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Original research article

Barriers to participation in educational programs for family caregivers of people with dementia

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Abstract

Introduction: In the Czech Republic, like in other European countries, we are witnessing an expansion of programmes for families who care for their relatives with dementia.

Objective: Our study aimed to investigate whether caregivers are interested in such psychoeducational programmes, what barriers prevent them from using them, and what form of programmes they would prefer.

Results: 85 adults who cared for a family member with dementia participated in our questionnaire survey. The results showed a link between the respondents' age and their willingness and ability to participate in psychoeducational programmes. With increasing age, interest in such programmes decreased. For older respondents, mainly providers of partner care, the most frequent obstacle was the impossibility of leaving the care recipient alone at home. Preferences regarding the format of psychoeducational programmes were also age dependent: younger participants preferred support groups, consultations in their own home, and meeting jointly with the care recipient more than the older caregivers, who tended to prefer 'traditional' forms of education (consultations or psychoeducational courses).

Conclusions: Our results indicate that it is unproductive to strive for a single 'ideal' form of psychoeducational programme that would suit everyone. Instead, the offer should reflect the differing demands of caregiver groups.

Keywords: Barriers; Dementia; Informal care; Preferences; Psychoeducation

Introduction

In the 21st century the world's population is rapidly aging, and the Czech Republic, like other developed countries, has embarked on a journey of longevity. The fastest growing age group is 80 years and over. The current number of people aged 80+, which in 2021 was 451,100 (4.3% of the total population; Czech Statistical Office, 2022), is projected to double to over 900,000 by 2045, *i.e.*, 8.4% of the total population (Czech Statistical Office, 2019, p. 46).

An increase in the number of older people also implies an increase in spending on health and social services. Search for optimal solutions (including support of informal care) is an urgent task because in Europe, care for the older people is provided to a large extent by informal caregivers. This reflects the European tradition of intergenerational care and solidarity. It is also in line with the older adults' wish to "age in place", and corresponds to current efforts to de-institutionalise long-term care (Ilinca et al., 2015; Wieczorek et al., 2022). Moreover, a high proportion of informal care contributes to the sustainability of the system of long-term care in European countries, and given the anticipated increased costs of institutional care its significance is likely to further grow (Spasova et al., 2018).

Dementia is a challenging health problem and its prevalence significantly increases with age. In Europe, only 6 people per 1,000 suffer from dementia in the 60–64 age group (0.6%), but in the 80–84 age group, it is almost every tenth person (12%), and in the 90+ group it is almost half (40.8%) of people (Alzheimer Europe, 2019, p. 9). Based on a study of the prevalence of dementia in Europe, it is estimated that there are about 150,000 people with dementia in the Czech Republic (ibid, p. 32). About 100,000 of them are cared for by their families, whereby the number of such informal caregivers is estimated at 250,000 (Czech Alzheimer Society, 2016, p. 25). Dementia is also the disease with the highest annual value of informal caregiving (Oliva-Moreno et al., 2017).

Over time, various studies have demonstrated an increased likelihood of health complications among informal caregivers (Pinquart and Sörensen, 2003; Vitaliano et al., 2003), as well as impacts on other areas of their lives (Lindeza et al., 2020).

Support interventions for dementia caregivers

Most of the earliest interventions focused on providing support to informal caregivers took the form of support groups or consultations. These became a recommended part of the treatment of Alzheimer disease because they were viewed as targeting the quality of life of the family as a whole (Group

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for the Advancement of Psychiatry, 1988). Such interventions included educational and therapeutic techniques, which is why they came to be known as "psychoeducation". Evaluation of their effectiveness showed a decrease in the levels of psychopathology and improved awareness of relevant information on the part of family members of dementia sufferers (Brodaty et al., 2003; Huis in Het Veld et al., 2015).

Interventions aimed at dementia caregivers which are comprehensive and individualised are currently viewed as the most effective (Gilhooly et al., 2016).

Caregiver support in the Czech Republic

In the Czech Republic (as in other post-communist states in Central and Eastern Europe), we find the "transition" type of European long-term care model, which is characterised by a high level of informal care and medium/low formal care (Ilinca et al., 2015).

