide adequate therapeutic activity (18). The accessibility of social support helps them adapt to the illness while its absence leads to a worsening in the outcome of caretaking (depression and caregiver’s stress) for the patient but also for the caregiver (19,20).

Which type of social support will be more important to a particular caregiver depends on the stage of the illness. Instrumental support will be very important in the acute stage of the illness, when the capacities of the affected person are limited when it comes to performing everyday activities. Emotional support in all stages of the illness can also improve coping with challenges in providing care (21). Social support presents accessible resources in a social environment, which contribute to the wellbeing of the care provider and help him/her in performing his/her role (22-24). There is a distinction between “connecting” support and “non-connecting” support, which is based on the perception of caregivers of individuals with dementia in receiving help, that is, support. “Connecting” support means interaction which the care giver perceives as helping his/her needs. “Non-connecting” support means interaction during which the detachment of the caregiver is enhanced because the support is not congruent with the needs perceived by the caregiver (2,25). The results of the research conducted by Kovacic-Petrovic and Repovecki point to the symptoms of burnout in family and professional workers and to insufficient care for people who take care of individuals with AD, which is a chronic illness and causes stress response in family members who are most often caregivers. It would be important to develop specific supporting programs for family caregivers that are present in many countries (26). About two thirds of people with dementia in countries with higher prije se provodi u zajednici. U zemljama s niskim bruto nacionalnim dohotkom ta brojka je mnogo veća iako ju je teško kvantificirati. Uobičajeno je da njegu pružaju članovi obitelji (najčešće kćeri ili snahe) kod kuće (27). Pozitivni čimbenici povezani s preuzimanjem uloge njegovatelja su osjećaj ponosa i zadovoljštine; motivi za preuzimanje te uloge su često složeni od mješavine očekivanja i obveze zajedno s ljubavlju i osjećajem zahvalnosti prema osobi s demencijom, ili vraćanje njege koju su primili kao djeca (28). U neformalnoj skrbi, razlozi odabira uloge njegovatelja razlikuju se. Ovdje navodimo četiri glavna razloga. Često je ta uloga nametnuta zbog kulturoloških razloga i tradicije. Na primjer, na Cipru se smatra prirodnom ulogom žene, a sličnog su stava u obiteljima Latinoamerikanaca u Sjedinjenim Američkim Državama (SAD) i Španjolskoj (27-29). Zatim, uloga njegovatelja je kulturološka i tradicijska u multigeneracijskim kućanstvima (Sri Lanka, azijske zemlje). Takva uloga je neupitna i altruistična. Kćeri i snahe su emotivna potpora, podrška u svakodnevnim aktivnostima, sinovi su financijska potpora (30,31). U SAD, u latinoameričkim obiteljima 78 % njegovatelja su kćeri i nevjeste, u kineskim obiteljima 63 %, a u ostalim obiteljima 49 % (32). U Nizozemskoj, u turskim i marokanskim obiteljima najstarija kći ili supruga najstarijeg sina, tradicionalno je njegovatelj (33). Proširena bračna uloga također je razlogom zašto žena preuzima ulogu njegovatelja te na kraju, žena će preuzeti ulogu njegovatelja zbog osjećaja ponosa i zadovoljstva (33). Žene čine najveći udio profesionalne njegovateljske radne snage u skrbi za demenciju te u pružanju formalne zdravstvene i socijalne skrbi i potpore osobi s demencijom i njenom ili njegovom njegovatelju. Mnoge žene koje rade kao njegovateljice skrbe i za svoju djecu i starije roditelje. To djeluje na njihovu sposobnost pružanja obiteljske skrbi i utječe na kvalitetu života cijele obitelji, uključujući i osobe koja živi s demencijom. Razlika u pla-

