

Mental Health of Informal Caregivers

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1

INTRODUCTION

Millions of “invisible” people worldwide provide care to family members or close persons that need it. Health, quality of life and, in many cases, the very lives of functionally dependent people are largely influenced by the involvement of informal caregivers. In the context of population ageing, changes in family structures and increased life expectancy, there is a growing need for care, which makes the contribution of informal caregivers vital for the sustainability of the social protection and healthcare, long-term care, economy and well-being of the people in need. Unfortunately, despite the high price they often pay in terms of their own health and economic status, they remain in the blind spot of policy analyses. Caregivers, who are most often close family members, have an important and unique role in providing support to children and adults with disabilities, older persons in need of care, or persons suffering from chronic noncommunicable diseases or serious illnesses. By providing adequate care, both social, psychosocial, and in some cases financial support, they enable these population categories to go on living with their families in a familiar environment and be equal members of the community.¹

An estimated 349 million people worldwide are in need of care and, among them, 18 million (5%) are children under 15 years of age, and

¹ Eurocarers’ Position Paper July 2020 Eurocarers’ analysis of the EUROPEAN SEMESTER: Informal carers, left aside again? <https://eurocarers.org/publications/eurocarers-analysis-of-the-european-semester-informal-carers-left-aside-again-2/>

101 million (29%) are persons over 60.²

Population ageing will certainly increase the need for formal and informal care. Estimates indicate that, at this moment, there are 728 million people aged 65 years or over worldwide. It is expected that this number will increase more than twofold over the next 30 years, and in 2050 reach the number of 1.5 billion people aged 65 years or over, which will mean that the share of the world population aged 65 years or over will increase from 9.3 percent in 2020 to around 16 percent in 2050. The largest increase is expected in East and Southeast Asia (+300 million persons), which is an increase from 272 million persons aged 65 years or over in 2020 to 572 million in 2050. Other regions also expect major increases in the number of older persons in the next 30 years, including Europe and North America (+91 million persons).³ Europe is the continent with the oldest population. It is estimated that by 2050 one in two inhabitants of Europe will be aged 50 years or over, and that 10% of the population in Europe will be older than 80 years of age.⁴

In Serbia, an increasingly ageing population has caused a continuous increase in the percentage of older people in the total population and a low and continuously declining percentage of younger people. Based on population assessments performed by the Statistical Office of the Republic of Serbia (SORS), the 2019 data for Serbia demonstrates that the percentage of persons aged 65 and over was at 20.7% (17.3% in 2011), and the percentage of people under 15 years of age amounted to 14.3% (14.4% in 2011). The average age of the Serbian population has increased from 42.2 years (2011) to 43.1

² Evidence profile: caregiver support <https://www.who.int/ageing/health-systems/icope/evidence-centre/ICOPE-evidence-profile-caregiver.pdf?ua=1>

³ Government policies to address population ageing https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/undesapd_2020_pf_government_policies_population_ageing_cover.pdf

⁴ Tsoleva, Svetla & Mortensen, Jørgen. (2019). THE CROSS-ATLANTIC EXCHANGE TO ADVANCE LONGTERM CARE.

(2019). The main characteristic of population movement projections in the period between 2011 and 2041 is the process of depopulation, with one in four persons being over 65 years of age at the end of the projected period (24% of the population will be 65 years of age and over), and the demographic dependence rate would, in this period, increase from 25% to 39%. For policies relevant to informal caregivers, it is also important to note that the 15 to 64 years of age cohort has reduced in Serbia from 68.3% (2011) to 65% (2019).⁵

Higher disability rates amongst older persons are a direct result of an accumulation of health risks across a lifetime of disease, injury, and chronic illness. In this respect, there is a disproportionately higher representation of older persons in the general population, and, as age progresses, so does the risk of disability. Therefore, for the population between 80 and 89 years of age, the risk of disability increases by 3.9% per year of age. Although the incidence of disability among older persons differs between countries, the trend of population ageing, as well as the fastest increase of the share of the “older elderly”, meaning people over 80 years of age, is consistent. Thus, it is expected that by 2050, persons over 80 years of age with some form of disability will constitute one-fifth of all the persons with disability over 60 years of age.⁶ More than 46% of persons aged 60 years and over have some form of disability, and more than 250 million older persons have moderate to severe disability.⁷

The number of persons with disabilities and their percentage in the general population varies due to differences in definitions, methodology, and data collection methods through censuses and

⁵ Zavod za statistiku Republike Srbije (2020), Statistički godišnjak str.25 <https://publikacije.stat.gov.rs/G2020/Pdf/G20202053.pdf>

⁶ World Report on Disability 2011: <https://www.who.int/teams/noncommunicable-diseases/disability-and-rehabilitation/world-report-on-disability>

⁷ Ageing and disability, United nations, Department of Economic and Social Affairs Disability, <https://www.un.org/development/desa/disabilities/disability-and-ageing.html#:~:text=Currently%2C%20it%20is%20estimated%20that,experience%20moderate%20to%20severe%20disability>

research.⁸ Current estimates are that 15% of the global population, or around one billion of individuals live with at least one form of disability one or multiple forms of disability. The prevalence of disability is higher in developing countries, and the risks of adverse socioeconomic outcomes, such as lower education, poorer health outcomes, lower employment levels and higher poverty rates are higher amongst persons with disabilities.^{9, 10} According to 2011 data, 8% or 571,780 citizens of Serbia can be considered persons with disabilities, 58.2% of whom are women.¹¹

The quality of life and social inclusion of persons with disabilities, in addition to formal services provided by various systems, largely depends on the involvement of informal caregivers. The burden of chronic noncommunicable diseases (NCDs) is trending in all age groups, and informal caregivers most often spend several years providing care to individuals with one or several chronic illnesses, without any training or adequate support by the health system.¹² Chronic NCDs include: cardio-vascular, carcinoma, diabetes, and chronic respiratory illnesses, and they are the leading cause of death and disability worldwide. Globally, out of the total of 56.9 million deaths in 2016, 40.5 million (71%) were caused by chronic NCDs. Over three-quarters of deaths from NCDs, or 31.5 million, occur in low and

⁸ Marković M. Milan, *Osobe sa invaliditetom u Srbiji*, Republički zavod za statistiku, 2014, <http://pod2.stat.gov.rs/ObjavljenePublikacije/Popis2011/Invaliditet.pdf>

⁹ Ageing and disability, United nations, Department of Economic and Social Affairs Disability, <https://www.un.org/development/desa/disabilities/disability-and-ageing.html#:~:text=Currently%2C%20it%20is%20estimated%20that,experience%20moderate%20to%20severe%20disability>

¹⁰ Disability Inclusion, The World Bank, <https://www.worldbank.org/en/topic/disability#:~:text=Results-,One%20billion%20people%2C%20or%2015%25%20of%20the%20world's%20population%2C,million%20people%2C%20experience%20significant%20disabilities>

¹¹ Milan M. Marković, *Osobe sa invaliditetom u Srbiji*, Republički zavod za statistiku, Beograd, 2014

¹² Financial support for informal care provision in European countries: a short overview. Health and Aging

middle income countries, with 46% of deaths occurring before the age of 70. Cardio-vascular diseases were the cause of death for 17.9 million people in 2016, which was 44% of all deaths from chronic NCDs; carcinoma caused 9.0 million or 22% of all deaths from chronic NCDs; and respiratory conditions, including asthma and chronic obstructive pulmonary disease, caused death in 3.8 million people or 9% of all deaths from chronic NCDs. Diabetes caused another 1.6 million deaths.¹³

In this context, attention should also be paid to mental health, which is another important factor of functional dependence and disability. It is expected that 5.4 million persons, who are at this moment diagnosed with dementia, will increase twofold in Western and threefold in Eastern Europe by 2030.¹⁴ Depression is a disorder that affects over 264 million people. Long-term and mild or severe depression may seriously impair general health. In the worst-case scenario, depression can lead to suicide and annually, nearly 800,000 people commit suicide. Further, suicide is the second leading cause of death for those aged between 15 to 29 years.¹⁵

Cardio-vascular disease and malignant tumours accounted for over three-quarters of all causes of death in Serbia in 2006. In the structure of mortality, cardio-vascular diseases accounted for over one-half of all fatal outcomes (57.3%), and nearly one in five persons (19.7%) died from malignant tumours. Out of the total number of deaths, in 3.8% of the population they were caused by injuries and poisonings, in 2.5% by diabetes-related complications, and in 1.8% by chronic

¹³ Total NCD Mortality, The Global Health Observatory, World Health Organisation, <https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-group-details/GHO/total-ncd-mortality>

¹⁴ Alzheimer Europe research, Who cares? The state of dementia care in Europe, <https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports>

¹⁵ Depression: Key Facts, World Health Organisation, <https://www.who.int/news-room/fact-sheets/detail/depression>

obstructive pulmonary disease (COPD) or asthma.¹⁶

A further important trend is a changed family structure, with fewer opportunities for children to be present and provide care to their parents – or their parents’ parents – in the way it was expected and customary in previous generations. People marry later, they have children later, they have fewer children, and some decide to live without children or to live alone. These circumstances often lead to an increased need for care, so countries throughout the world will have to plan the functioning of the system of long-term care more seriously, recognising the importance and complementarity of formal and informal services.

At the moment, informal caregivers globally play a central role in providing long-term care. It is estimated that between 70% and 95% of all care-related needs are provided by family members, relatives, friends and neighbours, thus covering gaps in short-term and long-term provision of formal care. This enables persons with need for care to live their lives with dignity and postpone the need for institutional care, also giving them the opportunity to remain in their own homes.^{17,18} Informal caregivers present an “invisible workforce”, which often does not receive support from the system or the society, and their time, financial, economic and health burdens are insufficiently recognised. In Switzerland, the value of informal care work is estimated at between 10 and 12 billion Swiss francs

¹⁶ Strategija za prewenciju i kontrolu hroničnih nezaraznih bolesti, “Sl. glasnik RS”, br. 22/2009, http://demo.paragraf.rs/demo/combined/Old/t/t2009_04/t04_0135.htm

¹⁷ Who Cares? Attracting and Retaining Care Workers for the Elderly, <https://www.oecd.org/fr/publications/who-cares-attracting-and-retaining-elderly-care-workers-92c0ef68-en.htm>

¹⁸ UNECE, The challenging roles of informal carers, Policy Brief on Ageing No. 22 September 2019, https://www.unece.org/fileadmin/DAM/pau/age/Policy_briefs/ECE_WG1_31.pdf

annually¹⁹, while in the USA, annual value of informal care work amounted to 470 billion US dollars in 2013²⁰, and in the Netherlands, the value of informal work is twice the amount spent on formal care services.^{21,22} The value of informal care work is certainly much higher than the estimates, because some aspects of the work and their engagement cannot be estimated.

For example, it should be noticed that approximately 16% of the working population in the European Union, in addition to their permanent employment, also have to provide informal care, and that 50% of informal carers providing care regularly have permanent employment, as well as 70% of those providing care occasionally. Informal caregivers, who are under significant burden for longer periods of time and without appropriate support, are at risk of burnout syndrome and mental and physical health issues, which is when the quality of care provided drops. Without the appropriate support, this can lead to the situation in which the caregiver would be in no state to provide adequate care anymore. Existing measures and public policies to mitigate or prevent this problem are currently not sufficient, nor evenly available.²³

The relevance of the mentioned trends and, above all, the relevance of population ageing, should be documented in public policies issued

¹⁹ Mestheneos, E. and Triantafyllou, J. (Eds: H. Döhner and C. Kofahl). 2005. Eurofamcare. Supporting family carers of older people in Europe – Empirical evidence, policy trends and future perspectives, the Pan-European background report. Hamburg, https://www.uke.de/extern/eurofamcare/documents/nab-ares/peubare_a4.pdf

²⁰ Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser, Valuing the Invaluable: 2015 Update, 2015, AARP Public Policy Institute

²¹ Timmerman, J. (ed). 2003. Mantelzorg. Over hulp van en aan mantelzorgers [Family care. About help for and by family carers]. Den Haag: SCP.

²² Ministry of Health, Welfare and Sport (VWS). 2004. En route to a sustainable system of long-term care and social support. The Hague. DVVO-U-2475093, 23 April.

²³ What do informal carers need? Towards a fair and rights-based deal, https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Needs_final.pdf

by governments worldwide. Furthermore, public policies should recognise the role of informal caregivers in the coming period, as the important system of support to individuals, families, communities, institutions and countries.

It is important that public policies, in addition to focusing on data, also pay attention to the caregiver burden and burnout syndrome, with the aim to design useful interventions to reduce them. These interventions can postpone the placement of dependent individuals in institutions and can improve the quality of life of both the informal caregiver and the care recipient.²⁴

More recently, during the COVID-19 pandemic, informal caregivers have found themselves in an even more demanding role, by becoming the first line of defence and one of the pillars of the healthcare and social protection systems. However, although it has been pointed out, informal caregivers remain “invisible” from the aspect of the system, policies and support services worldwide.

1.1. Informal care

Informal care is a type of care that is provided to functionally dependent persons by family members, friends and neighbours, rather than trained, licensed or certified healthcare and social protection professionals.²⁵ This type of care covers assistance in four main areas: 1. activities of daily living (e.g. washing, going to toilet and eating); 2. instrumental activities of daily living (e.g. housework, transport and managing finances, shopping); 3. socialisation and emotional support; and 4. healthcare.²⁶

Informal care may differ by intensity, type of assistance provided,

²⁴ Moving beyond caregiver burden: identifying helpful interventions for family caregivers, <https://pubmed.ncbi.nlm.nih.gov/24496059/>

²⁵ <https://medical-dictionary.thefreedictionary.com/informal+care>

²⁶ Formal and Informal Care https://link.springer.com/referenceworkentry/10.1007%2F978-3-319-69892-2_847-1

location, characteristics of the person in need of care and the duration of care provided. It is also necessary to pay attention to the time continuum and differences between the onset of caregiving and continuity over the years. Also, informal care depends on the needs and demands of the dependent person in need of care and support.²⁷

Care-related activities cover various areas and include social, health, psychological, but also educational services. Duties and responsibilities accompanying informal care, on one hand, represent regular and continuous activities and, on the other, in the majority of cases change over time. As the years pass, care becomes more and more demanding, both in terms of activities and in terms of time spent by informal caregivers providing support and care. Whether these caregivers are providing care to a child, an adult or an older person, if it lasts for a long time, it can lead to informal caregiver exhaustion, but also worsened health, both physical and mental.

1.2. Informal caregivers vs. informal carers

A factor making it more difficult to recognise informal caregivers is the use of different terms, such as “informal carer”, “family caregiver”, and also the fact that some authors use this term to denote only the provision of support and care to older persons. However, there are further variations related to whether the care provided requires physical presence, so it is expected that emotional and psychosocial support can be provided long-distance. In any case, “informal caregiver is a person providing continuous care and assistance, without compensation, to family members and friends that need support because of their physical, cognitive or mental issues”.²⁸

OSCE states that one in ten adults provide informal care to a family

²⁷ Providing informal care in a changing society <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4992501/>

²⁸ Statement on Caregiver Language, www.ccc-ccan.ca

member with some functional limitations. If this form of care also includes assistance with shopping or doing home finances (paying bills, taxes), then almost one-third of persons over 50 years of age provide some form of informal care. Also, there is no clear geographic distribution, meaning that informal care provision is equally distributed in both the north and the south of Europe. Women constitute the majority of informal caregivers, but over the age of 75 the balance changes in the favour of men in two-thirds of European countries. A little over one-half of all informal caregivers provide services for up to ten hours a week, and a little under one-fifth provide services for over twenty hours a week. Additionally, the probability of unemployment is higher for informal caregivers than for persons of the same age not providing care, and less than 50% of them are the main earners in their households. The socioeconomic status has a twofold impact here, because on one hand poorer families have fewer opportunities to participate in the labour market but, on the other, the probability is higher that their members would be involved in providing informal care.²⁹

Although it is often mentioned that informal caregivers are mostly women of average age over 50 years, informal caregivers can be of any sex, age, education, financial situation, but also of different health status. Therefore, we need to be careful when describing profiles of informal caregivers and designing support services, so as to somehow meet the general, but also specific needs of different caregivers. For example, a group that is often overlooked when it comes to informal caregivers are young providers of informal care, and here it needs to be considered that the provision of care often influences other areas of their lives – from education and social life to job search and starting their own families, but also their physical

²⁹ Help Wanted? Providing and Paying for Long-Term Care <https://www.oecd.org/health/health-systems/help-wanted-9789264097759-en.htm>

and mental health.³⁰ In a research conducted in Austria on a sample of 7,403 children, it was found that 4.5% have on average been providing care to an older person in the family for 12 and a half years, and that the specific needs of these caregivers need to be taken into account. Among others, one of the important recommendations from this study is the prevention of burnout syndrome and promotion of health and psychological well-being.³¹ Another group that should be taken into consideration when creating public policies and support services are employed persons providing informal care, who often encounter serious challenges in trying to strike a balance between their work and care-related responsibilities. This arrangement can reduce the efficiency in their work, slow down the progress of their careers, and also be the reason for losing their jobs. This, on one hand, can be seen as the violation of their human rights, but on the other represents loss for the society as a whole, in terms of unutilised potentials. For these reasons, it is not uncommon in practice that informal caregivers, more often women, find themselves in an unfavourable economic, but also social situation.³²

Informal caregivers can further be divided by types of persons to whom care is provided: child with a chronic illness or physical and psychological disability, to whom care is provided by young parents, middle-aged parents or older persons (grandparents); adult with physical and mental disability or similar health-related issue, to whom care is provided by middle-aged parents; and, finally, older persons to whom care is provided by their spouses/partners, their

³⁰ What do informal carers need? Towards a fair and rights-based deal. https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Needs_final.pdf

³¹ Prevalence and effects of caregiving on children. <https://pubmed.ncbi.nlm.nih.gov/24660847/>

³² What do informal carers need? Towards a fair and rights-based deal, https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Needs_final.pdf

adult/middle-aged children/grandchildren, friends or neighbours.³³

The provision of care to one's own child with disability or severe chronic illness represents a special category of informal care, and in many cases includes a large number of activities that the parent undertakes spontaneously or that are imposed on them. Often parents have to learn certain medical treatments and administer therapies, which are provided to a not insignificant extent (special diets, taking medicines, exercising, etc.), in addition to regular support with activities of daily living. They may be overwhelmed by the burden of these responsibilities, especially during emergencies, and this can also lead to different adverse effects on parents, ranging from insomnia, anxiety, depression and other health-related issues, to financial difficulties, which, in turn, may have negative effects on the child receiving care. Possible adverse effects range from poor quality of care, psychological burden to psychological and physical abuse and neglect. Informal caregivers of children with disabilities remain so throughout their lives, but activities are adapted to the age of the child and the caregiver. A special fear of informal caregivers typically starts when they reach older age, as they wonder what will happen to their children and who will take care of them after they had passed, which affects both their physical and mental health.³⁴

Sources also mention occasional caregivers, whose tasks begin when there is an acute condition. The challenges of this type of care are different from those experienced by informal caregivers of chronically ill, older persons, or children and people with disabilities. This occasional arrangement includes a sudden provision of care to

³³ Schulz R., Tompkins C. A. Informal Caregivers in the United States: prevalence, caregiver characteristics, and ability to provide care. In: *The Role of Human Factors in Home Health Care: Workshop Summary*. Washington, DC 2010: National Academies Press.

³⁴ Unapređenje položaja neformalnih negovatelja u Republici Srbiji, <http://humanas.rs/download/3333/>

a person who has left the hospital after, for example, hip surgery, treatment of a malignant disease, a stroke or a heart attack. Under such circumstances, informal caregivers are under pressure caused by the requirement to quickly master skills related to the provision of basic medical care in a home setting, to learn to monitor the recipient's health (to be able to recognise any deterioration of their condition), which is often a difficult task for persons without any prior knowledge. There is also a fear of doing something wrong and putting the care recipient at additional health risk. Also, with this type of care, it is necessary to quickly adjust the previous lifestyle to the life of a caregiver. In addition, the lack of necessary information is also a difficulty for them. During the COVID-19 pandemic, this was an additional burden because many services were limited and redirected to telephone consultations.³⁵

Globalisation and migration have brought about an increase in the number of long-distance informal caregivers. Here, we are referring to the provision of care to a person that lives more than one hour's journey away from the caregiver, which can also sometimes be a different town or country. This does not mean that these caregivers, only because they live far, are not responsible for finances, health-related medical care and personal needs of their family member. One of the most difficult aspects of long-distance provision of care is how to provide good-quality care to such a person. These care providers are most often secondary providers, supplementing the work of primary care providers, who live in the same space or close to the care recipient. The engagement of long-distance informal caregivers can include the organisation of care or supervision of care. These informal caregivers have the responsibility to select an adequate local care provider and keep informed about to what extent this care is of good quality and meets the needs of the recipient. They need to

³⁵ National Research Council. (2010). The Role of Human Factors in Home Health Care: Workshop Summary, <https://www.nap.edu/read/12927/chapter/1#ii>

have information and skills related to finding and choosing adequate local care providers, who will be in continuous contact with the care recipient. Additionally, a special challenge related to mental health is the psychological pressure because they are not able to provide direct care to the person close to them for the entire time.^{36,37}

1.3. Informal caregivers during COVID-19

The COVID-19 pandemic has changed the way of life, influenced the functioning of health systems, long-term care systems, transport, the economy, financial security, education, but also family and private life. Initial data show that around one-half of all COVID-19 related deaths during the first wave of the pandemic occurred among older persons residing in nursing homes.³⁸

According to one study, the mortality of persons over 65 years due to COVID-19 is significantly higher than the mortality among the younger population, with a ratio as high as 7.7:1 compared to the population between 55 and 64 years of age. The same study registers that more older men than older women died, in the proportion of 1.77:1.³⁹ Despite these findings, an awareness of insufficient funding and the fragmentation of the system for long-term care has only gradually increased.⁴⁰ However, while the attention has been firmly on the formal system of long-term care, formal service providers and

³⁶ National Research Council. (2010). The Role of Human Factors in Home Health Care: Workshop Summary. <https://www.nap.edu/read/12927/chapter/1#ii>

³⁷ Aging Care- Family Caring for Family. The Caregivers' Survival Guide (2017) <https://oak-meadows.org/wp-content/uploads/2017/02/AgingCare-FamilyCaringForFamily.pdf>

³⁸ COVID-19: Implications for the Support of People with Social Care Needs in England, https://www.researchgate.net/publication/341590052_COVID-19_Implications_for_the_Support_of_People_with_Social_Care_Needs_in_England

³⁹ COVID-19 mortality risk for older men and women, <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-020-09826-8>

⁴⁰ Preventing and managing COVID-19 across long-term care services: Policy brief, 24 July 2020, https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1

residential institutions, the needs of persons living in home settings and their informal caregivers has received relatively little attention⁴¹. This is both in terms of services and in terms of meeting their needs and protecting their health.

At the onset of the pandemic, many countries omitted to recognise the importance and the role of informal caregivers in the situations of care and support to functionally dependent older persons, children and chronically ill adults, children and persons with disabilities or persons diagnosed with COVID-19. Also, it is important to note that during the pandemic, a new group of informal caregivers emerged, providing assistance to older persons who were not functionally dependent or chronically ill, but were forbidden to leave their homes. This type of care was initially occasional, but it lasted for several months, which had an impact on the quality of lives of both informal caregivers and those in need of support.