A key element for family and close persons who provide home care is the provision of sufficient support to caregivers. In the Czech Republic, the subject of caregiving families and their needs has received increased attention in recent years, with surveys mapping the situation of caregivers undertaken (Janečková et al., 2017). The need to provide support – including education – to informal caregivers became part of the national policy (Ministry of Labour and Social Affairs, 2016). Recently, the Czech government adopted The National Action Plan for Alzheimer's Disease and Other Similar Diseases 2020–2030 (Ministry of Health of the Czech Republic, 2021), whose goals include the support and development of education for informal dementia caregivers, *i.e.*, those who are the focus of this study.

In the Czech Republic, various support initiatives and educational activities aimed at dementia caregivers began to form shortly after 1990, largely thanks to non-governmental organisations such as the Czech Alzheimer Society or Diaconia of the Evangelical Church of Czech Brethren. But these activities are neither systematically supported nor centrally coordinated, which is why they are only accessible in some regions and mostly in large towns. Due to the form of financing (from projects), their existence is temporarily restricted.

Underutilisation and barriers

Although the benefits of support interventions for dementia caregivers who are family members of care recipients are considered proven, evidence shows that this group of caregivers uses support interventions less frequently than persons who care for family members with other diseases or health conditions. This is despite the fact that dementia caregivers suffer from a higher incidence of stress and the care is more emotionally demanding; it more frequently has an impact on their health than in the case of non-dementia caregivers (Brodaty et al., 2005; Cherry, 2012).

Underutilisation of interventions by informal caregivers pertains especially to the early stages of care. Authors of a Dutch qualitative study described this with the term "early-stage needs paradox". In this study, participants retrospectively admitted that they would have benefitted from support during the early stage of care, but they did not want to receive it until they were able to accept the illness of their family member and their role of a caregiver (Boots et al., 2015).

Factors which prevent caregivers from using support interventions can be categorised depending on whether they are linked to the care giver, care recipient, or supplier of the intervention. Other classifications are based on the kind of factors that form a barrier to caregivers' utilization of support. Such models distinguish between institutional, psychosocial, situational, or informational barriers (Abrau et al., 2015); and eventually also emotional barriers (*e.g.*, inability to accept the diagnosis and their own caregiving role), concrete barriers (for instance the expense of the services), and systemic obstacles, which may include rigid rules of the services or insufficient education of intervention providers (Cherry, 2012).

Whittier et al. (2002) list five elements which influence whether caregivers will use support interventions: availability, accessibility, appropriateness, acceptability, and affordability. A systematic review of studies which investigated acceptability showed that refusal to participate and premature exit from support intervention aimed at informal dementia caregivers tend to be linked to a caregiver's lack of time (*e.g.*, due to employment), poor health, lower education, and paradoxically to a caregiving burden that is perceived to be large (Qiu et al., 2019).

On the other hand, it has been shown that utilisation of support interventions aimed at caregivers has a positive impact on the outcomes of further care. Research conducted in eight European countries has shown that utilisation of low-intensity, less intrusive services at the baseline (such as domestic help or meals on wheels) significantly predicted the use of home personal care (Kerpershoek et al., 2020). The use of interventions (such as psychoeducation) in the early stages of care provides caregivers with information about the formal care available, thus facilitating the use of other community services.

As noted above, in the Czech Republic psychoeducational programmes are currently available only in some localities. Many are provided free of charge or for a merely symbolic fee, while others even offer participants transport (for an overview of psychoeducational programmes in the Czech Republic, see Dragomirecká et al., 2018). Even so, it is evident that caregivers do not use these services to their full capacity, and this is especially common with structured programmes of a longer duration.

Aims of the study

The main aim of this study was to find out whether dementia caregivers are interested in psychoeducational programmes, what barriers may hamper their participation, and what form of programme they might prefer. A secondary objective is to analyse the obtained sample in relation to age and gender. The immediate impulse for this study was that in 2018, two planned psychoeducational courses organised by the Czech Alzheimer Society in Prague and Liberec were cancelled due to the low number of registered participants.

Material and methods

Procedure and sampling

This study was designed as a survey with convenience sampling: persons who contacted selected services aimed at families caring for dementia patients between November 2018 and January 2019 were offered the opportunity to complete our questionnaire. The services included the counselling centres of the Czech Alzheimer Society (CAS) in several regional centres in the Czech Republic (Prague, Liberec, Brno, Ostrava, Zlín) and the Alzheimer Café and Reminiscence Centre (RC) in Prague. Additionally, some caregivers were contacted through the CAS website. Sample recruitment methods are presented in Fig. 1.

