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**THE ROLE OF INFORMAL CAREGIVERS IN THE
FULFILMENT OF THE RIGHT TO A DIGNIFIED
OLD AGE IN SERBIA**

After brief observations about the definition of the old age, as well as the right to a dignified old age and demographic trends in Serbia, the author of this paper defines informal caregivers and their main tasks when it comes to taking care of elderly persons. The author also explains the importance of the role, which informal caregivers have in the fulfilment of the right to a dignified old age. Furthermore, the author analyses key problems and challenges, which informal caregivers are facing in Serbia, and makes suggestions for the improvement of their position as well as the position of elderly persons that they are taking care of.

Keywords: *dignified old age, informal caregivers, social welfare centre, elderly population, dignity*

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1. Introduction – Definitions and Perceptions of Ageing

Ageing is a complex and dynamic process that is not defined solely through passing of time (Solarević, Pavlović, 2018: 54). It is universal, it happens to everybody, it is inevitable, unstoppable and irreversible. There is no universally accepted definition or a general concept of ageing and, therefore, in order to understand the phenomenon of ageing, one should take into consideration physiological, social and cultural aspects (Petrušić, Todorović, Vračević, 2015: 27). Defining old age does not have only academic relevance, since different definitions of old age have different impacts on the way in which the society perceives and treats elderly persons, as well as on creation of public policies in the area of social welfare and health protection of the elderly (Petrušić, Todorović, Vračević, 2015: 27).

Ageing can be defined from chronological, physiological and social aspect. Chronological definitions are based upon the biological characteristics of old age and, according to them, old age begins at the age of 60 or 65, causing the change of person's role in the society, primarily in the sphere of labour and employment (Huenchuan, Rodriguez-Pinero, 2011 according to Petrušić, Todorović, Vračević, 2015: 27). Physiological definitions take the physical process of ageing as a starting point and, according to them, old age is related to chronological ageing, but does not depend directly and solely on that criterion (Huenchuan, Rodriguez-Pinero, 2011 according to Petrušić, Todorović, Vračević, 2015: 27). Physiological definitions of ageing are primarily related to the loss of functional capacities, gradual decrease in bones density and muscle tonus, changes in perception, as well as psychological changes on intellectual, emotional and motivational level (Huenchuan, Rodriguez-Pinero, 2011 according to Petrušić, Todorović, Vračević, 2015: 27). Social definitions of ageing are based upon cultural and historical approach and are related to the attitudes and behavioral patterns that are considered as suitable and typical for certain age (Huenchuan, Rodriguez-Pinero, 2011 according to Petrušić, Todorović, Vračević, 2015: 27).

Nevertheless, one should have in mind that ageing is an individual experience, which differs from one person to another, and which depends on person's genetics, environment, living conditions and lifestyle (Petrušić, Todorović, Vračević, 2015: 27). Some authors suggest that old age should be divided into 3 stages: 1) early old age (persons who have more than 65 but less than 75 or 80 years); 2) average old age (persons who have more than 75 or 80 but less than 90 years) and 3) late old age (persons who have more than 85 or 90 years) (Kostić, 2010: 18; Petrušić, Todorović, Vračević, 2015: 28).

2. Demographic picture – Ageing of Population

Demographic ageing seems to be one of the greatest social transformations in the 21st century with a strong impact on all the segments of the society (Janković *et al.*, 2018: 24). Ageing of the population is a universal phenomenon with a growing impact on all aspects of life and on all generations and their welfare (National Ageing Strategy 2006-2015, Official Gazette of the Republic of Serbia, No. 76/2006, hereinafter: NAS). Global population is experiencing an extraordinary and continuous change in the age structure, primarily due to rising levels of life expectancy and declining levels of fertility in the sense that people are now living longer and the share of older persons in the total population is rapidly increasing (UNDESA, 2020: 1). The increase in the duration of individuals' life has led to the increase of elderly persons worldwide (Kostić 2010: 19). According to World Population Prospects: the 2019 Revision¹, one in six persons worldwide will be over the age of 65 (16%) by 2050, up from one in 11 persons in 2019 (9%)². Moreover, it is expected that by 2050, 1 in 4 persons in Europe and Northern America will be aged 65 or over.³ Also, for the first time in history, in 2018, persons of 65 or more years of age outnumbered children under 5 years globally.⁴ This data also indicates that by 2050 the total number of persons aged 80 years or over is projected to be 3 times larger, from 143 million in 2019 to 426 million worldwide.⁵ In particular, the population over the age of 80 is also increasing and, associated with the increase of average life expectancy, there is also the increase in the number of elderly persons in the situation of dependence (Rocha, Pacheco, 2013: 51).

Today, the population of the Republic of Serbia is among the oldest populations in the world (NAS). Only six decades earlier, the population of the Republic of Serbia used to be among the youngest ones in Europe - its share of persons older than 65 was 5,6% of the entire population, average age was 29,1 years and ageing index was 0,19 (Devedžić, Stojilković Gnjatović, 2015: 21). Nowadays, the percentage of persons over 65 years of age in Serbia is 17,4%, average age is 42,2 years and ageing index is 1,22 (Devedžić, Stojilković Gnjatović, 2015: 21). This means that the population of persons over the age of 65 has almost doubled in the period between 1970 and the population census that took

¹ United Nations, Department of Economic and Social Affairs, Population Dynamics, <https://population.un.org/wpp/>, accessed on 02.06.2022.

² United Nations, Global Issues: Ageing, <https://www.un.org/en/global-issues/ageing>, accessed 02.06.2022.

