

Multiprofesionalni menadžment demencije

/ *Multiprofessional Management of Dementia*

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Održavanje kvalitete života prioritet je menadžmenta demencije. Kvaliteta života ljudi s demencijom primarno je određena autonomijom, nastavljanjem individualnog životnog stila, postizanjem pojedincu važnih ciljeva, značajnim aktivnostima i sudjelovanjem na ranom stadiju; sigurnošću, uvažavanjem i društvenom povezanošću na srednjem stadiju; te utjehom, dostojanstvom i empatičkim odnosima na kasnom stadiju. Pružanje tih izvora kvalitete života zahtijeva suradnju i koordinaciju više stručnjaka, uključujući liječnike, psihologe, medicinske sestre, socijalne radnike, radne terapeute, govorne i jezične terapeute te fizioterapeute vođene zajedničkim planom njege usmjerenim na pojedinca. Multiprofesionalni model njege osoba s demencijom temeljen na suradnji sadrži značajne prednosti, uključujući nefarmakološke mjere liječenja, uočavanje komorbidnih zdravstvenih stanja, manji teret za njegovatelje te niže stope smještanja u zdravstvene institucije. Stoga je multiprofesionalni menadžment poželjan u većini nacionalnih strategija ili planova za demenciju. Multiprofesionalno obrazovanje preduvjet je za njegu osoba s demencijom temeljenu na suradnji. Osposobljavanje stručnjaka različitih zanimanja unutar okvira timske suradnje vodi k dijeljenju znanja i principa vezanih za njegu osoba s demencijom, boljem razumijevanju uloge drugih stručnjaka te boljoj pripremljenosti za suradnju u svakodnevnoj praksi. Projekt INDEED (Inovacije za demenciju u dunavskoj regiji) koji financira Europska unija je transnacionalna inicijativa za unaprjeđenje njege za osobe s demencijom putem multiprofesionalne obrazovne intervencije koja spaja tradicionalne i moderne metode učenja.

/ Maintaining quality of life is a priority of dementia management. The quality of life of people with dementia is primarily determined by autonomy, continuation of individual lifestyle, attainment of personally important goals, meaningful activities and participation at the early stage; by safety, appreciation and social connectedness at the moderate stage; and by comfort, dignity and emphatic relationships at the severe stage. Providing these sources of quality of life requires the collaboration and coordination of multiple professions, including physicians, psychologists, nurses, social workers, occupational therapists, speech and language therapists, and physical therapists, guided by a joint person-centred care plan. A multiprofessional collaborative care model for dementia has significant benefits including referral for non-pharmacological treatments, detection of comorbid medical conditions, reduced caregiver burden and lower rates of institutionalisation. Therefore, multiprofessional management is a desideratum in most national dementia strategies or plans. A prerequisite for collaborative care in dementia is multiprofessional education. Training professionals of different occupations in a team framework leads to shared knowledge and principles regarding dementia care, enhanced understanding of each other's role, and better preparedness for collaboration in daily practice. The EU-funded project INDEED (Innovation for Dementia in the Danube Region) is a transnational initiative to improve dementia care by a multiprofessional educational intervention combining traditional and modern learning methods.

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NEUROBIOLOGIJA, OŠTEĆENJE I INVALIDNOST

U gotovo svim slučajevima demencija je posljedica kroničnih i često progresivnih te trenutno neizlječivih bolesti mozga, među kojima su najčešće Alzheimerova bolest, kardiovaskularna bolest malih krvnih žila, bolest Lewyjevih tjelešacate frontotemporalna lobarna degeneracija. Vrlo je malo potencijalno izlječivih uzroka, dok je potpuni oporavak od demencije rijetka iznimka (1). Strukturne i biokemijske promjene u mozgu koje se nalaze u podlozi demencije vode do vrlo širokog spektra oštećenja funkcija. One uključuju sve aspekte života, uključujući kognitivne sposobnosti, kontrolu emocija, aktivnosti svakodnevnog življenja, odnose u i izvan obitelji te tjelesnu dobrobit. Prema biopsihosocijalnom modelu bolesti Svjetske zdravstvene organizacije (2), nesposobnost koja proizlazi iz tih oštećenja jednako je značajna za pojedinca kao i oštećenje samih funkcija. Nesposobnost nije u potpunosti određena patologijom, ali na nju utječe društvena i fizička okolina u kojoj pojedinac živi, prepreke s kojima se susreću te podrška koju primaju. Menadžment demencije stoga nije ograničen na bavljenje patologijom ili simptomima, već mora uključivati održavanje funkcija, nadoknadu ograničenja, unaprjeđenje mehanizama olakšavanja, smanjenje prepreka te pružanje podrške. Opći je cilj pružanje optimalne kvalitete života tijekom cijelog toka demencije povećanjem sposobnosti i poticanjem neovisnosti, vraćanjem izgubljenih funkcija tamo gdje za to postoji mogućnost te prilagodbom izgubljenim funkcijama koje je nemoguće vratiti (3).

