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Ageing and intergenerational solidarity in institutional accommodation

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Abstract

This study aims to explore the relationship between presence of intergenerational contacts and support and well-being of older persons living in institutional care facilities. The research was implemented in 12 residential care facilities for older persons analysing the relationship between the services provided by the institutions and the support provided by the family remotely. Design wise this is a cross-sectional study using a 24 question quality of life assessment tool WHOQOL-BREF developed by WHO assessing the perception of a person on her or his position within the culture and the system they belong to as well as in relation to their life goals, expectations, standards and worries, measuring the quality of life in six domains: physical health, psychological wellbeing, level of independence, satisfaction with social relations, satisfaction with one's living environment and spiritual/ religious/ personal beliefs. Significant correlation is found important between the quality of life and social relationships with family and friends especially in relation to psychological wellbeing, satisfaction with the environment, and social relationships.

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Introduction and background

This article reviews the research done by the Red Cross of Serbia in 2019 and the results published in a report "Ageing and intergenerational solidarity in institutional accommodation" in 2019.

The trend marking the 21 century is demographic ageing – extension of life expectancy and lowering the birth rate that both contribute to increase of the share of persons over 65 in the population. In the countries of the CEB region⁵ it is expected that by 2060 the share of over 65 population will increase from 16% in 2010 to 29%. At the same time the share of "older older" persons – those over 80 is expected to rise to over 11% by 2060 from 4% in 2010. This will also increase the dependency rate⁶ from 24% in 2010 to 52% in 2060.

According to the 2013 Report on the Health of Population in Serbia, 75.8% of the over 65 population has some chronic health condition or other health problem, 37.1% has mobility issues, 10.7% sight issues and 23.6% has hearing problems. Furthermore, 37.6% has severe difficulties in performing daily activities (food preparation, light and harder house chores, shopping for groceries) and 11.1% has difficulties in maintaining personal care and hygiene (dressing and undressing, toilet use, bathing, showering etc.). Every third person in Serbia over 65 has in 2013 had to rely on somebody else's assistance to perform activities of daily life (33%) and every seventh needed it for personal care and hygiene (14.9%) (Institute for Public Health Serbia "Dr Milan Jovanovic Batut", 2013).

Additionally, the number of older persons living with dementia – which also lowers functional capacity and increases the need for formal and informal care – is only estimated in Serbia. WHO estimates there are currently approximately 50 million persons over 60 living with dementia at global level and that their average share in national population is 5–8% (World Health Organisation, 2020). This would mean there are between 90,000 and 143,000 persons living with dementia who are over 60 in Serbia. Furthermore, the Provincial Ombudsman estimated in 2014 that there are approximately 200,000 persons living with Alzheimer's in Serbia while there are no statistics for other forms of dementia, and that approximately 40% patients with moderate and severe dementia need 24-hour care and support (Penzin, 2014).

Globally the demographic trends clearly show that increased share of older – and especially "older older" – persons in the population increases the need for care due to decreased functional capacities to perform daily activities independently while the decrease of younger population and the changes of the family structure mean that the capacity to provide informal care services is lowered.

The EU projections of the expenditure for formal services of long term care until 2060 following different scenarios (based on demographic projections, expected de-

⁵ CEB Member Countries https://coebank.org/en/about/member-countries/

⁶ The ratio of population above 65 to population aged 15-64

pendency ratio, and the ratio between formal and informal care) place the expected average increase of expenditure between 2.7 and 4.1% of the GDP, which, today is 1.7% on the average (European Commission, 2015). And while many formal services of long term care can be provided in the client's home, in 2013 62% of the expenditure for these services in the EU and OSCE states was made for services provided in institutions – on the average around 1% of GDP (Hirose, K. Czepulis-Rutkowska, Z, 2016). On the other hand, in Serbia in 2014 only 0.08% of GDP was spent in the institutions while the total expenditure for these services was 0.53% (Hirose, K. Czepulis-Rutkowska, Z, 2016).

Most older persons wish to stay in their homes for as long as possible, and this is achievable as long as they can function with minimal support provided by another person. However, there comes a time when their health worsens and then the care they get in an institutions is of a better quality than at home, providing them with better quality of life (Aminzadeh, F. Dalziel, W.B. Molnar, F.J 2009). There are cases when a person who does function independently in their home decides to move to an institution for different reasons. Some, though, have no other choice (Senior Housing 2019).

As for collection of data on older persons, the population in heightened risk of chronical conditions that decrease functionality and independence – those living in institutional accommodation – is frequently not included since the research usually focuses on households. Therefore this research as well as the research focusing on social inclusion is based on the sample that is not representative for the overall population of older persons (United Nations, 2016).

