

SUPPORT FOR INFORMAL CARERS: HAS THE NEW BENEFIT IMPROVED THEIR ABILITY TO CARE?

Vladimír Barák^a , Vojtěch Krebs^a , Helena Mitwallyová^a 

Abstract

The purpose of this article is to evaluate the subjective impact of provided care on the quality of life of informal carers, to assess the institution of long-term carer's allowances from the viewpoint of informal carers, and to identify additional social policy tools that could, in carers' opinion, improve the provision of care. Our research shows that provision of care leads to a reduced quality of life for a significant number of respondents. It is confirmed that respondents' welfare is negatively influenced by a lack of funding and weak development of social services. It is not proven that the long-term carer's allowance is a comprehensible benefit increasing the carers' quality of life providing enough motivation to care. This sickness insurance benefit is intended primarily for a temporary lack of self-sufficiency, with the prospect of future improvement. Long-term or permanent lack of self-sufficiency and the related care must be secured by social support and assistance mechanisms, including respite care, and ought to be funded outside the framework of sickness insurance.

Keywords: Informal care, social policy, benefit, Czech Republic, de-institutionalisation

JEL Classification: H55, I3, J11

Introduction

According to COFACE (Confederation of Family Organisations in the European Union), we can define the term informal carer quite broadly to include “all men and women who are not professional carers, but who care for a dependant person who is their relative, based on their own decision or because they have no other choice. They provide basic care regularly or irregularly, in various forms. This may concern nursing care, help with education and social activities, help with arranging official matters, help with communication and housework” (COFACE, 2015). This is in counterpoint to formal

^a Prague University of Economics and Business, Faculty of Economics
E-mail: vladimir.barak@vse.cz; krebs@vse.cz; mitwayllova@vse.cz

care, which includes services controlled and qualitatively guaranteed by the state or other institutions, and provided by trained and licenced professionals.

The Czech Fund for Further Education under the Ministry of Labour and Social Affairs (Šimoník, 2015) defines informal care as “help exceeding normal family reciprocity, provided at least 20 hours a week, *i.e.*, in a scope that represents specific personal restrictions for the carer, *e.g.* in relation to the possibility of remaining on the job market”.

The issue of the life situation of people caring for a family member may be considered a very topical and widely discussed sphere of interest for organisers of social services, local governments and states. Informal carers have essentially been the “Cinderella” of European social policies for some time. We know that they exist and that they provide help for people in need close to them. Their benefit is indisputable, but not highlighted in any way. The Ministry of Labour and Social Affairs of the Czech Republic (2015) states that the position of informal carers can be termed “irreplaceable, but undervalued”. This situation applies even though the European Union (Zigante, 2018), of which the Czech Republic is a member, clearly states that informal care is the foundation stone of all long-term care systems in Europe and may be considered a cost-effective method of preventing institutionalisation and allowing recipients of care to remain at home.

It is true that social assurance guaranteeing a dignified life and based on solidarity can be considered a key human right defined by several multinational conventions in modern societies, for instance in the UN Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities, the European Social Charter or in the International Covenant on Economic, Social and Cultural Rights.

The status of the informal carer is not specified adequately in Czech laws or European legislation, and their rights and entitlements are not defined clearly. It is true that social policy remains the domain of individual member states, despite specific standardised measures. Holmerová (2004) stated that in the Czech Republic, institutional support is highly symbolic: the legal right to reduced working hours, to modification of working hours or acknowledgement of care for a family member as a substitute period from the aspect of a pension, cannot be considered comprehensive measures serving to improve the lives of informal carers, but rather individual instruments, which however do not lead to family care and the government’s family policy being of any significantly better quality. In subsequent years, expert authors have also stated that the conditions for family care are not ideal in the Czech Republic, due to low social prestige, stereotypical concepts, prejudice and expectations (*e.g.*, Geissler *et al.*, 2015). Indeed, in many respects, carers are a practically invisible group, whose needs are

mistakenly perceived strictly as the needs of the people for whom they provide care (Dobiášová and Kotrusová, 2017).

In recent years, legislative changes to Czech laws serving as support for informal care have set the goal of adequately resolving the situation, in compliance with the European trend of de-institutionalisation of social services (Knapp *et al.*, 2013).

However, legislators do not always manage to bring their intentions to a successful conclusion. The adopted legislation has sometimes actually been a step backwards. Before 2007, there used to be a benefit in the Czech Republic specifically intended for carers: a benefit for care for a family member. However, social service reform replaced the previous benefit with a care benefit from 2007, and this is paid out directly to the person being cared for. The effort for a more progressive approach by Czech legislators has not been a success, and the money is often lost from the social service system. It can be stated that the social service reform resulted in the needs of family carers as an independent group within the social system being neglected (Geissler *et al.*, 2015). States and their institutions are often only capable of defining the informal carer and effectively working with him/her with difficulty. Specific reasons can be considered relevant: informal carers provide a significant amount of care for family members, most often children with a disability or parents of older age, but do not brag about it very much. It is therefore quite difficult to recognize them and subsequently analyse their behaviour and needs.

The importance of informal carers will continue to increase, and support for this group should also grow. As a result, informal carers may become important actors in designing social policy. Based on a survey, this text analyses the problems faced by carers. The purpose of this article is to use a research survey to establish the subjective impact of the provided care on the quality of life of informal carers, to assesses, from the viewpoint of informal carers, the institution of the long-term attendance allowance (long-term carer's allowance) as a tool for their support, accepted for the purpose of moderating the negative impact on their quality of life, and to identify additional social policy tools that could make provision of care easier from the carers' viewpoint.

1. Theoretical Background

The actual policies intended as support for various social groups differ in practice. Distribution of benefits on the one hand and burdens on the other hand, including the specific rules for their distribution, are of crucial importance. The mechanisms by which the individual social groups are provided support by the state are described in detail by Schneider and Ingram (1993, 1997, 2005) and Schneider *et al.* (2014) in their theory of social construction of target populations. This is based on the statement that

the human world is a social construct. Here, normative concepts and symbols play a more important role than objective representation of reality. The issues that are considered problems in the public space are not considered as such due to their significance, but rather due to how they are defined, or to the fact that they have become part of the political agenda. This is the author's answer to the question why some social issues are often not recognised; their importance is sometimes highlighted, but no concrete political steps are taken that would actually resolve the issues.

Schneider and Ingram define the key concept of the target population as people, groups or organisations whose behaviour public policy strives to change. The authors recognise four basic types of target population, and these are all monitored in order to establish whether society perceives them positively or negatively, and also to determine their degree of political power.

Table 1: Social constructions and political power: types of target populations

	Positive construction	Negative construction
Strong political power	Advantaged (the elderly, business, veterans, scientists)	Contenders (the rich, big unions, minorities, cultural elites, moral majority)
Weak political power	Dependants (children, mothers, disabled)	Deviants (criminals, drug addicts, communists, flag burners, gangs)

Source: Schneider and Ingram (1993)

According to a number of authors, informal carers may find themselves either in the group of the *advantaged*, along with the group they actually care for (this is considered a positive perception and affords great political power), or in the group of *dependants* (a positive construction and little political power). This indicates that the boundaries between individual populations are not always sharp, and the target population may often not be clearly separated from the rest of the population (Pierce *et al.*, 2014). There is no need for us to go into the *deviants* and *contenders* groups in more detail for the purpose of this article.

Schneider and Ingram (2007) state that the content of policy intended for the *advantaged* is more about benefits, rather than sanctions and prohibitions. Of all the groups, this group of people is also the best informed about what they are entitled to, and they are provided with many opportunities to participate in the creation of the policy. It is worthwhile for legislators and policy creators to support the *advantaged* group, because these people are capable of generating considerable political capital. Policies directed in support of this group will often be presented as a specific national interest.