Inclusion criteria for participants were being an informal dementia caregiver and providing consent to participate in the study.

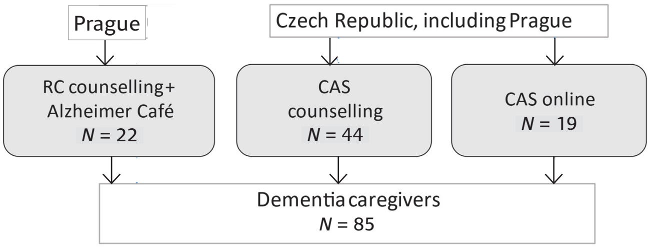


Fig. 1. Recruitment of the sample

Sample characteristics

In total, 85 caregivers completed the questionnaire: 65 women (76%) and 20 men (24%). Average age of the sample was 62 years (range 25–89 years). The sample included no men aged under 40. Average age of the women was 59 years, average age of the men was 71 years. Most participants (73%) lived in cities with over 100,000 inhabitants (mostly Prague and Liberec); the rest lived in smaller towns and villages. One half (50%) of participants cared for their own or partner's parents, 6.5% for another family member (such as a grandmother or aunt), and 43.5% for a partner.

Table 1 presents participants' basic characteristics by gender. The men were significantly older than the women ($F = 10.228$; $P = 0.002$) because they more frequently provided partner rather than intergeneration care. This difference, however, did not reach statistical significance: $\chi^2 = 3.150$, $p = 0.076$).

Table 1. Sample characteristics (*N* = 85)

	Male	Female	Total
Relative (absolute) number	23.5% (20)	76.5% (65)	100% (85)
Average age (range)	70.7 (47–89)	59.0 (25–86)	61.6 (25–89)
Caregivers aged 61+ (%)	50.0%	25.8%	31.3%
Caregivers living in large towns (100,000+) (%)	75.0%	72.3%	72.9%
Caregivers providing partner care (%)	60.0%	37.5%	43.5%
Total	**100% (20)**	**100% (65)**	**100% (85)**

For further analyses, we split the sample into two age groups, because we assumed that younger (60 years and under) and older (61+) caregivers may have different preferences and needs related to their employment status, the type of care they provide, cohabitation or no cohabitation with the care recipient, and their own health status.

Measures and instruments

The participants completed the Caregivers' Questionnaire, a short, one-page instrument developed by the team based on the results of the qualitative part of the project "Needs Assessment of Family Caregivers of the Elderly" (Dragomirecká, 2020, pp. 281–284). The questionnaire consists of three closed-ended questions asking about participants' interest in psychoeducation (answers: Definitely interested – Rather interested – Not sure – Not really interested – Not interested), preferred format (multiple choice from: Counselling – One-day course – Support group – Home consultation – With care recipients – Multi-day course – No need of education), and about potential barriers to utilisation of psychoeducation programmes (Lack of time – Cannot leave the person alone – Psychoeducation not available – Distance – I am too tired – My health problems – Group format – Financial expenses). Demographic data included participants' gender, age, relationship to the care recipient, and the size of the place of residence. Most participants (78%) completed a paper version of the questionnaire during personal contact with the service, the rest filled in an online version on the Czech Alzheimer Society's website (Fig. 1).

Statistical analyses

Differences in categorical variables were calculated by the Chi-Square test. Analysis of variance (one-way Anova) was used to compare the means of numerical variables. For all tests, statistical significance was set at $\alpha = 0.05$. Data were analysed using IBM SPSS Statistics 24.

Results

As presented in Fig. 2, respondents aged 60 and under provided care mainly to parents and other relatives (91.5%), while about two-thirds of participants aged 61+ cared for partners (68.9%).

