

## MENTAL HEALTH OF INFORMAL CAREGIVERS

## MENTALNO ZDRAVLJE NEFORMALNIH NEGOVATELJA

Tatjana Rajović<sup>1</sup>, Nataša Milić<sup>1</sup><sup>1</sup> Univerzitet u Beogradu, Medicinski fakultet, Institut za medicinsku statistiku i informatiku, Beograd, Srbija**Correspondence:** tanja.rajovic63@gmail.com**Abstract**

The aging society is facing an important public health problem related to provision of care to older and dependent people. The care provided on a daily basis includes a range of different social and health services, as well as the provision of emotional support to people who are not capable to function independently. Activities important for day by day functioning, such as bathing, dressing, feeding, shopping and health monitoring are only part of the responsibilities and obligations that the “invisible workforce”, i.e. informal caregivers, must provide. Even though, regardless of the heavy price informal caregivers often pay with their economic and health status, they still remain a blind spot in public policies. An informal caregiver provides ongoing care and assistance, without receiving payment, to family members and friends who need support due to physical, cognitive or mental problems. Depression is one of the most common problems experienced by informal caregivers and it is estimated that a large number, in the range of 40% to about 70% of all informal caregivers have depression symptoms. The COVID-19 pandemic has certainly left its mark on physical health, however, as the pandemic moves forward, it has begun to show an ever increasing impact on the mental health of people around the world, where informal caregivers fall into a particularly vulnerable category. Particularly those informal caregivers who provide long-term help to a member of the family, became of an increased risk of emotional and physical exhaustion due to the burden of care, reduced services, as well as the relocation to consulting by telephone and the digital sphere. While some of them managed to cope with stress and became resilient, others did not and the increasing psychological pressure led to the development of depression symptoms.

**Keywords:**informal caregiver,  
mental health,  
COVID-19

## Sažetak

Savremeno društvo, u kome se demografska slika menja prema sve starijem prosečnom životnom dobu, suočava se sa važnim javnozdravstvenim problemom koji se odnosi na pružanje pomoći starijim i zavisnim osobama. Svakodnevna pomoć obuhvata niz različitih zdravstvenih i socijalnih usluga, kao i pružanje emocionalne podrške osobama koje nisu u stanju da samostalno funkcionišu. Aktivnosti važne za svakodnevno funkcionisanje, poput kupanja, oblačenja, hranjenja, kupovine i kontrole zdravlja samo su deo odgovornosti i obaveza koje „nevidljiva radna snaga“, tj. neformalni negovatelji, moraju da obezbede. Iako pružanje neformalne nege značajno utiče na ekonomski i zdravstveni status neformalnih negovatelja, oni i dalje ostaju minimalno uključeni u kreiranje javnih politika. Neformalni negovatelj je osoba koja, bez finansijske nadoknade, pruža kontinuiranu negu i podršku osobama kojima je potrebna pomoć zbog fizičkih, kognitivnih ili mentalnih problema (najčešće članovima porodice ili osobama u okruženju). Depresija predstavlja vrlo čest problem sa kojim se suočavaju neformalni negovatelji (procenjuje se da između 40% i 70% neformalnih negovatelja ima simptome depresije). Pandemija KOVID-19 svakako je uticala na fizičko zdravlje, ali s obzirom na njeno trajanje, vrši sve veći uticaj i na mentalno zdravlje, a neformalni negovatelji spadaju u posebno ranjivu kategoriju. Neformalni negovatelji, posebno oni koji pružaju dugotrajnu negu članovima porodice, u povećanom su riziku od fizičke i emocionalne iscrpljenosti zbog dodatnog opterećenja pružanja nege u okolnostima nastalim tokom pandemije, smanjene dostupnosti neophodnih usluga, kao i premeštanja mnogih usluga u digitalno okruženje, što dodatno povećava stres i probleme sa mentalnim zdravljem. Dok su neki neformalni negovatelji uspeali da se izbore sa stresom razvojem odbrambenih mehanizama, drugi nisu, a psihološki pritisak je doveo do razvoja simptoma depresije.