Politicians also express interest in the group of *dependants*; however, the investment in this group will not be as great as the investment in the advantaged group, because dependants are usually not involved in generating wealth. Policies in support of them are often symbolic, for instance in the form of proclamations. Actual support is also often encumbered by burdens in the form of having to provide proof, increased bureaucracy and new obstacles (Pierce *et al.*, 2014).

Research into informal care often examines local issues with regard to the specific designs of policies of individual states. However, it can be observed from a number of individual research projects that the investigated areas of the lives of informal carers usually include mental and emotional support (*e.g.*, Jansen *et al.*, 2019), as well as legislative support and configuration of social policy, whether this concerns support in the form of benefits, or the importance of ancillary social services (*e.g.*, Brémault-Phillips *et al.*, 2016; Zhong *et al.*, 2020).

Eriksson *et al.* (2017) came to the conclusion that support of informal care must be provided on two levels. On a general level, *i.e.*, intended for a broad group of individuals providing care, and also on a highly individualised level, because every case of provided informal care is unique and faces different issues. According to Charles *et al.* (2017), this support is necessary, and the need for it will increase as the population of advanced countries ages. The capacity and resilience of family carers could be improved significantly through the use of various strategies, including help provided to carers in relation to self-identification (healthcare workers should help caregivers identify as such to gain access to resources that might help them maintain resilience), preparation of the next generation in providing care (the need to prepare younger adults for their potential future as family caregivers), and others.

In the field of general support, researchers around the world quite often notice deficiencies in the design of social policies and the related social services (see Horová *et al.*, 2021). According to a comparison by Průša *et al.* (2021), informal care is part of the so-called long-term social healthcare system, which has become a new branch of social security in a number of European countries, and something for which these countries were not prepared. This concept of long-term care has been developed into a number of different models in various countries. The main differences among these models are in the degree of importance of social aid and the degree of support in relation to providing security for individual social groups. Each research project on the topic of informal care is therefore affected by local conditions and the history of development of the social policy in the specific country. Czech informal carers and their support have been investigated from the aspect of the theory of social construction of target populations by Dobiášová and Kotrusová (2017). The researchers came to the conclusion that informal carers were perceived positively

as a group deserving support by public policies in the political and media space in the Czech Republic during the period 2005–2016. This also corresponds to the design of the long-term care policy in relation to this group. The social policy predominantly provided carers with advantages, but these were often only symbolic. However, a number of supporting measures were encumbered by burdens, for instance the manner in which the benefits were addressed and access to them was controlled. This means that the group of informal carers could be classified as so-called dependants.

The researchers examined the network of supportive services, psychotherapeutic services, community support (Eriksson *et al.*, 2017) and individualised care in the field of individual support (Schaepe and Ewers, 2018). Informal caring is an example of an intersection point between obligatory and natural solidarity and has a considerable impact on the quality of life of the carers themselves, the person being cared for and the people around them. Tomeš (2018) assumes that we can expect a rise in the need for home social services, which support, among other things, social communication and inter-generational communication. The goal of these services is to prevent isolation and loss of contact with the social environment. However, a number of researchers point out that this solidarity also causes some problems. If we consider family care from the aspect of the entire system of the closest interpersonal relations, then the need for the resilience of such relations also grows, regarding the arising obligations. According to Twigg (1994), this results in difficult situations. A close relationship evokes a feeling of obligation and responsibility. Family carers often exceed the limits of their strength, because they must also cope with situations that would be insoluble even for professionals (Baugman, 2018).

Verbakel (2014) confirmed the existence of links between providing care and welfare. It is evident that the significance of these links differs in individual countries. It depends on the generosity of funds for formal long-term care, consisting particularly of the availability and compensation of professional carers. The more funds available, the smaller the difference in welfare between carers and people who do not provide care.

In an international comparison, Verbakel (2014) pointed out the differences between the welfare of carers and persons who do not provide care. Using multiple regression analysis, he examined which aspects play a key role in the differing quality of the welfare of carers and non-carers across 18 countries (resources for formal care, familialism, religiosity, education, *etc.*). The gap between the welfare of carers and non-carers in the Czech Republic was identified by a coefficient of -0.22 , which means that carers in the Czech Republic rated their welfare on a ten-point scale on average 0.22 points worse than people who do not care for a close relative. Of the specific 18 countries, the Czech Republic was placed 13th in this aspect of the research; Czech informal carers therefore report quite a high degree of discomfort compared to the remainder of the examined countries.

The welfare of informal carers is most negatively affected in Spain, where the coefficient is -0.43 . On the other hand, research has shown that the gap between the welfare of informal carers and non-carers can also be positive, *e.g.e.g.*, in Norway the value of this coefficient is $+0.14$. We can also briefly mention the fact that thanks to her research, Verbakel proved that when a formal care (social services) sector of sufficient scope is established, there is a positive impact on the welfare of informal carers. On the other hand, it was not possible to prove that measures by the government which were intended to help this group directly had a positive impact. The measures were divided into financial aid, psychological aid and aid for a dynamic combination of work and care.

2. Situation in the Czech Republic

The most comprehensive data about the structure of informal carers in Europe is provided intermittently by the European Commission by way of research reports. According to the most recent document, carers who are close relatives provide over 80% of the total direct social care in EU countries. On average, informal carers form 17% of the population in the EU and 9% of the population in the Czech Republic. While slightly above half of those providing informal care in the EU are women, the ratio between the sexes is equal in the Czech Republic. The largest group of carers is aged between 35 and 64 years. A typical carer in the EU is mostly aged between 35 and 65 years and married; half of the informal carers are employed, half are not. Informal carers are most often recruited from among close relatives and more distant relatives of the person cared for, who is most often an old person (Zigante, 2018).

The amendment to Act no. 108/2006 Coll., on Social Services brought about crucial changes in the field of social security in the Czech Republic. The purpose of this act was chiefly to ensure a free choice of the manner of securing social services and a reversible transition from “passive dependent patient-hood” to “active client-hood”, and also to ensure the participation of the citizen (client and patient) when dealing with his social situation and start the process of de-institutionalisation and individualisation of care.

The adoption of the Act resulted in the introduction of a carer’s allowance, which became a response to the acknowledged fact that the state does not have sufficient competence or tools to guarantee the provision of social services, and the citizen thereby becomes entitled to draw social services at his/her deliberation if the specific terms are met.

The carer’s allowance replaced previous benefits increasing pensions due to helplessness and the contribution towards care for a close relative, and is still intended to cover part of the costs of the required care. To a large extent, the user of the benefit decides for himself/herself how to use the allowance.

However, termination of the contribution towards care for a close relative resulted in another issue: the carer's allowance was incapable of replacing it completely, as its provision cannot be applied to all cases of long-term care. For instance, an entitlement to a carer's allowance may not originate at all in relation to an injury or illness, when it is assumed that the state of health will improve significantly. In response to this, Bohuslav Sobotka's government (2014–2017) prepared the bill that amended Act no. 187/2006 Coll., on Sickness Insurance. Its most important element was implementation of time off for care and a long-term carer's allowance lasting for up to three months. According to the bill, the "purpose [was] to provide informal carers with the opportunity to provide care without fearing loss of their jobs" (MPSV, 2015). This measure has been in force in Czech legislation since 1 June 2018 and is funded by the sickness insurance system. Persons caring for a close relative who requires long-term care at home are entitled to a long-term carer's allowance. Carers may be wives/husbands, immediate relatives, registered partners, siblings, mothers/fathers-in-law, daughters/sons-in-law, nieces/nephews, aunts/uncles of the person being cared for, or another person living with the person being cared for in the same household (ČSSZ, 2018a).

The person receiving care is usually someone who has a serious health disorder which has required hospitalisation, during which medical care was provided for at least seven consecutive calendar days. The state of health of the person receiving care when discharged from hospital to the home environment essentially requires provision of long-term care for at least 30 calendar days (ČSSZ, 2018b).

