INFORMAL FAMILY CARERS' NEED FOR STATE-GUARANTEED SUPPORT. WHAT ARE THE IMPLICATIONS FOR SOCIAL POLICY?

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ABSTRACT: The article uses an interpretive and qualitative framework to analyze elderly care policy with a focus on the instrumental effectiveness of this policy. The framework of the research offers an understanding of informal family carers' need for formal support at the level of social policy measures. The micro-level inquiry – interviews with informal family elderly carers –, which both reveals the caregiver burden and evaluates the latter's need for formal (social policy) support – demonstrates how qualitative inquiry can inform about shortages associated with this policy. The findings of the research suggest that formal support for informal family caregivers in Lithuania is not adequate for their multifaceted care burden and should be therefore developed to encompass both direct and indirect support measures.

KEYWORDS: *informal family care, care burden, need for formal support, social policy measures, qualitative research*

INTRODUCTION

The extent and type of formal support (in this article understood as stateguaranteed support) available to informal caregivers largely depends on the extent to which the public elderly care system is relied upon, and how much the commitment of informal carers is promoted (Cooney–Dykstra 2011). Looking

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further ahead to forecast demographic changes (such as rapid population ageing and pressure on social security systems thereto closely related, the active participation of women in the labor market, and the increasing prevalence of smaller family units), many authors suggest that the role of informal care will substantially grow in the future (Jegermalm 2004; Colombo et al. 2011; Kehusmaa et al. 2013; Pickard 2015). Colombo et al. (2011) found that one-third of people aged 50 and over provide personal care for an elderly family member. According to a Eurofound survey (2020), 12% of individuals aged 18 and over care for one or more disabled or infirm family members, neighbors or friends, of any age, more than twice a week in EU countries. Taylor-Gooby (2004) qualifies this situation as a "new social risk" that threatens the wellbeing of carers unless they are provided with adequate support from the state.

Therefore, it is unsurprising that the topic of informal care has become such a demanding research field, addressing issues like the peculiarities of informal care work (Jegermalm 2005; Bettio-Verashchagina 2010; Triantafillou et al. 2010); health- and personal-freedom-related problems faced by informal carers (Cassie-Sanders 2008; Elsa 2014; Puig et al. 2015); the unattractiveness of the care sector and difficulties in attracting and retaining staff (Rubery et al. 2011; Franklin 2014); and the impact of family carers' responsibilities on their careers and stress at work (Neal-Wagner 2002; Dow-Meyer 2010; Trukeschitz et al. 2013; Heger 2014). There is a separate research field that focuses not only on support for informal caregivers in general within the context of demographic change (Jegermalm 2004; 2005), or states' intentions to reduce spending on social security (Kehusmaa et al. 2013, Chari et al. 2015), but which also more deeply analyzes the factors that attract informal carers to take on care responsibilities (Groenou-De Boer 2016), as well as evaluates support for informal carers within all systems of social policy measures (Triantafillou et al. 2010). The importance of research on the latter has increased in the context of the COVID-19 pandemic. Rodrigues et al. (2021) and Bergmann and Wagner (2021) have pointed out the vulnerability of informal carers to the consequences of the pandemic and noted the impact of the pandemic on the prevalence and intensity of informal care. The burden of informal caring has increased during the pandemic due to prolonged periods of social distancing and general regulations aimed at closing down some local services and community facilities for the period of the pandemic (Mak et al. 2021; Rodrigues et al. 2021).

The topic of informal care is attracting increasing attention in Lithuania too, first of all due to traditional family ties which are still rather strong in Lithuania, and the constitutional duty of children to take care of their parents in old age. Moreover, Lithuania is outstanding for being a country where the rate of population

