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THE BURDEN OF CARE, THE LACK OF SUPPORT: VOICES OF INFORMAL CAREGIVERS FROM SOCIAL WORK PRACTICE

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Abstract

Introduction. Informal caregivers provide a substantial share of long-term care in Europe, yet they often face psychological, physical, and financial strain, particularly where formal support is limited. In the South Bohemian Region of the Czech Republic, support remains fragmented, and caregivers frequently depend on NGOs.
Aim. The study examined the needs and experiences of informal caregivers providing home care to older adults in South Bohemia, with a focus on caregiver burden and the use of available support services. The research formed part of Project No. TL03000518, aimed at developing innovative support tools for informal caregivers.
Materials and methods. A quantitative cross-sectional study was conducted in the second half of 2020 among 168 informal caregivers aged 18 years and older. Participants lived in South Bohemia and had provided care for at least three months and a minimum of eight hours per week. Recruitment was carried out through local NGOs. Data were collected using structured questionnaires and analysed with descriptive statistics.
Results. Respondents reported major gaps in access to information, legal counselling, psychological support, training, and respite care. Information was insufficient for 56% of caregivers, legal counselling for 38.1%, and psychological assistance for 32%. Only 5% reported access to caregiver training. NGOs were positively evaluated by 76% of respondents, while formal institutions were often viewed as inflexible. In total, 93% felt unrecognised and excluded from care planning, 26% had no possibility of short-term relief, and 76% had no regular assistance. Awareness of caregiver rights was also inconsistent.
Conclusions. Informal caregivers in South Bohemia operate within a fragmented and under-resourced support system that increases psychological and socio-economic burden. Sustainable improvement requires legal recognition of caregivers, broader psychological and legal support, accessible training, respite services, and their formal inclusion in long-term care planning.

Keywords: **informal caregiving, social support, long-term care, South Bohemia, caregiver burden, NGO support, policy reform, ageing society**

INTRODUCTION

Informal caregiving is a cornerstone of long-term care systems across Europe. According to the European Commission, over 60% of all long-term care is provided by informal caregivers – most commonly family members – who support relatives with chronic illnesses, disabilities, or age-related decline [1]. These caregivers provide crucial help with daily activities and often bridge significant gaps in formal health and social care systems, especially in regions with underdeveloped service infrastructure [2].

While the societal value of informal caregiving is well recognised, the individual costs are often overlooked. Research highlights that caregivers frequently face emotional stress, physical burden, and economic insecurity, particularly when they lack institutional support or respite services [3, 4]. A recent study by Kramer and Bleidorn (2024) found a significant decline in subjective well-being among long-term caregivers compared to non-caregivers, pointing to psychological costs that are frequently invisible to the healthcare system [3].

In Central and Eastern Europe, and especially in countries like the Czech Republic, informal caregivers remain marginally integrated into care pathways. Despite policy rhetoric supporting community-based care, practical support systems remain fragmented and underfunded [1, 5]. Previous qualitative research from South Bohemia underlines the consequences of these systemic gaps: family members of stroke survivors reported that their roles were insufficiently acknowledged and supported, leading to confusion, burnout, and limited rehabilitation outcomes [1].

Further studies from the broader region echo similar challenges. In Slovenia, caregivers were found to operate largely outside formal support systems, relying primarily on personal resilience and altruism [4]. In Croatia, caregivers expressed uncertainty about their legal rights, access to training, and relationships with formal care providers [5]. These findings underscore a regional pattern: informal caregivers are essential yet institutionally invisible.

This article presents findings from a quantitative cross-sectional study conducted in South Bohemia. The study aimed to assess the support needs and experiences of informal caregivers caring for older adults with reduced self-sufficiency. By capturing the scope of caregiver burden and the use of available services, this study contributes to a deeper understanding of the realities informal caregivers face. It identifies implications for public policy and service provision.

AIM

This study aimed to investigate the support needs and experiences of informal caregivers in the South Bohemian Region of the Czech Republic. Specifically, it focused on understanding the degree of caregiver burden and the extent to which available services are utilised. The study forms part of a larger project (Project No. TL03000518) funded by the Technology Agency of the Czech Republic, which seeks to develop innovative support strategies – including audiovisual tools and virtual reality – to enhance psychosocial support for informal caregivers.

MATERIALS AND METHODS

This study employed a quantitative, cross-sectional descriptive design conducted in the South Bohemian Region of the Czech Republic during the second half of 2020. The focus was on understanding the experiences and support needs of informal caregivers providing home care to dependent family members.

A total of 168 informal (family) caregivers participated in the study. The inclusion criteria were as follows: (1) age 18 years or older, (2) permanent residence in the South Bohemian Region, and (3) having provided home care to a dependent relative for at least three months and for a minimum of eight hours per week. Participants were recruited purposively through selected NGOs providing caregiver services, including ARPIDA, Autis Centrum, and Ledax.