In Serbia in 2018 the existing accommodation capacity of institutions for accommodation of adults and older persons was 16,444 beds – 17% higher than in 2017 and 49% higher than in 2015. At the end of 2018, their capacity was 88% full – 8% higher than in 2017 and 12% higher than in 2015. Public facilities were fuller (93%) than private ones (83%).

It is important to keep in mind that, while accommodation capacities grow year upon year – they are available to 1.2% of the population in 2018 and were to 0.7% in 2015 – the waiting lists also grow longer: 1,163 persons in 2018 which is a 42% increase from 2017 and 230% increase from 2015. Additionally, the institutions lack staff of all profiles and especially caregivers and medical professionals. In the last ten years in Europe the number of private facilities grows as the number of public ones stagnates, decreases or grows at a slower rate. In Serbia the number of private facilities grows and the number of public ones stagnates.

Research methodology

The research was implemented in 2019 with the results published in September 2019 to increase the awareness and to advocate for better quality of life of older persons residing in care institutions. The research explored the relationship between the services provided by the institutions for accommodation and care for older persons and

the support provided by the family remotely in cases when older persons were accommodated in residential care institutions.

The research was part of the project supported by the Cabinet of the Minister without portfolio responsible for demographics and population policy of the Government of the Republic of Serbia. It was implemented in June and July 2019 in twelve residential care facilities for older persons – seven public and five private ones. Design wise this is a cross-sectional study.

For this research the 24 question quality of life assessment tool WHOQOL-BREF developed by World Health Organisation was used, as an abridged version of WHO-QOL-100 with a hundred questions. Both questionnaires assess the perception of a person on her or his position within the culture and the system they belong to as well as in relation to their life goals, expectations, standards and worries. WHOQOL-100 was developed over several years in different cultural environments and was tested in 37 different states. WHOQOL measures the quality of life in six domains: physical health, psychological wellbeing, level of independence, satisfaction with social relations, satisfaction with one's living environment and spiritual/ religious/ personal beliefs (World Health Organization, 1998).

Two additional questions relate to the overall quality of life and satisfaction with one's health status. Additionally, there are questions to assess general satisfaction with one's quality of life and to assess loneliness, from the integral WHOQOL questionnaire, as a set of indicators. In this analysis only scales were used. Self-assessment was done using the five-level Likert scale, focusing on the last four weeks before the interview.

Research Results

Sample

The research covered 373 participants (309 from public and 64 from private facilities). Average age was 76.8±9.5 years with the eldest participant being 96 at the time of the interview and two thirds of the participants were female.

The majority of the participants are widowed (238 (64.2%)) and 67 (18.1%) are divorced or separated which means they are without life partners and it can be assumed that they decided to live in the care facility because they have no partner and cannot live independently. Education-wise, the majority have completed primary school or less (140 (38.1%)) and secondary school (131 (35.7%)) while approximately one quarter have completed college or university education (96 (26.2%)).

Equal number of participants describe their financial situation as "Comfortable" and "Have to be careful but I manage" 122 (34.7%), while 55 (15.6%) are in a difficult situation and 26 (7.4%) have problems making ends meet.

272 (73.5%) of the sample reported having children. On the average, older persons see their eldest child most frequently.

Regarding the relationships between the older person and their children, the majority of participants have not had conflicts with their children (159 (60%)) while one fifth (55 20.8%)) reported some conflicts and 30 (11.3%) reported moderate conflicts. The interviewers registered that older persons needed to clarify that "a little" and "some" conflicts are usual conflicts that happen in every family. On the other hand, 21 participant (7.9%) come from families with serious conflicts.

Majority reported having pleasant relationship with their eldest child (58.8% "Almost always pleasant" and 20.6% "More often than not pleasant") while 4.9% reports having "Almost always unpleasant relationship".

71% of the participants have close friends and 18.3% see their friends every day or more often, 36.6% see them several times per year or less frequently than that. The fact that ¼ of the participants have no close friends indicates the risk of exclusion and affects their quality of life.

Discussion

Statistically high correlation was recorded between all the measured scales of the WHOQOL-BREF questionnaire and differences in quality of life measured using WHOQOL-BREF questionnaire for all scales are minimal between genders.

Correlation between marital status and scales of physical health and social relationships has been registered, the education level correlates with all four scales, income level correlates with scales of psychological wellbeing and satisfaction with the environment, having children correlates with scales of psychological wellbeing, social relationships and satisfaction with the environment and having friends correlates with scales of psychological wellbeing and social relationships. The number of residents per room negatively correlates with scales of physical health and psychological wellbeing.

For participants who have children or close friends we looked into the correlation between the frequency of seeing them with the scale for quality of life. Significant correlation was found between frequency of seeing the eldest child and the scales of psychological wellbeing and social relationships, frequency of seeing the second child and scale for psychological wellbeing, while the frequency of seeing close friends is in significant correlation with all four scales.