Although during the emergency situation it was clear how important informal caregivers are in responding to emergencies, our knowledge about the characteristics, needs and challenges faced by informal caregivers, especially during the COVID-19 pandemic, are still limited. Informal caregiver physical, mental health and social well-being are mostly neglected in practice, but also in the research literature. Also, this group is still seen as passive and is not included in the processes of preparation and response to disasters.

Further, policy makers often assume that informal caregivers have an adequate level of medical literacy, knowledge of diseases and illnesses, psychological preparedness and the capability to provide health-related care. Another assumption is related to the environment that the caregiver resides in. This is mostly not considered and it is automatically assumed that the living space is adequate and enables care and easy access to aids and meets the needs of both

⁴¹ Care in times of COVID-19: The impact of the pandemic on informal caregiving in Austria, <https://osf.io/preprints/socarxiv/bj3fk/>

caregivers and care recipients⁴². This is often not the case in practice, so these limitations have become even more pronounced during the pandemic.

The COVID-19 pandemic has influenced the functioning of health systems worldwide. Many of these systems have been exposed to serious pressures and challenges that have led to problems in their functioning and the need to quickly adapt to the new circumstances. Because of the rapid increase in the number of infections, on one hand, and limited resources of the healthcare system on the other, in many countries the focus has been on disease-related screening, with the people with more severe forms of infection referred to hospital treatment. However, those with milder symptoms were referred for home treatment, which made home care during COVID-19 one of the pillars of the health system to support people with confirmed or suspected COVID-19 infections. Despite this, the informal provision of home care and challenges faced by informal caregivers in home settings were not recognised as part of the required support to the health system to overcome the pandemic. Of course, it should not be forgotten that people with COVID-19 were not the only ones that needed care. A large percentage of care recipients in home settings were still persons with chronic illnesses, mental disorders or disabilities, who continuously needed the same basic assistance as before COVID-19. These are the persons that need support and care to function normally and live with dignity, and during the pandemic they needed additional support. Also, the pandemic led to support and care often being needed by healthy, but dependent individuals, such as newborns, small children, school children and healthy older persons.⁴³

⁴² Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7263813/>

⁴³ A review on implications of home care in a biological hazard: The case of SARS-CoV-2/COVID-19, http://www.ccouc.ox.ac.uk/_asset/file/a-review-on-implications-of-home-care-in-a-biological-hazard.pdf

Informal caregiver support during COVID-19 was particularly important when it comes to persons with mental disorders (e.g. schizophrenia, bipolar affective disorder), where individuals may have hallucinations (e.g. hear voices when there is no one there), individuals with cognitive disorders (e.g. difficulties in organising and clearly expressing thoughts) and pronounced difficulties with social functioning. The course and outcomes of these issues are often greatly improved by the support of caregivers⁴⁴. During the pandemic, this support was particularly important, but also insufficiently recognised, as with other situations. Without any support, the burden of care of these informal caregivers was more pronounced and further affected their health.

We may certainly say that the COVID-19 pandemic made the challenges faced by informal caregivers on a daily basis dramatically more complex. This is in terms of even greater limitations of health and social services, isolation and constant concern for the health of the care recipient, but also their own health. In some cases, their situation was also exacerbated by their poor material situation and inability to procure personal protection equipment and disinfectants.

The data indicates that the need for care and support services has increased significantly since the beginning of the COVID-19 pandemic, but this has not led to a corresponding increase in the number of informal caregivers. Data from the United Kingdom provided by Carers UK found that 81% of informal caregivers provided more services than before lockdown, 78% reported that the needs of the person they provided care to had increased significantly, 64% have not been able to take any breaks in the last six months, and 64% reported that their mental health had worsened (with 58% reporting

⁴⁴ Cognitive model of caregiving in psychosis, https://www.cambridge.org/core/services/aop-cambridge-core/content/view/62A2056D0D55CAE97895430DC0B7B820/S0007125000252148a.pdf/cognitive_model_of_caregiving_in_psychosis.pdf

impacts on their physical health).⁴⁵

During the state of emergency, the majority of social protection services were either on hold or were provided with limitations and under changed circumstances, such as the service of housekeeping for older persons. All of this brought more pressure on families and informal caregivers.

A quality study on informal caregivers for persons with dementia in the UK confirmed that the fear of infection among professional caregivers led to situations where informal caregivers increased hours of care when formal care ceased or reduced significantly. In Austria, four in ten caregivers of persons with diagnosed dementia and of poorer socio-economic status, confirmed that they stopped receiving assistance from other family members, and 20% no longer received assistance from neighbours.⁴⁶ Additionally, a study conducted by EuroCarers showed that employers with established flexible arrangements for informal care providers could better adjust to the changes brought about by the pandemic and epidemiological measures.⁴⁷

On the other hand, a study by the European Centre for Social Welfare Policy and Research indicates that informal caregivers have on average been more affected by the situation regarding employment and labour, and their income dropped on average more than that of the persons that do not provide informal care services. These differences were much more pronounced among older cohorts.⁴⁸

⁴⁵ <https://www.carersuk.org/news-and-campaigns/campaigns/caring-behind-closed-doors>

⁴⁶ Socioeconomic condition of informal carers during the COVID-19 pandemic, <https://www.euro.centre.org/webitem/3855>

⁴⁷ Supporting working carers in COVID-19: response and reflections, https://www.carersuk.org/images/News_and_campaigns/Supporting_working_carers_in_COVID-19.pdf

⁴⁸ Socioeconomic condition of informal carers during the COVID-19 pandemic, <https://www.euro.centre.org/webitem/3855>

1.3.1. Persons under increased risk during COVID-19 and informal caregivers

■ Older persons

The COVID-19 pandemic has disproportionately affected older people and their informal caregivers. Older adults and people with multiple chronic conditions have been under a much higher risk of severe complications, and also, the majority of deaths occurred among older persons. Throughout the Organisation for Economic Co-operation and Development (OECD) region, one in six people is over the age of 65, with 60% living with multiple chronic illnesses.⁴⁹ In addition to health-related risks, some older persons have trouble accessing social support or they developed mental health problems caused by the COVID-19 crisis.

In the majority of countries, older persons were advised not to go out, and in some countries people over the age of 65 were even forbidden to leave their homes. Regardless of the measures during the epidemic, services aimed at supporting older persons were reduced or suspended with day care centres and clubs closed. This placed an additional burden on informal caregivers, by increasing the volume and number of activities organised by them on a daily basis. The situation during the pandemic has been particularly difficult for older persons living alone, primarily regarding access to food, financial resources and other needs.⁵⁰ Thus, some friends, family members or neighbours became informal caregivers. Movement restrictions have had negative effects on the mental and physical health of older persons, and the possibility of going out only early

⁴⁹ OECD (2019), "Informal carers", in Health at a Glance 2019: OECD Indicators, OECD Publishing, Paris. DOI, https://doi.org/10.1787/health_glance-2017-78-en

⁵⁰ A review on implications of home care in a biological hazard: The case of SARS-CoV-2/COVID-19, http://www.ccouc.ox.ac.uk/_asset/file/a-review-on-implications-of-home-care-in-a-biological-hazard.pdf

in the mornings also affected their dignity.⁵¹ During the COVID-19 pandemic, isolation, which is connected with depression and other forms of physical and mental issues, alongside recommendations to maintain physical distance and reduce contacts, has exacerbated the health of some older persons, which has, in turn, increased the pressure on informal caregivers.⁵²

It has been found that social networks and virtual gatherings can help to eliminate and reduce emotional stress caused by reduced contacts and improve mental health. However, older people, who have been subject to the most restrictive measures, have the lowest levels of digital engagement. COVID-19 has therefore been something of a wake-up call in this regard. That said, it was already found that if the rights of older people to digital information, education and inclusion were not taken into account, this group would lose access to many rights, while, as a consequence, informal caregivers would bear a greater burden of providing services.⁵³

One of the apparent problems is also the abuse of older persons and it is generally reported considerably less than it occurs. The reasons for this are complex, ranging from fear of increased violence and economic dependence, shame and embarrassment, to the fact that those suffering violence often do not wish to see the perpetrator, often a partner or grandchild, punished, because they have ambivalent feelings for them. Simultaneously, the data collection on this type of violence is often not adequately disaggregated by age and sex, so the full extent of violence against older people is impossible to ascertain. The World Health Organization estimates that one in six people over 60 years of age have experienced violence, but only one in twenty-

⁵¹ Rodna analiza odgovora na COVID-19 u Republici Srbiji (2020), <https://www.osce.org/files/f/documents/3/9/459391.pdf>

⁵² Protecting older adults during social distancing, <https://science.sciencemag.org/content/368/6487/145.1>

⁵³ Starenje i digitalna uključenost, <https://www.redcross.org.rs/media/6183/starenje-i-digitalna-ukljucenost-web.pdf>

four have reported it.⁵⁴ Finally, data show that stress and burnout can increase the risk of violence against older people.

Since the onset of the COVID-19 pandemic, violence against older people has been on the rise, but it cannot be said that the reporting of it has improved. The organisations conducting monitoring and prevention of violence against the elderly, as well as providing support to persons experiencing violence, have reported increases. For example, reports from two UK organisations suggest an increase in elderly violence by 37% in one study and 17% in another.⁵⁵

During the COVID-19 pandemic, violence has occurred under specific circumstances where older people and perpetrators often spend more time together due to isolation and movement restrictions, which also increases the risk of violence. Groups in the population of older persons under particular risk include functionally dependent persons, persons over 80 years of age, older women, older people with mental issues and socially isolated older people. As movement restrictions have made older people more dependent on other people's assistance, not only has the risk of being the target of abuse increased due to caregiver stress and burnout, but it is also less likely that they will report the abuse, out of fear of losing much-needed support. In addition, under normal circumstances, some incidents of abuse are discovered by doctors when they routinely examine older persons. In the situation of the pandemic, this is highly unlikely to happen due to the burden on the health system and fewer visits to doctors.

As financial abuse is one of the most common forms of elderly abuse, it should be considered that during the pandemic and the related special measures, including movement restrictions, the risk of financial abuse has increased. This is because older people

⁵⁴ <https://www.who.int/news-room/fact-sheets/detail/elder-abuse>

⁵⁵ <https://www.telegraph.co.uk/news/2020/05/17/silent-scandal-elderly-abused-lockdown/>

must often entrust shopping, which they used to do themselves, to others. Due to general economic instability and the fact that many family members are at risk of losing employment and income, the eldest family member's pension is often the only regular income in the household. Further, fraud is not uncommon, as family members exploit fear of the pandemic to offer, for example, fake virus testing in exchange for money.⁵⁶

■ Persons with chronic illnesses

Persons with chronic illnesses are also under increased risk of COVID-19 infection and potentially greater complications. This primarily refers to persons with cardio-vascular disease, diabetes, pulmonary disease and cancer. For them, the most important thing has been to continue taking regular treatment and strictly adhere to instructions on hygiene maintenance. In addition to this, these persons have needed to continue their healthy lifestyles in terms of prevention. Also, mental health protection of the chronically ill has also been very important, as they have experienced fear of infection because it could lead to death, fear of not receiving adequate treatment for their original illness, followed by isolation and inability to maintain social contacts. Furthermore, regular check-ups and screenings for the chronically ill have presented a risk, including three differently perceived situations: cancelled and postponed check-ups, hospital visits that carry greater risk of infection, and, finally, paying for services out of one's own pocket. All of this has increased pressures on informal caregivers, both in terms of increased volume of old and new services, and financially, because they have had to pay for some health services and check-ups in private institutions (primarily during the emergency situation). The fear of infection of the care recipient and dilemmas around who to report the concerns

⁵⁶ <https://www.age-platform.eu/publications/covid-19-and-human-rights-concerns-older-persons>

to and whether they will be admitted, have additionally affected informal caregivers' mental health.

■ **Persons with mental disorders**

During COVID-19, persons with mental disorders have also been under increased risk as, in the majority of cases, their fear and anxiety related to the pandemic increased. This occasionally led to the deterioration of their psychological health and, as with the chronically ill, services have switched to telephone consultations. Worsening of psychological health of family members, in combination with uncertainty, may have also influenced the health and, in particular, the mental health of informal caregivers. Civil society organisations have indeed engaged in psychosocial support, which has provided access to a useful resource, so informal caregivers have not necessarily had to rely solely on institutions for support. In the short term, this has enabled them to face their personal problems, although with a risk of violating the privacy of care recipients, given that they have mostly shared the same space.

■ **Persons with disabilities**

The problems faced by persons with disabilities are different and it has been necessary during COVID-19 to look at their individual needs. Informal caregivers providing care to persons with physical disabilities face the same fears as caregivers of other at-risk groups, which primarily refers to the ways of organising their check-ups, grocery shopping (whether to use volunteers or to order food), how to organise education for their children with disabilities, etc. Informal caregivers have had to work on reducing the feeling of isolation of the care recipient, because of reduced or suspended community services, such as day care centres and clubs. A combination of fears, new responsibilities, a lack of support, changes in the functioning of the system, as well as a lack of information have led to significant

effects on informal caregivers' health, who have often felt afraid and powerless under these new circumstances.

1.4. Informal caregiver mental health

The literature mentions that the provision of informal care may have opposite effects on the mental health of caregivers, ranging from satisfaction and feelings of purpose and emotional fulfilment, to poorer physical and mental health when compared to persons not providing care. Further, informal caregivers are also at an increased risk of depression. Research confirms that the provision of care to a dependent person is, in a considerable number of cases, everyday work, which requires time, physical energy and emotional investment. If this activity is performed over a longer period of time, the caregiver is at risk of burnout, which can lead to deteriorating mental or physical health and an increased risk of depression. Studies indicate that, taking into account both positive and negative psychological effects of the provision of care on the provider, there is a risk of burnout, and it is more strongly influenced by the negative effects, including emotional exhaustion, a reduced feeling of achievement and depersonalisation. Research also indicates that individual problems having a negative impact on the psychological state of the caregivers need not be significant in isolation but that their cumulative effects are what consumes the caregivers' resources in coping with stress, while on the other hand the positive effects do not always provide an adequate balance.⁵⁷

Some of the *socioeconomic factors* increasing satisfaction of living conditions among caregivers and thus contributing to positive effects on their health include: good socioeconomic status, family support, possibility to participate in social activities, steady employment, availability of respite services. *Psychological factors* that increase

⁵⁷ Appraisals, Burnout and Outcomes in Informal Caregiving, <https://pubmed.ncbi.nlm.nih.gov/25030791/>

the satisfaction of caregivers with their living conditions and thus contribute to positive health effects include: higher level of general health and lower level of stress, religious or spiritual activity, positive attitude about the provision of care, positive attitude about oneself, ability to adapt to the demands of the caregiver role.⁵⁸

A longitudinal study on the relationship between stress factors related to the provision of care, depression in caregivers and quality of care confirms the findings of previous studies connecting weaker physical health of caregivers with increased risk of depression, which in turn reduces the quality of care. Also, in cases when caregivers perceive the person receiving care as intrusive or manipulative, the risk of depression rises, just as it rises when the caregiver is not able to perform their own routine life activities.⁵⁹

Depression is a problem faced by informal caregivers and it is estimated that between 40% and 70% of all informal caregivers have symptoms of depression, out of whom between one quarter and one half experience such intensity that they are meeting the diagnostic criteria for major depression.⁶⁰ The symptoms of depression worsen with increased burden of care so, for example, the frequency of depression and emotional stress is between 30% and 40% in those caregivers providing care to persons with dementia.⁶¹

Social exclusion has an important impact on quality of life, and it is mentioned in the literature as one of the factors recognised, but insufficiently explored, in informal caregivers. Studies on informal

⁵⁸ Ibid

⁵⁹ Depression and quality of informal care: a longitudinal investigation of caregiving stressors, <https://pubmed.ncbi.nlm.nih.gov/21417536/>

⁶⁰ Zarit, S. (2006). Assessment of Family Caregivers: A Research Perspective. In Family Caregiver Alliance (Eds.), *Caregiver Assessment: Voices and Views from the Field*. Report from a National Consensus Development Conference (Vol. II) (pp. 12 – 37). San Francisco: Family Caregiver Alliance.

⁶¹ Alzheimer's Association & National Alliance for Caregiving. (2004). *Families Care: Alzheimer's Caregiving in the United States*. Chicago, IL: Alzheimer's Association and Bethesda, MD: National Alliance for Caregiving.

caregivers of persons with dementia or mental health disorders often do not draw clear lines between the concepts of social caregiver exclusion, stigma or burden, and so far we cannot say that there is a clear picture of the impact of social inclusion of caregivers on their general mental health. However, it is obvious that there is significant variation within the population of informal caregivers and it must be taken into account that caregivers of persons with dementia and mental health disorders are two different groups. Specifically, it is more common that caregivers of persons with dementia are the children of care recipients.⁶²

The discussion about stress and burden of care recognises that the provision of care over a longer period of time is stressful, because it requires physical strain, creates psychological burden, is highly unpredictable and may affect other areas of life, such as employment, family relations, etc. The prevalence of mental health issues is higher in informal caregivers than in persons that do not provide care, and it is particularly high in those providing higher-intensity care – more than twenty hours a week.⁶³

Studies on burnout syndrome affecting informal caregivers providing care to persons with dementia who are dealing with objective (economic value of care, time) and subjective (emotional response in caregivers) characteristics of care indicate the impact of higher intensity care. This care, which entails many hours each week, can cause emotional stress, physical fatigue, limited opportunity to participate in social life or recreation, reduced appetite and sleep disorders, as well as increased risk of mortality and mental health disorders. The fact that informal caregivers are most often emotionally connected with the person they provide care to and

⁶² Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness, <https://pubmed.ncbi.nlm.nih.gov/29704916/>

⁶³ Burnout syndrome in informal caregivers of older adults with dementia: A systematic review, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6907708/>

that informal care does not entail specific working hours or material compensation, are additional factors. Also, social isolation, poor physical health and negative attitudes toward caregiving are also predictors of burnout syndrome, which further reduces the quality of care. This study has also found correlations between the extent of care, recipient limitations and overload felt by caregivers.⁶⁴

A study on emotional disorders found that whilst informal caregivers are not by definition under increased risk of emotional disorders, there are risk factors connected to some subgroups within this group: informal caregivers with no employment, those without life partners, as well as those without social support. As emotional disorders may have strong effects on the quality of life of caregivers, which in turn also affects the quality of care itself, it is important to develop a system of prevention and support measures focusing not on the overall population, but on those under risk of emotional disorders. These include caregivers closely related to the care recipient, caregivers providing higher intensity care (more hours per week) and/or living with the care recipient, those that are not employed, do not have community support, but also those that have additional responsibilities, for example to their own children, which takes up another significant portion of their time.⁶⁵

Research shows that informal caregivers providing care to family members with significant cognitive decline and pronounced needs related to performing everyday activities are at risk of depression, and there is also increased probability that they will exhibit aggressive behaviour towards persons close to them.⁶⁶ Pressure, stress and

⁶⁴ Ibid

⁶⁵ Emotional disorders among informal caregivers in the general population: target groups for prevention, <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-015-0406-0>

⁶⁶ Beach, S.R., Schulz, R., Williamson, G.M., Miller, L.S., Weiner, M.F. & Lance, C.E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatric Society*, 53: 255-61.

overload with care-related tasks can lead to burnout syndrome and mental health issues in informal caregivers, which, in some cases, increases the risks of violence and abuse. Two risk factors that can be prevented, which contribute to increased risk of abuse in the context of informal care provision are: caregiver anxiety and burden. Thus, according to WHO Report for the European region, the prevalence of physical abuse against the elderly with disabilities, cognitive disorders and dependency reaches 25%, and family caregivers are involved in one third of the cases of mistreatment, while data published by the National Center on Elder Abuse (NCEA) showed a prevalence of 47% in dementia patients. On the other hand, only 4.6% of caregivers acknowledged having mistreated their care recipient at some point in time. In any case, negative effects of caring for a dependent relative such as stress, caregiver burden, mood disorders, and social isolation have been reported as risk factors for mistreatment of the informal care recipient. Risk factors for the care recipient include: age over 74 years, female gender, disability (intellectual or physical), dementia, depression, as well as social isolation and dependency on other people's help.⁶⁷

Another study, a longitudinal investigation of caregiving stressors, which also focused on depression in caregivers, found that the increased intensity of stress (deterioration of the physical health of the caregiver, fewer opportunities for the caregiver to enjoy their personal activities, as well as the perception of the care recipient's behaviour as manipulative), may be connected with an increase in symptoms of depression for the caregiver. In turn, increased caregiver depression and decreased consideration towards the care recipient, could lead to abuse and violence. This indicates that monitoring stress factors related to the provision of care and symptoms of depression in caregivers and their behaviour may signal that intervention is

⁶⁷ Family caregiver mistreatment of the elderly: prevalence of risk and associated factors, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5778739/>

warranted in order to forestall or prevent poor quality of care. Here, it should be considered that the connection between deterioration of informal caregiver physical health and increasing depression symptoms has been well described and consistent in the literature, so monitoring the subjective perception of caregiver health may also indicate symptoms of depression.⁶⁸

Several studies have shown that the feeling of personal activities of caregivers being limited by their role of care providers are a strong cause of stress. Further, the perception that the recipient of care likes to boss them around and manipulate them has turned out to be a greater source of stress than the amount of care to be provided. This is common in the provision of care to persons diagnosed with Alzheimer's disease. However, while caregivers struggle even with the "typical" behaviour of such patients (hallucinations, constant repetition of the same questions), when they perceive that the recipient of care likes to boss them around and manipulate them, a resentment appears which is connected not with the disease but their personality. A longitudinal study shows that with an increase of the symptoms of depression in caregivers the frequency of potentially harmful behaviour toward the care recipient also rises.⁶⁹

Another metanalysis shows that informal caregiver stress is a predictor of the probability that the person with dementia receiving care will be placed in an institution, that their behavioural and psychological symptoms of dementia will worsen, but also that abuse will occur. There are correlations between stress under which informal caregivers of persons diagnosed with dementia are at an increased risk of abuse, and these correlations repeatedly appear in

⁶⁸ Depression and Quality of Informal Care: A Longitudinal Investigation of Care-giving Stressors, <https://pubmed.ncbi.nlm.nih.gov/21417536/>

⁶⁹ Ibid

studies.⁷⁰

10 COMMON SYMPTOMS OF CAREGIVER STRESS

1. *Depression*
2. *Withdrawal*
3. *Insomnia*
4. *Trouble concentrating*
5. *Anger*
6. *Health issues*
7. *Exhaustion*
8. *Anxiety*
9. *Drinking or smoking*
10. *Altered eating habits*

People who suffer from caregiving-related stress have a 63% increase in their mortality rate, according to a 2003 study conducted by the Ohio State University.⁷¹ Social and health policy measures that can contribute to improving some of the common symptoms include providing long-term care services through the formal service system, offering informal caregivers respite services and enabling them to find a functional balance between their participation in the labour market and their role as a caregiver. Formal services reduce the

⁷⁰Association of Informal Caregiver Distress with Health Outcomes of Community-Dwelling Dementia Care Recipients: A Systematic Review, <https://pubmed.ncbi.nlm.nih.gov/30536383/>

⁷¹Aging Care- Family Caring for Family. The Caregivers' Survival Guide (2017), <https://oak-meadows.org/wp-content/uploads/2017/02/AgingCare-FamilyCaringForFamily.pdf>

burden of informal caregivers, while respite services enable them to take a break from care provision and take part in social activities, so that, for a certain time, care is provided in a different manner (for example: day care centres, in-home respite, etc.). It is important to take into account that informal caregivers may feel reluctant to take such breaks because they are uncertain about the adequacy of respite care, but also because it may be expensive for them, so it is crucial to offer services suited to a wide range of beneficiaries and ensure that they are available and affordable. Informal caregivers can also benefit from information about the services available to them, but also from counselling services and case management assistance, where informal caregiver is provided with support in overcoming administrative challenges related to the provision of care.⁷²

1.1.1 Informal caregiver mental health and COVID-19

It is now well known that COVID-19 can have a lasting impact on physical health. However, as the pandemic continues, an increasing impact on the mental health of people worldwide has become evident, with informal caregivers falling under a particularly vulnerable category. Due to COVID-19, a wide range of protection measures have been put in place around the world, including the closing of schools and factories, physical distancing, quarantine, and the use of personal protective equipment. In addition, the adoption of curfews for some population categories has also resulted in reduced or suspended social protection and healthcare services. These measures have caused short-term effects on mental health, but long-term consequences are also expected, especially for the psychologically vulnerable.⁷³

⁷² The impact of caregiving on informal carers' mental and physical health, <https://eurocarers.org/publications/the-impact-of-caregiving-on-informal-carers-mental-and-physical-health/>

⁷³ Risk of Depression in Family Caregivers: Unintended Consequence of COVID-19, https://www.researchgate.net/publication/342257179_Risk_of_Depression_in_Family_Caregivers_Unintended_Consequence_of_COVID-19

A recently published meta-analysis has shown higher depression rates in first responders to COVID-19, compared to the rest of the population. There is also risk of this group developing anxiety, sleep problems and other mental health disorders.⁷⁴ Informal caregivers, particularly those that provide long-term care to a family member, have been under increased risk of physical and emotional exhaustion due to the burden of care and reduced number of services, or their shift to telephone consultations and the digital sphere, which has increased stress and the risk of mental health problems. While some informal caregivers manage to overcome stress and develop resilience, others do not, and psychological pressure can lead to the development of depressive symptoms and depression.⁷⁵

COVID-19 has increased the pressure on informal caregivers by increasing the volume and methods of usual care. Caregivers report that they do not have a chance to take breaks, with little time for self-help and themselves. Social isolation also affects their daily lives, with all of these circumstances potentially increasing the risks of depression. Alongside epidemiological protection measures, including the limitations on all levels which will probably extend into the future in some form, the impact of COVID-19 on the mental health of both formal and informal caregivers will also certainly increase.⁷⁶

It is very important to collect disaggregated data (by sex, age, health status) to conduct data analysis for research. Such analysis would enable the planning of support interventions and services that would have a direct impact on the quality of care, quality of life and health of informal caregivers. This would also indirectly improve the quality of life for people in need of care and support.