³ *Ibid.*

⁴ *Ibid.*

⁵ *Ibid.*

place in 2011 (Kozarčanin, Milojević, 2016: 5). The most intensive ageing of population in Serbia occurred as the demographic consequence of political and economic crisis during the last decade of the 20th century, followed by great emigration of younger population, delaying of childbirth and decrease in fertility (Devedžić, Stojilković Gnjatović, 2015: 21). The process of population's ageing in Serbia will continue in the future and the ageing of the already old population is expected to be particularly intensive, which means that the number of persons over 80 years of age will increase (NAS).

At the same time, significant weaknesses can be noticed in the when it comes to fulfilment of elderly persons' needs at the institutional level (NAS). Current demographic condition and projections for the future, together with flaws that still exist at the institutional level, indicate that the pressure on institutions in the field of social welfare and health care will continue to grow, which is the reason why the role of the family members taking care of their elderly relatives is becoming more and more important. Social welfare system and health protection system are under great pressure to minimise expenses and are often either insufficiently integrated or fragmented within their own frameworks, which questions their capability of providing all the necessary support (Matejić, Đikanović, 2019: 8).

As it is emphasized in NAS, demographic projections of population's ageing on the one hand, and limited resources of social protection on the other, impose the need for a new practical approach that would revive the substantial role and significance of the family when it comes to providing care and assistance for its oldest members (NAS). Accordingly, one of the goals of NAS is the re-affirmation of family's role and solidarity of family members in the promotion of elderly persons' life quality and community development (NAS). The increase of the number of elderly citizens causes an increase in the number of requests directed towards health services, retirement finds and social welfare centres, necessary for the fulfilment of these persons' needs (Kostić, 2010: 21). In the times when the sustainability of existing models of long-term care and the availability of formal institutional or non-institutional support of organised social systems is under question, the importance of informal caregivers is becoming more and more important (Todorović, Vračević, 2019: 11). This is the moment when the role of informal caregivers actually becomes essential for the fulfilment of elderly person's everyday needs (including both – physical as well as mental) and, in that way, for the accomplishment of elderly person's right to a dignified old age.

3. Ageing and Human Rights – the Right to Dignified Old Age

In the past couple of decades, there has been a growing interest in the improvement of human rights of elderly persons, on both – global and national levels, and the primary reason for that are the aforementioned demographic changes that include the increase in the number of elderly persons worldwide, requiring an adequate political response (Kostić, 2010: 21; Petrušić, Todorović, Vračević, 2015: 35). The second reason why the interest in elderly persons' human rights has been increasing is the presence of discrimination of elderly persons and prejudice about them (Petrušić, Todorović, Vračević, 2015: 35), also known as ageism (Solarević, Pavlović, 2018: 54; Ljubičić, 2021: 526). The latter causes their structural inequality among the rest of the population, in developing as well as in developed countries (Kostić, 2010: 29). During the 1980s, scientists began to study the population of elderly persons as a particularly vulnerable group, whereas in the 1970s the awareness of their human rights' violation is beginning to emerge (Kostić, 2010: 28). Nowadays, human rights of elderly persons are often not recognised and in some cases are severely violated (Petrušić, Todorović, Vračević, 2015: 35).

When discussing human rights of elderly persons, it should be highlighted that, first of all, elderly persons have all human rights that other persons have, because all human beings are born with the same rights and it is something that must not be changed as they grow older (Petrušić, Todorović, Vračević, 2015: 35). What does change is the way in which human rights are exercised, which should be intuitively recognised in the cases of elderly persons (HelpAge International and the Center for Financial Inclusion at Action, 2015 according to Petrušić, Todorović, Vračević, 2015: 35).

The United Nations began to deal with the phenomenon of ageing in the 1980s and, as a result, several international documents dedicated exclusively to the position and human rights of elderly persons have been adopted (Petrušić, Todorović, Vračević, 2015: 37). The most important of them include: 1) The Vienna International Plan of Action on Ageing (1982)⁶, containing more than 60 recommendations for governments and civil society for more efficient resolving of issues related to the ageing of population; 2) United

⁶ World Assembly on Aging, and Vienna International Plan of Action on Aging. (1983). Vienna International Plan of Action on Aging: [World Assembly on Aging, 26 July-6 August 1982, Vienna, Austria]. New York: United Nations, <https://www.un.org/esa/socdev/ageing/documents/Resources/VIPEE-English.pdf>, accessed on 02.06.2022.

Nations Principles for Older Persons (1991)⁷, recommending the governments to create their national programmes dedicated to elderly persons through the respect of independence social participation, social care self-realisation and dignity of elderly persons; 3) The Madrid International Plan of Action on Ageing (2002)⁸, advocating the establishment of society that is suitable for all ages and recognises three priority goals of action: elderly persons and development, improvement of health and welfare of elderly persons and providing supportive environment for elderly persons; 4) United Nations Economic Commission for Europe Regional Strategy for the implementation of the Madrid International Plan of Action on Ageing (2002)⁹, containing several obligations for the Member States related to the ageing of the population (Petrušić, Todorović, Vračević, 2015: 37).

Some of the conventions of the United Nations explicitly mention elderly persons in their provisions: 1) International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families¹⁰, which directly refers to discrimination based upon age; 2) Convention on the Elimination of All Forms of Discrimination against Women¹¹, which mentions the right of women to have to social security, particularly in cases of retirement and 3) Convention on the Rights of Persons with Disabilities¹², which mentions elderly persons in the context of the right to social security and access to health services (Petrušić, Todorović, Vračević, 2015: 37).

⁷ United Nations Principles for Older Persons, adopted on 16 December 1991 by General Assembly Resolution 46/91, <https://www.ohchr.org/sites/default/files/olderpersons.pdf>, accessed on 02.06.2022.