ageing is one of the fastest in the EU, and the level of emigration of the workingage population is very high. In Lithuania, over the period from 2000 to 2020, the proportion of the population aged 65 years or more grew from 13.7 percent to 19.9 percent (Eurostat, Population: Structure indicators). According to Statistics Lithuania, in 2018, 32,206 persons emigrated from Lithuania, of whom 85.4 percent were aged 15-59 years (Population of Lithuania 2021). Obviously, such a demographic situation creates uncertainty about the availability of informal care resources for the elderly in the future. At the present, in Lithuania, there is a large scale of informal care. This is due to both prevailing traditions of family care and the fact that the formal care sector is lacking capacity and private services are expensive. Therefore, family members, mostly women, take care of the elderly or disabled family members. Although it has been acknowledged that informal care constitutes a cornerstone of elderly care, and that the role of informal care will remain very important in Europe (Zigante 2018), this is not reflected in Lithuanian social policy. Lithuanian systems of personal social services, employment policy, and health care policy involve some separate state support measures for persons caring for elderly family members. However, in general, in social and health policy documents informal care is not treated as an integral part of elderly care policy, and informal family carers are left in the shadow of this policy. National strategies, such as The Action Plan for Promoting Healthy Ageing in 2014-2023 (Republic of Lithuania 2014), The National Strategy for Overcoming the Consequences of Ageing (Resolution of the Government of the Republic of Lithuania 2004) support action aimed at improving the quality and accessibility of elderly care services for users and improving their quality of life; however, they say nothing about support for informal carers. On the other hand, Lithuania is not the only country in the EU where the need for the support of informal family carers is an issue. Courtin et al. (2014) notes that in most EU countries informal care support policies are at an early stage of development, and countries still do not have any practices for identifying informal carers' needs for support. The present article analyses findings obtained from interviews with informal family carers for the elderly that were conducted in Lithuania, seeking to reveal informal family carers' need for formal support, while looking through the lens of understanding the care burden and structure of social policy measures. In this article, informal family carers are defined as individuals - spouses/partners, children, and other family members - who provide elderly care services on an unpaid basis and without a contract. Qualitative inquiry has become a promising strategy for social policy research, helping to create a more nuanced understanding of policy, and leading to more focused and in-depth investigations of policy implementation (Smit 2003:4). Thus, the aim of the article is to evaluate if the objective care burden of carers is covered by social policy support measures, and whether these measures address the subjective care burden.

CONCEPTUAL FRAMEWORK

Two concepts – the concept of the *care burden* and *the framework of informal carer support* – will be used when explaining the categories developed from qualitative data in this paper. The concept of the care burden allows for the structuring of the caregiver burden in psychological, emotional, social, and financial terms (Chou 2000) or for distinguishing between the objective and subjective burden (Montgomery et al. 1985). Objective care burdens are defined as perceived infringements or disruptions of tangible aspects of a caregiver's life (e.g., restrictions on caregivers' vacations due to care responsibilities, and the amount of time carers have for their own use). In other words, the objective burden refers to the time burden and the number of activities for which a carereceiver requires assistance (Tough et al. 2020:2), whereas the subjective care burden is understood as caregivers' attitudes about care, or emotional reactions related to care-giving experiences (Montgomery 2002; Montgomery et al. 1985). The subjective burden is a state characterized by fatigue, stress, perceived limited social contact and role adjustment, and perceived altered self-esteem (del-Pino-Casado et al. 2018:3). The objective and subjective care burden are closely related (Bastawrous 2013).

Another concept used in this article – *framework of informal carer-support* policy measures – was taken from Triantafillou et al. (2010). This framework was chosen because of two main considerations relevant to our study. First, this framework permits the classification of support measures through the lens of social policy, and second, it makes it possible to see the links between formal and informal care. *Specific policy measures*, according to Triantafillou et al. (2010), are those that target informal carers to help them undertake their caring tasks. These measures may not require the input of formal carers (specific direct measures) or may entail a 'hand-in-hand' approach between formal and informal carers (specific indirect measures). *Non-specific measures* are those that target informal carers, while *indirect measures* target the older person (Triantafillou et al. 2010).

METHODOLOGY OF RESEARCH

Data collection method and characteristics of informants

The article discusses the results of qualitative research conducted in the form of semi-structured interviews with informal family carers. The interviews were conducted as part of a project funded by the Research Council of Lithuania.² The interviews seek to disclose how informal family carers perceive that elderly care policy affects them in terms of caregiving activities, and what difficulties in care-related responsibilities they experience.