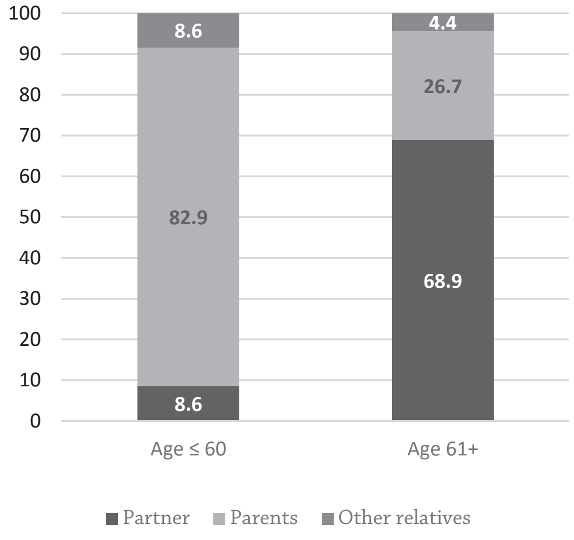


Fig. 2. Care recipients by caregivers' age group (*N* = 85)

Interest in psychoeducation

Participants were asked whether they would be interested in a psychoeducational program that would provide them with helpful information and skills. Almost three quarters of participants (74%) expressed interest, 8% were not sure, and 18% said they were not interested (Fig. 3).

Interest in participation in a psychoeducational program was related to age. The average age of those who expressed interest (answered "Definitely interested" or "Rather interested") was 59, while the average age of those who were not interested (answered "Not interested" or "Not really interested")

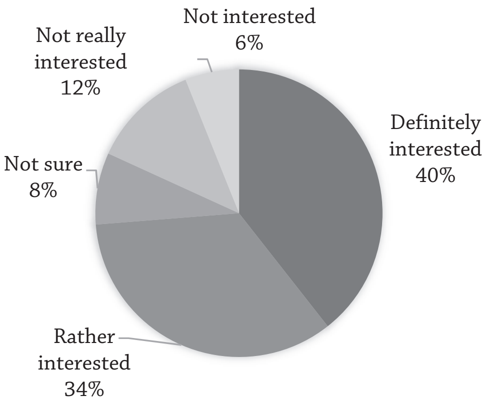


Fig. 3. Caregivers' expressed interest in participation in psychoeducation ($N = 85$)

or were not sure was 68 years. Of the participants under the age of 61, only 11% expressed a lack of interest in such programmes. In the 61+ group, 25% of participants expressed a negative attitude to psychoeducation. The lowest proportion of participants interested in psychoeducation was in the 71+ group, where 38% of respondents expressed a lack of interest in participation. Men expressed a lack of interest in psychoeducation more frequently than women (50% vs. 16%; $\chi^2 = 5.5$, $P = 0.019$); given the higher age of the male participants, a comparison was undertaken only for the 61+ age group.

Participants caring for parents and other relatives were more interested in psychoeducation (only 15% expressed lack of interest) than participants caring for a partner, where 23% of caregivers expressed lack of interest. In addition to the effect of age within the latter group, the fact they share a household with the care recipient (their partner) and cannot leave them alone may also have an effect.

Preferred course format

Participants indicated the forms of psychoeducation that would best correspond to their needs; they could choose more options. The most preferred form was *counselling* ("individual consultation in a counselling centre or the possibility of a telephone consultation when needed"); this option was chosen by 49% of participants. The second most preferred form was a *one-day course* ("a one-off course, half- to full-day, close to the place of residence"); this was chosen by 42% of respondents. Nearly one-third (31%) of respondents also chose *support group* ("regular meetings of caregivers accompanied by lectures"), while about one in four respondents (27%) chose *home consultation* ("consultations with an expert at my home after a phone call"). A similar proportion of respondents (25%) expressed an interest in meetings *together with care recipients* ("meetings of caregivers together with care recipients, with consultation and training of skills"). The least preferred format was a *multiday course* ("a series of several consecutive lectures"), which was chosen only by 19% of respondents.