KVALITETA ŽIVOTA U DEMENCIJI

Čimbenici koji određuju kvalitetu života ljudi s demencijom razlikuju se od osobina značajnih za postavljanje dijagnoze. Kvalitetu života unaprjeđuju odnosi s ljudima, aktivnosti,

NEUROBIOLOGY, IMPAIRMENT, AND DISABILITY

In almost all instances dementia is the result of chronic, often progressive and currently irreversible brain diseases, the most frequent being Alzheimer's disease, small-vessel cerebrovascular disease, the Lewy body diseases and frontotemporal lobar degenerations. There are very few potentially treatable causes, and full recovery from dementia is a rare exception (1). The structural and biochemical brain changes that underlie dementia give rise to a very broad spectrum of impaired functions. It includes all aspects of life, including cognitive abilities, emotional control, activities of daily living, interpersonal relationships within and outside the family, and physical well-being. According to the bio-psycho-social disease model of the World Health Organization (2) the disability that results from these impairments is at least as important for the person as the impairment of functions per se. Of note, disability is not completely determined by the underlying pathology, but it also influenced by the social and physical environment the person lives in, the barriers they encounter, and the support they receive. Therefore, the management of dementia is not limited to addressing the pathology or modifying symptoms but must include maintaining functions, compensating handicaps, increasing facilitators, reducing barriers and providing supportive conditions. The overall aim is providing an optimal quality of life throughout the course of dementia by maximising ability and promoting independence, regaining lost function when there is a potential to do so, and adapting to lost function that cannot be regained (3).

QUALITY OF LIFE IN DEMENTIA

The factors which determine the quality of life of people with dementia are different from the features that are important for establishing the diagnosis. Quality of life is improved by interpersonal relationships, activity, general health,

opće zdravstveno stanje te život u zajednici. Smanjuju ju depresija, problemi u ponašanju te samački život. Pamćenje, starost, spol, obrazovanje te vrsta i trajanje demencija nemaju veze s kvalitetom života (4). Kada je riječ o tijeku demencije, u ranom stadiju kvalitetu života određuju osobna autonomija, nastavak individualnog životnog stila, postizanje pojedincu važnih ciljeva, sudjelovanje u značajnim aktivnostima, održavanje uloga te osjećaj osobe da je potrebna drugima. U srednjem stadiju postaju važni sigurnost, uvažavanje te društvene veze. Na kasnom stadiju kvaliteta života određena je utjehom, dostojanstvom, empatijom te tjelesnom dobrobiti.

ULOGA FARMAKOLOŠKIH I NEFARMAKOLOŠKIH INTERVENCIJA

Postojeći farmakološki oblici liječenja, uključujući inhibitore kolinesteraze i memantin, imaju statistički značajne ali klinički marginalne učinke na kognitivne sposobnosti i težinu demencije. Njihova dobrobit za kvalitetu života ostaje upitna (5). Također su dostupni lijekovi za probleme u ponašanju kao što su agitacija, agresija, apatija i depresija. No, antipsihotici se povezuju sa značajnim nuspojavama i zdravstvenim rizicima (6), dok je učinkovitost anti-depresiva kod ljudi s demencijom i depresijom nedavno dovedena u pitanje (7). Iz svega navedenog jasno je da se cilj upravljanja demencijom ne može postići samo lijekovima. Uz njih, potrebne su i određene nefarmakološke intervencije koje mogu unaprijediti kvalitetu života, napose kognitivna stimulacija (8), radna terapija (9) i tjelesna aktivnost (10). Zdravstvene smjernice također predlažu nefarmakološke intervencije kao prvu liniju liječenja problema u ponašanju (11). Nadalje, ključne komponente u upravljanju demencijom su promjena okoline (12), uporaba pomagala (13) te podrška neformalnih njegovatelja (14,15).