Nineteen interviews with informal family carers were conducted from June to August 2016. The contacts of the informants were obtained through nongovernmental organizations and municipal social service offices (using the snowball principle). Respondent selection was based on three main criteria: the respondent should be caring for an ageing family member (spouse, parent, other relative) at home; the care recipient should be receiving cash-for-care benefits (meaning that the care recipient has high care needs); and the care recipient should not receive public home-help services. In addition, when selecting the interviewees, account was taken of the employment status of informal carers (with a view to including working and nonworking carers). As a result, 17 women and two men were selected for the research: 13 informal carers provided home care for their parents, and two informal carers each looked after a spouse, parent(s)-in-law, or grandparent(s). The interviewees were aged from 40 to 70, and the average age was 55. Of the 19 participants, seven reported to being in full-time employment, three were employed on a part-time basis, and the remaining participants reported being unemployed or retired. The sample of informants helped reveal the many-sided needs of carers, as various researchers claim that informal carers' need for support is related to caregivers' age and sex (Montgomery et al. 2016), education and financial situation (Tough et al. 2020), and employment status (Arksey 2002).

Strategy of data analysis

The data were analyzed using a literal transcription strategy, and conventional content analysis. Following the conventional content analysis approach, we used a strategy of inductive category development involving three phases: preparation,

² The project "Transformation of elderly care sector: demand for services and labour force and quality of work" was implemented between October 1, 2015 and April 30, 2017 (No. GER-012/2015).

organizing, and reporting (Schreier 2014). Accordingly, the interview data were divided into subcategories and then grouped into categories which were finally used to create the themes.

Ethical considerations and informed consent

The research was conducted in compliance with the main principles of research ethics: respect for individuals' privacy, confidentiality, and anonymity, an attitude of beneficence and avoidance of harm to the research subject, and justice. Research participants were informed about the purpose of the research. They were also provided with the broad explanation that the information received during the interviews would be used for scientific purposes and for making proposals intended to improve social policy in Lithuania. The interviewees' decision to participate in the research was voluntary, and the interview material has been cited and coded to ensure informants' confidentiality. Ethical approval for this research was obtained from the Ethics Commission of the Lithuanian Social Research Centre.

EMPIRICAL FINDINGS

Two themes referring to the formal support needs of informal family carers and the care burden that is experienced were chosen for the analyses in this article. The first theme concerns difficulties with day-to-day routines of informal family care, and the second expresses carers' need for formal support.

"You are completely excluded from life"

Difficulties with day-to-day routines identified during interviews with informal family carers for the elderly support the assumption that caring for a loved one at home is both a psychologically and physically demanding activity. The analyses of interviews revealed that the infinity of caregiving tasks competes for time and energy with other duties, such as paid work, and for activities that are enjoyable, such as going to the theatre. Also, the informal family carers we interviewed complained about their own physical health problems related to constant lifting or bathing the person they care for, and about psychological health problems related to emotionally demanding care work. Moreover, informal family carers were unsatisfied both with the compensation for nursing supplies and transport costs, as this represents an additional financial burden, and with the lack of information about nursing-related issues. The bureaucracy involved in the process of identifying care needs for cared-for persons was also mentioned in the list of difficulties (see Table 1).

Difficulties of informal family caregivers	Supporting quotes
Plenty of work related to the hygiene-related and daily living needs of the person being cared for	"First, what we do: get up, wash, comb, eat, give medicine, then massage, then relax, sit, then again – food, medicine, again the procedures and so on; then in the evening, in the evening, again the same – dinner, then massage again, then there are still days when you need to wash everything." (Interview 03)
Reconciling caregiving tasks and paid work	"You just get tired of that reconciling, and that constant thinking. If you are at work, you are here and there [but at home], you can't be like that – if you are at work, then at work, if you are at home, then at home, you can't be in two places all the time and, just, [it is] psychologically [challenging]." (Interview 09)
Reconciling caregiving tasks and personal life	"There's none. None. I'm telling you, eight years of my life just thrown away []. I mean, there's no [private] life and you can't go out anywhere, you simply can't []. You are completely excluded from life, [going] nowhere." (Interview 16)
Unsuitable housing and environment for a disabled person	" when an ambulance arrives, they have problems taking the patient. They say "ask some men for help." Then you knock at each neighbor's door looking for males able to help carry the person. Because sometimes only a nurse arrives and she is not always able to carry them, and this is the situation we have." (Interview 14)
Health-related problems	"I am an oncological patient myself, and for me in general it's hard to do everything, because I have had three surgeries, I find it difficult to lift her when needed, I hire [people to help]." (Interview 09). "And then I try to deal with myself as much as possible, although one's face very often betrays that it is not very easy." (Interview 18)
Emotional and psychological fatigue, tension	"You won't say it's hard work, but it's psychologically hard. [] There were all kinds of emotions. [] good and bad, and not so bad []" (Interview 06)