income live in their own homes. Care for persons with dementia is primarily conducted in the community. In countries with low income this number is much higher although it is not easy to quantify it. Care is usually provided by family members (most often daughters and daughters-in-law) at home (27). Positive factors connected with taking the role of a caregiver are the sense of pride and satisfaction; motives for taking that role are often complicated, from a mixture of expectations and obligations along with love and a sense of thankfulness towards the person with dementia or returning care that they received as children (28). In non-formal care the reasons for choosing the role of a care giver differ and here we state the four main reasons. Often, this role is imposed because of cultural reasons and tradition. For instance, in Cyprus it is considered the natural role of women and the similar attitude is in the families of Latin American descent in USA and Spain (27-29). Furthermore, the role of a caregiver is cultural and traditional in multigenerational households (Sri Lanka, countries of Asia). This role is unquestionable and altruistic. Daughters and daughters-in-law are emotional support and support in everyday activities, while sons are financial support (30,31). In the USA and Latin American families, 78% of caregivers are daughters and daughters-in-law, in Chinese families 63%, and in other families 49% (32). In Dutch, Turkish, and Moroccan families the oldest daughter or wife of the oldest son is traditionally the caregiver (33). Expanded marital role is also the reason why women take the role of caregiver and, finally, women will accept the role of a caregiver because of the sense of pride and satisfaction (33). Women present the majority of professional workers in taking care of people with dementia and in providing formal medical and social care and support to people with dementia and his/her caregiver. Many women who work as caregivers also take care of their children and elderly parents. This influences their ability to provide family care and affects the quality of life of the entire family, including the person ćama između muškaraca i žena koji rade u sustavu zdravstva i socijalne skrbi znači da žene u prosjeku zarađuju 10 % manje od muškaraca koji rade slične poslove (34). Žene čine 42 % radnog pučanstva, a u zdravstvenom sektoru u mnogim zemljama čine 75 % radne snage. Većina ih je zaposlena u skrbi za oboljele od demencije, kako u primarnoj, kućnoj njezi, socijalnoj skrbi, dobrotvornim organizacijama, udruženjima. U Velikoj Britaniji 87 % osoba koje rade u formalnoj skrbi su žene, ¾, su izravno uključene, a ¼ u radu kod privatnih poslodavaca (34).

Među zaposlenicima najveći je postotak imigranata, oko 20 %. Općenito, vrlo su loše educirani o demenciji. Zbog objektivnih i subjektivnih razloga mnogo radnika imigranata koji su 24 sata zaposleni kod oboljelih pate od simptoma depresije. Takav posao nije predviđen za muške njegovatelje (34). U Latinskoj Americi i Kini formalni njegovatelji imaju poprilično nereguliran status, nemaju treninga ni uvježbanih vještina za taj posao (34).

ZDRAVSTVENE TEGOBE NJEGOVATELJA I STRUKTURE POTPORE

Njegovatelji ljudi s demencijom, koji su ujedno i članovi obitelji, skloniji su razvijanju mentalnih zdravstvenih problema poput teške depresivne epizode i anksioznih poremećaja. Žene njegovateljice prijavljuju višu razinu tereta, stresa i simptoma depresije od muških njegovatelja, a rezultati su slični u svim zemljama i okruženjima (3). Njegovatelji-članovi obitelji razvijaju psihičke tegobe poput velikog depresivnog poremećaja i anksioznih poremećaja (16,35). Supruge-njegovateljice puno teže podnose ulogu njegovatelja i taj teret je osobito vidljiv nakon dvije godine brige za oboljelog člana; javljaju se teži distres, gubitak bliskosti, anksiozni i depresivni simptomi, manja je podrška okoline

who lives with dementia. The average difference in wages between men and women who work in the system of health and social care means that women earn 10% less than men who do similar jobs (34). Women make up 42% of workers, and in the health sector in many countries they make up 75% of workers. Most of them are employed in the care of people with dementia in primary, house care, social care, and charity organizations. In Great Britain, 87% of those who work in formal care are women, two thirds are directly included and one third is employed by private employers (34).

Among employees, the highest percentage are immigrants, around 20%. Generally, they are very poorly educated about dementia. Due to objective and subjective reasons, many immigrant workers who spend 24 hours a day with affected individuals suffer from symptoms of depression. This kind of job is not intended for male caregivers (34). In Latin America and China, formal care providers have a rather unregulated status, and do not receive training for this job (34).