### Ključne reči:

neformalni negovatelj,  
mentalno zdravlje,  
KOVID-19

The aging society is facing an important public health problem related to provision of care to older and dependent people. The care provided on a daily basis includes a range of different social and health services, as well as the provision of emotional support to people who are not capable to function independently. Activities important for day by day functioning, such as bathing, dressing, feeding, shopping and health monitoring are only part of the responsibilities and obligations that the “invisible workforce”, i.e. informal caregivers, must provide. Due to Europe’s demographic ageing and an overall increase in life expectancy, there is an increasing need for care in all age groups, leading to caregivers’ contribution to the sustainability of health care systems and to the well-being of people in need of care being simply vital. Even though, regardless of the heavy price informal caregivers often pay with their economic and health status, they still remain a blind spot in public policies (1).

An informal caregiver provides ongoing care and assistance to family members and friends who need support due to physical, cognitive or mental problems, without receiving payment. Data suggests that between 20% and 44% of individuals in Europe provide some form of informal care (2). In addition, around 13% of people aged fifty and over, across 18 OECD countries, provide informal care at least weekly (3). The Organization for Security and Cooperation in Europe (OSCE) reports that one in every ten adults provides informal care to a member of the family who has some functional limitations (4). It is often suggested that the informal caregiver is a woman of an average age of over 50. The informal caregiver can be of any gender, age, educational level, financial status,

but more importantly of different condition of health (5). Results of a study carried out in Austria, on a sample of 7403 children, showed that 4.5% of children, aged on average 12 and a half years, care for the elderly in the family (6). In the European Union, nearly 16% of the working age population, in addition to their every day job, has the obligation to provide some type of informal care and also, 50% of informal care providers who provide care regularly have a permanent job. According to the data provided by OECD, over half of all informal caregivers provide services for 10 hours or less per week, and just less than one fifth provide more than twenty hours per week (5).

Informal caregivers can be divided into three groups according to the type of person being cared for: a child with a chronic illness or disability cared for by young parents, an adult child with mental health problems or similar health problems cared for by middle-aged parents and older people cared for by their spouse/partner or their adult/middle-aged children (7). Providing care to a child with a chronic illness or disability is a special category of informal care and it often involves a complex program of therapies and treatments that are provided to a significant extent by the parent or guardian. Of course, a number of these children still need support in performing daily life activities, which again implies the involvement of parents. The burden on parents/guardians of these responsibilities can be very high and lead to various negative effects on their quality of life, including insomnia, anxiety, depression, as well as financial problems, which in turn can have negative consequences for the child being cared for. Possible negative consequences range from the care being provided is of poor quality, through having a

psychological burden and even neglect or physical abuse. Informal caregivers of children with disabilities continue their role from the birth of a child to the end of their life. When informal caregivers reach some late years, the special fear appears - who will take care of their children after their death and what will happen to them, which affects their health, mostly mental (8).

Informal caregivers are usually not trained or prepared for their role. It is often imposed on them by circumstances and they often provide care without the necessary knowledge and skills, as well as without support that would help them save and protect their own health. It is not uncommon for a caregiver to provide care to a person who needs it even with having health problems himself. Recent research shows that caregivers themselves are at increased risk of impaired health and that long-term efforts and tensions related to provision of informal care cause a variety of physical and mental health problems (9). Studies have shown that between 15% and 32% of caregivers estimate that they are under a heavy burden of care and that those who are socially isolated or could not organize an alternative way of care are particularly endangered. The burden on caregivers further increases when the health of the person being cared for deteriorates and they have to provide care 24 hours a day, seven days a week, but the burden also increases in people with poorer financial situation and lower education (8).

Providing of informal care can induce opposite effects on mental health of informal carers: ranging from the fact that this activity brings satisfaction, emotional fulfillment and a sense of purpose - to experiencing poorer mental and physical health and being of higher risk of depression compared to people who do not provide care. Literature states that if care is provided over a long period of time, caregivers are at risk of burnout syndrome, which can lead to worsening physical, mental health and risk of depression (10). Mental health problems are 20% higher among informal caregivers than among those who do not provide care, and are especially pronounced in people who provide care more than 20 hours per week (very intensive care). Depressive disorders, anxiety, anger and animosity are often associated with greater responsibilities of care and attention. Prolonged effort, uncertainty, inability to find an adequate balance between work, private life and care for the person who needs it - has a negative impact on the emotional and mental health of informal caregivers. For this reason, in this population, elevated levels of anxiety, stress, depression and other mental problems are often encountered (11).