and living in the community. It is reduced by depression, behavioural problems and living alone. Memory performance, age, gender, education, type and duration of dementia are unrelated to quality of life (4). When mapped onto the course of dementia, quality of life at the early stage is mediated by personal autonomy, continuation of the individual lifestyle, attainment of personally important goals, participation in meaningful activities, retaining a role, and being needed. At the moderate stage safety, appreciation and social bonds become important. At the severe stage, quality of life is defined by comfort, dignity, empathy and physical well-being.

THE ROLE OF PHARMACOLOGICAL AND NON-PHARMACOLOGICAL INTERVENTIONS

Current pharmacological treatments including cholinesterase inhibitors and memantine have statistically significant but clinically marginal effects on cognitive ability and global severity of dementia. Benefits on quality of life have remained questionable (5). Drugs are also available for the treatment behavioural problems in dementia such as agitation, aggressiveness, apathy or depression. However, antipsychotics are associated with significant side effects and health risks (6), and the efficacy of antidepressants in people with dementia and depression has recently been questioned (7). It is clear from the above that the aim of dementia management cannot be reached with medications alone. The need to be complemented by a number of non-pharmacological interventions which have a potential for improving quality of life, in particular cognitive stimulation (8), occupational therapy (9) and physical exercise (10). Also, non-pharmacological interventions are suggested by medical guidelines as first-line treatments for behavioural problems (11). Furthermore, environmental modification (12), use of assistive technology (13) and support of informal carers (14, 15) are key components of dementia management.

RAZLOZI U KORIST MULTIPROFESIONALNE SURADNJE U MENADŽEMENTU DEMENCIJE

Kako bi se pružio cijeli spektar mogućnosti u liječenju demencije tijekom njezinog trajanja, potrebna je suradnja više profesija (16), dok je obiteljski liječnik najčešće polazna točka u tijeku liječenja (17). Tim za menadžment demencije može uključivati liječnike, psihologe, medicinske sestre, socijalne radnike, radne terapeute, govorne i jezične terapeute te fizioterapeute. Također je moguće uključiti i nacionalne i lokalne volonterske organizacije pacijenata i njegovatelja. Bilo bi najbolje da se takav tim vodi planom njege koji se temelji na potrebama, željama i sredstvima pojedinca te da ga se redovito provjerava i prilagođava progresiji demencije (18). Uloga plana njege je uskladiti i poredati aktivnosti multiprofesionalnog tima, poticati komunikaciju među njegovim članovima te prepoznati prikladne usluge i pogodnosti (19). Osobu s demencijom nužno je uključivati u donošenje odluka dok god za to imaju sposobnost (20).

PREDNOSTI USKLAĐENOG SURADNIČKOG MENADŽMENTA

Postoje dokazi da usklađivanje usluga pruža značajne prednosti ljudima s demencijom i njihovim njegovateljima. Na taj se način unaprjeđuje kvaliteta njege i pridržavanje uputama o liječenju, povećava se zadovoljstvo uslugom, unaprjeđuje zdravstvena kvaliteta života te smanjuje probleme u ponašanju (21,22). Multiprofesionalnim suradničkim modelom njege osoba s demencijom promovira se nefarmakološko liječenje, unaprjeđuje prepoznavanje komorbidnih zdravstvenih stanja te smanjuje stopa smještanja pacijenata u zdravstvene institucije (23).