⁷⁴ Prevalence of depression, anxiety, and insomnia among healthcare workers during the COVID-19 pandemic: A systematic review and meta-analysis, *Brain Behav Immun*, 2020.

⁷⁵ Mental and physical illness in caregivers: results from an English national survey sample. *Br J Psychiatry*, 2014

⁷⁶ Risk of Depression in Family Caregivers: Unintended Consequence of COVID-19, https://www.researchgate.net/publication/342257179_Risk_of_Depression_in_Family_Caregivers_Unintended_Consequence_of_COVID-19



2

Methodology

2.1. Aim

The aim of this research is to present an overview of the impacts and effects of informal care on caregiver mental health, primarily during the COVID-19 pandemic. The results will be used to support recommendations for public policy planning and development in order to improve the quality of life and mental health of informal caregivers through the development of appropriate support services.

2.1.1. Objectives

- Identify common informal caregiver mental health needs
- Measure the level of burnout syndrome among caregivers, as well as the incidence of the symptoms of depression
- Identify subgroups within the population of informal caregivers that are under increased health risk
- Examine the impact of the COVID-19 pandemic on the quality of life of informal caregivers
- Develop a set of recommendations related to: the improvement of the quality of life of informal caregivers, improvement of the quality of care provided and on reducing the risk from abuse of older and other persons they provide care
- Ensure better understanding among the public, professionals, decision-makers as well as informal caregivers themselves about the caregivers' needs to preserve their mental health and the necessary support services in the public and civil sectors

2.2. Quantitative research

The sample was chosen so as to provide a statistically reliable assessment for the Republic of Serbia. The target group included informal caregivers on the territory of Serbia. Exclusion criteria were the following: discontinued provision of care over six months prior to the data collection and refusal to participate in the research. Stratified sampling was used, with strata including the regions of Belgrade, Vojvodina, Šumadija and Western Serbia, Eastern and Southern Serbia. Informal caregivers were then surveyed from a random selection of urban, suburban and rural municipalities (proportional to their distribution across regions)..

For the purposes of this research, a questionnaire was developed, consisting of nine parts: (1) socio-demographic characteristics of informal caregivers; (2) general information about care recipients; (3) functional status of care recipients; (4) caregiver burden; (5) depression; (6) fatigue; (7) health and functional ability; (8) social support and (9) COVID-19.

For the assessment of caregiver burden, a standardised instrument, the Zarit Burden Interview (ZBI), was used. The reliability and validity of this assessment tool has been supported by a number of studies. The questionnaire contained 22 questions showing how individuals sometimes feel when providing care to another person. Questions included caregiver health, psychological well-being, finances, social life and type of relationship between the caregiver and patient. Response were given on a Five Point Likert Scale, including the categories: never (0), rarely (1), sometimes (2), often (3) and almost always (4), with a maximum score of 88 in total for the 22 questions. Using this instrument, a higher score indicated higher caregiver burden. Score results ranging from 21 to 40 represent mild to moderate burden, from 41 to 60 moderate to high burden and from 61 to 80 indicate high caregiver burden.

Validated Activities of Daily Living (ADL) scales and the adapted Lawton Instrumental Activities of Daily Living (IADL) Scale were used to determine the functional status and independence of care recipients. Krupp's Fatigue Severity Scale was used for the assessment of informal caregiver fatigue, and Beck's Depression Inventory (BDI) for the assessment of depression.

2.3. Qualitative research

The qualitative part of the research into informal caregiver mental health was conducted through four focus groups in three municipalities in Serbia: Novi Sad, Pirot and Belgrade. Focus groups were organised in August and September 2020, with a total of 32 participants who were all informal caregivers, including 29 women and three men. Focus groups were led by two researchers and were based on predefined guidelines and interviewes, principally containing questions regarding informal caregiver mental health,

The average duration of a focus group was around one and a half hours. Informal caregivers that participated gave their signed informed consent, as well as permission for sound recording during the focus group discussion, which was then transcribed for the purposes of analysis. Notes were also taken during the discussions, which, alongside the transcripts, presented basic units for a qualitative analysis of the content. The focus groups were organised during the COVID-19 pandemic, so all the participants were provided with masks by the organisers and all proposed epidemiological protection measures were followed to protect the health of both participants and researchers.



3 Results

3.1. Socio-demographic characteristics of informal caregivers

The study included 798 participants – informal caregivers from 41 municipalities in Serbia (Table 1). Chart 1 shows the regional distribution of the informal caregiver sample.

Surveyors were trained volunteers with the Red Cross and several civil society organisations (CSOs), who had participated before in the studies of the Red Cross of Serbia, which provided them with the necessary experience. The following Red Cross of Serbia offices participated in the research: Sombor, Vrbas, Kikinda, Indjija, Pancevo, Novi Becej, Senta, Ruma, Kovin, Novi Sad, Sremska Mitrovica, Palilula, Savski venac, Obrenovac, Rakovica, Kragujevac, Kraljevo, Krusevac, Uzice, Pozarevac, Paracin, Cacak, Gornji Milanovac, Topola, Osecina, Jagodina, Knjazevac, Pirot, Prokuplje, Nis, Negotin, Vranje, Kladovo, Zajecar and Boljevac. The following CSOs participated in the research: Volunteering Service Zvezdara, Retirement Association Belgrade, Association for the assistance to people with developmental difficulties “Living Together”. The Factor Plus Agency also helped with data collection in municipalities Vračar, Zemun and Vozdovac.

In addition to training, all surveyors were provided with a short, written instruction on how to fill out the questionnaire and on how to conduct themselves professionally when conducting the survey.

Table 1. Distribution of caregivers by place of residence

Number of participants by regions and municipalities	n (%)
VOJVODINA	218 (27.3%)
Sombor	20 (2.5)
Vrbas	18 (2.3)
Kikinda	20 (2.5)
Indija	20 (2.5)
Pančevo	19 (2.3)
Novi Bečej	20 (2.5)
Senta	20 (2.5)
Ruma	20 (2.5)
Kovin	20 (2.5)
Novi Sad	21 (2.7)
Sremska Mitrovica	20 (2.5)
BELGRADE	184 (23.1%)
Novi Beograd	19 (2.4)
Palilula	13 (1.6)
Savski Venac	21 (2.6)
Stari grad	20 (2.5)
Voždovac	20 (2.5)
Vračar	20 (2.5)
Zemun	20 (2.5)
Zvezdara	20 (2.5)
Obrenovac	20 (2.5)
Rakovica	11 (1.4)
ŠUMADIJA AND WESTERN SERBIA	216 (27.1%)
Kragujevac	20 (2.5)
Kraljevo	20 (2.5)
Kruševac	20 (2.5)
Užice	19 (2.4)
Požarevac	19 (2.3)
Paraćin	20 (2.5)
Čačak	19 (2.4)
Gornji Milanovac	20 (2.5)

Topola	20 (2.5)
Osečina	19 (2.4)
Jagodina	20 (2.5)
SOUTH AND EASTERN SERBIA	180 (22.5%)
Knjaževac	20 (2.5)
Pirot	20 (2.5)
Prokuplje	20 (2.5)
Niš	20 (2.5)
Negotin	20 (2.5)
Vranje	20 (2.5)
Kladovo	20 (2.5)
Zaječar	20 (2.5)
Boljevac	20 (2.5)
Total	798 (100.0)

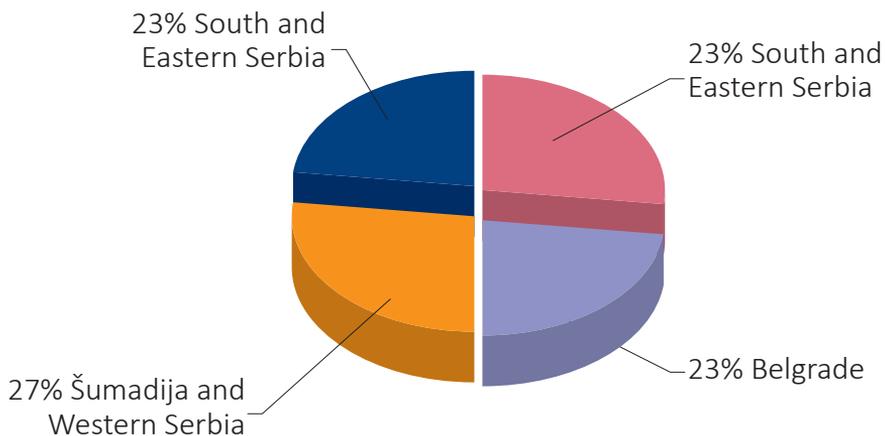


Chart 1. Regional distribution of surveyed informal caregivers

The majority of surveyed informal caregivers (68.7%) came from urban-type settlements (Chart 2).

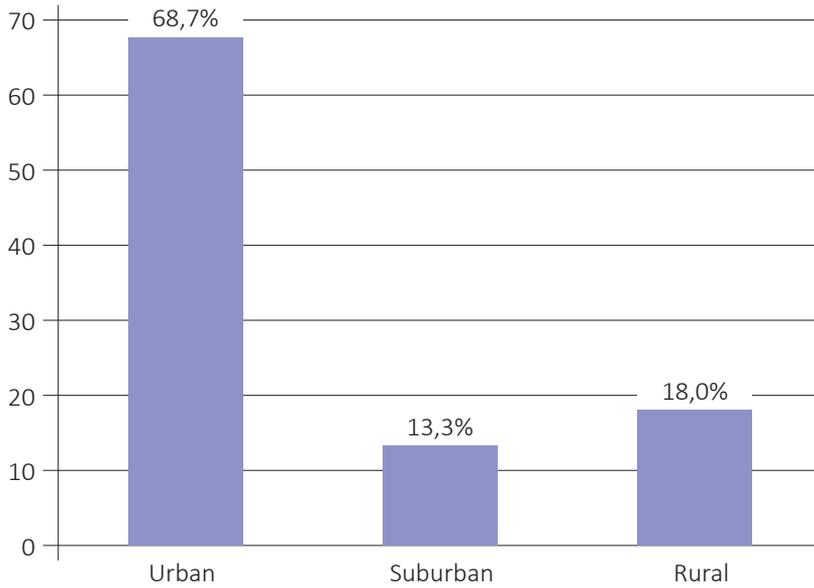


Chart 2: Settlement type

Sex, age and marital status of informal caregivers

The majority of informal caregivers in the sample were women (70.8%), and 29.2% were men (Chart 3). This is in compliance with global data which report that, in Europe, 76% of informal caregivers are female.^{77,78} Data shows that the situation is similar in the USA, with a mild increase in the percentage of men, recently reaching 40%.⁷⁹ In research on informal caregiver health conducted by Caritas Šabac in spring 2020, on a much smaller sample and during curfew with restricted movement, the sample included 20.5% men and 79.5% women.⁸⁰

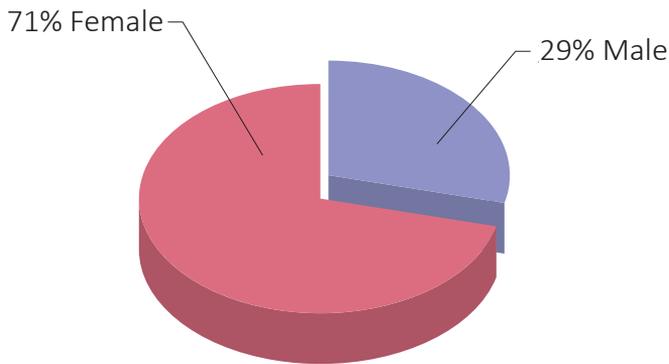


Chart 3: Informal caregivers by sex

⁷⁷ The National Survey Report for Greece. EUROFAMCARE – Services for Supporting Family Carers of Dependent Older People in Europe: Characteristics, Coverage and Usage, https://www.academia.edu/25912819/Triantafillou_J_Mestheneos_E_Prouskas_C_Goltsi_V_Kontouka_S_Loukissis_A_2006_The_National_Survey_Report_for_Greece_EUROFAMCARE_Services_for_Supporting_Family_Carers_of_Dependent_Older_People_in_Europe_Characteristics_Coverage_and_Usage <http://www.uk.uni-hamburg.de/extern/eurofamcare>

⁷⁸ Care Provision within Families and its Socio-Economic Impact on Care Providers, https://www.researchgate.net/profile/Nicola_Moran2/publication/242328256_Care_Provision_within_Families_and_its_SocioEconomic_Impact_on_Care_Providers_Report_for_the_European_Commission_DG_EMPL/links/556d6e4608aec22683055825.pdf

⁷⁹ Called to Care: A Guide for Family and Friends was inspired by Care for the Family Caregiver: A Place to Start, https://www.hopkinsmedicine.org/johns_hopkins_bayview/docs/community_services/called-to-care/C2C_called_to_care_booklet.pdf

⁸⁰ Zdravlje neformalnih negovatelja, Todorović N. et al., 2020, Caritas Šabac, Jun 2020

The age of the surveyed informal caregivers ranged from 18 years for the youngest to 92 years for the oldest. The average age was 54.1 ± 12.2 years. The data shows that even though many have an image of who the average caregiver is, they actually represent a very broad range of people, including high school students / teenagers to pensioners. This broad spectrum indicates the need to ensure special policy measures for different age groups providing informal care services under very different living conditions.

The majority of caregivers were in the age interval between 35 and 64 years (574 respondents or 71.9%), followed by the group of 65 years and over (167 respondents or 20.9%) (Chart 4). For comparison, the average age of caregivers in Europe is 55⁸¹,⁸² and in the USA 49 years.⁸³ In the above-mentioned Caritas research, the average age was 51.1 years.⁸⁴

Considering that the majority of informal caregivers in our sample comes from the working age population, they should be the special focus of support so that they can participate in the labour market, provide care and have time for themselves. This is particularly important in emergencies that can lead to a deterioration of their mental health.

⁸¹ The National Survey Report for Greece. EUROFAMCARE – Services for Supporting Family Carers of Dependent Older People in Europe: Characteristics, Coverage and Usage, https://www.academia.edu/25912819/Triantafillou_J_Mestheneos_E_Prouskas_C_Goltsi_V_Kontouka_S_Loukissis_A_2006_The_National_Survey_Report_for_Greece_EUROFAMCARE_Services_for_Supporting_Family_Carers_of_Dependent_Older_People_in_Europe_Characteristics_Coverage_and_Usage_http_www_uke_uni_hamburg_de_extern_eurofamcare_

⁸² Care Provision within Families and its Socio-Economic Impact on Care Providers, https://www.researchgate.net/profile/Nicola_Moran2/publication/242328256_Care_Provision_within_Families_and_its_SocioEconomic_Impact_on_Care_Providers_Report_for_the_European_Commission_DG_EMPL/links/556d6e4608aec22683055825.pdf

⁸³ Called to Care: A Guide for Family and Friends was inspired by Care for the Family Caregiver: A Place to Start, https://www.hopkinsmedicine.org/johns_hopkins_bayview/docs/community_services/called-to-care/C2C_called_to_care_booklet.pdf

⁸⁴ Zdravlje neformalnih negovateljica, Todorović N. et al., 2020, Caritas Šabac, Jun 2020

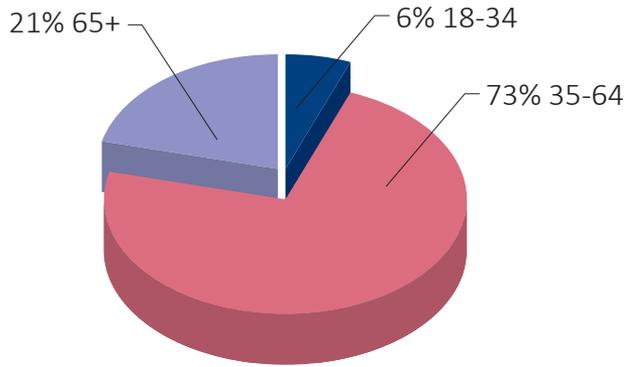


Chart 4: Informal caregivers by age

The majority of participants were married (59.4%), followed by single (12.8%), divorced (12.0%) and widowed (11.9%). The lowest share of caregivers were unmarried (or) living with their partners (3.9%) (Chart 5).

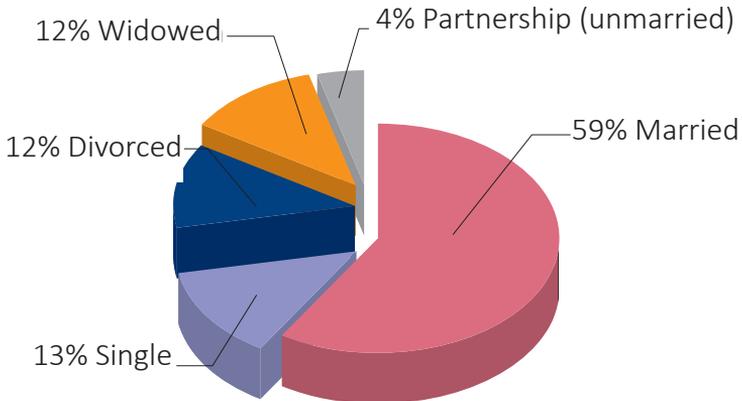


Chart 5: Informal caregivers by marital status

When it comes to informal caregivers' education levels, the majority completed high school (444 respondents or 55.6%), followed by 28.4% of respondents that completed college or university, while 18 respondents (2.3%) completed post-graduate studies. There were 11.7% informal caregivers that completed only primary school, and 14 or 1.8% that did not complete any school (Chart 6).

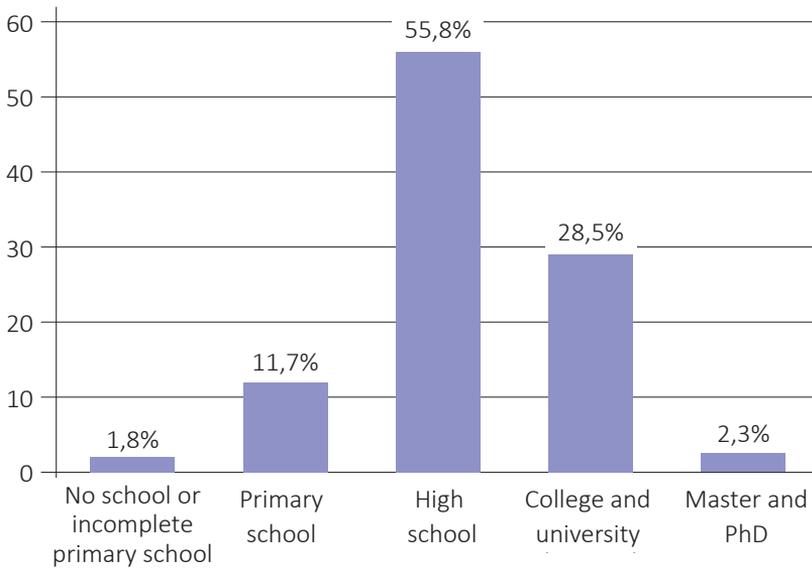


Chart 6: Informal caregivers by education levels

Among the surveyed caregivers, nearly one half (47.1%) had full-time employment, while 19.3% were unemployed. There were 192 or 24.1% pensioners (Chart 7)

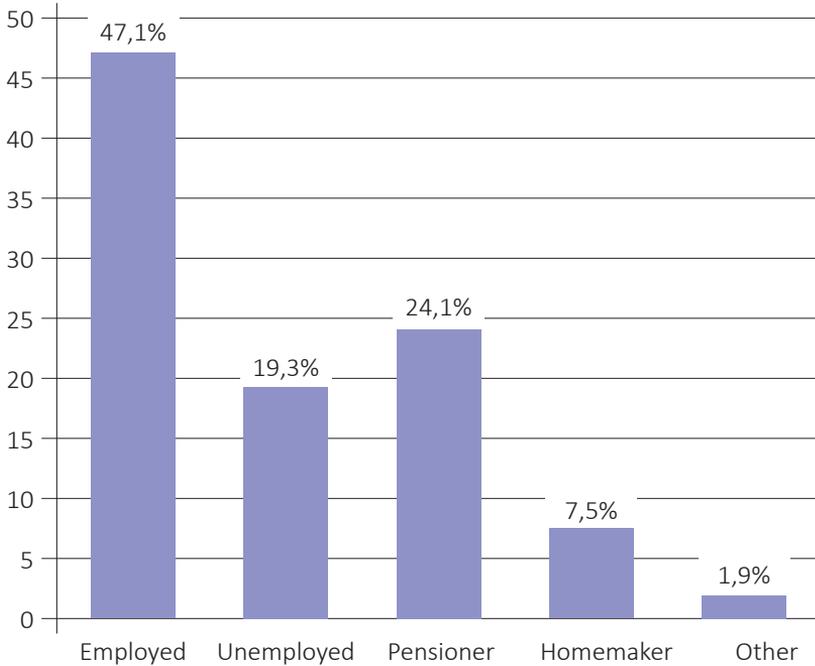


Chart 7: Informal caregivers by employment status

The results in Chart 8 show that the majority of respondents are currently providing care to a recipient with the percentage as high as 82.7%, while the remaining 17.3% did so until recently. The reason for not providing care anymore was, in the majority of cases (54.8%), the death of the recipient of care.