Data Collection. Data were collected using a structured questionnaire focused on socio-demographic characteristics, caregiving intensity, perceived burden, and service utilisation. The questionnaire was developed specifically for the project and consisted of eight thematic sections (A–H) with over 100 items. It included closed, scaled (e.g. Likert-type), and open-ended questions covering caregiver burden, burnout symptoms, institutional and NGO support, legal and psychological counselling, training opportunities, use of social services, and attitudes toward digital tools. For this article, the analysis focused on eight dichotomous items (F1–F12) related to caregivers' perceived access to services and systemic support.

The study was carried out as part of a larger applied research project funded by the Technology Agency of the Czech Republic (Project No. TL03000518: «Support for Informal Caregivers in the South Bohemian Region through Audiovisual Tools Including Virtual Reality,» 2020-2023).

Data Analysis. Quantitative data were analysed using descriptive statistical methods to determine frequencies, averages, and correlations. Although this article emphasises the quantitative results, the overarching project also includes a qualitative component involving interviews and focus groups to explore caregivers' experiences in depth.

Study Limitations. Several limitations should be considered when interpreting the findings of this study. First, the cross-sectional design captures a single point in time, which restricts the ability to assess changes in caregiver burden or service utilisation over time. Second, although the sample size (n = 168) is robust for regional analysis, the purposive sampling strategy and the focus on the South Bohemian Region limit the generalisability of the results to other regions or countries. Third, reliance on self-reported data may introduce response bias, as participants may have under- or overestimated their caregiving responsibilities or perceived burden. Finally, while this study primarily focuses on quantitative data, qualitative components of the larger research project were not analysed in this article, potentially omitting rich contextual insights into the lived experiences of informal caregivers.

RESULTS

A substantial proportion of caregivers reported engaging with public or civil institutions for assistance during caregiving. The most frequently contacted was the municipal or local office, with 88% of respondents indicating they had used its services. Over half also contacted the Labour Office (53%), the Czech Social Security Administration (58%), and non-governmental

organisations (57%). Additionally, 80% mentioned having reached out to other institutions or entities not specifically listed in the questionnaire, reflecting the wide spectrum of support channels that caregivers attempt to navigate.

Despite relatively high levels of institutional contact, perceptions of accessibility to social services varied. Only 22% rated social services as fully accessible, while another 26% considered them «rather accessible». A significant portion of respondents found services only «average» in availability (32%), and 9% evaluated them as «rather» or «completely inaccessible». Notably, 8% were unable to assess accessibility at all, possibly due to insufficient experience or information.

Regarding financial support, 79% of respondents stated they were using some form of financial aid for caregivers, while 20% reported they were not accessing any such financial instruments. This suggests that the majority are at least partially integrated into the state support framework, though a fifth remains outside or unaware of available assistance.

Data obtained from items F6 through F12 reveal significant deficits in social support, substitutability, and awareness among informal caregivers in the South Bohemian Region. More than three-quarters of respondents (76%) stated that they had no one to assist them with caregiving responsibilities, indicating a high level of social isolation. Nevertheless, some respondents reported the possibility of turning to others for support: most often to individuals outside the immediate family (93%), adult children (70%), neighbours (67%), or parents (61%). Only 44% reported relying on a spouse or partner. These findings suggest that although potential sources of support exist, their availability is often limited or insufficient in practice.

A total of 70% of caregivers indicated that someone could substitute for them at least once a week. However, 26% reported having no possibility of even short-term relief, which may significantly contribute to caregiver overload and stress.

Regarding interest in formal support in the home environment, 22% of respondents reported no interest in any type of assistance. The most frequently desired types included services of a physical therapist (27%), social worker (24%), volunteer (23%), and another caregiver (20%). Additional preferences included a nurse or psychologist (both 17%), a specialist doctor (16%), a general practitioner (14%), a special education teacher (11%), and a nutritionist (10%). About 10% could not assess their need, and 4% selected another form of help. Because respondents could indicate more than one preferred type of assistance, the total percentages do not sum to 100%.

The most commonly cited reasons for considering institutional placement were a lack of financial resources (91%) and insufficient family support (89%). Many also mentioned other personal reasons (83%), physical exhaustion (70%), psychological exhaustion (65%), and the inability to manage care at home (55%).

In contrast, the main reasons against institutionalisation included fear of negative social judgment (93%), other reasons (86%), a sense of duty (65%), and meaningfulness of caregiving (63%). Additionally, 59% indicated a desire to manage care independently at home, as respondents could select more than one reason.

Awareness of entitlements showed inconsistencies. While 79% stated they had a right to adjust their working hours, 59% reported eligibility for state-covered social insurance and 56% for health insurance. However, 66% claimed they had no entitlement to any of the listed options, indicating confusion or lack of access to information.