THE CASE FOR MULTIPROFESSIONAL COLLABORATIVE MANAGEMENT OF DEMENTIA

In order to provide the full spectrum of treatment options along the course of dementia multiple professions need to collaborate and coordinate their efforts (16), with the general physician usually being the entry point of the care pathway (17). The management team may include physicians, psychologists, nurses, social workers, occupational therapists, speech and language therapists, and physical therapists. National or local patients' and carers' voluntary organisations may also be involved. Ideally, the group should be guided by a care plan that is based on the person's individual needs, preferences and resources, is regularly reviewed and adjusted to the progression of dementia (18). The role of the care plan is to coordinate and sequence the activities of the multiprofessional team, facilitate the communication among team members, identify appropriate services and facilities (19). Decision-making must include the person with dementia as long as they have the capacity to contribute (20).

BENEFITS OF COLLABORATIVE AND COORDINATED MANAGEMENT

There is evidence that the coordination of services provides significant benefits for people with dementia and their carers. It improves quality of care and adherence to treatment guidelines, increases the level of service satisfaction, enhances health-related quality of life, and reduces behavioural problems (21, 22). Moreover, multiprofessional collaborative model of dementia care promotes the referral for non-pharmacological treatments, augments the detection of comorbid medical conditions and lower the rates of institutionalisation (23).

MULTIPROFESIONALNO OBRAZOVANJE I OBUČAVANJE

Multiprofesionalno obrazovanje stručnjacima pruža pomagala temeljena na dokazima za prepoznavanje onoga što sami mogu doprinijeti upravljanju demencijom (24). Zajedničko učenje ima utjecaj na pozitivne stavove prema stručnjacima te bolje razumijevanje suradnje u usporedbi s tradicionalnim kliničkim obučavanjem (25). Predlaže se da se programi multiprofesionalnog obučavanja za demenciju usredotoče na četiri kompetencije, koje uključuju ranu dijagnozu, podršku poslije dijagnoze, napredno planiranje njege za osobe s demencijom i njihove negovatelje te učinkovito umrežavanje.

PROJEKT INDEED

Projekt INDEED (Inovacije za demenciju u duнавskoj regiji) je transnacionalna inicijativa čiji je cilj unaprijediti njegu osoba s demencijom putem multiprofesionalne intervencije koja povezuje tradicionalne i suvremene metode učenja (<http://www.interreg-danube.eu/approved-projects/indeed>). Projekt podržava INTERREG-Danube Transnational Programme u periodu između 2018 i 2021 te je financiran iz sredstava Europskog fonda za regionalni razvoj (ERDF) i Instrumenta pretpristupne pomoći (IPA). INDEED razvija, procjenjuje i diseminira sveobuhvatni obrazovni program za stručnjake iz područja zdravstvene i socijalne skrbi, ali i poduzetnike. Projektom se unaprjeđuju znanje i vještine vezane za demenciju kod svih ciljanih skupina, uspostavlja veze pružajući alate za umrežavanje te inovira promovi-ranjem poduzetničkih aktivnosti u području njege osoba s demencijom. Kombinacija tradicionalnih radionica i multimedijalne platforme na internetu bit će dostupna u pet jezika te će se ocjenjivati unutar probne aktivnosti u četiri zemlje.

MULTIPROFESSIONAL EDUCATION AND TRAINING

Multiprofessional education provides professionals with evidence-based tools to identify what they can bring to the management of dementia (24). Shared learning has an impact regarding positive attitudes toward other professionals and increased knowledge of and skills in collaboration compared to conventional clinical training (25). It has been suggested that multiprofessional training programmes for dementia should focus on four competencies, including early diagnosis, post-diagnostic support, advanced care planning for people with dementia and carers, and effective networking.

THE INDEED PROJECT

The INDEED (Innovation for Dementia in the Danube Region) project is a transnational initiative which aims to improve dementia care by a multiprofessional intervention combining traditional and modern learning methods (<http://www.interreg-danube.eu/approved-projects/indeed>). The project is supported by the INTERREG-Danube Transnational Programme from 2018-2021 with funds from the European Regional Development Fund (ERDF) and the Instrument for Pre-Accession Assistance (IPA). INDEED develops, evaluates and disseminates a comprehensive educational programme for health and social care professionals as well as for entrepreneurs. The project educates by improving knowledge and skills about dementia in all target groups, it connects by providing and practicing networking tools, and it innovates by promoting business activities in the field of dementia care. The combination of traditional workshops and a multi-media online platform will be available in five languages and will be evaluated in pilot actions in four countries.

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