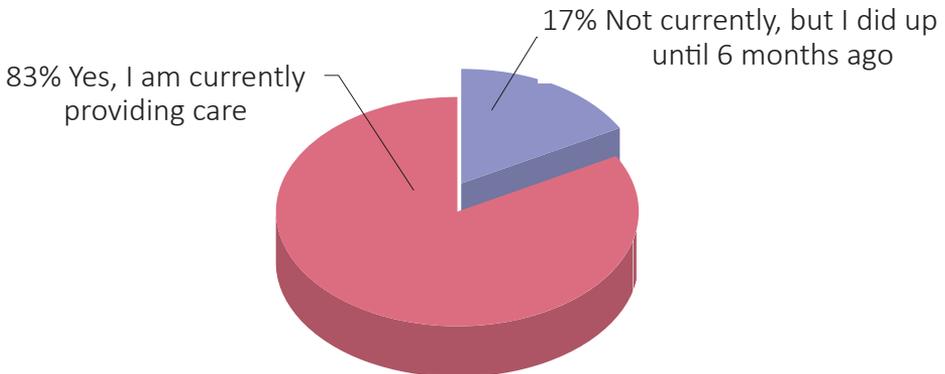


Chart 8: Informal caregivers by current status

The number of people informal caregivers provide care to

The majority of informal caregivers provide care to one person (84.9%), 12.6% provide care to two people, and 2.6% of respondents provide care to three or more people. The maximum number of people that one caregiver provided care to was six (Chart 9).

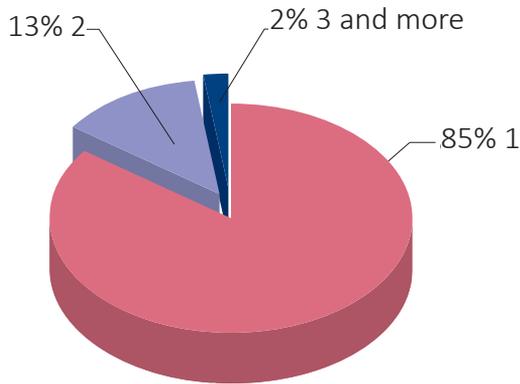


Chart 9: The number care recipients per informal caregiver

3.2. The characteristics of care recipients

Age and sex of care recipients

The average age of care recipients was 72.7 ± 17.5 . The youngest recipient was two years old, while the oldest person receiving care by an informal caregiver was 98 years old. The highest number of care recipients were in the age range between 75 and 84 years or 36.6% (Chart 10). The majority of recipients of care were female (60.2%) (Chart 11).

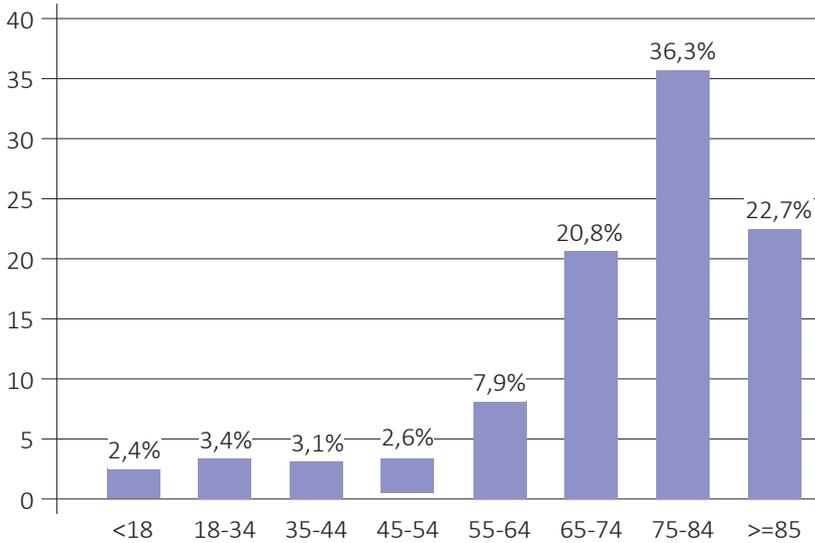


Chart 10: Care recipients by age categories

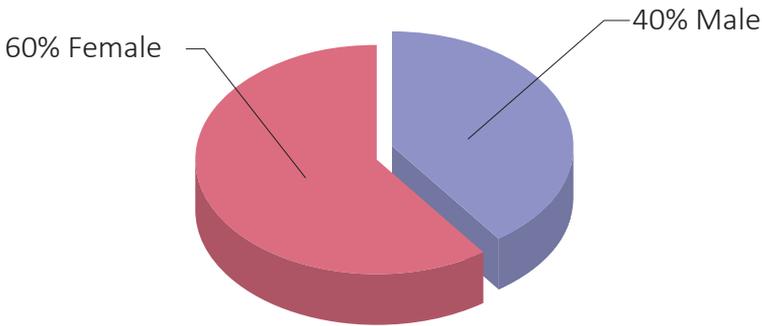


Chart 11: Care recipients by sex

Average duration of care was 6.2 ± 8.0 years. The shortest period of care was four months, while the longest care provided to a close family member was 57 years. The distribution of duration between two and five years was at 44.8%, followed by care lasting for up to one year (24.3%) and care for a recipient longer than ten years with 19.3% (Chart 12).

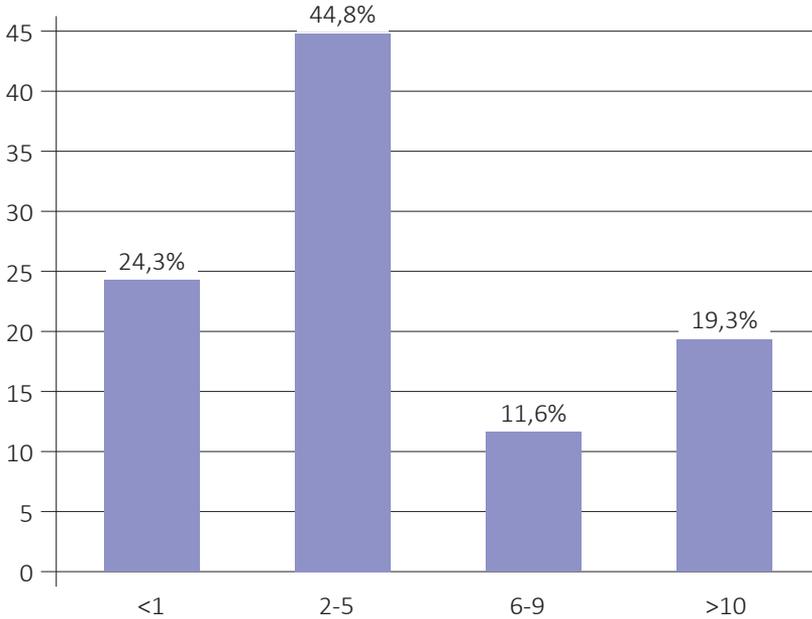


Chart 12: Care duration

The share of respondents living in the same household as the care recipient was 66.6% (Chart 13).

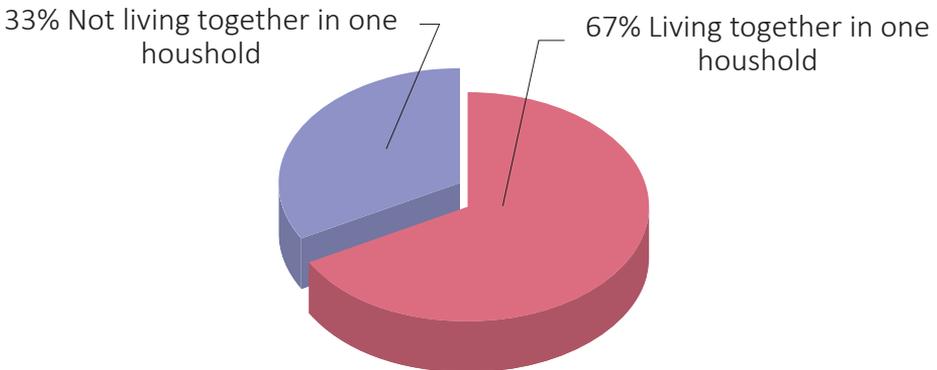


Chart 13: Informal caregivers living in the same household with care recipients

Distribution of care provided by respondents at monthly and weekly levels is provided in Chart 14. Seventy-eight percent of care recipients receive care every day, and 15.5% of caregivers visit care recipients several times a week.

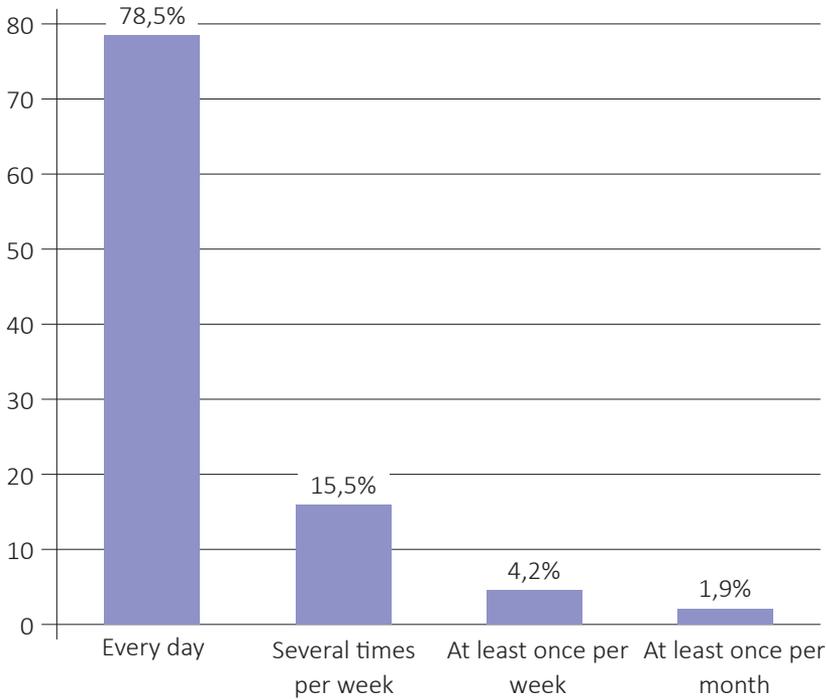


Chart 14: Frequency of care (monthly, weekly)

Average hours of care provided daily are 13.8 ± 9.4 . Up to six hours a day of care is provided by 38% of respondents, 15.7% spend 6 to 12 hours per day with the recipient of care, while 46.3% of caregivers provide care to the recipient over 12 hours per day (Chart 15).

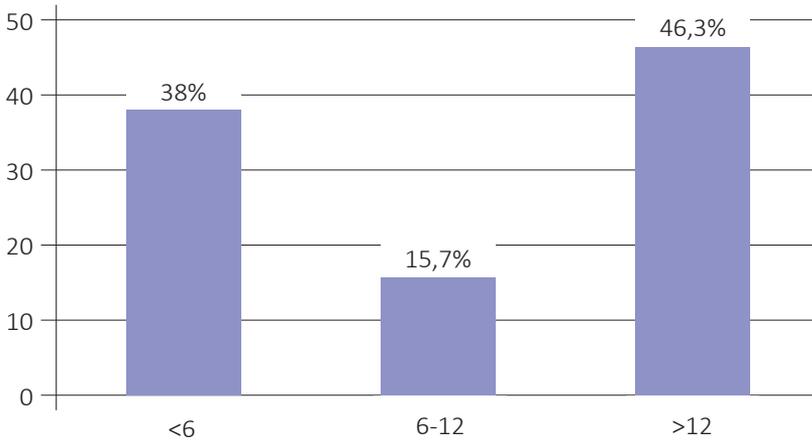


Chart 15: Frequency of care (daily, in hours)

There are different reasons for providing care to recipients. The highest number of care recipients have chronic illnesses (29.6%). One quarter need care after surgery, stroke and heart attack (25.4%) or because of old age (24.2%). Neurological conditions (15.7%) and dementia or Alzheimer’s disease (15%) also prevent care recipients from leading independent lives. The frequency of other conditions among care recipients is presented in Chart 16.

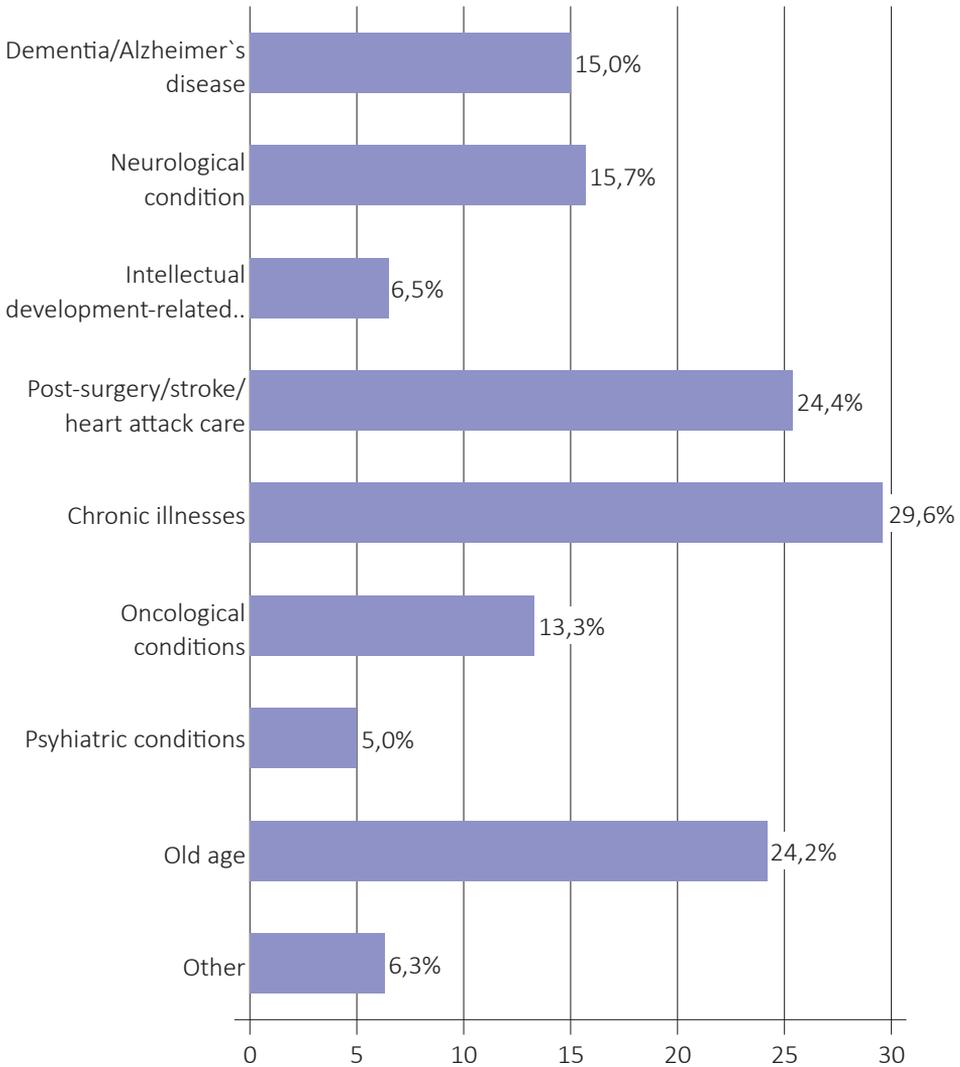


Chart 16: Care recipients by conditions

Over 90% of informal caregivers are related to the recipient of care (Chart 17). Nearly one half (45.8%) provide care to a parent (father/mother), followed by other blood relative (32.2%) and spouse (13.4%). Sixty-five respondents provide care to their own children (8.6%) (Chart 18).

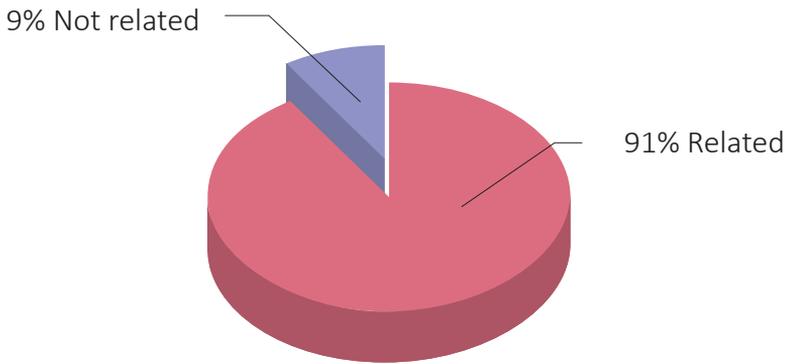


Chart 17: Relationship between the caregiver and care recipient

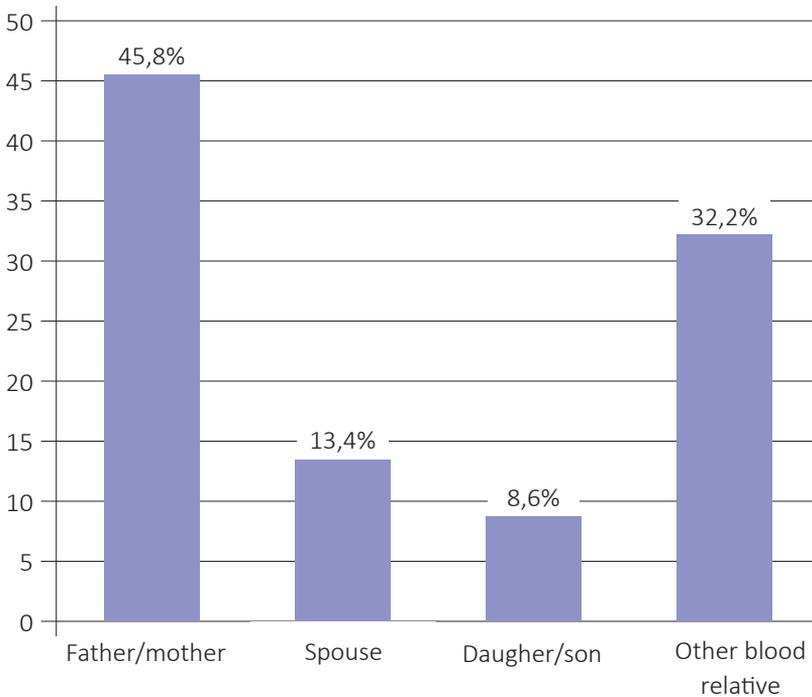


Chart 18: Kinship with care recipient

Chart 19 shows that as many as 68% of caregivers provide care to the recipient independently.

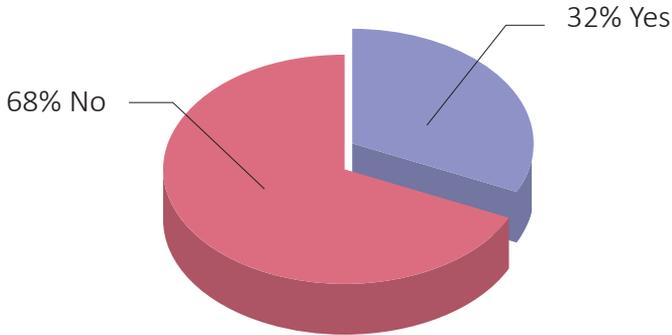


Chart 19: Assistance with care provided to the recipient

When it comes to caregivers' financial resources, more than one half (55%) considers that they do not have enough to meet the needs of the care recipient (Chart 20).

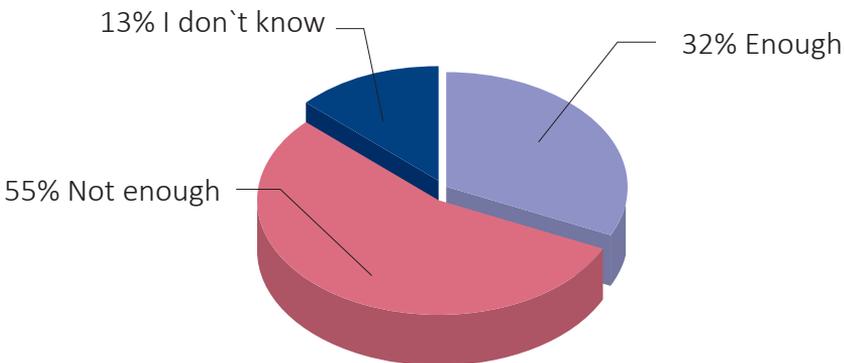


Chart 20: Financial resources to meet the needs of the care recipient

Thirty percent of informal caregivers receive regular financial assistance to provide for the needs of the recipient, 18% get occasional support, while 52% of respondents do not receive any financial assistance (Chart 21).

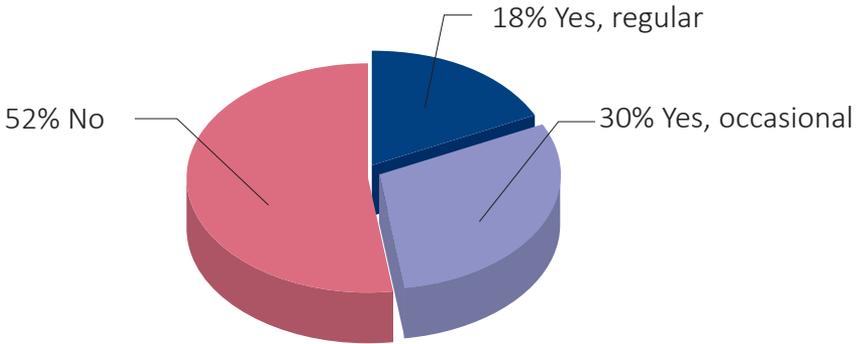


Chart 21: Financial assistance to provide for the needs of care recipients

The degree to which the care recipient is demanding ranges from 0 (not demanding at all) to 10 (maximally demanding). Score frequencies are presented in Chart 22. The highest number of respondents ranked their care as maximally demanding (30.7%).