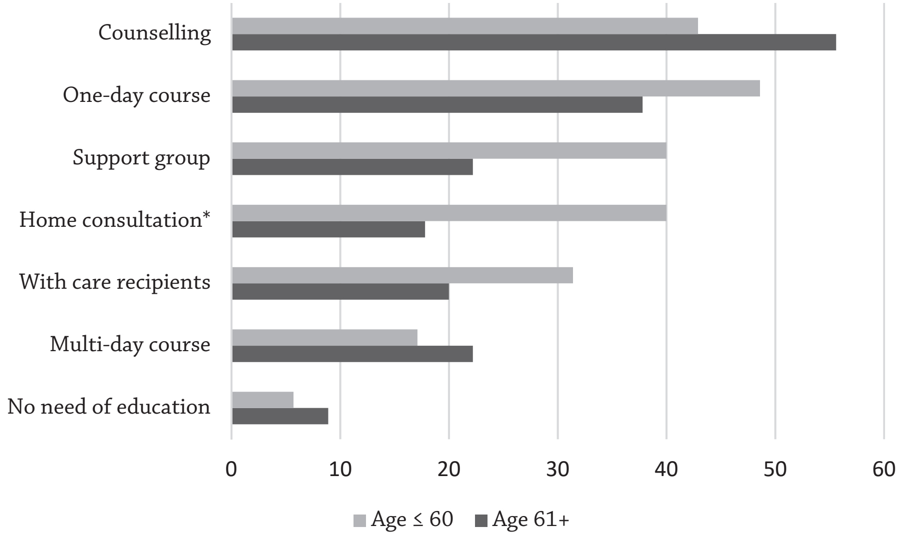
Compared to older respondents, the younger ones more frequently indicated interest in consultations in their own home, support groups, and meetings together with the person they care for (Fig. 4). However, only differences in the preference for home consultations reached statistical significance ($\chi^2 = 4.876$, $p = 0.027$).

Barriers to participation

The main barriers to participation in the courses available to carers were identified by 42% of participants as "lack of time" (due to the demands of caring, employment, concurrent childcare, etc.). Not being able to leave the care recipient (33%) was the second most important barrier, followed by difficulties in accessing the venue (21%). One in three participants said that there was no similar course in their area.

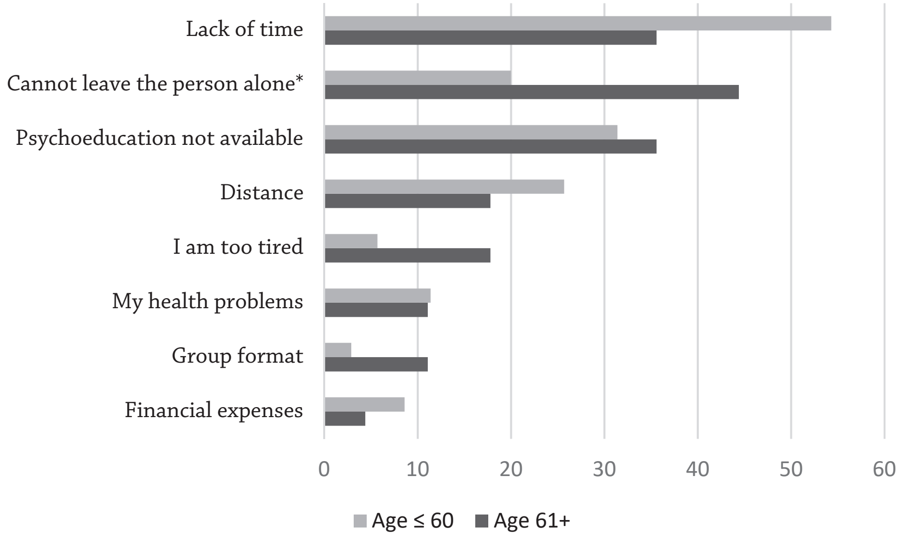
As with the previous question, we were interested in how participants differed in their assessment of barriers by age (Fig. 5).

Older participants were significantly more likely to state that it was their inability to leave the care recipient alone that prevents them from attending psychoeducation courses ($\chi^2 = 5.261$, $p = 0.022$). They were also more likely than younger participants to list fatigue as a barrier. Meanwhile, younger participants most frequently reported lack of time as a barrier.



Note: Courses are ranked according to the rate of preference expressed by all participants.

Fig. 4. Preferred format of psychoeducation according to caregivers' age ($N = 85$)



Note: Barriers are ranked based on responses from the sample as a whole (regardless of age).

Fig. 5. Barriers to participation in psychoeducation according to caregivers' age (*N* = 85)

Discussion

Our survey showed a considerable declared interest of informal dementia caregivers in educational programmes (only 26% expressed lack of interest, *i.e.*, answered "Not interested" or "Not really interested"). However, it should be taken into account that our respondents were contacted via counselling centres, and one can thus suppose that they had already obtained some basic information. These results are in line with the results of a survey that took place in German-speaking countries, which found that the interest of dementia caregivers in participating in psychoeducational programmes significantly exceeded what was on offer. In fact, it was even higher than the interest in psychoeducation expressed by informal caregivers who cared for a family member with schizophrenia (Rummel-Kluge et al., 2008).