HEALTH PROBLEMS OF CARE GIVERS AND STRUCTURES OF SUPPORT

Caregivers of people with dementia who are at the same time family members are more susceptible to developing mental health problems such as major depressive disorder and anxiety disorders. Women caregivers report a higher level of burden, stress, and symptoms of depression compared to male caregivers, and the results are similar in all countries (3). Caregivers who are family members develop mental health problems such as major depressive disorder and anxiety disorders (16,35). Wives who are caregivers tolerate the role of caregiver with much more difficulty, and this burden is especially obvious after two years of care for the affected family member; serious distress, loss of closeness, anxiety, and depressive symptoms

(16,36). Susreću se prvo s gubitkom kontrole, zbunjeno prihvaćaju novu ulogu, kvaliteta braka i bliskost stradavaju, te se moraju naviknuti na nove uloge u kućanstvu. Muškarci supružnici njegovatelji se žale na gubitak kvalitetne komunikacije, kognitivne i bihevioralne simptome, gubitak društva i financijski teret (37). Kćeri-njegovateljice bolje podnose stres njegovanja, imaju također vlastitu ulogu majke, ali više puše, smanjene su im tjelesne aktivnosti, više dobivaju na tjelesnoj težini, krvnom tlaku, a i češće obolijevaju od kroničnih bolesti pluća od majki njegovateljica. Latinoamerikanke bolje podnose stres u odnosu na kineske imigrante te bijelu populaciju u SAD-u (38).

Njegovatelji ljudi s demencijom su često primorani promijeniti svoje zaposlenje. Žene češće od muškaraca moraju reducirati svoje radno vrijeme na polovicu ili potpuno prestati raditi kako bi mogle pružati njegu (34,38).

Putevi njege i strukture potpore koje se nude njegovateljima ljudi s demencijom razlikuju se od zemlje do zemlje, a i unutar pojedine zemlje, ovisno o *setting*-u i lokaciji. U većini zemalja s visokim bruto nacionalnim dohotkom postoje usluge u zajednici koje pomažu ljudima s demencijom, no u zemljama s niskim bruto nacionalnim dohotkom takvih usluga je vrlo malo, pogotovo u ruralnim područjima (39). Tradicionalne strukture proširene obitelji s kulturološkim očekivanjima skrbi za članove obitelji unutar te obitelji opisane su u mnogim zemljama. No, kako se obiteljske strukture mijenjaju zbog razvoda, ponovnog sklapanja braka, opadajuće stope nataliteta, povećane mobilnosti i povećanja zaposlenosti žena, više se za pružanje njege ne može u istoj mjeri oslanjati na tradicionalne strukture (39). Potrebno je pobrinuti se za potrebe ljudi s demencijom i njihovih obiteljskih njegovatelja u ruralnim područjima zemalja s niskim bruto nacionalnim dohotkom, gdje je dostupno manje zdravstvenih i socijal-

occur, and the support from the environment is decreased (16,36). First, they encounter loss of control, they are confused when they accept the new role, the quality of marriage and closeness are impaired, and they have to get used to their new roles in the household. Husbands who are caregivers complain about the loss of quality communication, cognitive and behavioural symptoms, loss of companionship, and financial burden (37). Daughters who are caregivers endure the stress of caretaking better, they also have their own role of being mothers, but smoke more, their physical activities are decreased, they gain more weight, their blood pressure increases, and they more often become ill with chronic pulmonary diseases compared to mothers who are caregivers. Latin Americans endure stress better compared to Chinese immigrants and the Caucasian population in the USA (38).

Caregivers who take care of people with dementia are often forced to change their employment. Women, more often than men, need to reduce their working hours by half or to stop working completely in order to provide care (34,38).

Forms of care and structures of support offered to caregivers of people with dementia are different in different countries and also within particular countries depending on setting and location. In the majority of countries with high income there are services in the community which help people with dementia, but in countries with low income there are very few such services, especially in rural areas (39). Traditional structures of extended family with cultural expectations regarding the care for family members within the family are described in many countries. But along with changes in the family structures because of divorce, marrying again, decreasing birth rate, increased mobility, and an increase in the employment of women, it is not possible to rely on traditional structures in providing care to the same degree (39).