Finally, 52% of respondents had collaborated with a social worker, while 47% had not, suggesting that although professional support is accessible to some, nearly half remain unaided in navigating the care system.

DISCUSSION

The findings of this study reveal systemic shortcomings in the support infrastructure available to informal caregivers in the South Bohemian Region. Across multiple dimensions – informational access, institutional aid, psychological support, and caregiver training – respondents reported significant unmet needs. Over half of caregivers felt insufficiently informed about available services, and one-third lacked access to psychological or emotional support. Legal and social counselling was absent for 38% of respondents, and a striking 94% indicated that no adequate training or educational opportunities were available. These deficits align with broader evidence from Central and Eastern Europe, where caregiving systems are under-resourced and fragmented [7-9].

Institutional neglect was especially pronounced: 93% of caregivers reported a lack of recognition from local or regional authorities. This mirrors international findings, such as those from Poland, where caregivers of individuals with disabilities also face social isolation and emotional strain due to institutional indifference [10].

Globally, the burden on informal caregivers remains disproportionate. Studies from Germany show that while care quality may be satisfactory, emotional support and social inclusion are often lacking [11]. In low-resource settings like the Democratic Republic of Congo, informal caregiving constitutes the backbone of care in the absence of formal systems, reaffirming the universality of our observations [12].

This study further underscores the absence of short-term relief for a substantial share of caregivers. More than a quarter of respondents reported that they had no

one who could substitute for them even temporarily, a situation strongly correlated with stress and burnout. Additionally, more than three-quarters of caregivers indicated having no informal support network, placing them at heightened risk of overload.

Despite these systemic gaps, non-governmental organisations (NGOs) emerged as key providers of reliable support. A total of 76% of respondents rated NGO support positively, citing responsiveness and empathy. This mirrors experiences from palliative care in Africa and community-based services in Canada, where NGOs have bridged institutional failures effectively [15, 16].

Another noteworthy concern is the unclear awareness of legal entitlements. While majorities claimed entitlement to certain caregiver rights – e.g., adjustment of working hours (79.8%), state-paid social insurance (59%), and health insurance (56%) – 66% simultaneously reported not being aware of any such rights. This contradiction suggests either inconsistent communication from institutions or systemic opacity in eligibility criteria.

The lack of collaboration with professional support structures further compounds these challenges. Nearly half of the respondents (47%) had not cooperated with a social worker, and many navigated the care system independently. Although 70% had someone to substitute for them weekly, nearly 27% were left without any form of relief, reinforcing the need for better-structured respite care options.

The demographic profile of the caregivers, while not explicitly gendered in the data, suggests – consistent with broader research – that most caregivers are women. This reinforces the gendered nature of caregiving, with women disproportionately exposed to physical, emotional, and financial strain while receiving minimal institutional support [15].

Finally, the overall dissatisfaction with the social support system, expressed by 89% of respondents, reflects the cumulative impact of fragmented care provision, limited access to services, and a lack of meaningful inclusion in care planning. There is a growing international consensus – reflected in EU frameworks and Delphi expert panels – that caregivers should be formally included as stakeholders in health and social care governance [18].

In summary, this study exposes a multidimensional failure in the support system for informal caregivers. Addressing these issues requires targeted policy reform and cross-sectoral collaboration. Key priorities include:

- Legal recognition of informal caregivers as partners in care;
- Expansion of accessible psychological, legal, and social counselling services;
- Development of structured and accessible training programmes;
- Enhanced communication and information infrastructure;
- Institutional inclusion of caregivers in the design and planning of long-term care.

Strengthening partnerships between public institutions and NGOs may offer an effective transitional pathway toward a resilient, inclusive, and sustainable caregiving ecosystem – one capable of meeting the demands of Europe's rapidly ageing population. In line with Hajduchová et al. [19], our findings reaffirm the persistent gaps in health and social support systems within the South Bohemian Region, highlighting the urgent need for comprehensive counselling, psychosocial assistance, and targeted educational initiatives for informal caregivers.

CONCLUSIONS

This study shows that informal caregivers in the South Bohemian Region face a considerable burden and encounter significant gaps in institutional support. The most critical shortages concern access to legal counselling, psychological support, and educational opportunities, with only a small share of caregivers able to benefit from such services. A strong sense of insufficient recognition from formal institutions was also evident. By contrast, non-governmental organisations were perceived as an important and reliable source of help, confirming their central role in long-term care. These findings are consistent with European and global evidence showing that informal caregivers are indispensable to care systems but remain undervalued and insufficiently supported. It should be noted, however, that the data were collected only from the surveyed respondents and do not represent a nationally representative sample.