⁸ United Nations, The Madrid International Plan of Action on Ageing and the Political Declaration adopted at the Second World Assembly on Ageing in April 2002, Madrid, Spain. New York: United Nations <https://www.un.org/esa/socdev/documents/ageing/MIPAA/political-declaration-en.pdf>, accessed on 02.06.2022.

⁹ United Nations Economic and Social Council, Economic Commission for Europe, UNECE Ministerial Conference on Ageing Berlin (Germany), 11-13 September 2002, Regional Implementation Strategy for the Madrid International Plan of Action on Ageing, 2002 ECE/AC.23/2002/2/Rev.6, 11 September 2002, <https://www.un.org/esa/socdev/documents/ageing/unece-ris.pdf>, accessed on 02.06.2022.

¹⁰ United Nations General Assembly, International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families, 18 December 1990, A/RES/45/158, <https://www.refworld.org/docid/3ae6b3980.html>, accessed on 03.06.2022.

¹¹ United Nations General Assembly, Convention on the Elimination of All Forms of Discrimination Against Women, 18 December 1979, United Nations, Treaty Series, vol. 1249, p. 13, <https://www.refworld.org/docid/3ae6b3970.html>, accessed on 03.06.2022.

¹² United Nations General Assembly, Convention on the Rights of Persons with Disabilities, resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106, <https://www.refworld.org/docid/45f973632.html>, accessed on 03.06.2022.

At regional, i.e., European level, several documents containing provisions relevant to the protection of human rights of elderly persons have been adopted, including: 1) European Convention for the Protection of Human Rights and Fundamental Freedoms (1950)¹³, 2) revised European social charter (1996)¹⁴, 3) New Strategy and Council of Europe Action Plan for Social Cohesion (2010)¹⁵.

When it comes to the European Union, first of all, it should be underlined that the preamble of Single European Act (1986)¹⁶ and Article 6 of Treaty on European Union (1993)¹⁷ officially oblige European Union to respect the rights established by the European Convention for the Protection of Human Rights and Fundamental Freedoms (Petrušić, Todorović, Vračević, 2015: 38). Furthermore, Treaty of Amsterdam (1997)¹⁸ prohibits all kinds of discrimination, including the one based upon age, whereas Charter of Fundamental Rights of the European Union (2000)¹⁹ in its Article 34 proclaims the respect of the right to social security benefits and social services providing protection in the old age (Petrušić, Todorović, Vračević, 2015: 38). Also, Treaty of Lisbon (2007)²⁰ insists on eliminating exclusion and discrimination and on promoting intergenerational solidarity and equality (Petrušić, Todorović, Vračević, 2015: 38; see also: Simović, Simović, 2020: 380).

Another important document of regional scope of application is Recommendation of the Committee of Ministers to member States on the promotion of human rights of older

¹³ Council of Europe, European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, 4 November 1950, ETS 5, <https://www.refworld.org/docid/3ae6b3b04.html>, accessed on 03.06.2022.

¹⁴ Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163, <https://www.refworld.org/docid/3ae6b3678.html>, accessed on 03.06.2022.

¹⁵ Council of Europe, New Strategy and Council of Europe Action Plan for Social Cohesion approved by the Committee of Ministers of the Council of Europe on 7 July 2010, https://www.coe.int/t/dg3/socialpolicies/socialcohesiondev/source/2010Strategy_ActionPlan_SocialCohesion.pdf, accessed on 03.06.2022.

¹⁶ Single European Act, Official Journal of the European Communities L 169, vol.30, 29 June 1987, <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:L:1987:169:FULL&from=EN>, accessed on 03.06.2022.

¹⁷ Treaty on European Union, Official Journal C 191, 29/07/1992 P. 0001 – 0110, <http://data.europa.eu/eli/treaty/teu/sign>, accessed on 03.06.2022.

¹⁸ Treaty of Amsterdam amending the Treaty on European Union, the Treaties establishing the European Communities and certain related acts, Official Journal C 340, 10.11.1997, p. 1–144, <http://data.europa.eu/eli/treaty/ams/sign>, accessed on 03.06.2022.

¹⁹ Charter of Fundamental Rights of the European Union, Official Journal of the European Communities C 364/1, 18.12.2000., https://www.europarl.europa.eu/charter/pdf/text_en.pdf, accessed on 03.06.2022.

²⁰ Treaty of Lisbon amending the Treaty on European Union and the Treaty establishing the European Community, signed at Lisbon, 13 December 2007, Official Journal C 306, 17.12.2007, p. 1–271, <http://data.europa.eu/eli/treaty/lis/sign>, accessed on 03.06.2022.

persons, adopted in 2014²¹, as the result of normative work conducted within the Council of Europe by the Steering Committee for Human Rights between 2012 and 2013²². This document is expected to raise awareness of public authorities and civil society to human rights and freedoms of elderly persons and to facilitate their protection. Its aim is to promote the dignity of elderly persons, their autonomy, independence and participation in the society, to provide them with adequate information, health care, social security and employment and to protect them from violence and abuse (Petrušić, Todorović, Vračević, 2015: 38).

In the Republic of Serbia, there are several legal documents the provisions of which are either of direct or of indirect relevance to the protection of the rights of elderly persons and the prevention of their discrimination, including: 1) Constitution of the Republic of Serbia²³, 2) Law on the prohibition of discrimination²⁴, 3) Law on the prevention of discrimination of persons with disability²⁵, 4) Law on health protection²⁶, 5) Law on health insurance²⁷, 6) Law on public health²⁸, 7) Law on the rights of patients²⁹, 8) Law on the protection of persons with mental health issues³⁰, 9) Law on social protection³¹, 10) Law on pension and disability insurance³², 11) Family law³³, 12) Law on education

²¹ Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers' Deputies), https://search.coe.int/cm/Pages/result_details.aspx?ObjectID=09000016805c649f, 03.06.2022.