Table 1. Difficulties experienced by informal family caregivers related to their care activities

Additional financial burden	"The second thing, it costs a lot of money, even though there is that nursing [care allowance], he gets it, but I work for 'thanks,' let's say. [] The patient needs a lot more, and what is very bad is that the expanding [range of] medicinal products [that are required is] not reimbursed []and what is bad is when you go to the hospital, you don't get diapers, you no longer are prescribed them, and the hospital does not give them. And sit as you want - [if you] have money, [you can] buy, [if not] [you] do not buy." (Interview 10)
Lack of information about nursing-related issues	"There is a lack of information, a great lack []. There is a lot of information about violence for sure, but when it comes to diseases, the sick, especially old people – there is a great lack, I don't know." (Interview 13)
Bureaucracy in the process of identifying care needs for cared-for persons	"First of all, that's what, first of all, it's clear that caring at home, it takes time – all those walks to the doctors, a lot of time, as for a working person, it's just very difficult, because it's the biggest bureaucracy there, from the beginning, just handling the same nursing, the same paperwork, no one is there with you []." (Interview 15)

The quotations provided in Table 1 show that the informal family caregivers experience plenty of difficulties in many areas of life that may be related to the objective care burden. Moreover, the interviews results also revealed that caregiving work has an emotional and psychological impact on informal caregivers' lives too. Informants mentioned feelings and states of mind such as fatigue, tension, helplessness, and stress when trying to combine paid work with informal care or personal life, which – looking at the research of Montgomery (2002), Montgomery et al. (1985), del-Pino-Casado et al. (2018) – can be qualified as subjective care burdens.

What would help to reduce worries that are a part of everyday life?

Research on the experience of informal family caregivers revealed not only the burdensome nature of providing care activities for the elderly, but also indicated informal family carers' need for various types of support, which they expected to receive through state social policy.

The informal family carers who were interviewed highlighted the importance of measures related to the facilitation of their daily duties; in particular, such as housing/accommodation and adaptation to meet the special needs of the person being cared for (for example, staircases, the installation of lifting mechanisms, the replacement of bathtubs with wheelchair access, etc., meals on wheels, and special transportation services). There is insufficient access to transportation services in emergency cases, and reimbursement for transport costs is minimal:

What we need most of all, as I say, is an addition to all those transport costs. It's not enough. The amount they compensate per month is not enough for anyone. Let's say, one month you may not need transportation, maybe, but what if you have to go three or four times per month? (Interview 10)

Both the need for more information about care and training for carers and advertising stands and leaflets, as well as specialist consultations at home or nursing courses were mentioned:

[...] there must be something, some more information ... it might be even some special day or hour when carers would be trained during some special courses. Something that would be helpful. From time to time, one day a month [...]. (Interview 11)

In order to balance care and work, research participants referred to additional rest days - i.e. the possibility to take one or two days off from work per month without losing their salary for these days. With regard to the possibility of taking at least a short break from routine care duties, the informants identified the problem of the accessibility of respite care:

But I don't ask for them [days off/respite care]. I don't need it. You have to pay for it. But it is also a municipal institution. I've made inquiries. I also wanted it. Because here, although you are not imprisoned, the feeling is similar. Sometimes you want to go, well, to the cinema or theatre. But you can't. And then you stay the whole winter at home. So what? It's nothing. Or if you need a such service, you have to pay quite a lot for having a respite worker from an agency to let you go out, for example. (Interview 01)

Caring for an elderly person at home is physically and psychologically draining work, and informal family carers lack peace of mind, so the interviewees also admitted that they need psychological assistance to ...

[...] learn how to balance all those things, how to push away the worries that are part of our everyday lives. And if it [caring responsibilities] lasts too long, who knows what can happen then.