The observed lower interest among men is also in line with the results of other relevant studies. In our sample, every other male participant aged 61+ was not interested in psychoeducation, while among women in the same age category, only every fifth indicated a lack of interest. We can only speculate whether this is because men identify less with the caregiving role and are therefore less willing to accept help (as indicated by Greenwood and Smith, 2015, a systematic review of studies focused on gender differences), or whether men need educational support less because they satisfy their need for information and emotional support with other sources. In the Czech Republic, like in most European countries, family care mostly falls to women, and this applies especially to intergenerational care. Male caregivers are only found in more significant numbers among seniors, and they mainly provide partner care (OECD, 2021, p. 262).

It is important to investigate to what extent the utilisation of services is affected by the characteristics of the caregivers. It turns out that services are used less by dementia caregivers who provide partner care than by those who provide intergenerational care (Robinson et al., 2005) and those who share a household with the care recipient (Bruce and Paterson, 2000; Jegermalm and Torgé, 2021). Other studies have documented lower participation in psychosocial interventions for dementia caregivers among people with low education level, poor health, or a full-time job (Qiu et al., 2019). In our survey, we did not collect information about education or employment status. What we did note, though, was a significant effect of age. Interest in participation in psychoeducational programmes was highest in the age group 41–60, where only 11% expressed a lack of interest. Then, with increasing age, the interest decreased. Low interest was also listed among participants under 40 years of age, but this group was small. Nevertheless, the U-shape of association between age and interest in educational programmes in our sample corresponds to the ambiguous findings elsewhere (Abrau et al., 2015; Qiu et al., 2019).

Still, declared interest in educational support need not translate into actual attendance. Abrau et al. (2015) created a psychoeducational intervention in collaboration with informal caregivers to ensure the maximum chance of it responding to their needs; and even then participation in the programme which they helped create was low. It was apparent that the target group was highly motivated, but their attendance ran into various barriers, which were mainly "situational" (lack of time due to work or care for the care recipient, problems with transport, and the like). In contrast, "psychosocial" factors (opportunity to learn something new) and "institutional" aspects (interesting content and the instructors high-quality teaching skills) all facilitated participation (Abrau et al., 2015).

Similarly, in our research a lack of time and impossibility of leaving the care recipient home alone were among the most frequently listed barriers to participation in a psychoeducational programme. Another obstacle – one listed by over one-third of our respondents – was inaccessibility of an educational programme close to their place of residence. At the time we collected the data, educational courses were mainly provided in large cities and mostly by nongovernmental organisations. Education of family caregivers was not (and still is not) part of the standard system of social and healthcare services. Only about every tenth respondent listed their health status as a barrier to participation in educational programmes and, rather surprisingly (in contrast to the 'too tired' item) in this respect we found no difference between the younger and older respondents.

Regarding the format of the educational programme, longer-lasting interventions with a higher number of sessions are generally considered more effective (Brodaty et al., 2003; Huis in Het Veld et al., 2015). At the time of data collection (2019), existing educational programmes had different forms, from stand-alone workshops through day-long courses, to open or closed groups meeting once a week. One of the providers, the Czech Alzheimer Society, piloted three different formats of psychoeducation for dementia caregivers in 2014, all with identical content: a standard course (six meetings of two hours a week), an intensive course (two meetings, each six hours long), and an online course (also lasting twelve hours). A total of 37 participants registered and 22 completed a course. The most highly attended was the intensive course, which was completed by over 80% of participants. Lowest attendance was in the online course, which was completed by less than one-half of participants (unpublished internal report of the Czech Alzheimer Society).

Therefore, in our survey we focused only on in-person forms of education. Participants indicated a highest preference for consultations and one-day courses. Preference of other formats was age-dependent: younger participants more frequently opted for consultations in their home environment, support groups, or meetings together with care recipients. The least preferred format was a multiday course, which was only chosen by 19% of respondents; more frequently by younger caregivers (see Fig. 4).