²² Council of Europe, Promotion of human rights of older persons, <https://www.coe.int/en/web/human-rights-intergovernmental-cooperation/promotion-of-human-rights-of-older-persons>, accessed on 03.06.2022.

²³ Constitution of the Republic of Serbia, Official Gazette of the Republic of Serbia No. 98/2006, 115/2021 and 16/2022.

²⁴ Law on the prohibition of discrimination, Official Gazette of the Republic of Serbia No. 22/2009 and 52/2021.

²⁵ Law on the prevention of discrimination of persons with disability, Official Gazette of the Republic of Serbia No. 33/2006 and 13/2016.

²⁶ Law on health protection, Official Gazette of the Republic of Serbia, No. 25/2019.

²⁷ Law on health insurance, Official Gazette of the Republic of Serbia, No. 25/2019.

²⁸ Law on public health, Official Gazette of the Republic of Serbia, No. 15/2016.

²⁹ Law on the rights of patients, Official Gazette of the Republic of Serbia, No. 45/2013 and 25/2019.

³⁰ Law on the protection of persons with mental health issues, Official Gazette of the Republic of Serbia, No. 45/2013.

³¹ Law on social protection, Official Gazette of the Republic of Serbia, No. 24/2011.

³² Law on pension and disability insurance, Official Gazette of the Republic of Serbia, No. 34/2003, 64/2004, 84/2004, 85/2005, 101/2005, 63/2006, 5/2009, 107/2009, 101/2010, 93/2012, 62/2013, 108/2013, 75/2014, 142/2014, 73/2018, 46/2019, 86/2019 and 62/2021.

³³ Family law, Official Gazette of the Republic of Serbia, No. 18/2005, 72/2011 and 6/2015.

of adults³⁴, 13) Law on labour³⁵, 14) Law on gender equality³⁶, 15) Law on the prevention of family violence³⁷, 16) Criminal Code of the Republic of Serbia³⁸ etc.

There are also several strategic documents adopted in the Republic of Serbia that are either directly or indirectly relevant to the protection of the rights of elderly population, including: 1) Strategy for the prevention of and protection from discrimination for the period from 2022 until 2030³⁹, 2) Strategy of deinstitutionalisation and development of the services of social protection in the community for the period between 2022 and 2026⁴⁰, 3) Strategy for the improvement of the position of persons with disabilities 2020-2024⁴¹, 4) Strategy for the prevention and suppression of gender-based violence against women and family violence for the period between 2021 and 2025⁴², 5) Strategy of employment in the Republic of Serbia for the period between 2021 and 2026⁴³, 6) Strategy of public health in the Republic of Serbia 2018-2026⁴⁴, 7) National strategy for gender equality for the period from 2021 until 2030⁴⁵ etc. Republic of Serbia also adopted

National Ageing Strategy for the period between 2006 and 2015⁴⁶ in 2006, but this document is no longer in force and a new strategic document that would be dedicated exclusively to the rights of elderly persons has not yet been adopted.

³⁴ Law on education of adults, Official Gazette of the Republic of Serbia, No. 55/2013, 88/2017, 27/2018 and 6/2020.

³⁵ Law on labour, Official Gazette of the Republic of Serbia, No. 24/2005, 61/2005, 54/2009, 32/2013, 75/2014, 13/2017, 113/2017 and 95/2018.

³⁶ Law on gender equality, Official Gazette of the Republic of Serbia, No. 52/2021.

³⁷ Law on the prevention of family violence, Official Gazette of the Republic of Serbia, No. 94/2016.

³⁸ Criminal Code of the Republic of Serbia, Official Gazette of the Republic of Serbia, No. 85/2005, 88/2005, 107/2005, 72/2009, 111/2009, 121/2012, 104/2013, 108/2014, 94/2016 and 35/2019.

³⁹ Strategy for the prevention of and protection from discrimination for the period from 2022 until 2030, Official Gazette of the Republic of Serbia, No. 12/2022.

⁴⁰ Strategy of deinstitutionalisation and development of the services of social protection in the community for the period between 2022 and 2026, Official Gazette of the Republic of Serbia, No. 12/2022.

⁴¹ Strategy for the improvement of the position of persons with disabilities 2020-2024, Official Gazette of the Republic of Serbia, No.44/2020.

⁴² Strategy for the prevention and suppression of gender-based violence against women and family violence for the period between 2021 and 2025, Official Gazette of the Republic of Serbia, No. 47/2021.

⁴³ Strategy of employment in the Republic of Serbia for the period between 2021 and 2026, Official Gazette of the Republic of Serbia, No. 18/2021 and 36/2021.

⁴⁴ Strategy of public health in the Republic of Serbia 2018-2026, Official Gazette of the Republic of Serbia, No. 61/2018.

⁴⁵ National strategy for gender equality for the period from 2021 until 2030 Official Gazette of the Republic of Serbia, No. 103/2021.

⁴⁶ National Ageing Strategy 2006-2015, Official Gazette of the Republic of Serbia, No. 76/2006.

Human rights and freedoms guaranteed by the aforementioned documents belong to all citizens, including elderly ones. This is in accordance with the principle of equality, as universal ethical and legal principle of every modern society (Strategy for the prevention of and protection from discrimination for the period from 2022 until 2030).