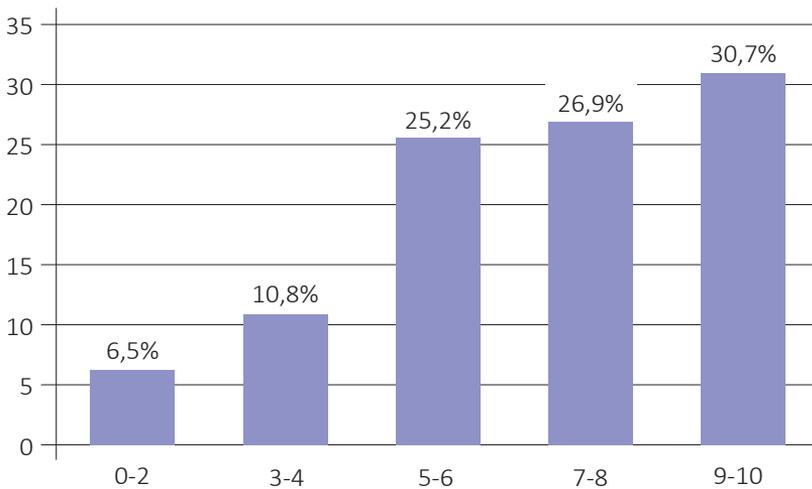


Chart 22: The degree to which care recipients are demanding

The functional status of care recipients was measured using basic and instrumental activities of daily living. The degree of dependence of care recipients in performing activities of daily living was measured using the ADL scale. The highest number of care recipients needed assistance with washing (61.5%), dressing (48.2%), moving (43.5%) and using the toilet (42.1%), continence (40%) and eating (32.2%) are also activities with which care recipients required assistance (Chart 23).

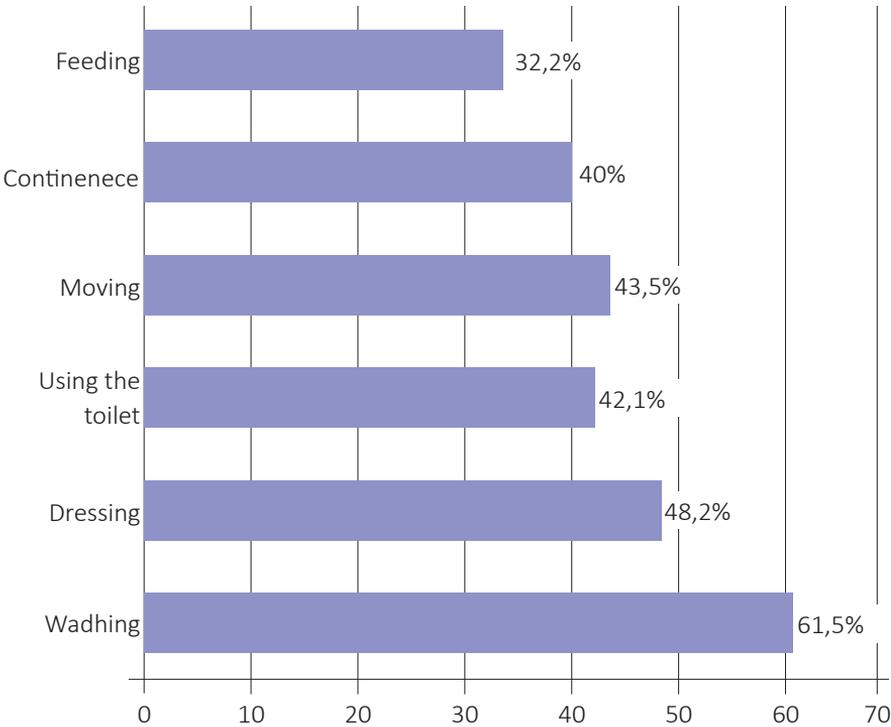


Chart 23: Level of dependence of care recipients in performing activities of daily living

Average ADL score of care recipients was 2.7 ± 2.5 . They range between 0 and 6, median 2 (Chart 24).

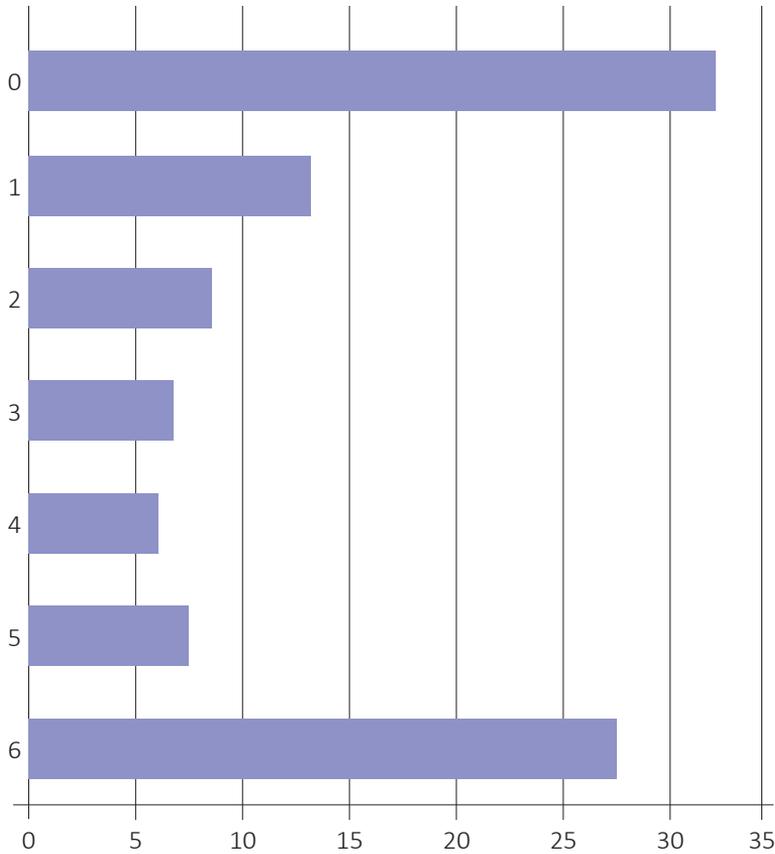


Chart 24: Care recipients by ADL score

The degree of dependence of care recipients in performing instrumental activities of daily living is presented in Chart 25. To examine instrumental activities of daily living, an adapted Lawton Instrumental Activities of Daily Living (IADL) Scale was used. Care recipients can maintain their own households (89.9%), do their finances (89.5%), maintain clothes (88.9%), buy groceries (84.8%), use transportation (84.8%) and prepare meals (81.5%). Also, taking medication (55.5%) and using the telephone (36%) are activities with which care recipients require assistance.

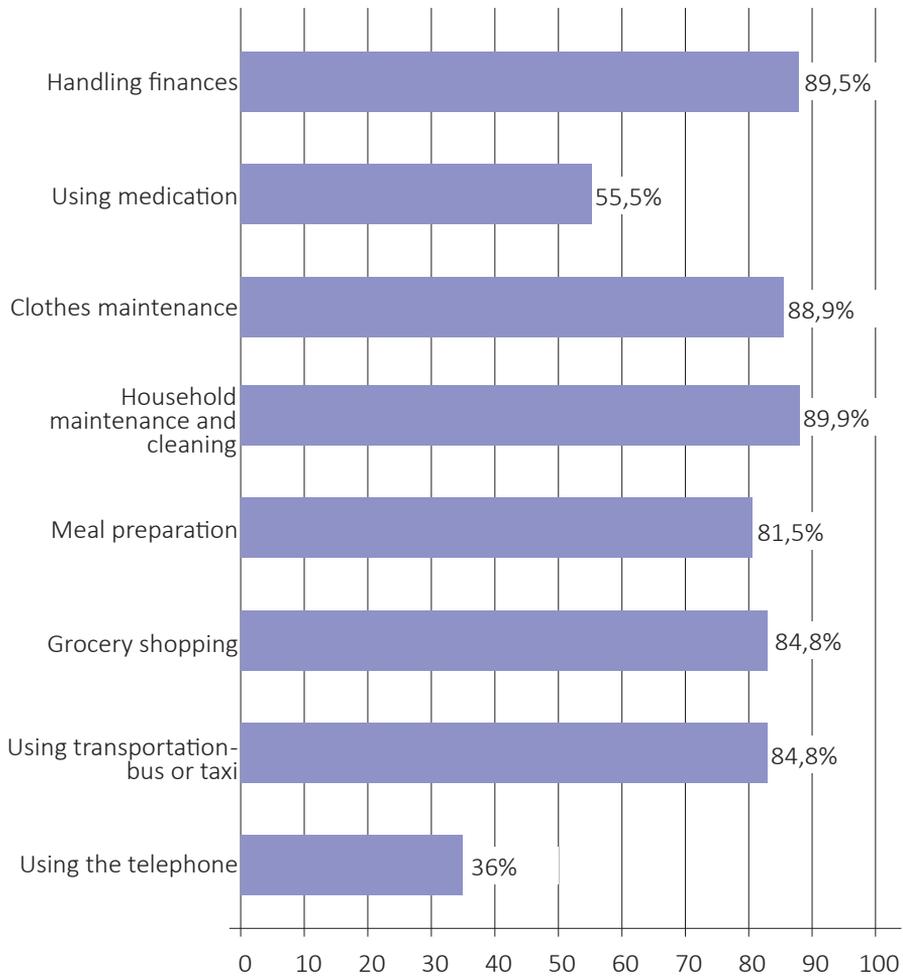


Chart 25: Degree of dependence of care recipients in performing instrumental activities of daily living

Average IADL score for care recipients was 6.1 ± 2.0 . It ranged from 0 to 8, median 7 (Chart 26).

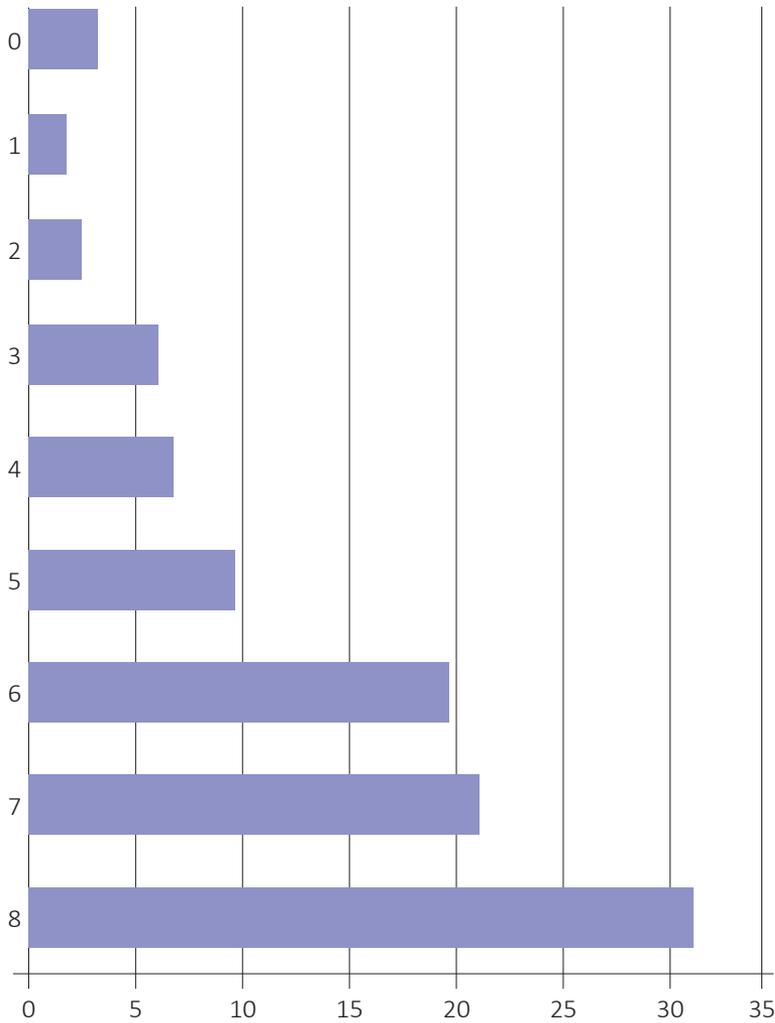


Chart 26: Care recipients by IADL score

When it comes to the provision of assistance and support, 78% of informal caregivers have confirmed that they have assistance or support with the provision of care (Chart 27). In the majority of cases this is a close person (63.1%), while civil society organisations and government institutions contribute to the provision of care equally (7.9%) (Chart 28).

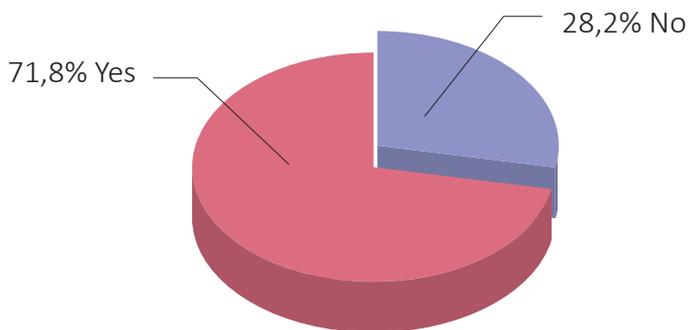


Chart 27: Existing support/assistance for the provision of care

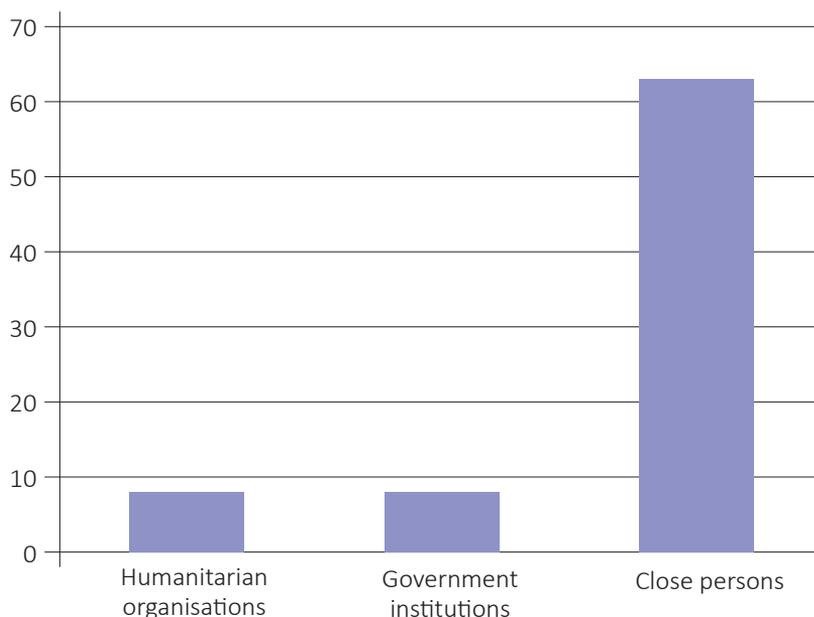


Chart 28: Support provided by close persons, humanitarian organisations and government institutions

Distribution of the needs of informal caregivers during the COVID-19 pandemic is presented in Chart 29. During the pandemic, informal caregivers needed protective equipment (32%). The lack of information also presented one of the main problems and needs (29.3%). Nearly one quarter of respondents needed respite services (21.9%). Additional assistance was needed by 18.5% of informal caregivers,

while hygiene products were required by 14.8% of respondents. A study conducted during the emergency situation on a sample of 112 respondents gave similar results. Informal caregivers mostly needed respite services (39.3%), followed by protective equipment (33%), and information (23%). Assistance with hygiene was also important to them (22%).⁸⁵

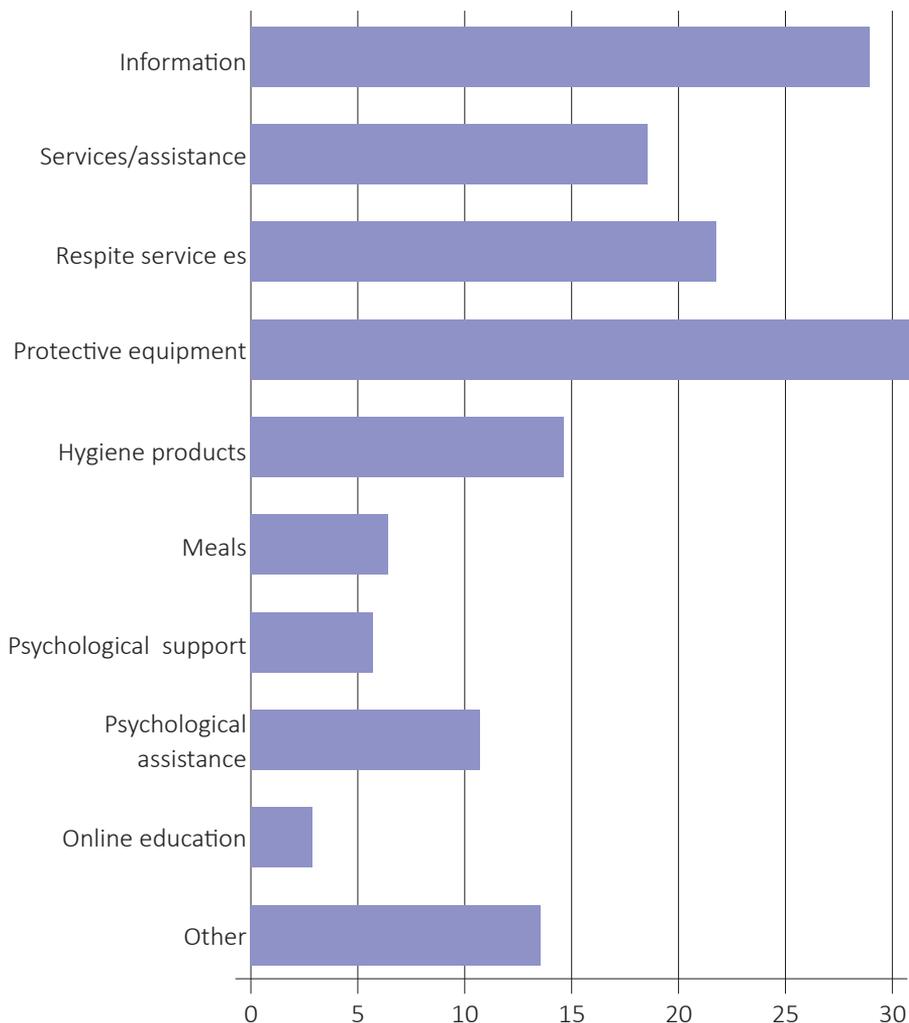


Chart 29: Informal caregivers' needs during the COVID-19 pandemic

⁸⁵ Zdravlje neformalnih negovatelja, Todorović N. et al., 2020, Caritas Šabac,

To the question of whether they consider their health to be more affected than before the pandemic, 61.5% of informal caregivers answered “yes”. A high number of respondents felt that during the pandemic, the health of the person they provided care to was affected more than before the pandemic (68.7%). Also 67.3% of them now feel more afraid for their own or the health of the care recipient (Chart 30).

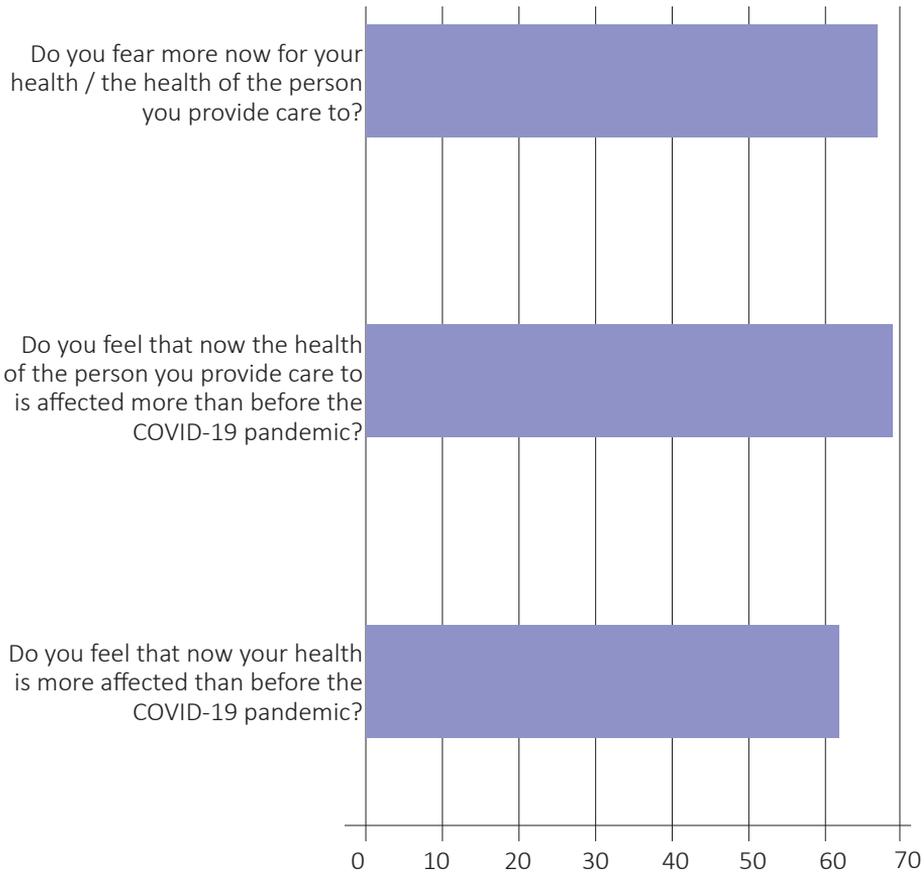


Chart 30: Concerns among informal caregivers for their own health and the health of care recipients during the COVID-19 pandemic

3.3. Informal caregiver burden

The Zarit Interview was used as the instrument for the assessment of informal caregiver burden. The average informal caregiver burden score was 32.6 ± 16.9 . The lowest measured score was 0 and the highest 88. The majority of respondents exhibited mild to moderate burden (38.7%). Nearly 30% exhibited no burden. Moderate to severe burden was measured in 26.4% of informal caregivers. Forty-eight respondents (6%) exhibited severe burden (Chart 31). Average score of the informal caregiver personal domain of burden was 16.3 ± 8.6 (minimum 0; maximum 48), while the average score of the informal caregiver role domain of burden was 8.8 ± 5.8 (minimum 0; maximum 24).

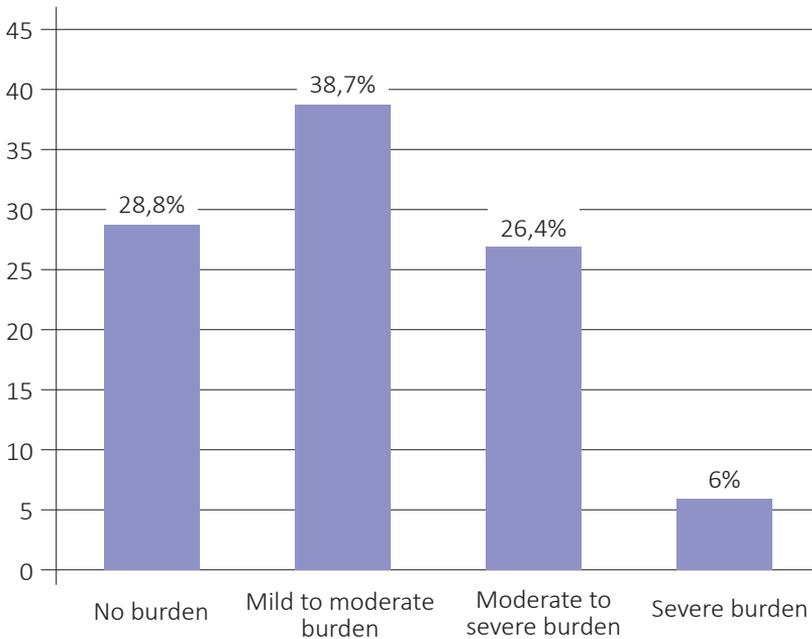


Chart 31: Caregiver burden (Zarit interview)

3.4. Depression, fatigue and the quality of life of informal caregivers

In terms of the Beck scale, 72.9% of respondents did not exhibit depression. Mild depression was present in 11.2% of informal caregivers, while 8.6% of respondents had moderate depression. Seven percent of informal caregivers were severely depressed (Chart 32). The average score was 9.9 ± 10.7 (minimum 0; maximum 55).