It is necessary to deal with the needs of people with dementia and their caregivers who are famnih usluga i gdje je ostvarivanje zdravstvenih usluga otežano zbog pomanjkanja infrastrukture, lokalne dostupnosti i poteškoća u prijevozu. Žene pružaju znatnu količinu neplaćene njege ljudima s demencijom na svim mjestima. Treba osigurati odgovarajuću potporu kako bi žene mogle nastaviti ulogu njegovatelja, uzimajući u obzir zdravstvene i financijske poteškoće povezane s ulogom njegovatelja (39). Žene je potrebno upoznati s pomoći koja im je dostupna, putem podizanja svijesti i boljeg obavještavanja od organizacija zdravstvene i socijalne skrbi o formalnim i neformalnim uslugama koje postoje i kako ih ostvariti. Sve zdravstvene radnike koji rade u zajednici treba obučiti o demenciji kako bi se povećalo njihovo samopouzdanje u shvaćanju ponašanja ljudi s demencijom i učinak koji to ima na njihove karijere, a kako bi im se omogućilo da pružaju učinkovitu podršku. Nizak ekonomski status, financijske nagrade i nedostatna obuka i podrška za rad u njegovateljskoj struci utječu na žene, njihove obitelji i na ljude koji žive s demencijom. Postoji potreba za stručnim kompetencijama zdravstvenih i njegovateljskih radnika koji rade s ljudima koji žive s demencijom s kompleksnim potrebama i komorbiditetima. Dostupnost socijalne podrške pomaže kod prilagodbe na bolest, dok njena odsutnost dovodi do pogoršanja ishoda skrbi u smislu depresivnosti i njegovateljskog stresa, kako za oboljelu osobu tako i za njegovatelja (20,21). Koji će oblik socijalne podrške pojedinom njegovatelju biti važniji ovisi svakako i o stadiju bolesti, pa će tako instrumentalna podrška biti iznimno značajna u akutnoj fazi bolesti kada su kapaciteti oboljele osobe ograničeni u izvršavanju svakodnevnih aktivnosti. Emocionalna podrška u svim fazama bolesti može također unaprijediti suočavanje s izazovima skrbi (22). Socijalna podrška označava dostupne resurse u socijalnoj okolini koji pridonose dobrobiti njegovatelja i pomažu mu u obnošenju njegove uloge (22,23). Postoji razlika između „povezujuće“ podrške i

ily members in rural areas of countries with low income where fewer health and social services are accessible and where the realization of health services is harder because of the lack of infrastructure, local accessibility, and problems in transportation. Women provide a significant amount of unpaid care to people with dementia in all settings. It is necessary to ensure adequate support in order for women to be able to continue with the role of a caregiver, taking into consideration health and financial problems connected with the role of a caregiver (39). It is necessary to inform women about the help that is accessible by raising awareness and providing better information through health and social care organizations about formal and non-formal services and how to realize them. All health workers who work in the community need to be taught about dementia in order to increase their confidence in understanding the behaviour of people with dementia and the effect that it has on their careers in order to enable them to give efficacious support. Low socioeconomic status, financial prizes, and insufficient training and support for working as caregivers affect women, their families, and people who live with dementia. There is a need for professional competences of health workers and caregivers who work with people who live with dementia with complex needs and comorbidities. The accessibility of social support helps in adapting to the illness, while the lack of it leads to a worsening in the outcome of caregiving in the sense of depression and care giver's stress for the affected person and for the caregiver (20,21). Which type of social support will be more important to the particular caregiver depends on the stage of the illness. Instrumental support is very important in the acute phase of illness, when the capacities of the affected person are limited in performing everyday activities. Emotional support in all stages of illness can also improve coping with challenges of caregiving (22). Social support signifies available resources in the social environment that contribute to the wellbeing of the caregiver and help him/her in