Therefore, it can be said that these rights, together with the rights that are guaranteed particularly for elderly persons with the aim to prevent their discrimination, constitute the right to dignified old age. However, “formal” equality is not sufficient to facilitate the equal treatment of the members of all groups in one society (Strategy for the prevention of and protection from discrimination for the period from 2022 until 2030), including the elderly. It is the application of this normative framework that matters, and upon which the fulfilment of the right to dignified old age depends in everyday life. The increase in human longevity has imposed various challenges for the governments and the community when it comes to ensuring the wellbeing of elderly persons and their families (Mendes *et al.*, 2019: 88). Having in mind a serious increase in the number of dependent elderly persons and insufficient capability of relevant institutions to meet all their needs, the informal caregivers appear to be key figures in the maintenance of the quality of life in a situation of dependence (Rocha, Pacheco, 2013: 51) and, hence, the dignity of elderly persons they take care of.

4. Informal Caregivers - Definition and Tasks

In Serbia, as well as worldwide, there is a large number of persons who take care of elderly family members in need of help with everyday activities significant for the quality of their lives (Todorović, Vračević, 2019: 11). Despite a growing interest in the topic of this spontaneous, i.e., informal caregiving, there have been very few studies providing information about who the persons engaged with this type of caregiving actually are and what their total number is (Matejić, Đikanović, 2019: 9). According to the definition given by Canadian Coalition of Caregivers, informal caregiver is a person providing constant care and assistance without receiving any compensation, to family members or friends who are in need of support due to physical, cognitive or mental health issues (Todorović, Vračević, 2019: 12). The terms: informal, non-paid and family caregiver are used as synonyms (Mendes et al., 2019: 88; Todorović, Vračević, 2019: 12). Although environment, education, economic status and professions of informal caregivers differ from one person to another, they all have one characteristic in common: they take care of a person that depends on their assistance and they wish to provide that kind of care in the best possible way (Todorović, Vračević, 2019: 12).

Informal caregivers represent a part of the so-called informal support network that includes: family members, acquaintances, friends and neighbours of the dependent elderly person (Mendes et al., 2019: 88). Most commonly, informal caregivers refer to: 1) parents who take care of their chronically ill or disabled children; 2) children and young persons who take care of their ill and functionally dependent parents or grandparents; 3) adults who take care of their own or their partner's parents; 4) elderly persons who take care of their partners; 5) brothers, sisters, cousins, neighbours and friends who take care of elderly persons and 6) volunteers from charity or religious organisations (Todorović, Vračević, 2019: 12). It is estimated that 8 out of 10 persons who take care of elderly persons are women between 45 and 60 years of age (Rocha, Pacheco, 2013: 51; Todorović, Vračević, 2019: 12, Matejić, Đikanović, 2019: 23-26). They typically have higher education level than average, they are usually employed and they mostly take care of their mothers (Matejić, Đikanović, 2019: 9).

There is a difference between informal caregiving and the care for elderly persons that is provided by relevant institutions, i.e., formal care. Informal care is provided within interpersonal relations that comprise emotional bonds, closeness, trust and love and the tasks and responsibilities that it includes go beyond regular reciprocal relations between adults, without any financial compensations (Pierson, Thomas, 2010: 65 according to Ananias, Strydom, 2014: 269; Todorović, Vračević, 2019: 15). This means that informal caregivers are not paid for the tasks they fulfil (Mendes et al., 2019: 88). The tasks within informal caregiving are adjusted to the needs of the dependent person, they can be gradually altered or adjusted, and they include emotional support, direct providing of services, communication with formal health and social welfare services and formal caregivers, as well as financial support (Todorović, Vračević, 2019: 15). In the majority of cases, informal care is provided by one caregiver to one person, without previous planning and specification (Todorović, Vračević, 2019: 15). Informal caregivers usually do not attend any professional education for their tasks and they are required to be available at any time, depending on the needs of the dependent person (Todorović, Vračević, 2019: 15). There are several reasons why informal caregivers take on their role, including: the obligation to care for a relative because of social rules of behaviour, bonds of affection, commitment, pity or altruistic reasons (Payne, 2010a: 240 according to Silva *et al.*, 2013: 792). Some persons become informal caregivers against their will, due to poor social and economic conditions and the necessity to care for an elderly member of their family (Ananias, Strydom, 2014: 275).

On the other hand, formal caregiving is based upon professional relation and rules of conduct, it includes financial compensation, the tasks of the caregiver are precisely

specified and his/her activities are planned, regulated and paid (Rocha, Pacheco, 2013: 51; Todorović, Vračević, 2019: 16). One professional caregiver takes care of several elderly persons, has defined working hours and right to vacation and free time (Todorović, Vračević, 2019: 16).

The following are the most common tasks of informal caregivers: 1) keeping up with person's medical condition and noticing any changes in that field; 2) assisting with everyday activities at home such as: cooking, laundry washing, cleaning, ironing, shopping, preparation of meals etc.; 3) supporting a person to continue with his/her activities as much and as long as it is possible; 4) assistance with personal hygiene; 5) helping a person to overcome physical barriers when walking or getting up; 6) assisting a person to manage his/her finances; 7) supervising and assistance with intake of medicines; 8) assistance when it comes to person's communication with friends and family members via internet or telephone; 9) assistance with transport; 10) communication with social welfare and health care institutions and other entities relevant to the fulfilment of person's physical, mental and social needs; 11) assistance when it comes to making medical appointments and using other e-portal services; 12) providing emotional support; 13) providing support for persons experiencing changes in behaviour and decision making due to of dementia (Todorović, Vračević, 2019: 26-27).