In relation to this benefit, it applies that the supported period is a maximum of 90 calendar days. The long-term carer's allowance mentioned above is provided in the amount of 60 percent of the reduced daily assessment base per calendar day. The employer provides the employee with consent to be absent from work for the purpose of providing long-term care. The employer is not required to provide this consent if serious operating issues prevent this.

Interest in the long-term carer's allowance increases year-on-year. The government expenditures on this benefit have been increasing along with the numbers of long-term carer's allowance payment cases. As of 30 June 2019, the state paid out nearly 2 million euros; this amount exceeded 4 million euros at the end of 2019. However, this is still far below the state's estimate. According to initial calculations by the MPSV (Sněmovní tisk 1029/0). The time off taken by carers had an impact on the state budget of about 67.5 million euros per year.

The Czech Republic offers informal carers several types of benefit support. However, it can be assumed that none of these benefits completely satisfies the carers' requirements due to a great number of restrictions. The fact that the state does not give enough protection

to carers, who are also economically active and have their own jobs, can be considered a serious problem. The state has implemented the long-term carer's allowance, which is directly related to time off for providing care.

Table 2: Number of payments of long-term carer's allowance

As of	30 Sep 2018	31 Dec 2018	30 Mar 2019	30 Jun 2019	30 Dec 2019	30 Jun 2020
No. of men drawing long-term carer's allowance	205	734	569	1 001	1 001	1 308
No. of women drawing long-term carer's allowance	769	2 505	1 951	4 026	8 470	4 742
Total	974	3 239	2 520	5 127	10 939	6 050
Costs (in millions of EUR)	0.3448	1.1005	1.1005	1.8745	4.0352	2.5679

Source: Czech Social Security Administration (ČSSZ, 2020). Conversion of CZK/EUR as of 2 November 2020

3. Research Investigation

3.1 Research goals

The goals of the research were to:

- establish the subjective impact of provided care on the quality of life of informal carers;
- assess the institution of the long-term carer's allowance as a tool for supporting informal carers, which is accepted for the purpose of moderating any negative impact on their quality of life, from the informal carers' viewpoint; and
- identify additional social policy tools that would make provision of care easier from the carers' viewpoint.

3.2 Research questions

In order to achieve our goals, we formulated the following research questions:

Q1: Does provision of care reduce the quality of life of carers?

We based the research question definition on theoretical information, particularly the risks posed by providing care, which are highlighted by Twigg (1994). They emphasise the great

importance of the impact of provided care, if the carer feels that the negative impact of the care predominates over the positive impact, from his/her subjective viewpoint. It is true that if the carer suffers from major mental and health strain, the quality of the care he/she provides is endangered (Zigante, 2018).

Q2: Is the long-term carer's allowance a comprehensible benefit for recipients, and one which adequately compensates them for the burden they assume and motivates them to provide informal care?

Dobiášová and Kotrusová (2017) found that the design of social policies provides informal carers with a number of benefits, which are, however, mainly of a symbolic nature and also include a number of hidden burdens. We based the definition of Q2 on the main reasons for implementing a new benefit, which included the goal of “improving the quality of life of the people for whom the care is provided, and also the care providers themselves” (particularly with regard to physical and mental exhaustion, concerns regarding loss of employment, *etc.*). The benefit was intended to be used to improve inter-generational relations within the family (Sněmovní tisk 1029/0).

Q3: Is the quality of life of informal carers negatively affected by a lack of funds and the low availability of formal and respite care?

We based the definition of Q3 on a study by Verbakel (2014), which confirmed the existence of a relationship between the provided care and welfare, and on the expert opinion of authors engaged in the issue of long-term care, who mentions long-term insufficient institutionalisation of social work with informal carers in the Czech Republic (Hubíková, 2017; Kuchařová *et al.*, 2019).

3.3 Research methodology

Data were compiled in the Czech Republic from 1 September to 15 November 2019. The difficulties suffered by informal carers, which they subjectively perceive in relation to the care provided, were established.

Pre-selection of respondents took place in order to assure the greatest diversity of the target sample, using several methods:

- 1) Contacting non-governmental organisations engaged in supporting informal carers. Institutions were addressed with an e-mail containing an explanation of the purpose of the research, along with an accompanying letter from the researchers. The non-profit organisations forwarded the letter to informal carers.

- 2) Screening of members of the Médea Research panel (<https://research.medeia.cz/>). The database of respondents of the Médea Research agency was chosen for the selection of respondents. Members of the panel were addressed using a standardised procedure, with a request, explanation of the project and a link to a screening questionnaire. Members of the panel meeting the requirements of the target group of informal carers were asked to complete the main questionnaire.
- 3) The “snowball” method, executed according to a manual for carrying out selection using the snowball method (Hartnoll, R. *et al.*, 2003), and according to the standards of Biernacki and Waldorf (1981). The snowball method was shown to be a very effective method. The authors introduced the research and the option to participate in it via a number of specialised internet forums and Facebook groups. It became apparent that the respondents themselves mentioned the research in progress on these platforms. Many respondents subsequently contacted the authors and proceeded to complete the screening questionnaire, and then the main questionnaire, after their suitability was approved.

Over two thousand people took part in the screening, and the respondents were then selected. People who met the specified criteria were chosen to be respondents for the main questionnaire survey after answering the identification questions: age category 18+, cares for a relative who requires the help of another person due to long-term poor health and needs help to manage basic living requirements. Having provided care for at least the last month and at least 20 hours per week, exceeding normal family reciprocity, was a condition.

The questionnaires contained closed, semi-open and open questions. These questions consisted of a main research section containing interval scales, a socio-demographic section focusing on general information about the respondent, and a supplementary section explaining the reasons and goals of the research. Absolute anonymity was guaranteed; the data cannot be assigned to any specific person.

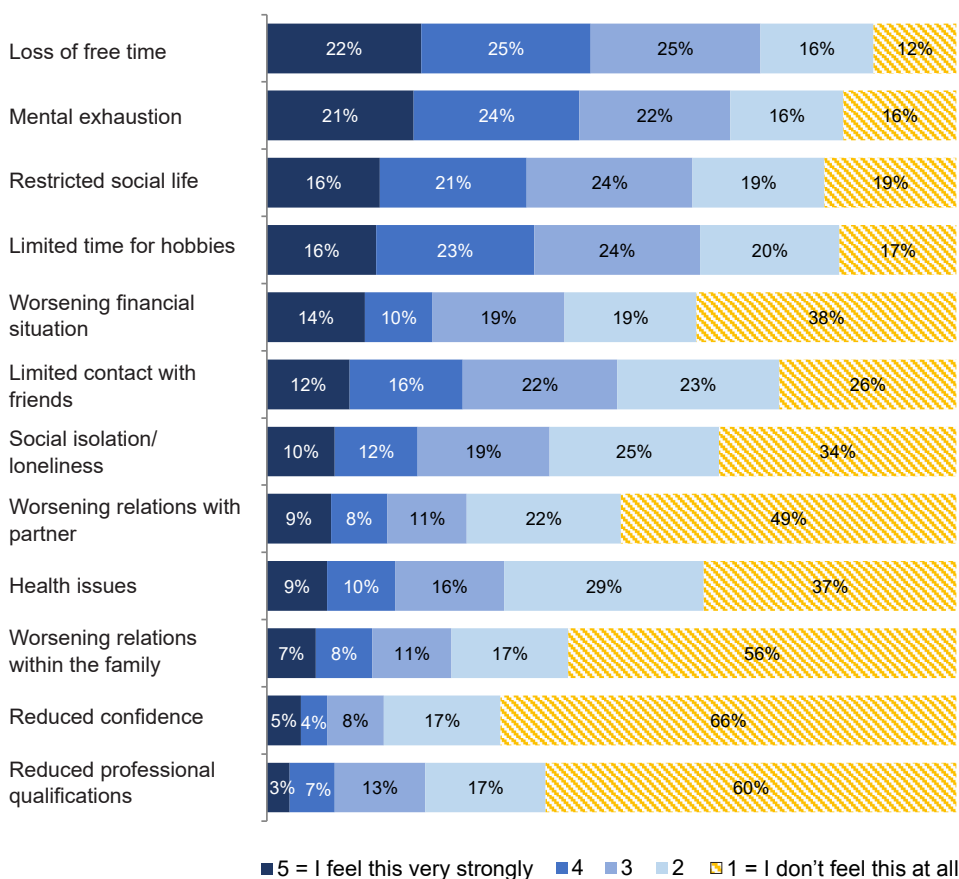
The CAWI (Computer Assisted Web Interviewing) questioning technique, using the internet, was used. According to method, the respondent completes an on-line questionnaire on the basis of a sent invitation, on his/her electronic device, without the assistance of the questioner. 283 relevant respondents passed through the screening process and 183 completed the main questionnaire, including optional open questions. This assured a representative sample, despite the fact of low penetration into the population and the fairly poor availability of the target group. The estimate of the number of informal carers, whose care exceeds normal family reciprocity, is not more than two percent of the population (ÚZIS, 2012).