Comparison with another research study, done in 2019, focusing on older persons living with their families showed that the quality of life significantly correlates with the existence of support provided by family/ children. So, in both cases, for older persons living with their families and living in institutional care facilities, there are significant correlations between having support/ contacts from children/ family and different domains of the quality of life (notably physical health, satisfaction with social relations and satisfaction with one's living environment). Marital status and number of residents in the room are significant predictors for physical health, education level, number of residents in the room and having close friends are significant predictors for psychological wellbeing, marital status, education level and having close friends are significant predictors for satisfaction with social relationships and income level and number of residents in the room are significant predictors of the satisfaction with the environment.

Furthermore, statistically significant correlation was found between psychological wellbeing of participants with and without provided support for transportation, finances, as well as the participants with and without emotional support. Also, in relation to financial support, there is statistically significant correlation in psychological wellbeing between participants getting and not getting financial support from time to time. Statistically significant difference in social relationships was found between participants with and without support in transportation and emotional support. Statistically significant difference in satisfaction with the environment was found between participants with and without emotional support.

Conclusions

A large majority of residents of the institutional accommodation facilities cites the following reasons for living in institutional accommodation: lack of capacity to live independently (49.7%), sudden illness (17.3%) and a wish not to burden their children (21.2%). This suggests that the capacity to provide services in the community at home is insufficient and that the scope of services is probably inadequate and that these persons who could – with some support – probably live independently in their homes, had to choose retirement home as their only viable option. Wanting to not be a burden for their children shows that demographic ageing and lower birth rate mean there are fewer children who can act as informal caregivers to their parents, this again meaning that those children that are there have to spend more time in this role, all without the support provided from the system: Therefore, we can speak about the perception of burden.

On the other hand, 64.2% are widowed and 18.1% are divorced or separated which means for majority of the residents of residential care facilities their spouse was the main source of support and now that this is gone, there is no other option for them than to be in a retirement home. This also fits the self-sacrifice model hypothesis where older persons choose to live in a retirement home to lift the burden of care from their children and sometimes to leave them their apartments (Petrusic, Todorovic, Vracevic & Jankovic, 2015). Approximately 20% moved to the residential care facility without this being their choice but accepting it which again suggests the self-sacrifice model. Similar percentage (22.9%) thinks that the responsibility for providing care to older persons should not be on their adult children.

As for the results on quality of life of the residents - which are partly in relation to the way the facilities function and various services they provide – it is important to note the relationship between the quality of life and social relationships with family and friends. This is especially visible in scales psychological wellbeing, satisfaction with the environment, and social relationships (Netuveli & Blane, 2008). Institutional care facilities should, therefore, pay special attention to help maintain the relationship between their residents and their families and friends as this affects the residents' mental health and can reduce the risk of disorders such as anxiety and depression. This is especially important as some disorders are, in line with ageist prejudices, normalised for older persons and are considered expected and unavoidable so the interventions tend to be inadequate. For example, subclinical forms of depression are often overlooked by medical professionals as they do not fulfil the criteria for clinical depression so they are not treated and for older persons the risk of subclinical depression is higher than for clinical, and especially high for persons living in institutional accommodation (Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2011). Negative effects of subclinical depression to health of older persons include increased use of healthcare services - which increases the expenses too - cognitive disorders, deteriorated physical health, risk of disability and suicidal ideation (Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2011).

Statistically significant difference in quality of life – psychological wellbeing, is found between participants with and without emotional support and this does not just relate to the support provided by family and friends, but also by the staff in the residential care institution. Even for persons with decreased autonomy, their sense of personal dignity and quality of life is more a function of how they are treated in the facility and how socio-cultural context and institutional structures in the facility support or decrease their autonomy. This is important to have in mind as moving into a facility is a radical change in one's life and can be perceived as a threat to their independence and dignity and this perception is a function of the sense of dependence, limits to one's freedom, as well as the attitude of the staff in the facility (Heggestad, A. & Høy. Bente & Sæteren, B. & S. Åshild & Lillestø, B. & R. Arne & Lindwall, L. & L. Vibeke & Råholm, M-B. & A. Trygve & Caspari, S. & N. Dagfinn. 2015).

As the research showed that the number of persons sharing a room is in negative correlation with scales physical health and psychological wellbeing, it is important to remember that an institutional care facility is not just a healthcare institution for medical treatment but also a living space with everything this entails: personal space, privacy and the sense of ownership of a certain space (Mann, J, 1998). If a resident does not feel this to the extent they expected it, this may produce continuing stress that again may affect their health, for example, lead to hypertension (Tao, Y., Lau, S., Gou, Z., Fu, J., Jiang, B., & Chen, X., 2018).

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