There are five types of informal caregiving of elderly persons: 1) anticipatory, 2) preventive, 3) supervisory, 4) instrumental and 5) protective (Bowers, 1987 according to Matejić, Đikanović, 2019: 13-14).

In anticipatory informal caregiving, the caregiver notices the potential needs of the dependent person and gradually starts preparing the conditions for the indispensable changes of life organisation (Bowers, 1987 according to Matejić, Đikanović, 2019: 13). This type of informal caregiving most commonly emerges when children do not live with their parents and it has a strong impact on the planning of their future – for example, the children plan to stay close to their parents despite their professional obligations, knowing that their parents might need their assistance in the future (Bowers, 1987 according to Matejić, Đikanović, 2019: 13). Anticipatory caregiving of elderly persons is considered almost invisible, since children consciously avoid to discuss these issues with their parents in order not to insult or disturb them (Bowers, 1987 according to Matejić, Đikanović, 2019: 13).

Preventive informal caregiving consists of the activities that younger family members take with the aim to prevent illness, injuries or any kind of physical and mental

degradation of elderly ones (Bowers, 1987 according to Matejić, Đikanović, 2019: 13). Compared to anticipatory, preventive caregiving includes more intensive supervision of elderly persons, the adjustment of physical surroundings to their safety needs, frequent conversations about their health etc. (Bowers, 1987 according to Matejić, Đikanović, 2019: 13).

Supervisory informal caregiving of elderly persons involves a more active and direct participation of their younger family members in their care. It includes the organisation of various activities for elderly persons and further supervision of their condition and its development (Bowers, 1987 according to Matejić, Đikanović, 2019: 13). It can be performed when the elderly person is aware of the assistance provided or when he/she is convinced that he/she is independent (Bowers, 1987 according to Matejić, Đikanović, 2019: 13).

Instrumental informal caregiving is an active form of caregiving that comprises the activities that are commonly recognised as caregiving, i.e., everything that caregivers usually do with the purpose to maintain health and physical integrity of elderly persons (Bowers, 1987 according to Matejić, Đikanović, 2019: 14). It is usually conducted in the case of an elderly person who already has health issues and is directed towards the preservation of his/her physical capacities (Bowers, 1987 according to Matejić, Đikanović, 2019: 14).

Protective informal caregiving refers to the activities that the majority of caregivers consider the most important and, at the same time, the most difficult ones – the activities that have the aim to preserve elderly person's emotional state and to protect them from events and circumstances that might have a negative impact on their self-confidence (Bowers, 1987 according to Matejić, Đikanović, 2019: 14).

When types of informal caregivers are concerned, one can also distinguish: 1) main or primary caregiver and 2) secondary caregiver (Rocha, Pacheco, 2013: 51). The main or primary caregiver is the person who is the most responsible for everyday care of the dependent elderly person and he/she fulfils the majority of daily tasks therein (Rocha, Pacheco, 2013: 51). The secondary caregiver is the person who also performs the tasks related to the care of the dependent elderly, but he/she does not do that on a regular basis and does not have much responsibility or power of decision (Rocha, Pacheco, 2013: 51). Secondary caregiver assists the primary caregiver with complementary activities and may appear as a significant source of support to the main caregiver (Rocha, Pacheco, 2013: 51).

All the aforementioned types of informal caregiving for elderly persons imply that informal care is much more than helping an elderly person with basic daily activities (Matejić, Đikanović, 2019: 14). Moreover, a simplified view of informal caregiving may lead to the neglect of potentially harmful behaviour of the caregiver such as: raising one's voice, insulting, threatening by placement into an institution, hitting, slapping or other violent, disturbing or activities by which pain and suffering are caused to already vulnerable elderly persons (Matejić, Đikanović, 2019: 14), recognised as "elder abuse" (Kostić, 2010: 28; Ananias, Strydom, 2014: 269). Namely, it is estimated that almost 10% of elderly persons who are cared for by their family members are exposed to the risk of elder abuse (Strydom, 2003: 77 according to Ananias, Strydom, 2014: 268). That is the reason why it is important to emphasize that informal care of elderly persons goes beyond the assistance with the fulfilment of their basic and instrumental needs and functions and also includes the emotional aspect embodied in tactical and patient care of elderly person and the protection of his/her safety and self-confidence (Matejić, Đikanović, 2019: 14).

5. Key Challenges for Informal Caregivers

Taking care of a dependent elderly person is a situation of crisis, causing significant changes in the course of caregiver's life, where the care emerges as the stressor agent, disturbing or threatening caregiver's daily activities (Rocha, Pacheco, 2013: 51). The demand for special care and a variety of daily tasks, may be worrying for a family member who has a dependent elderly person at home (Mendes *et al.*, 2019: 88). However, caring for a dependent elderly person does not necessarily have to be a source of emotional, physical, financial and social difficulties (Rocha, Pacheco, 2013: 51). It can also be followed by the reward of satisfaction and improve the quality of caregiver's life (Rocha, Pacheco, 2013: 51) But, no matter how rewarding caring can be considered, it is also very challenging in physical, social and financial sense (Payne, 2010a: 240). Playing the role of an informal caregiver is not an easy task and it is commonly followed by physical and psychological demands as well as by numerous sociocultural difficulties (Rocha, Pacheco, 2013: 51), including physical, psychological and social isolation (Mendes *et al.*, 2019: 88)

There are several circumstances that might affect the needs of caregivers, including: the characteristics of the dependent elderly person, the type of elderly person's illness, the context in which the caregiving is being provided, the motivation for caregiving, as well as the characteristics of the caregiver (Silva *et al.*, 2013: 800). Studies confirm that informal caregivers in general mostly need: 1) psychological support (emotional, bereavement, social, as well as spiritual), 2) information, 3) assistance when it comes to

personal, medical and nursing care for the elderly person, 4) out-of-hours and support during the night, 5) respite care and 6) financial assistance (Payne, 2010b: 286). A review by Silva *et al.* confirms that the most important needs of informal caregivers of elderly persons living at home include: 1) information and training, 2) professional support, 3) effective communication with professionals, with dependent elderly persons and with their families and 4) financial and legal support (Silva *et al.*, 2013: 800).