3.4 Basic research results

3.4.1 Negative impact of care

The aspect of the negative impact of providing care, as felt subjectively by the respondents, was monitored. The respondent was not supposed to rate the care, but rather whatever had a negative impact on his physical or mental state. The assumption is that the less a carer is subjected to the negative effects of providing care, the better quality of care he/she provides. Respondents rated predefined negative effects of care that are typical for assisting professions – doctors, nurses, carers and social workers. These are related to role strain and burnout syndrome.

Figure 1: Perceived worsened quality of life



Source: Authors' own elaboration

Respondents feel a worsening of their quality of life most markedly due to loss of free time, mental exhaustion, restricted social life, limited time for hobbies and worsening financial situation. The aforementioned spheres can be considered serious (around 40 percent of carers feel this effect very strongly and strongly), and the first two are actually critical (nearly half of all carers feel this effect very strongly and strongly). Women feel the strain more often. While women most often mentioned mental and relationship issues (mental exhaustion, loneliness, worsening inter-personal relations with their partner and people around them), men most often mentioned worsening financial situation and loss of free time, as well as health issues.

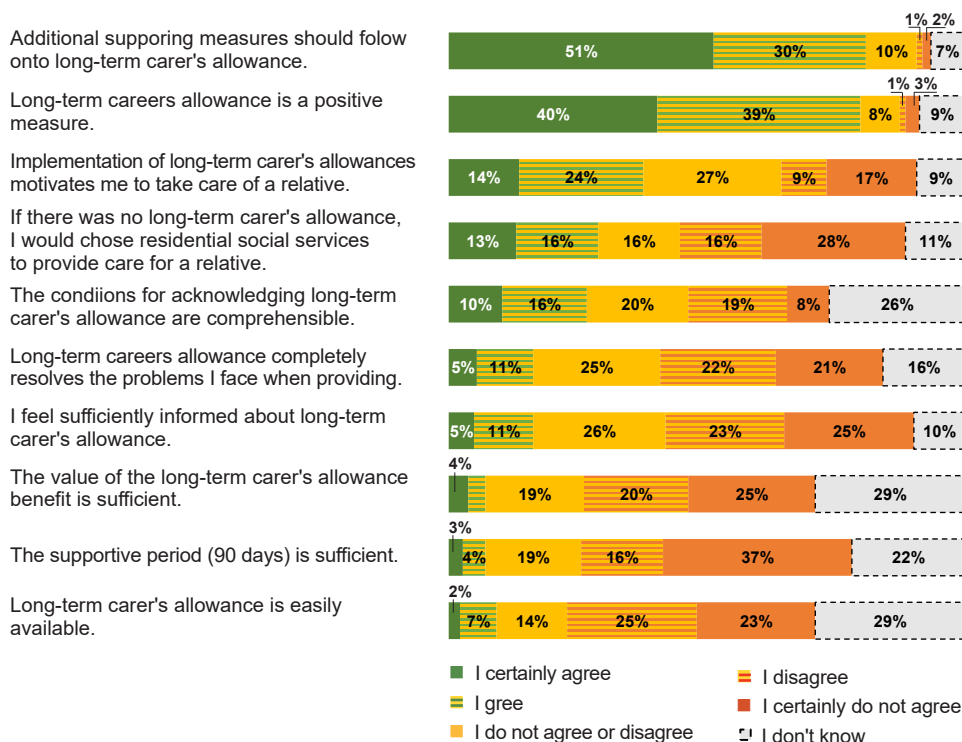
Respondents were also asked about the positive impact the provided care had on them. Subjective feelings of enrichment of oneself (a good feeling that one is able to help a relative) and the increased social prestige afforded by people around them (appreciation from people that they provide solidarity care) were introduced. The results were fairly unequivocal. Enrichment of oneself – advancement of oneself in self-evaluation – was refuted by 72 percent of respondents, while 85 percent of respondents denied an increase in prestige and improvement of their social image as perceived by people around them.

Respondents acquainted with the definition of the long-term carer's allowance, its legislative description and the requirements for providing this benefit, subsequently expressed their subjective degree of agreement with the statements applying to the long-term carer's benefit, using a linear scale. Even though most of the respondents did not utilise this instrument and did not plan to utilise it, they consider it a positive measure overall. However, it is not enough by itself and there should be additional measures linked to it. In the space for additional comments, carers mentioned care advisory centres, more involvement by the municipality/town social workers, and also education in the form of courses. Proposals for other types of benefits were also mentioned.

Some carers would welcome a contribution towards social services in the field of personal assistance, which would be a supplement to care benefits. This contribution should not be used as payment for the provision of social services, but rather as a reward for a professional carer for demonstrating basic care and providing instruction in it.

In other statements, informal carers expressed their disagreement more or less, whereby they pointed out the possible issues of disinterest in allocation of a carer's allowance.

Figure 2: Opinions regarding long-term carer's allowance



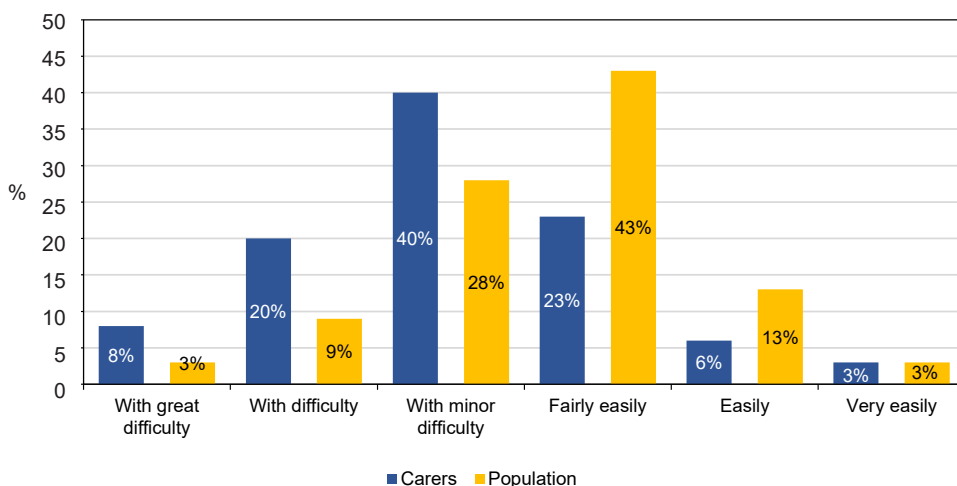
Source: Authors' own elaboration

3.4.2 Informal carers' income

In order to understand the situation of informal carers, we must know their incomes. Carers may receive a wage/salary for their activities if they remain employed while providing care. The carer's partner or spouse may contribute to the family budget, and the income of other family members may also play a role. Carers may also use their own savings. In our research, respondents provided information about their income – not only the amount, but also its significance for the running of the household.

