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ATTITUDES OF ROMA/GYPSY ADULTS TOWARDS THE CARE OF THEIR ELDERLY LOVED ONES

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Abstract

Caring for older people is a challenge for all societies. There has been a lot of research on elderly care to help make it as effective as possible. The aim of this study is to provide an overview of the Roma/Gypsy elderly care among ethnic minorities, using national and international trends. The choice of the target group in our framework was not accidental - the Roma/Gypsy minority is considered vulnerable in terms of several factors, which means risks for elderly care in terms of inequalities. In addition to the main concepts of elderly care, the paper will address the opportunities and constraints of the legal environment, the relationship between elderly care and health care, and the factors that shape quality of life and well-being, as well as strategies (formal and informal) that are emerging as trends at national and international levels.

A roma/cigány hozzátartozók attitűdjei időskorú hozzátartozóik gondozásával kapcsolatban

Kulcsszavak: idős gondozás; szociálpolitikai megközelítés; kvalitatív kutatás; vulnerabilis társadalmi csoportok; roma/cigány

Absztrakt

Az idősök gondozása minden társadalom számára kihívást jelent. Számos kutatás látott már napvilágot az idősgondozással kapcsolatban, amelyek segítenek abban, hogy az idősgondozás minél hatékonyabban tudjon megvalósulni. Jelen tanulmány célja, hogy áttekintést nyújtson az etnikai kisebbségek közül a roma/cigány idősök gondozásához hazai, illetve nemzetközi trendek segítségével. Szempontrendszerünkben a célcsoport választása nem volt véletlen – a roma/cigány kisebbség több tényezőt tekintve is vulnerabilisnak tekinthető, mely az időskori gondozásra nézve veszélyeket rejt a gyakorlatban az egyenlőtlenségi viszonyokat tekintve. A tanulmányban az idősgondozás főbb fogalmain túl kitérünk a jogi környezet adta lehetőségekre és korlátokra, az idősgondozás és az egészségügy kapcsolatrendszerére, illetve az életminőség és jóllét alakulásának tényezőin túl olyan stratégiákra (formális és informális), melyek hazai és nemzetközi szinten is trendként rajzolódnak ki.

Introduction

Elderly care is present both at the individual level (*informal care*) and at the macro level (*formal care*), which are closely linked to the values and motivations of individuals (Allport, et al. 1960) and to the characteristics of the welfare care system (Fariidah, & Gallouj, 2006).

However, elderly care also raises several problems due to the specificities of the care group, which are examined through different perspectives. The following have emerged as key concepts in the national and international literature: the concept and characteristics of elderly care (KSH, 2004; Orimo, et al. 2006; Monostori, 2015), the legal context (Asztalosné Zupcsán, 2018; Czigler, 2010), the health care system as an important factor in care (McAdam, 2008; Lakatos, et. al 2017), and strategies for ageing care (Djellal, & Gallouj, 2006; Da Roit, 2010; Schwiter ,et al. 2018; Nárai, 2019). In the following, we discuss these issues.

Elderly care

Eurostat data mostly define young people according to cohorts as 0–19-year-olds and older people who are 60 and over (KSH, 2004). Nowadays, the age limit of 65 years is used (EU,

UN) because it is the age at which welfare benefits are defined at state level (Bálint, & Spéder, 2012). The Hungarian Central Statistical Office (KSH) has studied the age structure of the elderly in Hungary up to 2060, which clearly shows that it is an ageing society we live in. Data measured in 1990 and 2013 reported an increase in life expectancy between men and women (Monostori, 2015).