The situation is similar in Serbia, where the majority of informal caregivers point out the following needs as the most essential ones: 1) financial and legal support; 2) better availability of information; 3) improving informal caregivers' knowledge and skills; 4) increasing the visibility of informal caregivers within the community; 5) stronger institutional support; 6) including local community in providing support for informal caregivers; 7) psycho-social support for informal caregivers (Matejić, Đikanović, 2019: 65).

The term "burden of caregiving" is used to describe the caregiver's subjective, personal perception of the difficulties related to caregiving. The burden of caregiving is defined as the degree in which the caregiver estimates that his/her engagement related to taking care of a dependent person negatively affects his/her emotional, social, financial, physical and spiritual functioning (Adelman *et al.*, 2014: 1052-1057 according to Matejić, Đikanović, 2019:15). Also, the burden of caregiving is described as resistance to care caused by the inclusion of new or the expansion of the existing activities related to care, and it depends on several circumstances including: the characteristics of the elderly person, the degree of his/her dependence, and the social support of both – the care giver as well as the care receiver (Rodríguez-González *et al.*, 2017 according to Mendes *et al.*, 2019: 88).

When it comes to caregivers' physical problems, the most common include: back, shoulders and neck pain due to physical activities such as assisting elderly person with getting up, taking a bath or similar activities, whereas psychological problems include: lack of energy, sleeping disorders, stress, panic attacks, depression, lack of concentration, feeling of sadness, guilt or insecurity (Todorović, Vračević, 2019: 19). The caregivers are also at greater risk of depressive disorders and anxiety and of substance abuse such as hypnotics, anxiolytics and smoking (Valle-Alonso *et al.*, 2015 according to Mendes *et al.*, 2019: 88).

Research confirms that between 15% and 32% of all informal caregivers feel great burden of caregiving, particularly in the cases of caring for elderly and seriously ill persons (Matejić, Đikanović, 2019:15). The burden of caregiving increases when caregivers have

financial problems, when they are less educated, when they share the household with the dependent person, when they dedicate more hours to caregiving and when the condition of the dependent person is getting worse (Matejić, Đikanović, 2019:15). The burden of caregiving is often associated with the feeling of stress due to the changes in caregiver's life and functioning, additional financial obligations, managing the actual and potential problems of the dependent person and it significantly differs from one caregiver to another (Sundar, Fox, Phillips, 2014: 750-765 according to Matejić, Đikanović, 2019:16). This is of particular importance since the stress that the caregivers feel can often be a risk factor for elder abuse, particularly in the form of verbally abusive behaviour (Ananias, Strydom, 2014: 277).

When it comes to financial issues, it should be emphasized that research conducted by Matejić and Đikanović in 2019 suggests that more than 1/2 of informal caregivers in Serbia assume that the financial resources that they have are not sufficient to cover the needs of the person they care for and that they do not receive any kind of additional financial support (Matejić, Đikanović, 2019: 48). According to the aforementioned study, informal caregivers in Serbia consider the following expenses as the greatest ones: medications, additional services of professionals such as health protection in private sector, adult diapers, nutrition, hygiene and transport of the dependent person (Matejić, Đikanović, 2019: 50).

Employed informal caregivers often cannot organise their working engagements on the one hand and obligations related to the care for the dependent person on the other, and they feel as if they were failing in both – their job and their duties as caregivers (Todorović, Vračević, 2019: 18). That is the reason why informal caregivers often have to shorten their working hours or quit their jobs, which causes them additional financial difficulties (Ananias, Strydom, 2014: 277; Mendes *et al.*, 2019: 92; Todorović, Vračević, 2019: 18-19).

Another important need of informal caregivers of elderly persons is the need for information, including: 1) information on the condition or diagnosis, the evolution of the illness, symptoms and prognosis of the person they care for; 2) information on medications, treatments, nutritional needs and rehabilitation of the person they care for and 3) information about the services available for the elderly such as disease-specific services or daytime activities for elderly persons (Silva *et al.*, 2013: 799). It is estimated that in Serbia almost 2/3 of informal caregivers assume that they have sufficient knowledge and skills as well as relevant information to take care of and communicate with the dependent person (Matejić, Đikanović, 2019: 56). At the same time, the majority

of informal caregivers in Serbia claim that they need somebody that they could talk to or from whom they could ask assistance and advice, for example, via telephone line for support and help (Matejić, Đikanović, 2019: 57). Informal caregivers in Serbia are also in need of information on how to access the services of social welfare and health protection (Todorović, Vračević, 2019: 19).

When institutional support is concerned, it is important to mention that in Serbia, the traditional model of caring for elderly persons, which is conducted within the family is still the most frequent one (78% of elderly persons), whereas only 2,3% of elderly persons have the access to paid assistance and only 0,7% to the assistance provided by the state (Matejić, Đikanović, 2019: 15; compare with: Mendes *et al.*, 2019: 91). A rather small percentage (15%) of informal caregivers of elderly persons in Serbia admitted that they would consider placing the person they care for in an institution, whereas the majority did not consider such option, claiming that the conditions are better at home, that they can still handle everything or that they cannot afford the cost of institutional care (Matejić, Đikanović, 2019: 51; see also: Mendes *et al.*, 2019: 88).