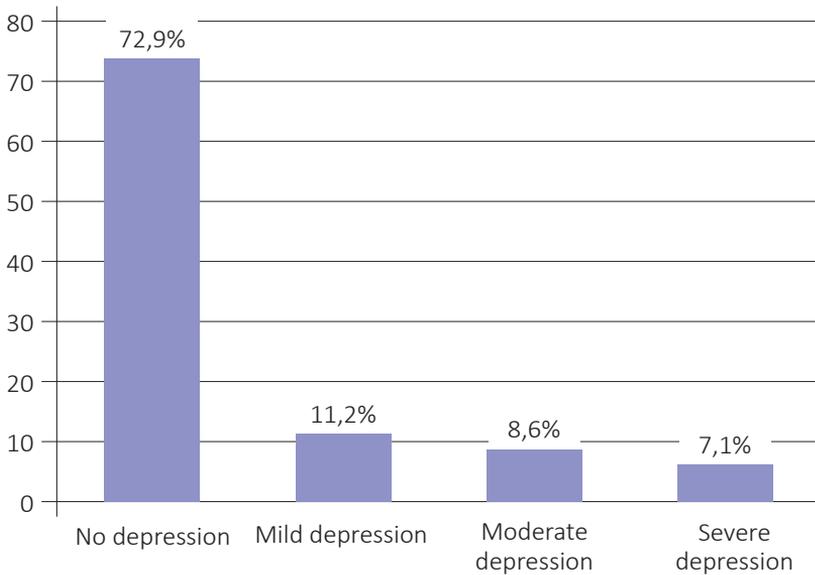


Chart 32: Beck Depression Inventory

The average score on the Krupp Fatigue Severity Scale (FSS) was 3.5 ± 1.8 (minimum 1; maximum 7). Distribution of informal caregivers' answers to each of the questions in Krupp FSS is presented in Chart 33.

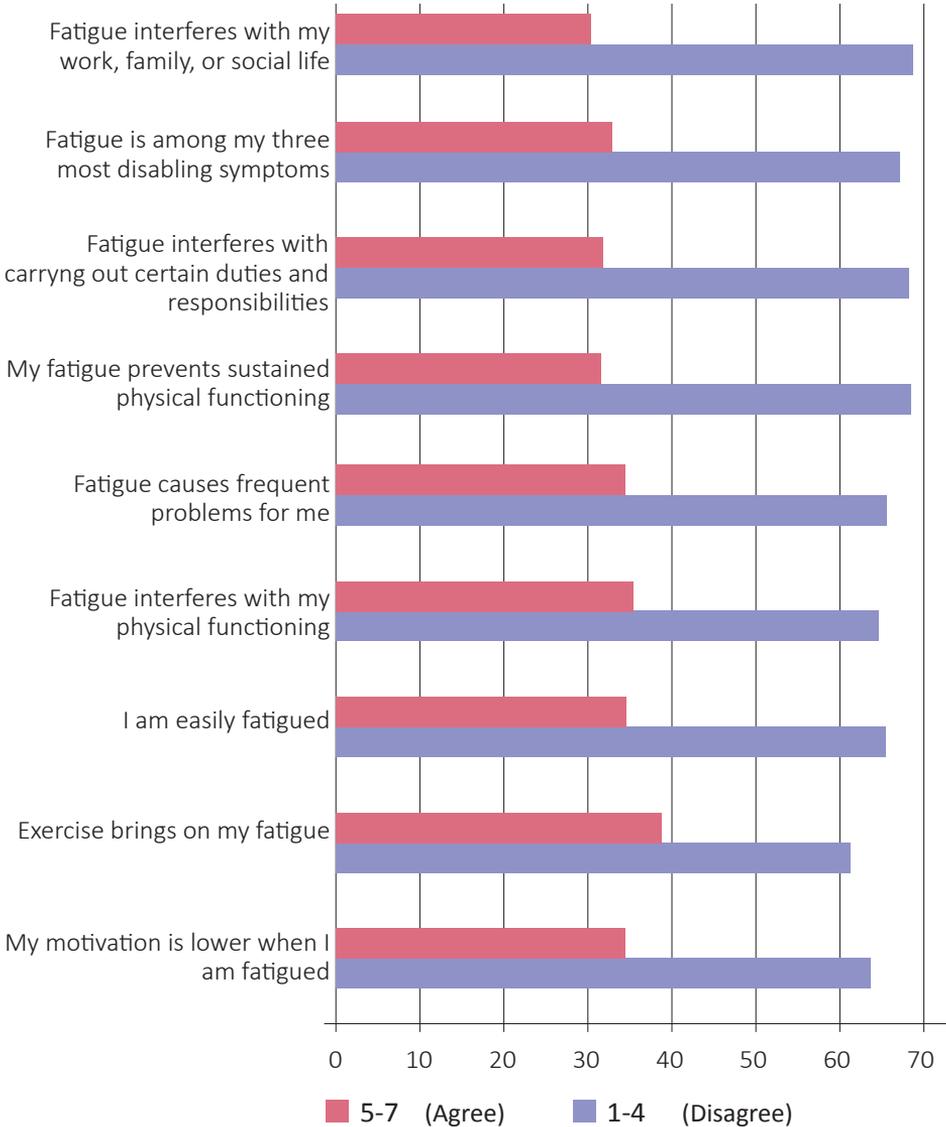


Chart 33: Krupp Fatigue Severity Scale

The SF 12 questionnaire was used to measure the quality of life of informal caregivers. The average value of the SF 12 physical health score was 45.6 ± 63.5 (minimum 19.1; maximum 63.5), and of SF 12 mental health score was 41.0 ± 6.3 (minimum 22,1; maximum 56.9), Chart 34.

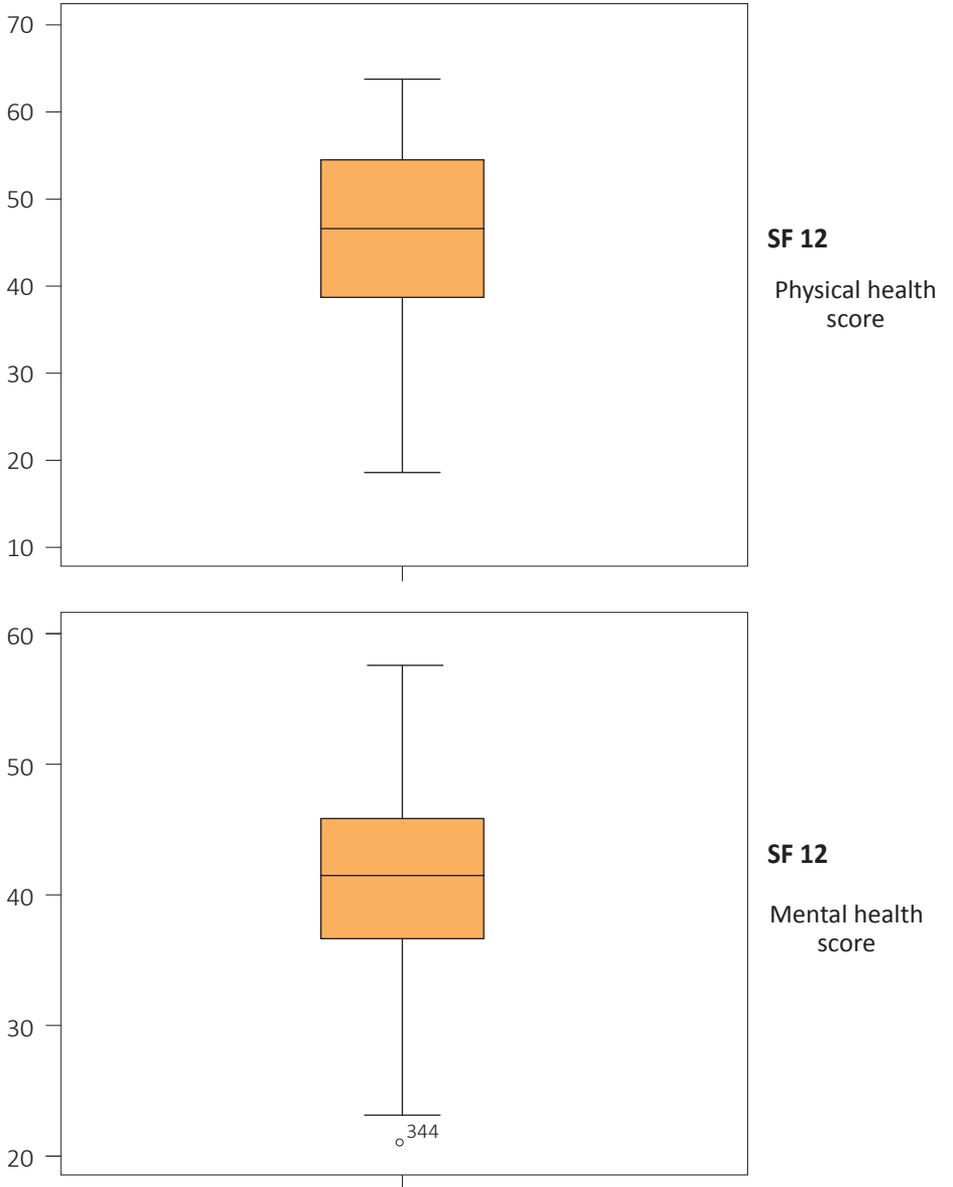


Chart 34: SF 12 Mental and physical health scores

3.5. Informal caregiver burden according to examined characteristics

Caregiver burden according to socio-demographic characteristics, characteristics of care recipients and care, existing social support, available financial resources, financial assistance and informal caregivers' concern for their own and for the health of care recipients during the COVID-19 pandemic are presented in Tables 2-4. All statistically important characteristics presented in the above-mentioned tables were then tested using regression models with caregiver burden, personal and role domains as dependent variables.

Table 2. Caregiver burden by socio-demographic characteristics

		Caregiver burden (Zarit interview)	p	Caregiver burden Personal domain	p	Caregiver burden Role domain	p
Sex	Male	31.6 ± 17.1	0.363	15.9 ± 8.7	0.429	8.7 ± 5.7	0.903
	Female	32.8 ± 16.8		16.4 ± 8.5		8.7 ± 5.8	
Age	18-34	23.6 ± 14.2	<0.001	11.9 ± 7.0	<0.001	6.3 ± 4.9	<0.001
	35-64	31.5 ± 16.3		15.6 ± 8.2		8.6 ± 5.6	
	65+	17.8 ± 1.4		20.1 ± 9.1		10.1 ± 6.4	
Marital status	With partner	32.8 ± 16.6	0.614	16.3 ± 8.4	0.810	8.8 ± 5.7	0.566
	Without partner	32.1 ± 17.4		16.2 ± 8.8		8.6 ± 5.9	
Education	No education / Incomplete	47.6 ± 19.8	<0.001	24.3 ± 10.5	<0.001	12.7 ± 6.1	0.005
	Primary	35.2 ± 19.1		18.1 ± 10.1		8.8 ± 6.4	
	Secondary	32.5 ± 16.5		16.1 ± 8.1		8.8 ± 5.7	
	College and University	31.7 ± 16.0		15.8 ± 8.3		8.7 ± 5.5	
	Postgraduate (Master/PhD)	21.0 ± 14.0		11.9 ± 7.2		4.9 ± 4.6	
Employment Status	Employed	28.7 ± 15.0	<0.001	14.4 ± 7.5	<0.001	7.8 ± 5.2	<0.001
	Unemployed	33.6 ± 17.5		16.6 ± 8.8		9.1 ± 5.9	
	Pensioner	38.3 ± 17.9		19.4 ± 9.2		10.1 ± 6.3	
	Other	41.1 ± 14.7		19.3 ± 6.8		12.2 ± 5.8	
Type of settlement	Urban	32.9 ± 16.7	0.767	16.5 ± 8.5	0.525	8.8 ± 5.7	0.880
	Suburban	31.9 ± 18.0		16.0 ± 9.2		8.5 ± 5.9	
	Rural	31.9 ± 16.6		15.6 ± 8.3		8.9 ± 5.9	

Table 3. Caregiver burden by care recipient and care characteristics

		Caregiver burden (Zarit interview)	p	Caregiver burden Personal domain	p	Caregiver burden Role domain	p
The number care recipients		0.027*	0.452	0.019*	0.596	0.033*	0.351
Sex	Male	33.4 ± 16.6	0.202	16.6 ± 8.4	0.303	9.0 ± 5.7	0.366
	Female	31.8 ± 17.1		16.0 ± 8.6		8.6 ± 5.7	
Age	<18	40.1 ± 15.5	0.016	18.2 ± 7.8	0.092	11.4 ± 6.3	0.077
	18-34	35.0 ± 10.6		16.7 ± 5.4		9.1 ± 4.4	
	35-44	38.7 ± 18.6		19.5 ± 9.2		9.4 ± 6.7	
	45-54	32.7 ± 19.0		15.8 ± 9.5		8.4 ± 6.7	
	55-64	36.0 ± 18.8		18.1 ± 9.8		9.4 ± 5.7	
	65-74	30.6 ± 17.8		15.5 ± 8.7		7.9 ± 6.1	
	≥85	33.9 ± 16.1		16.9 ± 8.4		9.5 ± 5.5	
Shared household		34.6 ± 16.8	<0.001	17.1 ± 8.5	<0.001	9.5 ± 5.8	<0.001
Frequency of care	Every day	34.1 ± 17.1	<0.001	16.9 ± 8.6	<0.001	9.4 ± 5.9	<0.001
	Several times per week	26.9 ± 14.5		13.9 ± 7.8		6.7 ± 4.7	
	At least once per week	25.0 ± 13.4		13.1 ± 7.2		5.7 ± 4.2	
	Several times per month	22.0 ± 13.9		11.3 ± 6.4		5.6 ± 4.4	
	At least once per month	21.7 ± 21.6		13.0 ± 10.2		3.8 ± 6.8	
Duration of care, Daily in hours	<6	27.1 ± 15.5	<0.001	13.9 ± 8.1	<0.001	6.8 ± 5.2	<0.001
	6-12	29.4 ± 15.3		14.7 ± 7.6		8.2 ± 5.2	
	>12	38.2 ± 16.9		18.8 ± 8.6		10.6 ± 5.9	
Kinship	Father / Mother	32.1 ± 16.6	<0.001	16.2 ± 8.5	<0.001	8.6 ± 5.7	0.007
	Spouse	38.7 ± 18.8		19.1 ± 9.4		10.3 ± 6.7	
	Daughter / Son	39.0 ± 13.4		19.0 ± 6.8		10.0 ± 5.5	
	Other blood relative	30.0 ± 16.2		15.0 ± 8.3		8.3 ± 5.4	
ADL score		0.335*	<0.001	0.276*	<0.001	0.377*	<0.001
IADL score		0.345*	<0.001	0.299*	<0.001	0.361*	<0.001
The degree to which care is demanding		0.453*	<0.001	0.393*	<0.001	0.469*	<0.001

*correlation coefficient

Table 4. Caregiver burden by existence of social support, available financial resources, financial assistance and caregivers' concern for their own and the health or the care recipients during COVID-19

		Caregiver burden (Zarit interview)	p	Caregiver burden Personal domain	p	Caregiver burden Role domain	p
Social support /assistance with care		32.1 ± 16.5	0.291	16.2 ± 8.4	0.626	8.7 ± 5.7	0.506
Available financial resources to meet the needs of care recipient	They are sufficient / I don't know	26.2 ± 15.9	<0.001	17.8 ± 8.0	<0.001	6.9 ± 5.4	<0.001
	They are not sufficient	37.8 ± 15.9		18.4 ± 8.4		10.3 ± 5.6	
Financial assistance to provide for the needs and care to care recipient	Yes, regularly	28.3 ± 15.9	0.002	14.3 ± 7.9	0.007	7.7 ± 5.4	0.033
	Yes,	33.2 ± 16.3		16.5 ± 8.4		8.9 ± 5.4	
	No	33.8 ± 17.2		16.9 ± 8.7		9.1 ± 6.0	
Do you feel that your health is now more affected compared to the period before the COVID-19 pandemic?	Yes	34.5 ± 16.9	<0.001	17.4 ± 8.6	<0.001	9.2 ± 5.9	0.004
	No	29.3 ± 16.2		14.5 ± 8.1		8.0 ± 5.5	
Do you feel that the health of the person you provide care to is affected now more compared to the period before the pandemic?	Yes	33.5 ± 17.1	0.031	16.8 ± 8.7	0.019	8.9 ± 5.9	0.289
	No	30.7 ± 16.2		15.3 ± 8.2		8.4 ± 5.6	
Do you now fear more for your own and/ or the health of the person you provide care to?	Yes	34.5 ± 16.8	<0.001	17.3 ± 8.5	<0.001	9.2 ± 5.8	0.002
	No	28.6 ± 16.5		14.1 ± 8.2		7.8 ± 5.6	

3.6. Multiple regression analysis of informal caregiver burden

A multiple regression analysis was applied to investigate the impact of multiple independent factors (caregivers' socio-demographic characteristics, general information about care recipients, care recipients' functional status, self-assessment of caregiver health, social support, finances) on overall informal caregiver burden, as well as the domains of caregiver burden, personal domain and role domain. By applying a hierarchical multiple regression to model informal caregiver burden, independent factors related to the COVID-19 pandemic were also investigated. The multiple regression models also included variables that were, using univariate analysis, found to be in high correlation with caregiver burden.

The results of the multiple regression analysis for total informal caregiver burden (dependent variable) are presented in Table 5. Self-assessment of caregiver health, degree of care recipients' dependence, insufficient financial resources, degree of dependence of care recipients in performing basic activities of daily living (ADL) and daily duration of care are factors that highly correlate with total informal caregiver burden. Informal caregivers of poorer self-assessed health, providing care to a person that is more demanding and dependent in performing basic activities of daily living, with insufficient financial resources to meet the needs of the care recipient and longer daily duration of care, exhibit higher total burden (Model 1).

Table 5. Multiple regression analysis with informal caregiver burden as dependent variable – Model 1

Variables	β	SE _{β}	p
Caregiver self-assessed health	0.333	0.599	<0.001
Degree of care recipient dependence	0.246	0.261	<0.001
Insufficient financial resources	0.148	0.563	<0.001
Care recipient dependence in performing basic activities of daily living	0.089	0.254	0.018
Duration of daily care, hours	0.073	0.062	0.037
Adj R ²	0.383		

ADL= Activities of Daily Living

A set of independent factors related to COVID-19 was added in the further analysis of total informal caregiver burden (Model 2). Multiple regression analysis results show that, in addition to the above-listed factors, the need for psychosocial assistance, lack of care support from services, need for respite, fear for own health and the care recipient’s health, as well as the need for hygiene products, highly correlate with higher total informal caregiver burden (Table 6).

Table 6. Multiple regression analysis with informal caregiver burden as dependent variable – Model 2

Variables	β	SE _{β}	p
Caregiver self-assessed health	0.269	0.580	<0.001
Degree of care recipient dependence	0.217	0.248	<0.001
Insufficient financial resources	0.157	1.069	<0.001
Care recipient dependence in performing basic activities of daily living	0.083	0.243	0.020
Duration of daily care, hours	0.070	0.060	0.036
COVID-19			
Psychosocial assistance	0.135	1.596	<0.001
Help needed	0.118	1.271	<0.001
Respite needed	0.105	1.206	0.001
Fear for health	0.096	1.067	0.001
Hygiene products	0.091	1.380	0.002
Adj R ²	0.456		
R ² promena (COVID-19)	0.008**		

ADL= *Activities of Daily Living*

** $p < 0.01$

Multiple regression analysis results for the personal domain of informal caregiver burden (dependent variable) are presented in Table 7. Self-assessment of caregiver health, the degree to which the care recipient is demanding, employment status and insufficient financial resources are factors that highly correlate with the personal domain of informal caregiver burden. Informal caregivers of poorer self-assessed health, providing care to a person that is more demanding and with insufficient financial resources to meet the needs of the care recipient, also have higher burden expressed in the personal domain (Model 1).

Table 7. Multiple regression analysis with the personal domain of informal caregiver burden as dependent variable – Model 1

Variables	β	SE _B	p
Informal caregiver self-assessed health	0.329	0.0324	<0.001
The extent to which the recipient of care is demanding	0.260	0.118	<0.001
Employment status, retired	0.088	0.699	0.011
Insufficient financial resources	0.086	0.610	0.016
Adj R ²	0.294		

A set of factors related to COVID-19 was added in further analysis of the personal domain of informal caregiver burden (Model 2). Multiple regression analysis results show that, in addition to the above-listed factors, the need for psychosocial support, help with care, need for respite, fear for own health and the health of the care recipient, as well as the need for hygiene products are in high correlation with higher informal caregiver burden expressed within the personal domain (Table 8).

Table 8. Multiple regression analysis with the personal domain of informal caregiver burden as a dependent variable – Model 2

Variables	β	SE _{β}	p
Self-assessed caregiver health	0.265	0.318	<0.001
The extent to which the recipient of care is demanding	0.206	0.126	<0.001
Employment status, retired	0.065	0.686	0.054
Insufficient financial resources	0.093	0.585	0.007
COVID-19			
Psychosocial assistance	0.160	0.867	<0.001
Help needed	0.103	0.697	0.001
Fear for health	0.099	0.582	0.002
Hygiene products	0.080	0.747	0.011
Respite needed	0.077	0.659	0.019
Adj R ²	0.367		
R ² promena (COVID-19)	0.005*		

* $p < 0.05$

Multiple regression analysis results for the role domain of informal caregiver burden (dependent variable) are presented in Table 9.

The extent to which care recipients are demanding, self-assessed caregiver health, degree of care recipients’ dependence in performing basic ADL, and insufficient financial resources are factors that highly correlate with the role domain of informal caregiver burden. Informal caregivers of poorer self-assessed health, providing care to a person that is more demanding and dependent in performing basic and instrumental ADL, with insufficient financial resources to meet the needs of the care recipient, exhibit higher burden expressed within the role domain (Model 1).

Table 9. Multiple regression analysis with the role domain of informal caregiver burden as dependent variable – Model 1

Variable	β	SE _{β}	p
The extent to which the recipient of care is demanding	0.268	0.092	<0.001
Self-assessed caregiver health	0.254	0.204	<0.001
Care recipient’s dependence in performing basic ADL	0.098	0.098	0.023
Financial resources	0.122	0.395	<0.001
Care recipient’s dependence in performing IADL	0.083	0.121	0.042
Adj R ²	0.330		

ADL= Activities of Daily Living; IADL= Instrumental Activities of Daily Living;

A set of factors related to COVID-19 was added in further analysis of the role domain of informal caregiver burden (Model 2). Multiple regression analysis results show that, in addition to the above-listed factors, the need for psycho-social support, respite, help with care and hygiene products highly correlated with higher informal caregiver burden expressed within the role domain (Table 10).