Prospects for Future Research. Future research should investigate the long-term impact of caregiving on physical and mental health, as well as on the social and economic situation of caregivers. Gender differences in caregiving roles also deserve more attention, as care responsibilities still fall disproportionately on women. Further studies could evaluate new forms of support, such as group counselling, peer-to-peer initiatives, or workplace flexibility measures. Finally, cross-national comparative research would be valuable to identify transferable examples of good practice and to help policymakers design more effective and context-sensitive support systems.

COMPLIANCE WITH ETHICAL REQUIREMENTS

All personal information collected during the study was processed in accordance with Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons

concerning the processing of personal data and on the free movement of such data (General Data Protection Regulation, GDPR).

The research was conducted as part of Project No. TL03000518, «Support for Informal Caregivers in the South Bohemian Region through Audiovisual Tools Including Virtual Reality,» implemented from 2020 to 2023. The study was approved by the Ethics Committee under approval No. 005/2019. The research was conducted in accordance with the ethical principles of the Declaration of Helsinki, the Universal Declaration on Bioethics and Human Rights, and the Convention on Human Rights and Biomedicine (1997).

Research Limitations. The study has several limitations. First, its cross-sectional design captures caregivers' experiences at a single point in time and does not allow changes in caregiver burden or service utilisation to be assessed over time. Second, the purposive sampling strategy and the focus on the South Bohemian Region limit the generalisability of the findings to informal caregivers in other regions or countries. Third, the study relied on self-reported questionnaire data, which may be affected by response bias, including the underestimation or overestimation of caregiving responsibilities and perceived burden. Finally, the qualitative components of the broader research project were not analysed in this article, and potentially important contextual insights into caregivers' lived experiences are therefore not included.

Primary Data and Materials. The primary data used in this study consisted of questionnaire responses collected from 168 informal caregivers in the South Bohemian Region of the Czech Republic.

Declaration on the Use of Artificial Intelligence. Generative artificial intelligence tools were used solely for language editing, stylistic refinement, and improvement of the clarity of selected parts of the manuscript. Artificial intelligence was not used for data collection, data analysis, interpretation of the findings or formulation of the scientific conclusions. The authors reviewed, verified and approved all AI-assisted content and take full responsibility for the final version of the manuscript.

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AUTHOR CONTRIBUTIONS

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Резюме

ТЯГАР ПІКЛУВАННЯ, БРАК ПІДТРИМКИ: ГОЛОСИ НЕФОРМАЛЬНИХ ДОГЛЯДАЛЬНИКІВ З ПРАКТИКИ СОЦІАЛЬНОЇ РОБОТИ

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Вступ. Неформальні доглядальники забезпечують значну частку довготривалого догляду в Європі, однак часто зазнають істотного психологічного, фізичного та фінансового навантаження, особливо за умов недостатньої формальної підтримки. У Південночеському краї Чеської Республіки система допомоги залишається фрагментованою, а доглядальники нерідко змушені покладатися переважно на неурядові організації.

Мета. Дослідити потреби та досвід неформальних доглядальників, які надають домашній догляд особам похилого віку в Південночеському краї, з особливим акцентом на рівень навантаження та використання доступних послуг підтримки. Дослідження виконано в межах проєкту № TL03000518, спрямованого на розроблення інноваційних засобів підтримки неформальних доглядальників.

Матеріали та методи. У другій половині 2020 року проведено кількісне поперечне дослідження за участю 168 неформальних доглядальників віком від 18 років, які проживали в Південночеському краї та здійснювали догляд щонайменше три місяці і не менше восьми годин на тиждень. Учасників залучали через місцеві неурядові організації. Дані збирали за допомогою структурованих анкет і аналізували методами описової статистики.

Результати. Респонденти повідомили про суттєві прогалини в доступі до інформації, юридичних консультацій, психологічної підтримки, навчання та послуг тимчасового перепочинку. Недостатній доступ до інформації відзначили 56% доглядальників, до юридичних консультацій – 38,1%, до психологічної допомоги – 32%. Лише 5% мали доступ до спеціального навчання. Неурядові організації позитивно оцінили 76% респондентів, тоді як формальні установи часто сприймалися як негнучкі. Загалом 93% доглядальників почувалися невизнаними та виключеними з процесу планування догляду, 26% не мали можливості до короткочасного перепочинку, а 76% – до регулярної допомоги. Обізнаність щодо прав доглядальників також була нерівномірною.

Висновки. Неформальні доглядальники в Південночеському краї діють у межах фрагментованої та недостатньо забезпеченої системи підтримки, що посилює їхнє психологічне й соціально-економічне навантаження. Стійке покращення потребує правового визнання доглядальників, розширення психологічної та юридичної допомоги, розвитку доступних навчальних програм і послуг перепочинку, а також їх формального залучення до планування довготривалого догляду.

Ключові слова: **неформальний догляд, соціальна підтримка, довготривала опіка, Південночеський регіон, навантаження доглядальників, підтримка неурядових організацій, політичні реформи, старіюче суспільство**

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