The treatment and respect for the elderly still carries a moral obligation - albeit at a lower level than in the past - which we believe is increasingly difficult to meet in the XXIst century in a capitalist society. In Hungary, because of the ever-decreasing birth rate, the number of potential family breadwinners, who can provide care as close relatives is decreasing. For this reason, it may be necessary to employ external professionals (e.g., professionals in social care and nurses) (Österle, & Bauer, 2016). This is not effortless, as a study by KSH (2019) has pointed to the phenomenon of migration of Hungarian home assistants from southern Baranya to Austria (Gábrriel, 2019), as in Hungary this low-prestige job is not willingly undertaken by home assistants (Österle, & Bauer, 2016). Even if such professions can be found in our country, the low amount of the care fee cannot cover the costs of a professional. The low care allowance socialises family members and relatives into active labour market participation instead of caring. Since there is no culture in Hungary of family members paying professional nurses in addition to the home assistance and nursing staff working in primary care - for financial reasons, because of lack of professionals. Our point of view contains that because of low levels of trust - many people are forced to either place their loved ones in nursing homes - if there is room and funding - or someone else in the family is left out of the 8-hour employment to care for a relative. This drop-out is either 24/7, or it may be possible to take up a 4-hour job on the labour market, or a professional carer may be able to take on something as a home-based task in addition to caring - depending on the level and intensity of care required by the elderly person. In a rapidly developing world, to be excluded from the labour market is a problem, as there is not much chance to guarantee of reintegration since the less effective reintegration programmes. Another factor is a socio-cultural environment that can be also a barrier of the reintegration process. The care of the elderly is a real challenge in an ageing Hungarian society, and it is certainly not economically worthwhile for the state, if the relative is willing to care for the family member at home, instead of being active in the labour market. This is why elderly care is sometimes left to people, who are not active earners for other reasons (e.g. students, parents getting the support of GYED, retired relatives or neighbours, etc.). We raise the rhetorical question of the relationship between solidarity-based elderly care and professionalism. As for some examples: does someone who cares for a loved one at home or learns the most basic care

and nursing tasks in an emergency situation? Do they get any help from health professionals? The low level of care allowance indirectly determines the quality of care, too?

Legal context

Article XV of the Fundamental Law already declares that Hungary has special measures to protect the elderly in addition to families, women and children. This commitment on the part of the Hungarian state means that it is making rules to protect the existence and interests of vulnerable groups. For example, in the Civil Code (Act V of 2013, amended in 2016), the Hungarian state has created a rule that obliges a child to support a parent in case the parent is unable to support him/herself. By this we mean primarily financial support, but by mutual agreement the court may also order other forms of parental support if justified by the circumstances of the elderly person. It is not only the parent who can sue the child, but also the care institutions and nursing homes that can sue the child of the elderly person they are caring for if the cost of care is too high. While in the case of child support, the parent is also obliged to support the child at his or her own expense, parental support does not follow such strict rules, i.e. if the child's income is used to support him or herself, the court is unlikely to impose parental support. Since most adults do not have enough income to pay parental support for themselves and their family, it is difficult to recover the amount of parental support.

Being female, having children, being elderly or unemployed is a risk factor for poverty (European Commission, 2007). Age-related ill health among older people can have further undesirable consequences, such as an increased risk of becoming a victim of crime (Asztalosné Zupcsán, 2018), physical injuries and a higher incidence of diseases such as dementia and Alzheimer's (Czigler, 2010). Government Decision 17/2013/2013, which states that people over 60 years of age (elderly) are the most vulnerable age group in terms of crime victimisation.

Digital illiteracy is known to be present in older people, which can be a barrier to the computer and internet-related activities that are increasingly part of our daily lives, e.g. online administration, online shopping, etc., but can also represent a digital divide in terms of connecting with younger generations. In Hungary, there is a special telephone helpline for older people, and the demand for this service is a social imprint of the phenomenon of loneliness, with 25 % of older people living alone, which also carries a risk of poverty (Bartal, & Habók, 2007). Dissatisfaction with life can be exacerbated by isolation, lack of security and a sense of loneliness (Fekete, 2006).