Table 10. Multiple regression analysis with the role domain of informal caregiver burden as dependent variable – Model 2

Variables	β	SE _{β}	p
The extent to which the recipient of care is demanding	0.241	0.088	<0.001
Self-assessed caregiver health	0.197	0.200	<0.001
Care recipient’s dependence in performing basic ADL	0.084	0.095	0.042
Insufficient financial resources	0.130	0.381	<0.001
Care recipient’s dependence in performing IADL	0.074	0.116	0.058
COVID-19			
Psychosocial assistance	0.132	0.568	<0.001
Respite needed	0.141	0.431	<0.001
Help needed	0.099	0.446	0.001
Hygiene products	0.089	0.493	0.004
Adj R ²	0.386		
R ² change (COVID-19)	0.008**		

ADL= Activities of Daily Living; IADL= Instrumental Activities of Daily Living

** p<0.01

3.7. Analysis of the correlation between caregiver burden and scales for depression, fatigue and quality of life

Below we have investigated the correlation of informal caregiver burden, personal domain and role domain with Beck Depression Inventory, Krupp Fatigue Severity Scale, and SF 12 physical and mental health scores (Charts 35 and 36). A statistically high correlation was found among the investigated scores with the following correlation strengths: Beck Depression Inventory is moderately to strongly correlated with caregiver burden, personal domain and role domain (Table 11). Other scales have demonstrated moderate correlation with caregiver burden, personal domain and role domain.

Table 11. Correlation between informal caregiver burden, personal domain and role domain and Beck Depression Inventory, Krupp Fatigue Severity Scale and SF 12 physical and mental health score

		Caregiver burden (Zarit Interview)	Caregiver burden Personal domain	Caregiver burden Role domain
Beck Depression Inventory	r	0.613	0.594	0.539
	p	<0.001	<0.001	<0.001
Krupp Fatigue Severity Scale	r	0.436	0.417	0.373
	p	<0.001	<0.001	<0.001
SF12 Physical Health Score	r	-0.490	-0.475	-0.400
	p	<0.001	<0.001	<0.001
SF12 Mental Health Score	r	-0.380	-0.350	-0.360
		<0.001	<0.001	<0.001

r - Pearson correlation coefficient

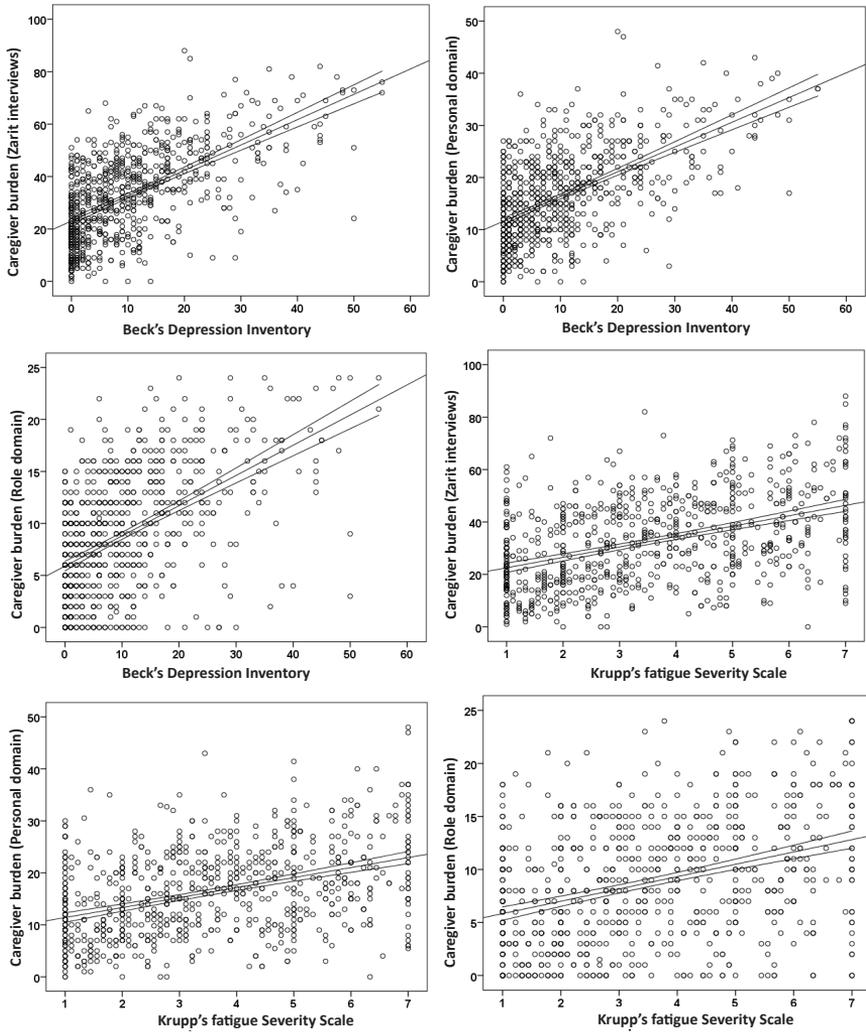


Chart 35: Correlation between caregiver burden and Beck Depression Inventory and Krupp Fatigue Severity Scale

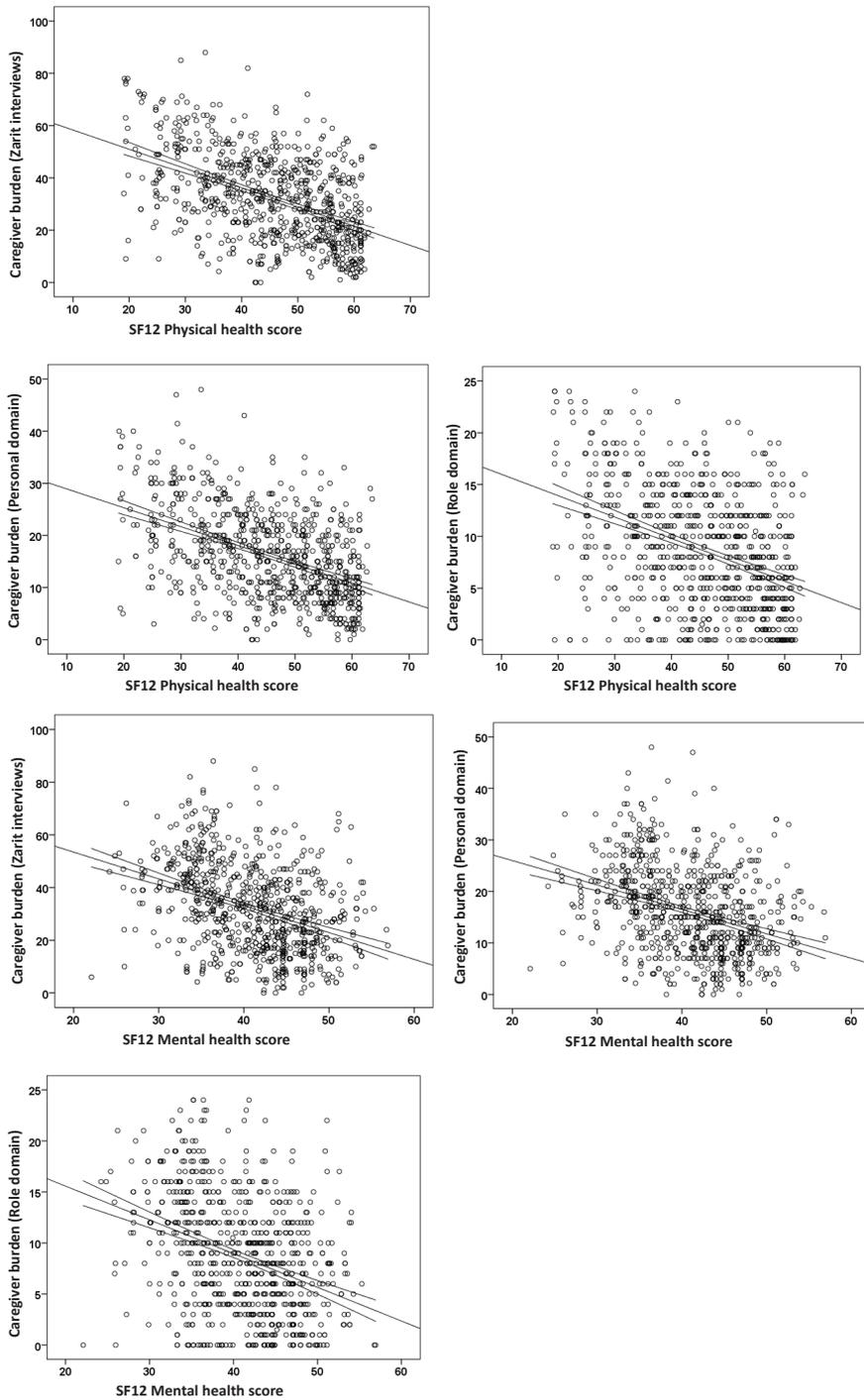


Chart 36: Correlation between caregiver burden and SF 12 physical and mental health scores

3.8. Qualitative research conclusions

Informal caregivers that participated in focus groups confirmed that the care for their own health came “last” and that they did not think much about their mental health. Only one person confirmed to have undergone psychiatric therapy while providing care to her mother. This respondent claimed that this has put significant pressure on her and she had feelings of guilt for not caring for her mother well enough and she thought that she had not done enough to make things easier for her. Further, she developed insomnia and anxiety. Therapy helped her to overcome negative feelings and go on with her life after her mother’s death.

Another participant provided care to her neighbour with the diagnoses of schizophrenia. For her, this was a very stressful “job” as no one wanted to provide care to this man due to his aggressive and demanding demeanor. He would often yell, both inside his home and on the balcony. This situation made the participant cry, caused her blood pressure to rise and, sometimes, she would even be frightened. Everyone knew what this man was like and no one else would want to help him. Without his neighbour as informal caregiver he could not survive, and it was an act of goodwill that she was helping him.

The majority of informal caregivers felt that they needed more cooperation with formal care providers, as cooperation with professional services may improve the quality of care for the dependent person, but also reduce stress faced by informal caregivers on a daily basis. The COVID-19 pandemic has only increased their efforts, and also brought about fears that are directly and indirectly related to the pandemic. Some of those fears were related to concerns about infecting the person they are providing care to or making their condition worse to the point where they would die. Additionally, there was a fear that they would not immediately get adequate services in the hospital even if they were infected with the

virus, or if their health worsened. One focus group participant had a particularly difficult situation as his father suffers from Alzheimer's disease, and his mother, having had a stroke during COVID-19, was released for home care during curfew. It was difficult to provide care to two dependent persons, change diapers, wash and feed them, but the knowledge gained in medical school helped this informal caregiver perform all activities professionally. He also admitted that sometimes he reflected on whether he is providing good enough care to his parents, or whether he, perhaps, gives priority to one of them.

Some focus group participants considered what happened to those informal caregivers that have no prior healthcare knowledge and found themselves in a new situation requiring a quick response and adaptation to new circumstances: how they cope, who helps them, how they learn the necessary skills, whether they receive psychosocial support and how they access information. Some informal caregivers also noticed that their care recipients were less demanding during the emergency situation and more understanding of them. Since the onset of the pandemic, one of the main problems that informal caregivers faced was the lack of timely and clear information or contradictory information. This often led to fear and dilemma around what to do, how to introduce new activities in the care routine and how to learn new skills to compensate for the reduced or suspended services.

In addition to improved cooperation with formal service providers and institutions, the focus group participants agreed they needed more education in learning how to improve their care-related skills and communication. It is also necessary to provide training to informal caregivers which would include self-care in order to enable them to face the requirements of care more easily.



4

Conclusions

The results of this research confirm the findings of past studies and the available literature in showing that the role of informal caregivers bears certain risks related to the mental, but also the physical health of each informal caregiver. An additional level of complexity in the given situation was brought about by the COVID-19 pandemic, during which time this study was conducted. This increased the complexity of the provision of care and the level of stress, thus increasing also the risk of adverse mental health outcomes. One of the key findings of this study is the need to observe informal caregivers as a heterogenous population, within which certain groups are at a higher risk of adverse effects to physical and mental health. This is also important so that public policies and the way in which long-term care services are funded better recognise the needs of different groups, in order to provide them with additional adequate support. The argument that informal caregivers are a heterogenous group is also supported by data found in the literature, stating that, especially among caregivers providing lower-intensity services, the care itself can have positive effects to their mental health.

As for the depression levels in the sample, 72.9% of respondents did not exhibit any depression, while 7.1% exhibited severe depression symptoms, 8.6% moderate and 11.2% showed mild symptoms of depression. It was found that the key factors for the occurrence of depression symptoms were primarily the burden of care, personal domain and role domain. Considering key demographic trends in

Serbia, it can be expected that the number of informal caregivers will continue to decrease. These trends include low natality rates and negative migration balance, particularly for the working age population, together with population ageing, which also means there is a higher share of people over 80 years of age in the population with greater needs for care^{86, 87}, including the risk of different types of dementia,. This trend could increase the burden of care on them and also elevate the risks for depression. Therefore, now is the time to think about the ways in which to provide this population with additional support and reduce the risks of negative mental health outcomes.

When designing new support services, this study further indicates which subgroups in the informal caregiver population are at increased risk, as well as the nature of circumstances increasing the risk. The factors that influence increased care burden were self-assessed caregiver health, the extent to which care recipients are demanding, insufficient financial resources, the level of dependence of care recipients in performing basic activities of daily living (ADL) and the number of hours spent providing care during the day.

Many studies on informal caregivers have shown that there is a correlation between the extent to which care is demanding and subjective perception of caregiver health, with more demanding care corresponding with poorer self-perception of health.⁸⁸ In other words, the caregiver profile with expressed needs for additional support would cover older caregivers (for whom it is probable that

⁸⁶ World Report on Disability 2011, <https://www.who.int/teams/noncommunicable-diseases/disability-and-rehabilitation/world-report-on-disability>

⁸⁷ The prevalence of disability in the oldest-old is high and continues to increase with age: findings from The 90+ Study, <https://pubmed.ncbi.nlm.nih.gov/19259982/>

⁸⁸ Dahlrup, B., Ekström, H., Nordell, E. and Elmståhl, S., 2015. Coping as a caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life. *Archives of Gerontology and Geriatrics*, 61(2), pp.261-270.

the self-assessed health would be poorer), caregivers with low income or unemployed caregivers and those providing care to persons with low level of independence requiring many hours of care (immobile persons, persons with different forms of dementia and other cognitive and mental health disorders). The extent to which care is demanding is one of the reasons why informal caregivers opt for residential care for the persons they provide care to.⁸⁹

In this context, it is important to have in mind that among the respondents in this study, 78% report getting assistance and support with the provision of care, but the vast majority of this support comes from persons close to them, meaning family members, spouses, etc. Therefore, it should be noted once more that demographic changes, changes in the family structure and plans for the future in which this type of support will be less and less available. On the other hand, considering that the state provides the same amount of support as the civil sector (7.9% each), it is clear that there is room for both these sectors to increase the scope and diversity of support services offered. Special attention should be given to providing support with regards to informal caregiver mental health issues – particularly considering depression increasingly becoming a public health issue, as well as that, according to WHO data, mental health conditions now cause 1 in 5 years lived with disability.⁹⁰ Depression is considered the leading cause of disability worldwide, as well as the fourth leading contributor to the global burden of disease.⁹¹ Here, it is also important to have in mind that mild (subclinical) forms of depression should not be overlooked because, if left untreated, they may become severe forms, regardless of the lower intensity of symptoms. This is why it is

⁸⁹ Buhr, G., Kuchibhatla, M. and Clipp, E., 2006. Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions With Families Prior to the Transition. *The Gerontologist*, 46(1), pp.52-61.

⁹⁰ https://www.who.int/health-topics/mental-health#tab=tab_2

⁹¹ Depression: The Disorder and the Burden, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3137804/>

important that mental health services also cover the persons below the threshold used to define clinical depression.⁹² If there are other chronic illnesses, their health outcomes worsen in combination with even mild forms of depression. It is particularly important not to overlook milder forms of depression in older persons, because there is a tendency to normalise depressive symptoms in the elderly, even among health professionals, which often prevents them from receiving adequate treatment.

As this study was conducted during the COVID-19 pandemic, the impact of these circumstances on informal caregiver mental health was also analysed. It can be concluded that there are factors directly connected to the infection, such as the fear for one's own health and the health of the care recipient, but also factors related to the availability of support services (respite, psychosocial support) and reduced availability of hygiene products, which are linked with epidemiological measures, movement restrictions, supply issues, and which have their own economic dimensions. On one hand, certain care-related costs increased (e.g. health protection costs, which, due to the burden on the health system, were now more often paid out of own pocket, in order to reduce waiting times), and on the other, disturbances on the labour market make income of a significant part of the population irregular and at risk. Here, we should have in mind the additional complexity during the pandemic where extra support often also means more contacts, which increases the risk of infection. This further indicates that it is necessary to find the right balance between seeking support and maintaining safety in this context. In relation to this, additional support services should be designed with full participation of informal caregivers, including opportunities to provide remote support, made possible by modern communication technologies.

⁹² From depressive symptoms to depressive disorders: the relevance of thresholds, <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/from-depressive-symptoms-to-depressive-disorders-the-relevance-of-thresholds/9C5A9EB8FED55BA678E95603FB286EFA>

Finally, it is important to bear in mind that health prevention measures ensure better caregiver mental health and also have a positive impact on reducing care burden and reducing the risks of violence against older persons receiving care.⁹³

⁹³ Family caregiver mistreatment of the elderly: prevalence of risk and associated factors, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5778739/>



5 Recommendations

Recommendations for the improvement of the situation of informal caregivers with special focus on their mental health

This study, as well as others before it, shows a connection between caregiver burden and negative mental health outcomes. The recommendations, therefore, aim to reduce informal caregiver burden in different ways.

- Continuous efforts are needed to develop an integrated and efficient long-term care user-centred system, which would recognise the role of informal caregivers as irreplaceable for its maintenance. In Serbia at the moment, parts of the long-term care system can be found in the healthcare, social protection and pension insurance systems, which makes access to services complex, and coordination among different services more complicated, with higher resource utilisation. The advantages of an integrated system could be in improved coordination among different services provided, reduced costs and increased availability of formal care services, which would lead to reducing burden of care on informal caregivers. Further, such system, recognising and acknowledging the role of informal caregivers, would be developed with the idea to ensure different types of support, which would increase the quality of care and reduce burden and risks to the mental health of caregivers.

- Informal caregivers should be recognised as a part of the formal long-term care system, which would result in additional health and social protection entitlements, as well as labour related rights. These measures should be created in cooperation with informal caregivers themselves, so as to include as broad a spectrum of needs as possible in this diverse and heterogenous group. This would make the first step in providing support to informal caregivers, which would have positive outcomes on their mental and physical health, as well as the quality of care they provide.
- A significant segment of informal caregivers' rights is related to the labour market. Here, the law should regulate flexible working hours, more days off and, in the case of acute worsening of the care recipient's condition, the possibility to work from home with more paid vacation days. On the other hand, existing public policies related to the provision of support to child caregivers could be taken as a basis to adequately extend reliefs and benefits they enjoy to also include carers for other family members. This recommendation is in line with the European Commission directive on work-life balance where new policies need to ensure support, especially to the middle generation, and achieve and maintain balance between work, care provided to children and care provided to older parents. This support should also recognise the contribution of informal caregivers to the family, savings incurred on the level of formal care systems and other positive effects of their work on health, mental health and social cohesion.
- By improving anti-discrimination legislation, an even better protection of informal caregivers from workplace discrimination should be ensured.⁹⁴

⁹⁴ Međugeneracijska razmena u Republici Srbiji Vračević M. et al., (2019) Crveni krst Srbije <https://www.redcross.org.rs/media/5286/medjugeneracijska-razmena-u-republici-srbiji.pdf>

- Support services intended for informal caregivers should be designed in a way to meet the specific needs of informal caregivers, depending on their characteristics and their life circumstances (age, employment, family situation, income) and needs related to the care recipient. As the research has shown, not all groups in the informal caregiver population are under equal risk of potential mental and physical health problems, so services should be designed in a way to be available to groups at higher risk. Support services should empower them to more easily perform their duties, and they should include information-sharing (about available services, tools, rights, important contacts in the community, etc.), counselling and psychological support (access to mental health services also supporting resilience-building), technical support (related to the provision of care, organisation of daily responsibilities, etc.), respite services (which currently exists in the social protection system, but not available enough) and training (related to care provision skills, but also communication, coordination, planning, etc.). Such services will be more available and more efficiently provided if they are a part of a comprehensive, integrated service package, developed with the participation of informal caregivers themselves and other stakeholders, especially at the local level.⁹⁵
- The healthcare system should adopt protocols for identifying and strengthening caregivers while the family member is still in hospital by training and preparing them to learn some care-related skills after hospitalisation. Further, they should be made aware of the situation that awaits them after the care recipient is released from the hospital for home treatment (such as telephone calls related to the questions on the person's condition and check-ups after discharge). There should be consultations between health

⁹⁵ What do informal carers need? Towards a fair and rights-based deal, https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Needs_final.pdf

professionals and caregivers that will take over care during the recovery, before and after hospitalisation.

- Annual physical examination should be provided which would, in addition to the parameters for monitoring physical health, also include screening for depression and other symptoms related to the provision of care and mental health. It is hoped that this would have a preventative role and help with early identification of risks and adequate design of interventions, including psychological counselling and referrals.
- Capacity development also includes continuous cooperation with the local community and civil society organisations, because it is at the community level that substantive support could be provided to informal caregivers. This is undertaken using the self-help group model where informal caregivers would provide support and assistance to one another, in appropriate groups according to care recipients (older, functionally dependent persons, older persons with dementia, children with cerebral palsy, children with Down syndrome, etc.). Different respite service models (day care centres, mutual caregiver assistance, etc.) would allow informal caregivers time for other responsibilities, their own family or social activities etc. All this would, in turn, have a positive effect on caregiver mental health and the overall quality of care.
- Existing good practice examples at the local level should be promoted, such as day care centres. Also, in other places where there is need and possibility it is recommended to build adequate support capacities. The Standing Conference of Towns and Municipalities is an ideal partner for such activity, due to its operational presence at the local level.
- Volunteerism, intergenerational and intragenerational solidarity should also be promoted as an essential response to demographic changes and the evolving needs of an ageing population.

- Invest more in health-prevention programmes throughout the life cycle, to reduce the risk of disability in older age, linked primarily with chronic, non-infectious diseases, including depression.
- Guidelines on the rights of informal caregivers should be developed, made available to them and adapted to their needs and opportunities. In addition to printed material (leaflets, handbooks) and radio and TV programmes (videos, shows), a centralised and user-friendly database available online should be created on issues of importance for caregivers. This database would enable them to learn about good practice examples, the available formal services, support services, etc., in addition to learning about their rights. Such a resource could also be made interactive, where questions asked by caregivers could be answered by experts. Additional thematic (printed and digital) guidelines on caregiver rights should be issued, related to social protection and healthcare entitlements, but also providing important information, such as telephone numbers and websites of relevant institutions.
- Regular data collection related to informal care providers is necessary: the number of informal caregivers, types of services, time spent providing care and similar. This is important in order to create more efficient public policies related to long-term care services. In relation to this, more involvement by academia and researchers is needed.