The carer's own income, or the partner's income, is the most important household income. The use of savings is quite significant. The carer's benefit is the most important element of financial support from the state. On the contrary, the long-term carer's allowance is practically not drawn at all, so it is not of importance in the running of the household.

Figure 3: How carers make do with their income



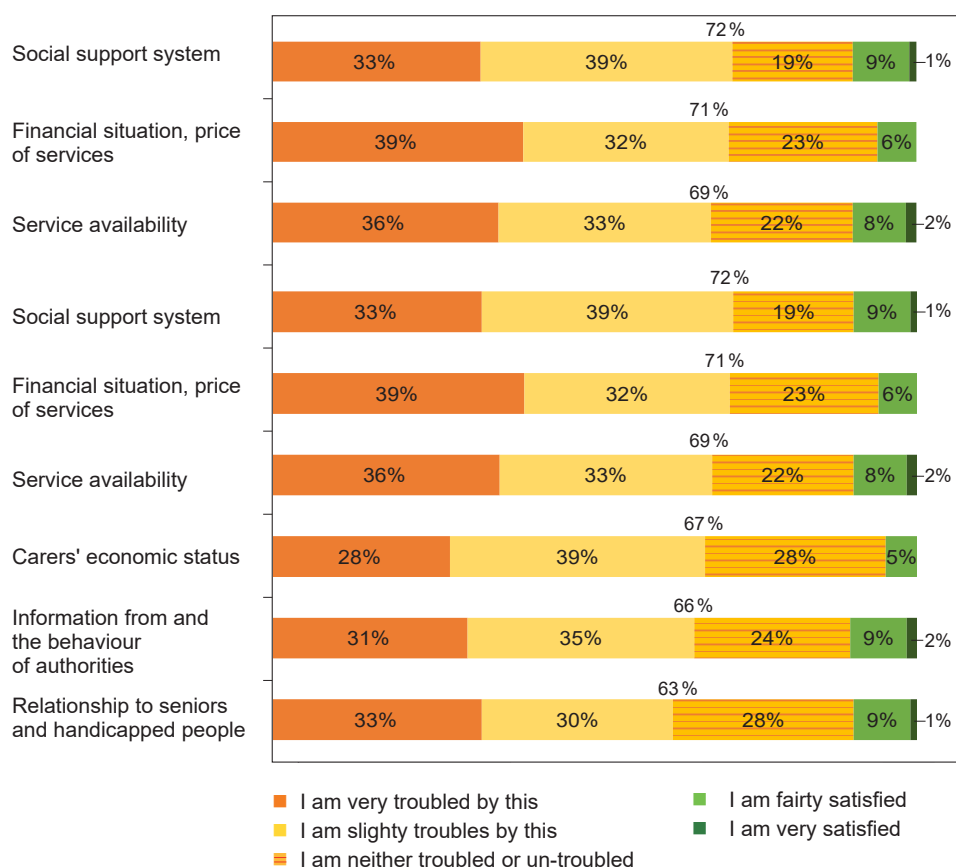
Source: Authors' own elaboration

Respondents do not mind that the care benefit is not the carer's income, but rather the income of the person being cared for (89%); however, they do consider it administratively demanding (65%). Respondents mention their doubts regarding incorrect assessment of the degree of dependence of the person being cared for (40%). They consider the period of time spent waiting for the issuance of a decision regarding the care benefit to be problematic, and they consider the amount of the benefit to be insufficient.

Most carers (68%) state that they only make do with their income with difficulty. The care provided has a direct economic impact on the quality of their lives. Carers make do with their income with more difficulty in general compared to the population (Median MML-TGI ČR, 1 + 2Q 2019). Forty percent of the carers' households make do with their income with minor difficulties. Carers with a secondary school education, without a school-leaving certificate or with a vocational certificate, make do with their income with great difficulty statistically significantly more often compared to carers with a school-leaving certificate. Carers from larger municipalities with 20,000 to 100,000 inhabitants make do with their income quite easily statistically significantly more often compared to carers from municipalities with up to 5,000 inhabitants.

Informal carers are the preferred source of provided care. The need for this care should be socially acknowledged and supported by the state. However, carers do not perceive this support, or perceive it negatively.

Figure 4: What troubles carers?

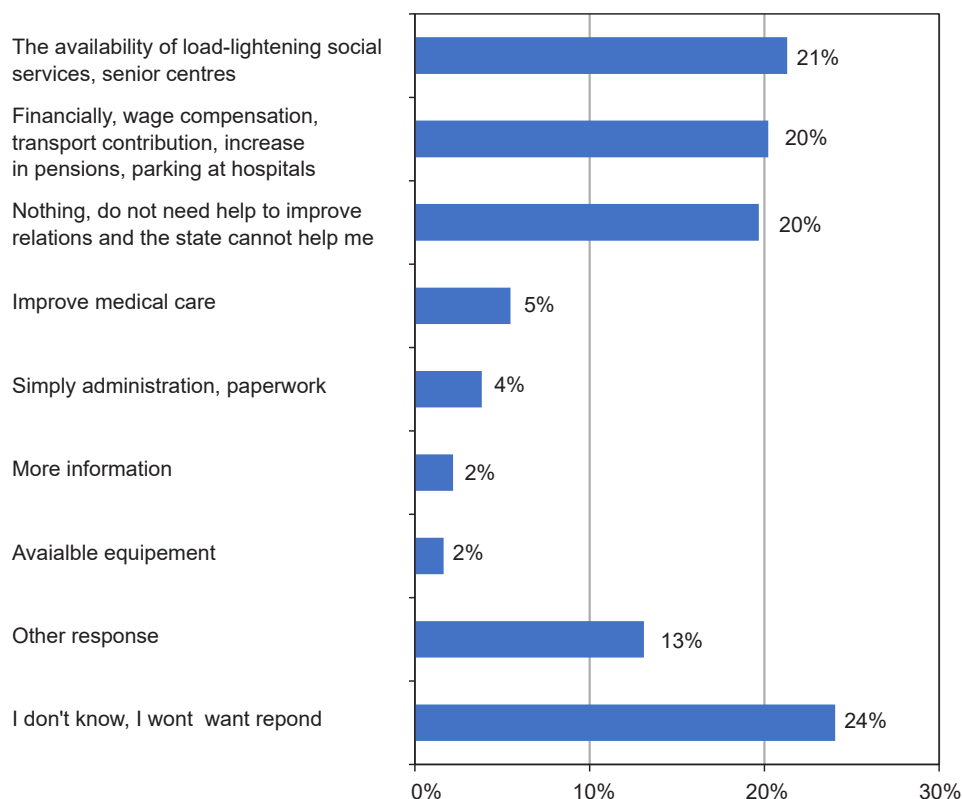


Source: Authors' own elaboration

Nearly two-thirds of carers are not satisfied with state support in the field of care. Nearly three-quarters of carers are troubled by the social support system, as well as their financial situation and the price of services. The remaining spheres also trouble approximately two-thirds of carers.

One-fifth of carers believe that the state should help improve the availability of relief social services and senior centres. One-fifth of carers agree with the opinion that the financial compensation of wages, contributions towards transport, increased pensions, benefits and parking at hospitals could help improve their situation.

Figure 5: What would help?