„nepovezane“ podrške, koja se temelji na percepciji njegovatelja oboljelih od demencije u primanju pomoći, tj. podrške. „Povezujuća“ podrška označava interakciju koju njegovatelj shvaća kao pomažuću u bavljenju njegovim/njezinim potrebama. „Nepovezana“ podrška označava interakcije/u koja pojačava otuđenost njegovatelja, jer podrška nije u skladu s potrebama koje percipira njegovatelj (25). Njegovatelji s manje socijalne podrške i s nižim stupnjem zadovoljstva primljenom socijalnom podrškom imaju značajno viši stupanj sagorijevanja nego njegovatelji koji socijalnu podršku percipiraju višom i socijalne veze jačima (21). Nadalje, njegovatelji s višom emocionalnom i socijalnom podrškom imaju niži stupanj depresivnosti, te svoju kvalitetu života i zadovoljstvo životom percipiraju višima. Neformalni njegovatelji osoba oboljelih od demencije izvješćuju o višoj razini stresa, psiholoških problema, problema s fizičkim zdravljem, većoj socijalnoj izolaciji te lošijem obiteljskom funkcioniranju od osoba koje nisu u ulozi pružatelja skrbi oboljeloj osobi. Kod njegovatelja koji su pod visokim stresom veća je vjerojatnost pojave depresije, zlostavljanja i zanemarivanja oboljele osobe, te u konačnici institucionalizacije oboljelog. Navedeno može biti posljedica nedostatka emocionalne podrške, socijalne izolacije, ljutnje koja se javlja kod njegovatelja, nemogućnosti nošenja sa zahtjevima bolesti i njegovateljske uloge. Niža razina socijalne podrške povezana je s višim stupnjem sagorijevanja i depresijom njegovatelja, kao i s nižom razinom iskazanog zadovoljstva (22,25,40,41). Druga studija značajnim prediktorima za negativne ishode za njegovatelja navodi razinu prihoda i percepciju zdravstvenog stanja, te manjak socijalne podrške i osjećaja obiteljske napuštenosti (42). Istraživanje Yurtsever i sur. potvrđuje da njegovatelji mlađi od 50 godina, šire socijalne mreže te boljeg obrazovnog statusa iskazuju više zadovoljstva i manje sagorijevanja (43). Andren i Elmståhl (44) su istraživali

performing his/her role (22,23). There is a distinction between “connecting” support and “non-connecting” support, which is based on the perception of caregivers of people with dementia in receiving help, that is, support. “Connecting” support signifies interaction which a caregiver perceives as helping in attending his/her needs. “Non-connecting” support signifies interaction/s which enhances a caregiver’s detachment since the support is not congruent with the need perceived by the caregiver (25). Caregivers with less social support and a lower level of satisfaction with received social support have a significantly higher level of burnout compared to caregivers who perceive a higher level of social support and stronger social connections (21). Furthermore, caregivers with higher emotional and social support have a lower level of depression and their quality of life and satisfaction with life are perceived as higher. Non-formal caregivers of persons with dementia report a higher level of stress, psychological problems, problems with physical health, higher social isolation, and poorer functioning in the family in comparison with persons who do not have the role of caregivers. In caregivers with a high level of stress, the chance for the occurrence of depression, maltreatment, and neglect are higher, and may ultimately lead to the institutionalization of the patient. This can be a consequence of a lack of emotional support, social isolation, care giver’s anger, or the incapacity for coping with the demands of the illness and the role of a caregiver. A lower level of social support is connected with a higher level of burnout and depression of a caregiver, as well as a lower level of reported satisfaction (22,25,40,41). Another research considers the level of income, perception of health condition, lack of social support, and feeling of being abandoned by family as significant predictors for negative outcomes for caregivers (42). The research by Yurtsever et al. confirms that caregivers younger than 50 years of age with a broader social network and a higher level of education report more satisfaction and less burnout (43).