Informants indicated that higher levels of compensation for nursing expenses and higher levels of financial assistance for nursing supplies, particularly diapers, would be very helpful:

Look, they compensate you for one diaper, but you have to change three or sometimes four diapers a day. This means you have to pay full price for the rest you need. (Interview 01)

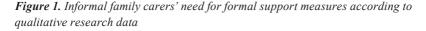
The formal procedure of establishing the need for care and being awarded benefits is a heavily bureaucratized process, creating additional care burdens for informal family caregivers:

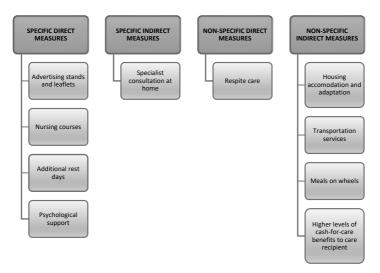
In fact, this bureaucratic indicator related to processing documents should be simplified in essence. I've heard a lot of stories about the service for the disabled, and the numerous evaluations required there.... That the institution for disabilities and capacity for work, the disability office, does evaluations very subjectively, on the basis of nobody-knows what. So, in some cases it would be reasonable to have a commission to visit a person at home and evaluate the situation. Not one or two persons, and not necessarily from the disability office, but possibly more persons. (Interview 14)

DISCUSSION

Informal family carers are in need of different types of formal support in Lithuania, starting with better access to information about care, and ending with various services and financial support. Our findings support the results of research conducted in other EU countries that claims that family carers need complex forms of support that cover a wide range of measures (Courtin et al. 2014; Stoltz et al. 2004). Additionally, our results underline that these support measures should be aimed at alleviating both the objective care burden – i.e. the impact of caregiving tasks on resources such as time, physical health, and finances –, and the subjective care burden (the emotional impacts of caregiving tasks). Courtin et al.'s (2014) study, which was based on assessments by EU experts rather than by carers themselves, states that across the EU the support for informal carers varies significantly. However, the most commonly expressed need of carers is for financial benefits and respite care and training, as confirmed by the results of our study.

In order to take a systematic look at the results discussed above, we applied *the framework of informal carer support policy measures* explicated by Triantafillou et al. (2010), which entails a variety of social policy instruments in the area of elderly care. Using this framework, we not only obtain a broader picture of informal carer support from the elderly-care policy perspective, but can also evaluate gaps in the structure of this policy in the country (see Figure 1).





Source: Prepared by the authors.

The results reported here confirm that informal family carers emphasized the need for both specific and non-specific, as well as direct and indirect, formal support measures. This qualitative research, of course, does not allow for the quantitative assessment of which measures are requested more frequently, and which less. However, some studies conducted in the area of support for informal caregivers demonstrate that direct and indirect support measures are not evenly distributed. For example, findings of the study carried out by Jegermalm (2004) show that formal direct support measures for informal carers are far less common in practice. The author identifies two main reasons for this. The first one is the often vague and uncertain relationship between carers and the public sector. Carers are neither clients nor patients, but are a part of the system consisting of the public sector, informal care, and voluntary organizations

(Jegermalm 2004: 9). The second reason why measures directly targeting caregivers are too thinly spread is, according to the author, the lack of awareness of informal carers about the support measures available to them. Inter alia, our study results support the claim that information dissemination and the clarity of various issues is a quite relevant problem for informal family caregivers, as they complained about the lack of information about elderly nursing and the complicated process of identifying care needs.

In terms of specific policy measures (i.e. measures that are targeted at helping informal carers accomplish their caring tasks), our research informants mentioned the need for more specific and direct policy measures (i.e. measures that do not require the input of formal carers), as opposed to specific indirect ones (i.e. measures that entail a 'hand-in-hand' approach between formal and informal carers). Other studies (Triantafillou et al. 2010; Hengelaar et al. 2018; Wittenberg et al. 2019) also pay attention to the gaps that exist in the care sector between formal and informal carers regarding working 'hand-in-hand' that emerge due to the unwillingness of professional care providers to integrate their skills with the practical skills of informal carers, the lack of mutual trust, and an inability to cooperate. Wittenberg et al. (2019) propose that caregivers' disposition to share care with professionals depends on personal and situational characteristics (for example, the gender of the carer, their health, the recipient's specific impairment, the relationship between caregivers and care recipients, etc.).

In addition, it is obvious that the opinions of our study participants reflect the great need of informal family carers for support in kind as opposed to cash support. However, when it comes to the required cash support, informants reported the need for higher levels of cash-for-care to support recipients, but did not mention that carers might need such allowances for themselves. Although some European countries use carer allowances for caregivers as a social policy instrument, this is not the case in Lithuania. This circumstance echoes the earlier findings by Colombo et al. (2011) and Triantafillou et al. (2010) which provided evidence that in European countries cash-for-care benefits paid to care recipients are more widespread than cash-for-care benefits paid to carers.