Source: Authors' own elaboration

4. Discussion

Our research indicates that provision of care results in a worse quality of life for a significant number of respondents (Q1). Respondents felt that the provided care had a negative impact on their mental and physical health. The most frequent effects of the provided care were loss of free time, mental exhaustion, limited social life, restriction of their own hobbies and a worsened financial situation. Most respondents felt mental exhaustion, while a third of respondents suffered from effects on their physical health. These negative effects are quite normal in assisting professions. They may even lead to burnout syndrome, mental difficulties of a long-term nature, and feelings of guilt due to failure to cope with the situation. The feeling of failure may exceed the carer's limits considerably. The carer

then blames not only himself/herself, but also the people around him/her. It seems that these subjective feelings lead to worsening relations in the family. Loss of free time complicates the establishment of new friendships. Loneliness does not allow interpersonal contact, and worsening relations with a partner increase the carer's feeling of isolation from normal life.

We can note that informal care for a close relative is often not provided on the basis of a voluntary decision. It is the result of external circumstances. A number of factors affect this result: the carer's income situation, the legislative basis and the conditions for provision of care. The institutional context must also be mentioned (Kuiper *et al.*, 2015). If the goal of a social policy is to assure high-quality social care, the parameters of satisfaction of informal carers must also be monitored, particularly the consequences of providing care. However, from a long-term perspective in the Czech Republic, this parameter is not monitored very closely by government institutions. As pointed out by Průša *et al.* (2021), the problem is of a systemic nature. There is a long-term lack of conceptual measures; the Ministry of Labour and Social Affairs and the Ministry of Health only deal with acute issues, and there are no efforts to prevent them.

Some authors (*e.g.*, Jeřábek, 2009; Twigg, 1994) mention that the negative impacts of provision of care cannot be perceived separately from the positive impacts. These may include a subjective feeling of mental enrichment, for instance, as well as increased social prestige afforded by people around them. In a Canadian study by Cohen *et al.* (2002), a total of 80% of the respondents stated that they feel at least one positive effect of providing care; they mentioned most often a feeling of pleasure, fulfilment or reward. If these positive effects predominate over the negative effects, a number of difficult situations can be resolved much more easily, and with greater objectivity. However, could this simply be a cliché? The proposal that long-term care mentally enriches the person providing the care was refuted by Valenta *et al.* (2010) in the Czech environment. In their research, which mapped the situation in the Capital City of Prague, half of the respondents stated that they did not agree with this statement. Half of the respondents also did not perceive any social acknowledgement from people around them. In our research, the number of respondents who disagreed was even higher: 72 percent of the respondents did not agree that the care they provide enriches them in some way mentally, and 85 percent of the respondents did not perceive any social acknowledgement from people around them. Even though these surveys are not fully compatible, they do indicate that the generally widespread impression that care provides enrichment cannot be accepted unequivocally. The negative effects of providing informal care can be mitigated by providing relief (respite) services; however, this is conditional on their availability and acknowledgement that they are necessary for the persons providing care.

We endeavoured to establish whether the long-term carer's allowance is a comprehensible benefit, which increases the quality of life of the persons providing care and motivates them to provide informal care (Q2). After more than two years in use, it is clear that it does not completely fulfil the concept that the Czech government promised in the causal report. The benefit was supposed to provide money for people who wish to care for a seriously ill relative at home. Only people whose relatives were hospitalised for at least 7 days are entitled to this benefit. It is the specific hospitalisation condition that cannot be met by a number of people. This means that, for example, families of oncologically ill or dying people are not entitled to this benefit if these people do not agree to hospitalisation, which objectively can no longer help the dependant. The long-term carer's allowance does not resolve the issues perceived by the carers. It can be assumed that it is of specific supplementary significance, but not of crucial importance. Quite a lot of carers feel that they do not have enough information about the benefit. They consider the maximum 90-day period during which they receive this support rather insufficient.

We have overwhelming evidence that this measure is considered positive and carers would like additional follow-up measures, we must also not ignore data that prove to us that, in this form, the long-term carer's allowance is considered a poorly accessible benefit with unsatisfactory duration as well as insufficient financial performance. The respondents' responses indicate that the allowance is another measure which classifies them in the group of *dependants* according to the theory of social construction of target populations, with little political power. The allowance is a positive measure, but is encumbered with a number of obstacles. The result therefore supports the findings of Verbakel (2014), who proved that governmental measures do not have a positive impact on informal carers. The question remains whether the poor design of this measure is at fault, as discussed above. According to Rievajová *et al.* (2017) and Sika *et al.* (2018), the design of the benefit should be assessed regularly. We are basing this assessment on the general theory of construction of social security benefits, in relation to which we are monitoring the personal extent, amount and duration, as well as the material content of the benefit. Attention must also be paid to demotivating elements. It is true that a benefit that is unattainable, or the construction of which demotivates people from using it, has no purpose in the social security system. On the other hand, it is also necessary to thoroughly analyse parametric changes that may appear minor at first glance. If respondents are convinced that 90 days is too short a period, what would the ideal duration of the long-term carer's allowance be? The fact that it is easier to alternate care in combination with employment, while returning to work is more complicated the longer a person spends out of work, is one reason for the current 90-day duration of this benefit. As an analogy – also in relation to the duration of this benefit – we can mention the issue of mothers returning to work following maternity (or subsequent

parental) leave, where we are forced to deal with similar difficulties. Making the benefit accessible to a greater number of people would also lead to other complicated issues. One of the most crucial of these is the impact on the job market itself. If the benefit was so accessible that a great number of people took long-term carer's leave, who would replace them? And this is not just an operating issue. Vostatek *et al.* (2013) highlighted the fiscal impact on the government and public budgets when informal carers leave the job market, creating a negative impact on the balance of public budgets. We are therefore convinced that if the benefit was further modified, it would be necessary to take into consideration not only the quality of life of both the recipient and the provider of the care, but also the potential impact on public finances and the job market. While the current 90 days could be the standard support period, taking into consideration the specific diagnoses of patients when acknowledging the benefit could be a potential compromise. The benefit could be acknowledged for a longer support period (for another three months) in the case of a specific diagnosis, for instance the aforementioned oncological, orthopaedic, neurological or other diagnoses, in relation to which extension can be objectively justified due to development of the patient's treatment and the assumed reduced need for care. In these cases, extension of the supported period could enable completion of the patient's treatment at home. We could also consider support mechanisms in addition to the framework of such potential extension, but these would not be funded from the sickness insurance system. Once again, we can mention the parallel of maternity leave, during which a monetary maternity benefit is initially provided for 28 weeks following birth, funded from the sickness insurance system. A parental benefit is provided subsequently from the state social support system.

Our research confirmed that the welfare of informal carers is negatively affected by the shortage of funds as well as the feeling of insufficiently developed social services (Q3). Informal carers participating in our research found it significantly more difficult to make ends meet on their monthly income compared to the average population. Two-thirds of the carers were concerned about their own economic status. The long-term carer's allowance, which should lead to increased financial stability and an improved quality of life of the carers, should provide a partial solution to this issue. However, most respondents consider the amount of the benefit to be too low. The research indicated that most respondents do not feel sufficiently informed about the benefit. The question is, therefore, whether they are aware of its actual purpose, which is to allow care for a close relative for the essential period, not to fully replace employment and income from employment. Comparison of the amount of the benefit to the amount paid as wages in the field of professional formal care is also not justified. Employees in the field of social services must meet strict qualification requirements and have a specific amount of experience. It is therefore impossible to expect that an amount corresponding

to the full-value wages of a social service worker will be acknowledged within the terms of the benefit. For example, Průša (2021) goes even further when seeking suitable forms of material welfare for carers. He proposes that this be based, for example, on the way Czech legislation regulates the standing of foster parents. According to Act no. 359/1995 Coll., on Legal Protection of Children, as amended, foster parents are entitled to the provision of a foster care allowance valued up to 30 thousand CZK (1,106 EUR as of 1 November 2020) for their activities when caring for a child who is the recipient of a care allowance on the 2nd, 3rd or 4th level of dependence. This reward is considered income from gainful activities for the purposes of both tax laws and social security and health insurance. It is evident that this proposal of support is much broader than the existing support for carers in the form of a long-term carer's allowance, and is intended for those cases that assume a longer or even permanent need for care at home, without the prospect of any significant improvement of the situation, unlike the carer's allowance. However, in this case as well, we must ask what effects such an increase in support would have on the job market and the government budget, and whether such a sum would be acceptable in the long term from the aspect of the quality of life of the carers.