Recommendations to improve the situation of informal caregivers related to emergencies, especially pandemics

Recommendations in case of emergencies and pandemics, such as COVID-19, are divided into various steps and prioritised in terms of time. These measures protect the physical and mental health, as well as well-being of informal caregivers, and care recipients.

Information

- Information should contain facts about the situation and the illness, as well as advice on how to recognise symptoms, how to mitigate them and what the most efficient prevention measures available are. This information should be adjusted to the situation, but also the living conditions of informal caregivers, their age, education and other resources, with a special emphasis on topics relevant to the protection of their own and the care recipient's health (personal and general hygiene maintenance, waste disposal, etc.). They must be clear, presented using easy-to-understand language, concrete and time-specific. Also, it is very important that information is provided through different channels which would overcome the digital gap problem, but also help those informal caregivers with sensory, reading difficulties, etc. In addition to the Internet, television and newspapers, even smaller formal information-sharing networks should be taken into account, which are particularly important in remote and rural areas, ranging from radio-amateurs to local post officers or volunteers. Publishing information only on the Internet leads to the exclusion of an entire category of the population and violation of their rights to information. Clear information helps reduce stress and gives informal caregivers security in performing their everyday activities.

The Law on Disaster Risk Reduction and Emergency Management, Article 36: “Citizens have the right to information on disaster risks, measures and activities undertaken to reduce them, threats and possible effects of disasters, as well as all the necessary information related to protection and rescue.”⁹⁶ However, even though the law recognises the right to information, research has shown that during the COVID-19 pandemic, information has not been clear enough and not only psychologists, but also informal caregivers should be included in creating messages and information, which would improve their knowledge and response to the pandemic, but also reduce informal caregivers’ stress.

The Handbook for Families in Emergencies provides clear and precise instructions, but it should also be expanded to include instructions related to the pandemic and made available to the population at risk.⁹⁷

Protective equipment

- Interventions during the COVID-19 crisis show that it should be ensured at all levels that formal and informal caregivers have appropriate protective equipment and devices to protect them and their care recipient from infection. Sufficient quantities of this equipment also have positive effects on caregiver mental health, because they reduce the fear of infecting the care recipient.

A good practice example would be local councils that made disinfectants freely available in the streets to be used by the citizens, which helped both financially, but also psychologically, by providing solutions for use in their households.

⁹⁶ Zakon o smanjenju rizika od katastrofa i upravljanja vanrednim situacijama (“Sl. glasnik RS”, br. 87/2018), <https://www.paragraf.rs/propisi/zakon-o-smanjenju-rizika-od-katastrofa-i-upravljanju-vanrednim-situacijama.html>

⁹⁷ Porodični priručnik za ponašanje u vanrednim situacijama, Republika Srbija ministarstvo unutrašnjih poslova, Sektor za vanredne situacije

Support

- Psychological first aid and psychosocial support need to be provided to informal caregivers, both via the Internet and telephone (sometimes they do not have the privacy they need because they live with the care recipient), and, finally, face-to-face as sometimes caregivers need privacy to be able to talk about the issues they face related to the provision of care.
- In emergencies, cooperation between organisations providing psychosocial support and mental health institutions needs to be further strengthened, to facilitate referrals of those informal caregivers that need specialised services, which would protect their mental health from worsening further.
- Organise and/or support informal caregiver mutual support systems during emergencies where they can share experiences, learn and potentially provide support to one another.
- COVID-19 effects need to be taken as a clear signal that adequate care for older persons and persons with disabilities is required, now also based on evidence, demands from at-risk groups, accountability and social protection. A strong response from the public health system is needed, in the form of urgent and joint action, to improve response preparedness and protect at-risk groups. There is no other way to combat COVID-19 and similar risks.⁹⁸
- In the future, telemedicine will enable a reduction in informal caregiver burden. It will be particularly important during pandemics and emergencies, because it has been evident that health status monitoring and providing certain remote health services can considerably contribute to improve the health and quality of life of both care recipients and caregivers.

⁹⁸COVID-19 and the Elderly: Who Cares?, <https://www.frontiersin.org/articles/10.3389/fpubh.2020.00151/full>

Education

- Continued education provided to informal caregivers also needs to contain elements of crisis management with clear protocols and steps to easily learn about positive practices, self-protection and general protection techniques, including from infections. This training should be flexible in terms of how it is provided, with the possibility to adapt to different needs of informal caregivers, but also covering advice to improve mental health and recognise the burnout syndrome.

Legislative framework

- As a group under increased risk in emergencies, informal caregivers are recognised in the Law on Disaster Risk Reduction and Emergency Management. During COVID-19, it turned out that they were not visible enough and that they were viewed as passive participants. It is important to plan procedures and coordination of all systems in advance, including informal caregivers, for different types of emergency situations and the way in which to move from the regular to the emergency work regime. This would help in avoiding problems that occurred during the first two weeks of the pandemic, when informal caregivers remained “invisible” in the Republic of Serbia, as well as worldwide, until they were given permission to move around.

The Law on Disaster Risk Reduction and Emergency Management, Article 7: “The principle of equality and human rights protection. Competent authorities and other stakeholders included in the implementation of disaster risk management measures and activities must consistently protect human rights, gender equality and especially protect the poor, elderly, children, persons with disabilities, refugees and displaced persons, as well as other vulnerable groups. Disaster risk reduction measures and activities must be accessible and also pertain to persons with disabilities,

*children, elderly and other persons particularly exposed to risk.*⁹⁹

- In the context of emergencies, pandemics like COVID-19 should be especially included, so it is recommended to develop protocols (nationally and locally) about clear communication between formal and informal caregivers. Further, the representatives of informal caregivers should be included in the planning and designing of an adequate response and potential transitional care, in cases when it is necessary (such as when a caregiver is ill or cannot work from home). Clear procedures can reduce uncertainty and enable the reduction of stress and burden in informal caregivers.
- Institutions and organisations in the local community must be solidary and also take into account the needs of the vulnerable population, as well as caregivers' needs. In some situations, they will require help with buying groceries, providing care to children with disabilities, as well as more complex services, such as micro-loans, or urgent placement of a functionally dependent person in an institution, if necessary.¹⁰⁰

In Serbia, there were volunteers that helped older persons, informal caregivers, who could not go outside, who bought groceries for them or took their adult children with disabilities for walks.

- Employers and labour law in general should formally recognise the importance and role of informal caregivers in emergencies. This is especially true during a pandemic. Opportunities to work from home should be created wherever possible, thus reducing the negative effects to financial security and the economic status of caregivers. Further, this step will also reduce the psychological

⁹⁹ Zakon o smanjenju rizika od katastrofa i upravljanju vanrednim situacijama ("Sl. glasnik RS", br. 87/2018), <https://www.paragraf.rs/propisi/zakon-o-smanjenju-rizika-od-katastrofa-i-upravljanju-vanrednim-situacijama.html>

¹⁰⁰ Cahan, E., Fulmer, T. and Shah, N., 2020. Protecting Healthcare's Family Caregivers Amidst The COVID-19 Pandemic | Health Affairs. [Healthaffairs.org](https://www.healthaffairs.org), <https://www.healthaffairs.org/doi/10.1377/hblog20200421.666035/full>

burden related to balancing work and care and the likelihood of burnout syndrome.¹⁰¹

¹⁰¹ Protecting Healthcare's Family Caregivers Amidst The COVID-19 Pandemic, <https://www.healthaffairs.org/doi/10.1377/hblog20200421.666035/full/>



6 ANNEXES

Red Cross Serbia

INFORMAL CAREGIVER HEALTH

Place (municipality, town): _____

Questionnaire no. (registered during data entry): _____

Survey start: _____

Survey end: _____

GUIDELINES FOR SURVEYORS

Sir/Madam, my name is (*surveyor full name*) _____ and I would like to inform you that we are currently conducting a research about the health of informal caregivers, implemented by the Red Cross of Serbia with the support of the United Nations Population Fund (UNFPA). This questionnaire is for people that provide or provided (until up to 6 months ago) care to an ill or functionally dependent family member. Informal caregivers represent an important group of people that provide daily (or almost daily) care to their close ones, who are ill or functionally dependent, without this being their job or receiving financial compensation for their work. We would like to use this questionnaire to investigate the impact and effects of informal care on caregivers' health.

The purpose of the research is to collect data and improve knowledge in this area, and to develop **recommendations** for decision makers, to improve **planning** and the situation of informal caregivers in Serbia.

Your participation in this research is completely voluntary and anonymous. Anonymous means that your personal information will not appear anywhere, and voluntary means that you can at any time decide to stop the interview, or you can refuse to answer any of the questions asked.

Do you agree to participate in the research? **1-YES** **2-NO**
(thank the person and stop the interview)

Instructions for surveyors:

- *During the interview, it is important to help the respondent answer the question without suggesting or imposing your own views.*
- *Questions should be asked loudly and clearly.*

I Socio-demographic characteristics

1. Respondent sex:

- 1- female
- 2- male

2. How old are you? _____

3. Your marital status is:

- 1- Married
- 2- Single
- 3- Divorced
- 4- Widowed
- 5- Partnership (unmarried)

4. Your attained education level:

- 1- No education or incomplete primary school
- 2- Primary school

- 3- High school (three or four years)
- 4- College or university
- 5- Master or PhD

5. Your employment status:

- 1- Employed
- 2- Unemployed
- 3- Pensioner
- 4- Homemaker
- 5- Other

6. Type of settlement you live in:

- 1- Urban
- 2- Suburban
- 3- Rural

II General information about the care recipient

(if the respondent used to provide care to the person, ask the questions in the PAST tense)

1. Do you currently provide care to a person (or persons) in your environment, without it being your profession for which you receive compensation? Or in other words, are you an informal caregiver?

- 1- Yes
- 2- Not at the moment, but I used up to 6 months ago

2. The reason for not providing care anymore is:

- 1- The person is deceased
- 2- The person was transferred to a residential institution (“nursing home”)

3- Another family member took over the care

4- Other

3. Number of people you are currently (simultaneously) providing care to, or you provided care to until up to 6 months ago: _____

If you provide care to more than one person, please answer the following questions having in mind the person most in need of care

4. How old is the person you provide care to ? _____

5. What is the person's sex?

1 - female

2 - male

6. How long have you been providing (or did you provide) care to?

_____ years (*if less than one year, write down the approximate decimal number, e.g. 0.5 for half a year, or 0.25 for 3 months*)

7. Do you live (did you live) in the same household with the person you provide(d) care to?

1- Yes

2- No

3- Now yes

8. How often do you provide care to (or visit) the person?

1- Every day

2- Several times a week

- 3- At least once a week
- 4- Several times a month
- 5- At least once a month

9. How many hours a day to you provide care to the person? (if they say the whole day, write down 24h)_____

10. What condition does the person you provide care to have? (mark all mentioned)

- 1- Dementia/Alzheimer's disease
- 2- Neurological condition (cerebral palsy, multiple sclerosis, ALS, muscle dystrophy and similar...)
- 3- Some form of intellectual retardation in growth and development
- 4- Post-operation/stroke/heart attack (hip surgery, brain stroke, heart attack...)
- 5- Several chronic diseases (diabetes, hypertension, rheumatoid arthritis...)
- 6- Oncological condition (tumours, carcinoma)
- 7- Psychiatric condition
- 8- Simply old age
- 9- Other

11. Are you related to the person you provide/provided care to?

- 1- Yes
- 2- No

12. What is your kinship with the person you provide care to?

- 1- Father/mother
- 2- Spouse/partner (married or unmarried)
- 3- Daughter/son
- 4- Sister/brother
- 5- Mother-/Father-in-law
- 6- Uncle/aunt (related to you or your partner)
- 7- Uncle/aunt (unrelated to you or your partner)
- 8- Niece/nephew
- 9- Other blood relative

13. Other than you, does anyone else participate and help with the provision of care to the person? (here we mean technical and logistical support, personal efforts)

- 1 - Yes
- 2 - No

14. How would you assess the financial resources at your disposal to meet the needs of the person you provide care to? Would you say that:

- 1- They are sufficient
- 2- I don't know
- 3- They are not sufficient

15. Is someone else providing financial support to meet the needs and care for the person close to you?

- 1- Yes, regularly
- 2- Yes, occasionally, when needed
- 3- No

16. What is the greatest financial expense regarding the care you provide?

- 1- Hygienic diapers for adults
- 2- Medicines
- 3- Additional staff engaged (nursing staff, medical nurses, personal assistants)
- 4- Additionally engaged professionals and services (medical check-ups with private doctors, lab analyses, physical therapists, speech therapists...)
- 5- Specific diet
- 6- Other

17. How would you describe the extent to which the care you provide to this person is demanding, on a scale from 0 (minimum) to 10 (maximum)? _____

III Care recipients' functional status

The degree of dependence of care recipients in performing basic activities of daily living (ADL)

I will now mention some basic activities of daily living of the person you provide care to. Please state whether this person is independent or dependent on somebody's assistance in performing them

Activity	Level of dependence	Description of required assistance
Washing	1- Person is independent	-Washes themselves completely alone or they need little assistance for certain body parts (e.g. back, genital area or immobile extremity)
	2- Person is dependent on somebody's assistance	-Requires assistance with washing of more than one body part or assistance with going into or going out of the bathtub/shower or the person is completely incapable of washing themselves
Dressing	1- Person is independent	-Takes clothes from where they are stored by themselves, puts them on and can close zippers and buttons. May need assistance with tying shoelaces
	2- Person is dependent on somebody's assistance	-Needs assistance with dressing or needs to be dressed entirely
Using the toilet	1- Person is independent	-Goes to the toilet on their own, can sit down on and up from the toilet, put clothes up and down and wipe their genital area without someone else's assistance
	2- Person is dependent on somebody's assistance	-The person needs assistance to use the toilet or needs toilet aids for bed or toilet wheelchair
Moving	1- Person is independent	-Gets in and out of bed by themselves, sits down on and up from chairs. May be using walking aids
	2- Person is dependent on somebody's assistance	-Needs assistance with moving from bed to chair or is completely unable to move on their own
Continence	1- Person is independent	-u potpunosti kontrolira obavljanje male i velike nužde
	2- Person is dependent on somebody's assistance	-Partial or complete lack of control over urination and defecation
Eating	1- Person is independent	-potpuno samostalno jede. Pripremu hrane može obaviti drugo lice
	2- Person is dependent on somebody's assistance	-Needs partial or complete assistance with eating, or the person is on parenteral nutrition

Level of dependence of care recipients in performing instrumental activities of daily living. Adapted Lawton Instrumental Activities of Daily Living (IADL) Scale

I will list some more activities of daily living. Can the person you provide care to perform these activities on their own?

Activity	Able to perform the activity on their own	
Using the telephone	YES	NO
Using transport – bus or taxi	YES	NO
Grocery shopping	YES	NO
Meal preparation	YES	NO
Household cleaning and maintenance	YES	NO
Clothes maintenance (washing, drying, ironing)	YES	NO
Taking medication	YES	NO
Managing finances (withdrawing income, paying bills...)	YES	NO

IV Caregiver burden

The following questions listed show how some people feel sometimes when they provide care to another person. After each question please state how often you feel like that: never, seldom, sometimes, often or nearly always. There are no right or wrong answers.

(‘relative’ in the questions refers to the person you provide care to)

1. Do you think that your relative asks more help from you than they need?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

2. Do you think that because of the time you give to your relative you don’t have enough time for yourself?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

3. Are you under stress because you provide care to your relative and because you try to meet your other family and work responsibilities?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

4. Do you feel ashamed because of your relative’s behaviour?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

5. Are you angry when you are around your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

6. Do you think that your relative's condition is currently having an impact on your relations with other family members or friends in a negative way?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

7. Do you worry about the future that awaits your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

8. Do you think that your relative depends on you?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

9. Are you tense when you are around your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

10. Do you think that your health is suffering because of your engagement around your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

11. Do you think that you do not have enough time for your personal activities, as much as you would like to, because of your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

12. Do you think that your social life is suffering because you are providing care to your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

13. Do you feel uncomfortable inviting friends to your home because of your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

14. Do you feel that your relative expects you to provide care to him/her as if you are the only person they can rely on?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

15. Do you think that with all your other expenses you do not have enough resources to provide care to your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

16. Do you think that you won't be capable of providing care to your relative for much longer?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

17. Do you think that you have lost control over your life since your relative has fallen ill?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

18. Do you wish that, if it were possible, you could turn the care of your relative over to someone else?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

19. Are you uncertain about what to do about your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

20. Do you think you should do more for your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

21. Do you think that you should provide better care to your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

22. Overall, do you feel overburdened with care you provide to your relative?

0. Never 1. Seldom 2. Sometimes 3. Often 4. Nearly always

V Beck Depression Inventory

This questionnaire contains different state groups. Carefully read each one. Then choose one state from each group that best describes the way you have felt this past week, including today. Circle the number next to the chosen state.

1. 0 I do not feel sad

1 I feel sad

2 I am sad all the time and I can't snap out of it

3 I am so sad and unhappy that I can't stand it

2. 0 I am not particularly discouraged about the future

1 I feel discouraged about the future

2 I feel I have nothing to look forward to

3 I feel the future is hopeless and that things cannot improve

3. 0 I do not feel like a failure

- 1 I feel I have failed more than the average person
- 2 As I look back on my life, all I can see is a lot of failures
- 3 I feel I am a complete failure as a person

4. 0 I get as much satisfaction out of things as I used to

- 1 I don't enjoy things the way I used to
- 2 I don't get real satisfaction out of anything anymore
- 3 I am dissatisfied or bored with everything

5. 0 I don't feel particularly guilty

- 1 I feel guilty a good part of the time
- 2 I feel quite guilty most of the time
- 3 I feel guilty all of the time

6. 0 I don't feel I am being punished

- 1 I feel I may be punished
- 2 I expect to be punished
- 3 I feel I am being punished

7. 0 I don't feel disappointed in myself

- 1 I am disappointed in myself
- 2 I am disgusted with myself
- 3 I hate myself

8. 0 I don't feel I am any worse than anybody else
- 1 I am critical of myself for my weaknesses or mistakes
 - 2 I blame myself all the time for my faults
 - 3 I blame myself for everything bad that happens
9. 0 I don't have any thoughts of killing myself
- 1 I have thoughts of killing myself, but I would not carry them out
 - 2 I would like to kill myself
 - 3 I would kill myself if I had the chance
10. 0 I don't cry any more than usual
- 1 I cry more now than I used to.
 - 2 I cry all the time now.
 - 3 I used to be able to cry, but now I can't cry even though I want to
11. 0 I am no more irritated by things than I ever was
- 1 I am slightly more irritated now than usual
 - 2 I am quite annoyed or irritated a good deal of the time
 - 3 I am no longer irritated by things that used to irritate me before
12. 0 I have not lost interest in other people.
- 1 I am less interested in other people than I used to be.
 - 2 I have lost most of my interest in other people.
 - 3 I have lost all of my interest in other people.

13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions more than I used to.
3 I can't make decisions at all anymore
14. 0 I don't feel that I look any worse than I used to
1 I am worried that I am looking old and unattractive
2 I feel there are permanent changes in my appearance that make me look unattractive
3 I believe that I look ugly
15. 0 I can work about as well as before
1 It takes an extra effort to get started at doing something
2 I have to push myself very hard to do anything
3 I can't do any work at all
16. 0 I can sleep as well as usual
1 I don't sleep as well as I used to
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
3 I wake up several hours earlier than I used to and cannot get back to sleep
17. 0 I don't get more tired than usual
1 I get tired more easily than I used to
2 I get tired from doing almost anything
3 I am too tired to do anything

18. 0 My appetite is no worse than usual

1 My appetite is not as good as it used to be

2 My appetite is much worse now

3 I have no appetite at all anymore

19. 0 I haven't lost much weight, if any, lately

1 I have lost more than 2.5 kg

2 I have lost more than 5 kg

3 I have lost more than 7.5 kg

20. 0 I am no more worried about my health than usual

1 I am worried about physical problems like aches, pains, upset stomach, or constipation

2 I am very worried about physical problems and it's hard to think of much else

3 I am so worried about my physical problems that I cannot think of anything else

21. 0 I have not noticed any recent change in my interest in sex

1 I am less interested in sex than I used to be

2 I have almost no interest in sex

3 I have lost interest in sex completely

VI Krupp Fatigue Severity Scale

Please score each of the statements from 1 to 7:

1 being COMPLETELY DISAGREE

7 being COMPLETELY AGREE

	1-7
1. My motivation is lower when I am fatigued.	
2. Exercise brings on my fatigue.	
3. I am easily fatigued.	
4. Fatigue interferes with my physical functioning.	
5. Fatigue causes frequent problems for me.	
6. My fatigue prevents sustained physical functioning.	
7. Fatigue interferes with certain duties and responsibilities.	
8. Fatigue is among my three most disabling symptoms.	
9. Fatigue interferes with my work, family, or social life.	

VII Health and functionality (SF12)

1. In general, would you say your health is:

(circle one number)

- Excellent..... 1
- Very good..... 2
- Good 3
- Fair 4
- Poor 5

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number in each row)

ACTIVITIES	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities such as moving a table, pushing a vacuum cleaner, riding a bicycle, working in the garden	1	2	3
Climbing several flights of stairs	1	2	3

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number in each row)

	YES	NO
Accomplished less than you would like	1	2
Were limited in the kind of work or other activities	1	2

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number in each row)

	YES	NO
Accomplished less than you would like.	1	2
Did work or activities less carefully than usual	1	2

5. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

(circle one number)

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

6. These questions are about how you have been feeling and how well things have been going for you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling and how much of the time during the past 4 weeks you have been feeling like that:

(circle one number in each row)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have you felt full of life?	1	2	3	4	5	6
Have you felt calm and peaceful?	1	2	3	4	5	6
Did you have a lot of energy?	1	2	3	4	5	6

7. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(circle one number)

- All of the time..... 1
- Most of the time..... 2
- Some of the time 3
- A little of the time..... 4
- None of the time 5

VIII Social support

1. Do you have support/assistance with the care you provide?

- 1 – Yes
- 2 – No

2. If the answer is yes, who do you receive assistance from?

(circle all that apply)

- 1 – Close person/relative
- 2 – Government institutions
- 3 – Humanitarian organisations

IX COVID-19

1. What do you need the most in the circumstances during the COVID-19 pandemic?

- 1-Information
- 2-Services – assistance with buying groceries and needed items, assistance with paying bills
- 3-Respite services – assistance with care I provide to the person
- 4-Protective equipment (masks, gloves, disinfectants)
- 5-Assistance with home hygiene maintenance
- 6-Assistance with the preparation of meals
- 7-Psychological first aid
- 8-Psychosocial support
- 9-Online education
- 10-Other

2a. Do you feel your health is more affected now compared to the period prior to the COVID-19 pandemic?

- 1-Yes, I do
- 2-No, it was equally affected in the period before COVID-19

2b. Do you feel that the health of the person you provide care to is more affected now compared to the period before COVID-19?

- 1-Yes, I do
- 2-No, it is equally affected as in the period before COVID-19

3. Do you fear more now for your own and/or the health of the person you provide care to?

1-Yes, I am more concerned now

2-No I am concerned the same

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