učinak podrške njegovateljima tijekom 5 tjedana stručne podrške i tri mjeseca sudjelovanja u grupama za podršku, te naveli sljedeće pozitivne ishode: povećanje osjećaja zadovoljstva i smanjenje osjećaja napora i razočaranja koji traju minimalno 12 mjeseci od sudjelovanja u programu formalne podrške (44). Budući da članovi obitelji koji brinu o oboljeloj osobi od AB nemaju dostatna saznanja o samoj bolesti i pristupu oboljelom te veći dio vremena provode s oboljelim za pretpostaviti je kako je kod njih veća učestalost anksiozno depresivnih simptoma u odnosu na zdravstvene djelatnike (26,45). Skrb oboljelima pružaju i profesionalci i neprofesionalci, najčešće članovi obitelji. Ponašajni i psihički simptomi u AB povezani su sa stresom i psihičkim simptomima kod osoba koje se skrbe o oboljeloj osobi od AB (45). Obiteljski njegovatelji (najčešće djeca i unuci) osoba oboljelih od AB imaju češće izraženu anksioznost i depresivnost u odnosu na profesionalne njegovatelje; život s oboljelom osobom povećava razinu anksioznosti kod obiteljskih njegovatelja; viša životna dob je rizični čimbenik za nastanak anksioznih i depresivnih simptoma kod obiteljskih njegovatelja; duži radni staž negativno utječe na pojavu anksioznih i depresivnih simptoma, ali ne i razina obrazovanja profesionalnih njegovatelja (srednja, viša ili visoka razina obrazovanja medicinskih sestara/tehničara) (26). Sun i sur. (46) navode da žene njegovateljice rjeđe koriste usluge pomoći u kući, češće koriste usluge prijevoza te podršku iz neformalnih izvora u odnosu na muškarce njegovatelje (46). Wallsten te Sun i sur. nalaze da žene primaju više neformalne podrške od muškaraca (46,47). Pinquart i Sorensen navode da su muškarci motiviraniji i spremniji tražiti pomoć izvana što se povezuje s manjom pripremljenošću i osjećajem ugode u ulozi njegovatelja, odnosno teorijom socijalnih uloga (48). Analize pokazuju i kako je percepcija osjećaja izolacije raširenija kod ekonomski siromašnih (49). Rano prepozna-

Andren and Elmståhl researched the effect of support provided to caregivers during five weeks of professional support and three months of participation in groups for support and stated the following positive outcomes: an increase in the sense of satisfaction and a decrease of the sense of effort and disappointment that last at least 12 months from participation in the program of formal support (44). Since the members of the family that take care of the person with AD don't have sufficient knowledge about the illness and approach to the patient and spend most of the time with the person, it can be assumed that they have a higher frequency of anxiety symptoms compared to health workers (26,45). The care for the affected persons is provided by professionals and non-professionals, most often members of the family. Behavioural mental symptoms in AD are connected with stress and mental symptoms in persons who take care of the person with AD (45). Family caregivers (most often children and grandchildren) of the person with AD have more often expressed anxiety and depressiveness compared to professional caregivers; life with an affected person increases the level of anxiety in family caretakers; older age is a risk factor for the occurrence of anxiety and depressive symptoms in family caregivers; longer occupational record negatively affects the occurrence of anxious and depressive symptoms, but not the level of education of professional caregivers (middle, higher, or high level of education of nurses) (26). Sun et al. state that women caregivers use the services of help in the house more rarely, and use transport services and support for non-formal sources more often when compared to male caregivers (46). Sun et al. and Wallsten find that women receive more non-formal support than men (46,47). Pinquart and Sorensen state that men are more motivated and readier to seek help from outside, which is connected with less preparedness and a sense of comfort in the role of the caregiver, that is, with social roles theory (48). Analyses show that the perception of the sense of isolation is more widespread among the finanvanje emocionalnog stresa kod njegovatelja nužno je kako bi se uspjelo preventivno djelovati (savjetovanje, suportivna psihoterapija, kognitivno-bihevioralni tretman), te spriječiti razvoj ili pogoršanje već postojećih tjelesnih bolesti (npr. kardiovaskularne), odnosno mentalnih poremećaja od kojih su, osim nesanice, najčešći anksioznost i depresivnost (50). Zbog izazova skrbi o oboljeloj osobi većina njegovatelja ima potrebu za dodatnom edukacijom i većom podrškom u lokalnoj zajednici. Kada je njegovateljima podrška dostupna, a prisutna je veća opterećenost zahtjevima dnevne skrbi i niži stupanj sagorijevanja, zadovoljstvo formalnom podrškom je veće (50). Zato je ključno da članovi obitelji i skrbnici razumiju pojedinosti u vezi s promjenama u ponašanju bolesnika s demencijom, te da su educirani kako se nositi s njima. Strategije koje uključuju održavanje pozitivnog konteksta komunikacije, jasnog izražavanja, postavljanja jednoznačnih pitanja, pojednostavljivanja kompleksnih zadataka, te sposobnost odvraćanja pozornosti s negativnih aspekata i preusmjeravanje na trenutne zadatke, omogućuju kvalitetan odnos s bolesnikom, te znatno pridonose kvaliteti života (51). Komunikacija s osobama oboljelima od demencije vremenom postaje otežana, a na kraju se može i gotovo potpuno izgubiti. Već od rane faze bolesti potrebno je raditi na poboljšanju komunikacije. Koristeći se određenim tehnikama njegovatelji mogu poboljšati komunikaciju s oboljelim osobama i zadržati je na toj razini dulje vrijeme. Nefarmakološke intervencije mogu biti od koristi u ublažavanju bihevioralnih poremećaja koji se često javljaju tijekom progresije demencije, a kombinacija nefarmakoloških tehnika i lijekova u pravilu je učinkovitija od primjene samih psihofarmaka (52,53). Alzheimerova demencija je kronična bolest čije razdoblje može obuhvaćati godine njegovateljske skrbi, stoga je važno da podrška njegovateljima bude dostupna od inicijalne sumnje na bolest do njenog kraja, tj.