Practice recommendations

The need for a wide range of projects aimed at educating informal caregivers is reflected in the Czech National Action Plan for Alzheimer's Disease and Other Similar Diseases 2020–2030 (Ministry of Health of the Czech Republic, 2021, p. 57). To meet the target of supporting forms of education which correspond to the real possibilities and needs of informal caregivers, it has been suggested that education intended for them ought to be located as close as possible to where the care is provided. It has also been proposed that follow-up centres should be established to provide long-term individualised support to people with dementia and the families who care for them. Moreover, a recent European review study pointed out that "only two out of 15 countries – Austria and the Czech Republic – do not report interventions to support informal caregivers through public campaigns" (Tokovska et al., 2022). This could be an impulse to strongly support the growth of public awareness on topics related to dementia, including destigmatization, creating a dementia-friendly society, and psychosocial support and education for carers through campaigns. Another important area that needs to be further addressed is the care for dementia patients among refugees, especially since we have been witnessing large waves of migration due to the war in Ukraine. Due to their familial, cultural, or religious beliefs, as well as their perceived responsibilities, people with dementia, their informal caregivers, and even professionals often assume that caregiving tasks will be solved within the family or the community (Duran-Kiraç et al., 2022). Yet, psychosocial support for immigrants in the Czech Republic is novel territory that awaits thorough examination and solutions.

Conclusions

The main finding of our survey pertains to the differences between the younger sample of caregivers (who were in almost all cases providing intergenerational care) and the older caregiver sample. These differed both in what they experience as barriers to participation in psychoeducational programmes and in their preferences regarding the format of the programme.

In general, our results show that dementia caregivers are a heterogeneous group and their different situations and consequent needs ought to be taken into consideration – in relation to the research, planning, and creation of suitable support interventions.

Limitations

We addressed informal dementia caregivers via specialised centres. Therefore, our study does not include people who are yet to contact any support services. On the other hand, it is difficult to find such people and we are not aware of any efforts of this kind being undertaken in the Czech Republic.

For the same reason (access to counselling centres for family caregivers), our sample is characterised by an overrepresentation of people who live in large towns, where the possibility of participation in support programmes for relatives is greater than in smaller town and rural areas.

Our study is also limited by the relatively low sample size and the limited range of demographic information collected. Also, the low representation of men in our sample did not allow us to analyse gender differences in more detail.

It is important to note that the survey took place before the start of the Covid-19 pandemic and its associated restrictions, which led to a rapid increase in familiarity with online communication in the Czech population. Thus, the transfer of educational programmes to the online environment is a subject that is yet to be investigated in the Czech Republic.

Ethical statement

This study was carried out according to the Data Protection Regulations (GDPR) and the Helsinki Declaration (2013). The questionnaire survey was anonymous and voluntary. Participants received written information about the objectives and relevance of the study and the data processing, including guarantees of anonymity and confidentiality of any data they provide.

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Conflict of interests

The authors have no conflict of interests to declare.

Bariéry účasti na vzdělávacích programech pro rodinné pečovatele o osoby s demencí

Souhrn
Úvod: V České republice, stejně jako v jiných evropských zemích, jsme svědky rozšiřování programů pro rodiny, které pečují o své příbuzné s demencí.
Cíl: Cílem naší studie bylo zjistit, zda mají pečovatelé o takovéto psychoedukační programy zájem, jaké bariéry jim brání v jejich využívání a jakou formu programů by preferovali.
Výsledky: Našeho dotazníkového šetření se zúčastnilo 85 dospělých, kteří pečovali o člena rodiny s demencí. Výsledky ukázaly souvislost mezi věkem respondentů a jejich ochotou a schopností účastnit se psychoedukačních programů. S přibývajícím věkem zájem o takové programy klesal. U starších respondentů, především poskytovatelů partnerské péče, byla nejčastější překážkou nemožnost nechat ošetřovaného samotného doma. Preference týkající se formátu psychoedukačních programů byly také závislé na věku: mladší účastníci preferovali podpůrné skupiny, konzultace ve svém vlastním domě a společné setkání s příjemcem péče více než starší pečovatelé, kteří měli tendenci preferovat „tradiční“ formy vzdělávání (konzultace nebo psychoedukační kurzy).
Závěry: Naše výsledky ukazují, že je neproduktivní usilovat o jedinou „ideální“ formu psychoedukačního programu, která by vyhovovala všem. Místo toho by nabídka měla odrážet rozdílné požadavky skupin pečovatelů.

Klíčová slova: bariéry; demence; neformální péče; preference; psychoedukace

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