During our research, we were also interested in the subjective viewpoint of carers regarding support by the government and the configuration of social policy. Informal carers are concerned about the configuration of the social security system as well as the availability of services or information from, and the behaviour of, the authorities. If a vast majority of carers are dissatisfied with the current social policy of the Czech Republic, or more precisely with state support in the field of informal care, then it is important to know carers' ideas about what would help them in their efforts. It is difficult for the state to intervene in a number of cases, for example with regard to disrupted relations in a family or unwillingness of people around. However, social policy can sometimes help, and it is true that this intervention should be included in any analysis of the development of long-term care policy (Łuczak, 2018). In addition, the social care system should be capable of responding flexibly to crucial events and the changing climate in society by reinforcing current instruments, and possibly by implementing new ones. In this regard, we must emphasise that research respondents would also welcome additional supportive measures, as they are inclined to support changes to the configuration of the social system. A full 20 percent of the respondents would, for instance, welcome greater availability of respite, or so-called relief services. However, research data are not sufficient to formulate a clear proposal for changes of such an extensive scope. It is necessary to investigate what troubles informal carers on the institutional level. To what degree do the government and its institutions affect the lives of carers and the persons being provided with care? How much does this affect the quality of the provided care? These are significant impulses for further

related investigations. However, based on the aforementioned findings, we would like to express our support to the voices of experts calling for a more thorough strategy for developing long-term care in the Czech Republic. These experts also criticise, to some extent, the not very systemic work by government institutions in relation to modification of social policy design with regard to the prognoses of further demographic development (Horová *et al.*, 2021; Průša *et al.*, 2021; Smetánková *et al.*, 2020; Vostatek, 2020; Wija *et al.*, 2019). In our opinion, the performed research indicates that this absence of a long-term, responsible approach by the government will not only cause issues in the future, but is already affecting the lives of informal carers.

Conclusion

Despite it being called informal, this type of care is very important. It has not only social benefits, but also a benefit for the whole economy. It reinforces family cohesiveness and inter-generational solidarity, and can stabilise the social system. It is an alternative to professional care in full-time facilities, when the condition of the patient allows, and when the patient's relatives are willing to provide this care. However, Czech public policy has ignored the issue of informal carers for many years, despite the voices of experts who have drawn attention to the need for conceptual and effective support for this social group for many years.

The goal of our research was to identify the subjective impact of the provided care on the quality of life of informal carers. We also established their opinion on the new institution of the long-term carer's allowance, which the government has presented as a tool in support of informal care, as a benefit and also as time off from employment for the purpose of providing care. We have also identified additional social policy tools that can simplify provision of care from the carers' viewpoint.

Our extensive research survey confirmed that provision of care leads to a reduced quality of life for a significant number of respondents – informal carers – and that the respondents feel the negative impact of caring for a close relative on their mental and physical health, as well as their financial situation. Other previous research has confirmed the relationship between the carer's welfare and the quality of care he/she provides. The situation of informal carers is fundamentally difficult and assumes personal service along with a willingness to sacrifice some of one's energy to care for a close relative. Therefore, it cannot be assumed that measures implemented in this field will result in full compensation for informal carers, as it is provided to qualified employees at full-time facilities or in the social care sector in general. However, if our goal is to increase the quality of informal care, obstacles that informal carers perceive as limiting or that

actually prevent them from carrying out their activities, ought to be removed. According to the research respondents, such obstacles include a complicated social support system, lack of availability of supporting services, the behaviour of public administration and authorities, and, in some cases, also the duration and amount of the provided financial support.

The Czech government introduced a new long-term carer's allowance benefit as one of the tools for direct financial support of informal carers. It is evident that, based on its construction, this benefit is intended to span a longer period for the required care for a close relative than the standard carer's allowance; however, it makes sense particularly in situations where it can be assumed that self-sufficiency will be regained in the foreseeable future. Our research findings should also be interpreted from this aspect; it only makes sense to take into consideration suggestions to optimise the long-term carer's allowance if these improve the situation of temporary informal carers, with the prospect that care will be terminated within the horizon of several months. One of the conclusions of our research is, paradoxically, that a tool other than the long-term carer's allowance must be chosen for supporting care for persons at home who are not self-sufficient in the long term or permanently, if development of home and informal care is wanted by Czech social policy. We could, for example, choose the path of effective innovation of the design of the entire social service system and effective functioning of full-time social service facilities. Further support, funded not from sickness insurance but from general taxes (state social support), could be considered from the aspect of benefits. In addition to directly supporting carers, it is therefore also desirable to work conceptually with the entire social service system by expanding formal care to create an environment assuring stable support for informal care. This is also related to the development of respite care and relief services in the Czech Republic, and the conducted research has also confirmed the need for these.

References

- Baugman, R. (2018). Employment in long-term care: The role of macroeconomic conditions. *B.E. Journal of Economic Analysis*, 18(4), 1–12, <https://doi.org/10.1515/bejeap-2017-0078>
- Biernacki, P., Waldorf, D. (1981). Snow-ball sampling: problems and techniques of chain referral sampling, *Sociological Methods & Research*, 10(2), 141–163, <https://doi.org/10.1177/004912418101000205>
- Brémault-Phillips, S., Parmar, J., Johnson, M. *et al.* (2016) The voices of family caregivers of seniors with chronic conditions: a window into their experience using a qualitative design. *SpringerPlus*, 5(620), <https://doi.org/10.1186/s40064-016-2244-z>
- COFACE (2015). *Intergenerational Solidarity*. [Cit. 2020-05-10.] Available at: http://www.sciencebuddies.org/science-fair-projects/project_mla_format_examples.shtml