In disadvantaged Roma families, we can also observe the phenomenon of several family members, generations living together as a kind of coping strategy, so that the coexistence of

family members functions as a cohesive, mutually supportive community (for cost-effectiveness reasons, among others). Respect for the elderly in Bali's (2018) research is so present in the Roma family she studied that it is mostly the elderly who have decision-making power within the family (Bali, 2018:7). Elderly have an influence on the younger ones (Lakatos, et. al., 2007). Where there is a large family, it is undoubtedly easier to share care responsibilities. Lakatos et. al. (2007) describe Roma family relations in terms of the extended family, as beyond the narrow family network, the patient is e.g. hospitalised, but also the extended family in the broader sense.

Roma¹ and health care

Several surveys have looked at the health of Roma (Hajioff, & McKee, 2000; Vivian, & Dundes, 2004). A multi-municipal programme on Roma health included encouraging participation in screening tests, encouraging screening for cardiovascular and respiratory diseases in elderly Roma, and providing advice on healthy lifestyles. The programme was implemented in 3 counties, with 76 health clubs. An important objective was to promote contact with health professionals (GPs, nurses), to facilitate interaction between Roma and health professionals, which also promoted trust between Roma patients and professionals in health institutions. Thus, an important task was to stimulate participation in needs assessment surveys, screening programmes and counselling (Csépe,, et al. 2017). The formulation of these objectives indicates that there is still work to be done in relation to Roma. In this programme, the participation of Roma was encouraged through food vouchers, which shows that the need for Roma to address their health in more depth has not yet been internalised in many places.

Prejudices against Roma are also found in the health care sector (Marek et al. 2020). Attitudes towards the health care system affect the health status of Roma, such that they rarely attend screening tests, and when necessary, they visit doctors for complaints of acute illnesses (Lakatos, et al., 2017). Lack of trust in the health care system and the traditional habits are significant determinant of attitudes towards doctors, for example, in terms of compliance with medical instructions. The latter is also influenced by the cost of medicines and medical aids to the individual or family. Those who have regular monthly expenditure on medical care can apply for a certificate of entitlement to public medical care, accompanied by a certificate from their general practitioner.²

¹ In the following, the term Roma will be used considering the terminology.

² Sections 49-53 of Act III of 1993 on Social Administration and Social Benefits Sections 6/A (3) (f-g) of Government Decree 63/2006 (27.III.) on the detailed rules for the application for and the establishment and

If older people have reached retirement age, they can remain active members of the household and help other members of the household with tasks such as childcare, childminding, cleaning, cooking, etc., thus relieving the burden on the household and indirectly contributing to the economy (Sik, 2017). At the time of the 2011 census, 23.5% of the total population (2 331 000 people) was aged 60 and over. It is clear that the elderly are also a burden on the state, e.g.: they have to pay for their pensions, and as many people over 65 retire, they do not pay taxes, and they are a burden on the health and social care system (hospitals, nursing homes, home help services, reduced-price medicines, etc.) and the increasing life expectancy makes them a particular focus of attention, with the average age of the elderly being 71 years between 2001 and 2011 according to the KSH, and this average age is increasing over time, thanks in part to advances in medicine (KSH, 2014). Research by Delphoi Consulting (2004, cited in Orsós, 2013) has shown that Roma life expectancy can be up to 10-15 years lower than that of non-Roma, and that they are 1.8 times more likely to develop cancer. The research identified poor health indicators associated with disadvantage as a reason.

Quality of life and well-being

The WHO (2006) definition of health is based on a holistic approach, which includes not only physical well-being, but also mental and social well-being. At the same time, it argues that it is not enough to be healthy to be free of disease, but that health is made up of much more complex components (biological, spiritual, mental, emotional and social health). This is also evidenced by Maslow's (2017) hierarchy of needs, which places the satisfaction of basic needs at the bottom of the hierarchy on the path to self-actualisation. Relevance for older people is Meikirch's (Csizmadia, 2018) approach to health, in which he argues is a state of well-being that is the result of the challenges experienced during an individual's life course, the individual's capabilities, and the interaction of social and environmental factors (Bricher, & Kuruvilla, 2014; Bircher, & Hahn, 2016). This also implies that a life course full of suffering and challenges, which is not easy for Roma due to discrimination, has a negative impact on health-related well-being (also due to the challenges experienced and the role of the social environment).