There is reason to finish the discussion by mentioning some facts about the elderly care policy instruments that are used to support informal care in Lithuania. In terms of support measures aimed at balancing informal family caregivers' work and care responsibilities, it is noticeable that in Lithuania family members are entitled to paid leave and unpaid leave to care for a sick family member (including elderly persons) (Republic of Lithuania 2000; 2016a). However, persons caring for adult family members are not given any additional paid days off (in Lithuania, only employees who are raising a disabled child under the age of 18, or two children under the age of 12 are given one extra day off per month). Regarding other specific formal support measures mentioned in our study (that is, those related to the need for more information about care and training for carers), it can be concluded that formal carers, according to their job descriptions, should inform and consult informal family caregivers (Republic of Lithuania 2006a). Unfortunately, there is a lack of systematic practice and action in this regard in the area of informal elderly care.

In terms of non-specific support policy measures - first of all, respite care - it is important to note that until 2019 in Lithuania informal carers for the elderly were entitled to respite care only once a year in the form of placing the cared-for person in a social care or nursing home for a period of up to one month (since 2019, respite care has been available in the form of home help, day social care, and temporary social care) (Republic of Lithuania 2006a). However, these services were launched only in some municipalities, and covered only about 180 elderly persons in 2013 (Lazutka et al. 2016). When it comes to higher levels of cash-for-care benefits to care recipients, it should be noted that there are two kinds of benefits in Lithuania which are allocated to elderly persons in need of care to compensate for their care needs: these are called special compensations for nursing and attendance benefits, and cash benefits for help (Republic of Lithuania 2006b; 2016b). However, the level and coverage of these payments, especially when it comes to the cash-for-help benefit, are low. In 2019, this benefit was paid to as few as 103 elderly persons (Statistics Lithuania 2021). Participants of our study mentioned the need for measures such as housing accommodation and adaption, transportation services, and meals on wheels, which are also specified in Lithuanian legislation; however, not all of these measures are available to informal family caregivers. For example, in accordance with the currently valid procedure, meals on wheels are available only to persons who receive home help services from their local authorities, and those who are cared for only by their family members are not eligible for them (Description of the Procedure... 2010).

It can be concluded that although most of the support policy measures for informal caregivers are set out in Lithuanian law, informants are nonetheless lacking such support in reality. A similar conclusion was the result of research about the informal carer support system in Sweden, which stated that it is unclear whether carers benefit from government policy support measures (Stoltz et al. 2004). Additionally, our results suggest that the implementation of state guarantees for caring for a family member is hampered by bureaucratic obstacles, such as the organizational peculiarities of the process aimed at identifying care needs for cared-for persons.

CONCLUSION AND IMPLICATIONS FOR FURTHER RESEARCH

The results of the research suggest that caregiving for an elderly person has an impact on informal family caregiver's time, physical health, and financial resources, and affects their emotional and psychological wellbeing. The results also reveal a close relationship between the objective and subjective burdens of caregivers. Therefore, the results create important insights into social policy; namely, that the development of formal support measures for family carers that is intended to minimize objective burdens can be also expected to reduce the subjective burdens on carers, and vice versa.

By looking at carers' need for formal support through the framework of social policy measures, we see that carers in Lithuania formally have the possibility to apply for a majority of these measures according to the legislation. However, study results reveal the restricted accessibility of such support for informal family carers. In other words, it can be observed that both the objective and subjective burden faced by informal family caregivers and assessments of the need for formal support presuppose that the availability of the discussed social policy measures (i.e. information services, adaptation of home environments to special needs, etc.) is insufficient, and that these measures are not enough to alleviate the burden of informal caregivers. On the other hand, the research data do not explain properly the reasons for the unavailability of certain specific support measures, even though they formally exist. One of the reasons for this may be a lack of financial resources, as the informants emphasized that measures such as, for example, respite care and hygiene products, are quite expensive. Another reason mentioned by the informants is the bureaucratic obstacles associated with the process of assessment that make it difficult to access support measures. However, additional studies are needed to more comprehensively explore the factors that are associated with use of formally available support measures, or the lack thereof.

Limitations of the study

The fact that the interviews only included two male family carers did not allow the authors to distinguish between gender-based formal care needs. In Lithuania, the informal care sector is completely dominated by women, making it difficult to attract more men to the study. This can be seen as a limitation of the research.

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