Informal caregivers in Serbia are in particular need of stronger professional support, including the services of professional caregivers (Matejić, Đikanović, 2019: 70). However, the social service of home assistance for elderly persons provided by local self-government units is present in only 85% of these units (Strategy of deinstitutionalisation and development of the services of social protection in the community for the period between 2022 and 2026). Moreover, in 2018 social service of home assistance for elderly persons provided by local self-government units was continuously provided for all 12 months in only 51% of cities and municipalities that send reports about these services (Matković, Stranjaković, 2018). This type of assistance was provided continuously between 6 and 8 months in 39% of local self-government units and less than 6 months in 9,8% of them (Matković, Stranjaković, 2018). These data show that the principles of availability and continuance are not fulfilled in approximately 50% of local self-government units, which indicates that assistance at home is not a permanent and sustainable social service in many cities and municipalities (Matković, Stranjaković, 2018).

One aspect of support for informal caregivers that is often overseen and neglected is emotional support from both – their families as well as professionals. Even when they are satisfied with their role of caregiver, family members who take care of elderly persons are exposed to constant sources of stress, including the roles and tasks they are not prepared for (Mendes *et al.*, 2019: 91). A review study from 2013 showed that there are

several researches confirming that informal caregivers of elderly persons need emotional support provided by professionals, particularly in identifying the strategies for managing and coping with stress (Silva *et al.*, 2013: 799). This study also confirmed that some informal caregivers felt like crying and needed an opportunity to be heard, whereas some highlighted the need for assistance in resolving emotional issues, burnout and creating support groups (Silva *et al.*, 2013: 799). In Serbia, more than 2/3 of informal caregivers feel that they lack company and approximately 1/2 of informal caregivers feel excluded from the society and isolated from other people (Matejić, Đikanović, 2019: 62-63). Despite this feeling of isolation, sadness and loneliness (Todorović, Vračević, 2019: 18), only 26,4% of informal caregivers in Serbia admit that they have the need to be heard and understood (Matejić, Đikanović, 2019: 60).

6. Conclusions and Recommendations to Improve Informal Care in Serbia

The support that should be given to families that take care of their elderly and dependent members is not yet sufficiently defined and developed in Serbia (NAS). The families that take care of their elderly members, especially of those suffering from dementia, are still in need of better support, which requires the planning of improvements in the development of the capacities of all institutions in the area of social welfare and health protection (Kozarčanin, Milojević, 2016: 31). The network of at home care and various social welfare services such as daily centres and at home assistance should be further developed and a more efficient coordination between public, private and non-profit sector as well as family, friends and neighbours in providing services for elderly persons should be established (NAS).

Moreover, it is necessary to enhance informal education of both – informal caregivers as well as professionals, in the field of providing assistance for elderly persons suffering from dementia and other serious illnesses (Kozarčanin, Milojević, 2016: 31). For that purpose, workshops, courses and trainings, including those that can be attended on-line, should be organised. An example of good practice in that area is the program of Belgrade Red Cross entitled as “Support for Assistants”, which provides free practical training for informal caregivers who take care of elderly persons, free advice via telephone and e-mail as well as educative video materials available via YouTube (Matejić, Đikanović, 2019: 73).

Also, the rights of the families with informal caregivers to obtain financial support should become broader and the services of caregiving at home and palliative care should be further developed (Kozarčanin, Milojević, 2016: 31). One form of financial support could

be to minimise the prices of some basic products that are necessary for a dignified life of immobile persons or persons who have difficulties to move (in general, and particularly elderly ones) such as, for example, adult diapers (Matejić, Đikanović, 2019: 71).

Informal caregivers should be given the opportunity to have flexible or shorter working hours, or to be able to work from home, so that they could adjust their professional obligations to the needs of the person they are taking care of (NAS; Kozarčanin, Milojević, 2016: 31; Matejić, Đikanović, 2019: 70).

Volunteers in the community are an important source of support for both – informal caregivers as well as elderly persons who do not have anybody to rely on. However, it seems that their potentials are not being used sufficiently in our country, which is the reason why a support mechanism for volunteers and intergenerational solidarity should be encouraged (Matejić, Đikanović, 2019: 72). So, as a way to support families with elderly members, volunteers should be more intensively involved with taking care of them, particularly elderly volunteers who would be able to help by sharing their own experiences (NAS; Kozarčanin, Milojević, 2016: 31).

The number of available informal caregivers is expected to decrease in the future due to the changes in family structure, higher divorce rate, delayed marriages, increase in unemployment rate, larger number of households with only one member, larger number of women at the labour market etc (Lowenstein, 2010: 219 according to Ananias, Strydom, 2014; Todorović, Vračević, 2019: 10). Another reason for a potentially smaller number of informal caregivers and the transfer of the responsibility for taking care of elderly persons from their families to the community lays in gradual disappearing of moral responsibility, traditional forms of family functioning and affirmation of individualistic approach to life (NAS). That is the reason why informal caregiving and taking care of elderly persons not only by their closest family members, but also by their friends and neighbours, should be promoted via various campaigns and activities (NAS). In order to contribute to the increase of interest in informal caregiving, positive aspects of this experience should be emphasized, including the sense of additional life purpose and quality and the satisfaction that many informal caregivers feel because they can do something for their closest ones (Buyck *et al*, 2011 according to Matejić, Đikanović, 2019: 16). Emphasizing positive aspects of informal caregiving should encourage a larger number of persons, who are potential informal caregivers, to take this important role in some period of their life.

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