cially poor (49). Early detection of emotional stress in caregivers is necessary in order to perform preventive actions (counselling, supportive psychotherapy, cognitive-behavioural treatment) and to prevent the development or worsening of already existing somatic illnesses (for example cardiovascular), or mental disorders, among which, beside insomnia, the most frequent ones are anxiety and depression (50). Because of the challenges of caring for the affected person, most caregivers have the need for additional education and more support in the local community. When support is available for care givers and a higher burden of requirements of daily care is present with a lower level of burnout, satisfaction with formal support is higher (50). Therefore, it is crucial that family members and care givers understand the details connected with changes in the behaviour of patients with dementia and be educated to cope with them. Strategies involve the maintenance of a positive context of communication, clear expression, asking clear questions, simplifying complex tasks, and the ability to distract attention from the negative aspects and redirect it to present tasks enable a quality relationship with the affected person and contribute significantly to quality of life (51). Communication with people with dementia becomes more difficult over time and finally can be lost altogether. Since the early stage of the illness, it is necessary to work on the improvement of communication. By using certain techniques, caregivers can improve communication with the patients and maintain it at that level for a longer time. Non-pharmacological interventions can be useful in the alleviation of behavioural disorders which often occur during the progression of dementia, and a combination of non-pharmacological techniques and medications is generally more efficacious then the use of psychopharmaceuticals only (52, 53). AD is a chronic illness the duration of which can include years of caregiving. Therefore, it is important that the support to caregivers is available from the initial doubt regarding the illness until the end of the illness, smrti oboljelog, te i poslije toga u fazi žalovanja odnosno adaptacije na proživljeni gubitak (54).

ZAKLJUČAK

Postoji potreba za daljnjim istraživanjima utjecaja demencije na žene kao njegovateljice u longitudinalnim studijama. Potrebno je napraviti ili poboljšati postojeće nacionalne programe za liječenje demencije te u njima jasnije naglasiti ulogu žena i njihovu specifičnost vezanu za ovaj entitet. Buduća se translacijska istraživanja trebaju seusredotočiti na pitanja kako njegovateljima, a to su poglavito žene, pomoći se prilagodili novonastaloj situaciji, dugoročno se s njom nositi i iz toga izaći zdrav, odnosno sa što manjim posljedicama.

that is, death of the affected person, but also afterwards, during the period of bereavement, that is, adaptation to experienced loss (54).

CONCLUSION

There is a need for further research of the influence of dementia on women as caregivers in longitudinal studies. It is necessary to make or improve existing national programs for the treatment of dementia and to more clearly emphasize the role of women and their specific issues related to this disease. Future translational research needs to focus on questions such as how to help caregivers, who are most often women, to adapt to the new situation, cope with it in the long term, and finally to come out of it healthy or with as few consequences as possible.

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