Peer support can make a significant contribution to improve an individual's quality of life (Albert, & Dávid, 2016). A peer support system not only helps with everyday life, however, is also essential for dealing with crisis situations and transitions. It also enhances a person's sense

payment of social benefits in cash and in kind, Sections 35-49 of Act III of 1993 on Social Administration and Social Benefits

of security, happiness, optimism, and sense of balance (Fekete 2007). "*Developing a sense of subjective well-being is also essential because it is associated with a lower risk of mortality.*" (Kazai, 2017).

In the case of Roma, we believe that strong family ties can also contribute to an older person's quality of life if the trusting relationship is strong and can increase the individual's sense of security knowing that they have someone to rely on. Family-centeredness is therefore seen as a value that supports elderly care. Fekete's (2007) research has shown that religiosity can be a protective factor, however, lags the level of trust in family relationships and wider human relationships (co-workers, friends, neighbours, etc.). In the research, distrust was found to be associated with anxiety and subjective feelings of incompetence (Fekete, 2007). The natural safety net thus plays a key role at all stages of human existence, especially in vulnerable infancy and childhood and in old age. The family therefore appears in these contexts not only as a possible safety net, but also as a necessary safety net.

Strategies for elderly care

There are two key words in the literature that have a strong emphasis on the social care system: primary care and special care. Through the lens of these terms, we have collected national and international research on elderly care. The key elements of ageing care frameworks can be summarised in two aspects: ageing care within the family and within institutional settings. The overarching phenomenon is that of primary and specialised care, which is available to the recipients and providers of care, regardless of the place of care (Arlotti, Aguilar-Hendrickson, 2017).

Whether care is provided within the family or in an institutional setting, there is a systemic presence of organisations and movements that provide support in practice. These phenomena have been grouped by Barbara Da Roit (2010) into four categories: umbrella structures, multidisciplinary case management organisations, organised networks of service providers, and organisations responsible for creating financial incentives that focus on prevention and rehabilitation in their decision-making.

In the literature review, we noticed that in all the studies, financial aspects played a cardinal role in both informal and formal care. Kehusmaa et al. (2013) conclude that current neoliberal processes are fomenting increasing inequalities between the two forms of care, both between nations and within societies, with the result that the degree of inequality is increasing (Schwiter, et al., 2018).

Informal care

The image of elderly care and the way it is put into practice are shaped by internal and external factors. Internal factors are the needs, motivations, habits and current financial situation of individuals and families. External factors are the specificities of the care system in a country/region/municipality, which are concentrated in the welfare system (Da Roit, 2010).

Barbara Da Roit (2010) has associated two distinctive trends with the impact of social policies, citing the Italian and Dutch examples in her work. The Italian model is characterised by familiarity features, which in practice are reflected in the fact that the elderly tend to be cared for in a family environment and that there is a high level of mistrust in institutional care in society. In contrast, the Dutch example shows a set of aspects that can be described as a formal model. The well-organised nature of institutions and the trust placed in them is linked to the strategies and attitudes of the people they care for and the carers.

Formal care

The welfare state means that the state takes responsibility for the basic well-being of its citizens. It can do this in several ways (Zombori, 1997). Through laws, through various social policies. In the following, we have compiled a list of measures that are available to the elderly within the framework of basic or specialised care, depending on how the municipalities organise them. It is also important to consider, when accessing different types of care, the information and awareness that older people have about the care they can access. During our interviews, we also ask how much access to different types of primary and specialised care is influenced by, and whether it supports, the provision of elderly care.