- Cohen, C. A., Colantonio, A., Vernich, L. *et al.* (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17(2), 184–188, <https://doi.org/10.1002/gps.561>
- ČSSZ (2018a). *Dlouhodobé ošetrovné*. [Cit. 2020-06-15.] Available at: <https://www.cssz.cz/web/cz/dlouhodobé-osestrovne>
- ČSSZ (2018b). *Komu je dlouhodobé ošetrovné určeno a kdo novou dávku může čerpat* [Cit. 2020-05-15.] Available at: <https://www.cssz.cz/web/cz/-/komu-je-dlouhodobé-osestrovne-urceno-a-kdo-novou-dávku-muze-cerpat>
- ČSSZ (2020). *Přehled vybraných statistických ukazatelů z agendy ČSSZ 2018, 2019 a 2020*. Praha: Česká správa sociálního zabezpečení.
- Dobiášová, K. and Kotrusová, P. (2017). Zaslужují si neformální pečující větší péči? Změny v sociální konstrukci neformálních pečujících a designu politiky dlouhodobé péče v ČR. *Sociální práce / Sociálna práca*, 17(6), 22–41.
- Eriksson, M. Wennerberg, M. M. T.; Lundgren, S. M.; Danielson, E. (2017). Self-Employed in Caregivinghood: The Contribution of Swedish Informal Caregivers Environmental and Contextual Resistance Resources and Deficits. *Societies*, 7(3): 1–19, <https://doi.org/10.3390/soc7030019>
- Geissler, H., Holeňová, A., Horová, T. *et al.* (2015). *Výstupní analytická zpráva o současné situaci a potřebách pečujících osob a bariérách pro poskytování neformální péče v ČR*. [Cit. 2020-07-10.] Available at: https://socialnipolitika.eu/wp-content/uploads/2018/11/1_V%C3%BDstupn%C3%AD-analytick%C3%A1-1-zpr%C3%A1va.pdf
- Greenhaus, J., H., Beutell, N. J. (1985) Sources of conflict between work and family roles. *Academy of Management Review*, 10, 76–88, <https://doi.org/10.5465/amr.1985.4277352>
- Hartnoll, R. *et al.* (2003). *Průručka k provádění výběru metodou sněhové koule – Snowball Sampling*. Praha: Úřad vlády ČR. 1. vyd. ISBN 80-86734-08-0.
- Holmerová, I. (2004) *Eurofamcare National Background Report for the Czech Republic*. [Cit. 2020-07-14.] https://www.ukr.de/extern/eurofamcare/documents/nabares/nabare_czech_rc1_a4.pdf
- Horová, J., Bártlová, S., Hajduchová, H., *et al.* (2021) Mezinárodní přehled podpory neformálního (rodinného) pečovatelského. *Sociální práce / Sociálna práca*, 21(2), 20–43.
- Hubíková, O. (2017). Otázka ustavení rodinných pečujících jako cílové skupiny sociální práce. *Sociální práce / Sociálna práca*, 17(6), 5–21.
- Charles, L., Brémault-Phillips, S., Parma, J. *et al.* (2017). Understanding How to Support Family Caregivers of Seniors with Complex Needs. *Canadian geriatrics journal: CGJ*, 20(2), 75–84, <https://doi.org/10.5770/cgj.20.252>
- Jansen, L., Lieze, E., Vanwing, A., Schoenmakers, B. (2019). You never walk alone: An exploratory study of the needs and burden of an informal care group. *Health Soc Care Community*, 27, 375–382, <https://doi.org/10.1111/hsc.12655>

- Jeřábek, J. (2009). Family care for seniors as a 'labour of love' – new arguments. *Sociologický časopis/Czech Sociological Review*, 45(2): 245–262, <https://doi.org/10.13060/00380288.2009.45.2.03>
- Knapp, M., Bauer, A., Perkins, M., Snell, T. (2013). Building community capital in social care: Is there an economic case? *Community Development Journal*, 48(2), 313–331, <https://doi.org/10.1093/cdj/bss021>
- Kuchařová, V. et al. (2019). *Česká rodina na počátku 21. století: životní podmínky, vztahy a potřeby*. Praha: Sociologické nakladatelství (SLON) v koedici s Výzkumným ústavem práce a sociálních věcí. Studie (Sociologické nakladatelství). ISBN 978-80-7416-333-3.
- Kuiper, J., Zuidersma, M., Voshaar, R. C. O., et al. (2015). Social relationships and risk of dementia: A systematic review and meta-analysis of longitudinal cohort studies. *Ageing Research Reviews*, 22, 39–57, <https://doi.org/10.1016/j.arr.2015.04.006>
- Łuczak, P. (2018). How do pension and healthcare systems frame long-term care policy? Comparison of the Czech Republic and Poland. *Social Policy Administration*, 52(7), 1396–1409, <https://doi.org/10.1111/spol.12399>
- MPSV – Ministerstvo práce a sociálních věcí ČR (2015). *Neformální pečovatelé – nenahraditelní, ale nedocení*. [Cit. 2020-08-10.]. Available at: <https://socialnipolitika.eu/2015/06/neformalni-pecovatele-nenahraditelni-ale-nedoceni/>
- Parliamentary Press (Sněmovní tisk) 1029/0. Důvodová zpráva k zákonu, kterým se mění zákon č. 187/2006 Sb. o nemocenském pojištění, ve znění pozdějších předpisů, a další související zákony.
- Průša, L. (2021). *Dlouhodobá péče nejen v České republice*. Tábor: Asociace poskytovatelů sociálních služeb ČR. ISBN 978-80-88361-09-1.
- Rievajová, E. et al. (2017). *Sociálne zabezpečenie*. Bratislava: Ekonom. ISBN 978-80-225-4381-1.
- Schaepe, C., Ewers, M. (2018). I see myself as part of the team – family caregivers contribution to safety in advanced home care. *BMC Nurs*, 17(40), <https://doi.org/10.1186/s12912-018-0308-9>
- Schneider, A., Ingram, H. (1993). Social Construction of Target Populations: Implications for Politics and Policy. *The American Political Science Review*, 87(2), 334–347, <https://doi.org/10.2307/2939044>
- Schneider, A., Ingram, H. (2005). *Deserving and Entitled: Social Construction and Public Policy*. Albany: State University of New York Press.
- Schneider, A., Ingram, H., DeLeon, P. (2014). Democratic Policy Design: Social Construction of Target Populations, in P. Sabatier, C. Weible, ed. *Theories of the Policy Process*. 3th edition. Boulder: Westview Press.
- Sika P. et al. (2018). *Sociálna politika*. Bratislava: Ekonom. ISBN 978-80-225-4544-0.
- Šimoník, P. (2015). *Podpora neformálních pečovatелů, závěrečná zpráva z výzkumu*. [Cit. 2020-04-10.] Available at: https://socialnipolitika.eu/wp-content/uploads/2018/11/2_Z%C3%A1v%C4%9Bre%C4%8Dn%C3%A1-zpr%C3%A1va-z-dotazn%C3%ADkov%C3%A9ho-%C5%A1et%C5%99en%C3%AD-mezi-neform%C3%A1ln%C3%ADmi-pe%C4%8Dovateli.pdf

- Smetánková, R. et al. (2020). *Analýza segmentu sociálních služeb*. Tábor: APSS ČR. ISBN 978-80-88361-08-4.
- Tomeš, I. (2018). *Povinná sociální solidarita*. Praha: Karolinum. ISBN 978-80-246-3835-5.
- Twigg, J. (1994). *Career Perceived: Policy and Practise in Informal Care*. Buckingham: Open University Press. ISBN 978-0335191116.
- ÚZIS (2012). Poskytování a financování dlouhodobé péče v zemích OECD (III). [Cit. 2020-10-10.] Available at: <http://www.uzis.cz/index.php?pg=record&id=5215>
- Valenta, M., Michalík, J., Grofková, I. et al. (2010). *Kvalita života osob pečujících o člena rodiny se vzácným onemocněním – zpráva z výzkumu*. Olomouc: IRVS. Available at https://web.archive.org/web/20170313010639/http://vcizp.cz/doc/2010/KVAL_ZIV_VZ_ONEM_IRVS.pdf
- Verbakel, E. (2014) Informal caregiving and well-being in Europe: What can ease the negative consequences for caregivers? *Journal of European Social Policy*, 24(5), 424–441, <https://doi.org/10.1177/0958928714543902>
- Vostatek, J., Průša, L., Krebs, V. et al. (2013) *Financování a nákladovost sociálních služeb: pobytové a terénní služby sociální péče*. Tábor: Asociace poskytovatelů sociálních služeb ČR. ISBN 9788090466876.
- Vostatek, J. (2020). Modely financování dlouhodobé péče. *Fórum sociální politiky*, 14(6), 2–13.
- Wija, P., Bareš, P., Žofka, J. (2019). *Analýza sociálních a zdravotních služeb dlouhodobé péče v ČR*. Praha: Institut pro sociální politiku a výzkum. ISBN 978-80-907662-2-8.
- Zhong, Y. Wang, J., Nicholas, S. (2020). Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden. *BMC Geriatr*, 20(3), <https://doi.org/10.1186/s12877-019-1403-9>
- Zigante, V. (2018) *Informal care in Europe: Exploring formalisation, availability and quality*. 2018. Brussels: European Commission, Directorate-General for Employment, Social Affairs and Inclusion. ISBN: 978-92-79-86583-1, <https://doi.org/10.2767/78836>