Depression is one of the most common problems experienced by informal caregivers and it is suggested that a large number, in the range of 40% to 70% of all informal caregivers have some symptoms of depression, of which between 25% and 50% have symptoms of such severity that they meet the criteria of major depression (12). These symptoms get worse with increasing care load, so the presence of emotional stress and depression is very high (from 30% to 40%) in caregivers providing care for

people with dementia (13). Women informal caregivers are particularly exposed to the negative effects on mental health, with more frequent symptoms of depression and anxiety and thus more compromised physical health (14). High levels of stress lead to feelings of frustration, anger, exhaustion, guilt and helplessness. This is especially pronounced when caregivers cannot notice that the person they are caring for is improving in any way (15). Caregivers also report lower levels of self-esteem, a constant feeling of worry and loss of control over their lives. This is further associated with insomnia, but also with the risk of impaired cognitive functions - poor memory, impaired attention, etc (16).

The perception of a caregiver's burden is multidimensional and complex. In 1986, Zarit and collaborators defined caregiver burden as „the degree to which a caregiver's emotional or physical health, social life or financial status had suffered as a result of caring for their relative” (17). In addition, Dang et al. suggested that caregiver burden includes the overall psychological, emotional, physical and financial toll of providing care (18). Up to date literature showed that the main factors relating to the patient which contribute to caregiver burden are the patients' severity disturbances, extent of changes in personality, as well as the development of psychiatric symptoms. Some studies reported that older caregivers experienced great perception of burden, whereas in other studies, a greater sense of burden experienced younger caregivers. Results of both studies are reasonable: older caregivers generally have poor psychological and physical health, while younger caregivers are less experienced in care giving (19). When it comes to stress and the burden of care, it is recognized that providing care over extended periods of time is stressful because it mandates at least some physical effort, creates a psychological burden, has a high level of unpredictability and can pour into other areas of life such as employment, family relationships and etc (20). Studies analyzing burnout syndrome in informal caregivers that provide care for people with dementia and who observes the objective characteristics of care (economic cost, time required for care) and subjective, emotional response in caregivers, indicates that more intensive care, involving several hours a week, can result in emotional stress, physical exhaustion, limiting opportunities to partake in social life or recreational activities, decreased appetite and troubles maintaining regular sleep, as well as an increased risk of mental disorders and mortality. Emotional attachment to the person informal caregiver cares for, as well as the fact that informal care does not have defined working hours, nor does it provide any material payment, is an additional factor. Together with social isolation, poorer physical health and an unenthusiastic attitude towards providing care are all predictors of burnout syndrome, which further diminishes the quality of care. Scholars such as Alves and collaborators in their systematic review reported a correlation between the extent of the limitations in the person receiving care and the burden felt by the informal caregiver (20).

The COVID-19 pandemic has certainly left its mark on physical health, however, as the pandemic moves forward, it has began to show an ever increasing impact on the mental health of people around the world, where informal caregivers fall into a particularly vulnerable category (21). Informal caregivers, particularly those who provide long-term help to a member of the family, became of an increased risk of emotional and physical exhaustion due to the burden of care, reduced services, as well as the relocation to consulting by telephone and the digital sphere. While some of them managed to cope with stress and became resilient, others did not and the increasing psychological pressure led to the development of depression symptoms. In addition, COVID-19 increased the pressure on informal caregivers, since it increased the scope and manner of their usual care. Caregivers reported that they did not have the opportunity to have a break and had little time for self-help and for themselves (22). Bearing in mind the impact of the COVID-19 pandemic on the circumstances under which informal care is provided, it is essential to design appropriate measures in order to help informal caregivers overcome the stress they are encountering, the subjective sense of burden, and depression. They should be recognized as being a part of a formal long-term healthcare system, which would provide additional rights concerning social and health protection, as well as in the field of labor law. In this way, the first step would be taken in providing them with support, which will have a positive impact on the outcomes of physical and mental health, in addition to the level of quality of care they provide.

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## Literature

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