1. table: Primary and specialised care for the elderly³

Primary care	Specialised care
social catering, home help (separately for social assistance and personal care), signalling home help, day care - including day care for the elderly (39,000 places), including day care for people with dementia, and, as a support service, personal transport, personal assistance ⁴	elder people's home (care home), care home for the elderly (temporary accommodation)

³ depending on the organisation, number and capacity of the municipality

⁴<http://tamogatoweb.hu/index.php/olvasnivalo1/infograf/381-szocialis-alapszolgaltatasok> (Last download: 2022. 11. 09.)

Methods

We performed half-structured qualitative research (N=20), focusing on the approaches of elderly care in connection with familiarisation and institutionalisation. Our research was held between November 2021 and March 2022 in Hungary. The data collection was formed according to the regulations of the pandemic, thus we recorded online interviews which lasted 31-57 minutes. We considered GDPR regulations which have an effect on the publication of the data as participants are anonymous.

Our target group was Roma/Gipsy adults living in Budapest, mostly doing manual work, thanks to whom we can get to know the challenges of elderly care in the capital. We chose this target group because there is a wide range of social benefits in the capital, thus we could get an idea of the trust factor or lack of it in the social care system. We used an interview register to consider GDPR regulations. In this paper we labelled the interviewees with codes that were according to the following logic:

- the first item shows the gender of the interviewee: F - female, M - male;
- the second item contains two letters, that is the age of the interviewee;
- the third item is the gender of the elderly: F - female, M - male;
- the fourth item shows the age of the elderly.

There are cases where there is data for both parents. In these cases, the fifth and sixth items show the same as the third and fourth items.

The studied dimensions

The main dimensions of our research contain the following approaches:

- responsibility for caring for the elderly;
- elderly care assistance;
- attitudes towards the social welfare system;
- resources;
- preparedness for care for the elderly.

Measures of content analysis

We investigated different aspects of our study by using qualitative analysis tools: half-structured interviews and participant observation while recording data.

The half-structured interviews were focusing on

- the responsibilities towards the elderly relatives;

- the situation of the breadwinner of the family;
- the forms of help that have been expected by the elderly;
- the expectations about caring for the elderly;
- the history of caring in the family in habits;
- the use of social services in the family;
- the effect of elderly care in the interviewee's life;
- the traditions related to elderly care;

Results

In our research we had three aspects while analysing the data. These were the responsibility and assistance, the confidence in the social welfare system, and the resources that we considered as human and financial backgrounds. In the following chapters we introduce the most relevant empirical results.

Responsibility and assistance

The responsibility and assistance can be seen from the point of view of the place of care (Arlotti, & Aguilar-Hendrickson, 2017). It contains several responsibilities according to presence or absence of professional assistance. These can be seen as dividing lines in attitudes towards institutions and caring of the elderly at home.

"With us, children in the family also help care for the elderly, just when they get to it." (M40F74)

"I've already learned to deal with decubitus." (F37M68)

"We have a mom with us because we're scarce, but that's how it's worth it." (F35F67)

"I took care of my mom too. The neighbour helps in sometimes and relatives." (F30F69)

It was also considerable for the interviewees to get a professional knowledge in order to be able to care for the elderly. However, the meaning of professional knowledge often meant something else both for the interviewer, and the interviewee. The difference of the mental and social representations of these habits show the cultural barriers that are supported by the objectivity by analysing data.

Confidence in the social welfare system

The second approach of our analyses was the confidence in the social welfare system which we investigated through the glasses of attitudes as the sources of decisions and actions. According to Barbara Da Roit's categorisation (2010), we found examples for every type she divided. However, there was a differentiation between the knowledge and the services that were taken

into account when making decisions. As the following quotes show, the two most considered types were the organised networks of service providers, and organisations responsible for creating financial incentives.

“When I gave birth, I didn’t have a good experience with the hospital. I don't want to be disrespectful to my mother. There are so many patients anyway and so few doctors and nurses that there is hardly time for anyone. I don't want my mom to die impersonally.” (F45F81)

“Mom and Dad don’t like and don’t get used to being in the hospital. If there's a problem, they have to come home that day. I could also tell them that being at home also affects their well-being and state of mind. They don't go on a trip or vacation for 1 day, let alone in a nursing home...” (F31F67M80)

“I love my parents and I want them to die among the family, not in a nursing home or a hospital.” (M50F72M73)

At the same time, it can be said that the financial background and the attitudes of the family are the main factors when relatives choose between institutions and caring for the elderly at home.

Resources

As it has already been mentioned above, resources are one of the most important approaches in the decision-making processes about elderly care among Roma/Gipsy people of our target group in the research.

“We are happy to be able to pay for the medicines. There is still luck in public health care.” (F45F85)

“We don’t have money for a nursing home. We wouldn't give in anyway because Mom doesn't want to and we can't afford it.” (F56F73)

Viewing the phenomena from a broader perspective, the role of the welfare state pins up as it takes responsibility at a basic level for well-being and also wellbeing issues of its citizens in several ways (Zombori, 1997). According to the literature (Csizmadia, 2018), the approach to health and to elderly care, well-being as a factor is named as an important factor. However, in our research the phenomenon occurred, that the elder one’s life course, capabilities and the interaction of social and environmental factors have almost the same importance as the one who is the relative - having a part in the decision process of elderly care.

Discussion

As a conclusion it emerged from the research that Roma/Gipsy women play a key role within their community. They teach, care for children and the elderly, and they are responsible for passing on the values and rules of culture. In general, women are more open to change, especially when it comes to health. Some Roma/Gipsy communities are 'self-healers'. Older people are especially familiar with and apply the healing possibilities and folk remedies provided by nature. A significant proportion of Roma communities rarely or not at all use methods and techniques to maintain health or prevent disease, mainly due to their poverty, although there are many other aspects of their health situations (Neményi, & Takács, 2015). According the above mentioned approaches, care is defined by the following factors among the interviewees:

- relationship to traditions;
- coexistence of generations (it can also be a situation of compulsion);
- the labour market position of the given family⁵;
- confidence in the social care system⁶
- the low amount of the care fee is not able to cover the costs of a lay caregiver in Hungary either, which socialises people to actively participate in the labour market instead of caring for their relatives;
- financial difficulties when entering a nursing home⁷;
- family cohesion is decisive.

Summary

In our study we paid particular attention to the situation of the Roma/Gypsy ethnic minority in the context of elderly care, exploring the legal environment, health, quality of life and well-being, and also care strategies.

Within the framework of the research, we qualitatively investigated the attitudes and experiences of Roma/Gipsy people towards elderly care using an interview method, for which the literature review was described. Our aim was to explore the views of adult Roma people on the subject and to discover possible cultural specificities in this area. We selected as our target

⁵ And also increasing labour market expectations like training, further training versus care time and leisure time as care time - leisure care.

⁶ If the trust in the social care system is lower, the Roma/Gipsy people are afraid of discrimination, they try to delay the hospitalization of the elderly as much as possible it affects the quality of care.

⁷ It is even more difficult as a Roma/Gipsy or poor person, and due to the lower average age they could expect.

group of Roma/Gipsy adults who are likely to face or are already facing the issue of caring for their elderly loved ones in the near future. We sought the opinions and thoughts of 20 Roma/Gipsy people with whom we conducted semi-structured interviews. We sought to capture Roma/Gipsy cultural attitudes towards elderly care along different dimensions according to the literature: individual responsibility, patterns in the family, financial and other resources - assistance, trust in the social care system, preparedness for elderly care. Our research was held between November 2021 and March 2022, in compliance with the COVID-19 situation measures. It is likely that the data obtained were affected by the COVID-19 situation. In the light of this, we had to be aware of the cause-and-effect relationships in our analysis to examine the specificities of care in the family and institutional care through this lens.

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