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Family caregivers in primary care: a survey of German general practitioners on procedures and problems experienced in day-to-day practice

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Abstract

Background By providing both assistance and support, GPs can play a central role for family caregivers. By catering to the needs of caregivers, they are capable of stabilising in-home care settings over the long term. The aim of the present study is to provide a status quo analysis of how GPs assess their options for supporting individuals providing care, as well as the focal points set by their practice, and their estimation of obstacles and challenges encountered in day-to-day practice.
Method An online questionnaire was used to survey a total of 5112 GPs in North Rhine-Westphalia between April and November 2022 (response quota: 46%). A heterogeneous random sample was obtained (58% male, 42% female; average age: 57; 50% medium-sized town/city practice, 50% rural/small town practice). To determine significant differences between two groups, a t-test was used with independent random samples. Answers to free-form questions were analysed using a subsequent coding based on a qualitative content analysis.
Findings A total of 70% of respondents have frequent contact with family caregivers. Some 79% consider GPs to be well-suited to the role of primary contact point for caregivers and coordinating care. GP-carer support relationships typically arise as a result of caregivers approaching GPs (90%). Topics frequently addressed involve a worsening of the care situation (77%) and changes in the care needed (86%); consultations in the initial phase of the care situation are less common (44%). While respondents perceive a complex constellation of needs on the part of family caregivers, differences in priorities are observable between GPs in urban and rural environments (involvement of consultant/support network versus proactive and psychosocial assistance). GPs experience a wide range of challenges in providing assistance to caregivers, including the timely organisation of appropriate relief programmes (87%), referring caregivers to suitable help services (80%) or the early identification of informal caregivers (60%).
Discussion In order to strengthen the GP role, the practice team should talk to caregivers as early as possible, and refer them to suitable help and support programmes. To achieve effective support for successful care, it is important to cater equally to the needs of the persons giving and receiving care as part of the caregiver-care receiver-GP triad.

Abbreviation

GP(s)	General practitioner(s)

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1 Introduction

Twenty-one percentage of the population in the 27 countries of the European Union are now 65 or older [1, 2]. This is driving a growing need for care and support services. For Germany, this need is expressed in the figure of roughly 4.1 million people formally recognised as needing care [3]. If informal and unpaid support/care activities are also included, this figure rises to approximately 5.5 million people [4, 5].

Informal in-home care services are primarily provided by private caregivers, who shoulder a substantial part of the caregiving and support required by those of their close friends and relatives who are dependent on care services [6–8]. According to representative data, more than 17% of people aged 40–85 help at least one person manage their day-to-day lives; of these, at least one in three provide care as understood in a formal sense [9, 10].

Although studies have demonstrated that caring for an individual can be a subjectively rewarding experience [11, 12], the physical and psychological stress involved is associated with elevated health risks [10, 13–15]. Complaints such as exhaustion and depression-like symptoms are therefore commonly found among caregivers [8, 16–18]. Caregivers may also find themselves unable to cope in situations where the consequences of the illness have not been clarified beforehand and precautionary measures therefore not adopted [15].

A wide range of support services have been established to avoid such crises and to promote the long-term resilience of caregivers. In Germany, these include carer support services, outpatient psychiatric services and dementia networks, for example. However, studies have shown that such services are utilised by only a subset of individuals providing care [19, 20].

As a result of the continuous support provided and long-standing relationship, GPs are considered well-placed to provide assistance to in-home care settings and address the specific needs of family caregivers [6, 21–23]. Apart from the diagnosis and treatment of health complaints, GPs can also provide information and advice when talking to caregivers, offer psychosocial support, and establish a detailed picture of the care situation, so as to ensure that needs can be addressed in good time. By referring caregivers to help and advisory services, GPs can establish a foundation for successful care over the long term, while also informing caregivers about compensation and relief programmes [19, 24].

Since the status of an informal caregiver is often poorly defined, the general practice team may find it challenging to identify family caregivers at an early stage in care provision [7, 22]. Difficulties arise if the person cared for is not registered at the practice where the family carer is themselves a patient [10]. In these cases in particular, GPs may primarily perceive the needs of the person receiving care [25, 26] while being less aware of the burden borne by the family carer [21].

A survey conducted among members of the Federal Association of Public Health GPs (KBV) found that approximately 60% of family caregivers talk to their GP about their care activities [23]. In terms of the degree and nature of support provided by GPs, as well as carer support requirements, there is currently a lack of robust studies for German-speaking countries. Conducted in 2020, an online survey of a total of 612 caregivers that was posted to 17 internet forums dealing with the subject of care [27] revealed that a significant majority of caregivers had a positive opinion of their GP's knowledge of the care situation, the availability of their GP for care-related issues and the attention paid to the carer by the GP. Roughly half of respondents stated that they had received information about advice and help services from their GP; a similarly large proportion also said that they felt their GP had identified and involved them as the carer at an early stage. The results of a regression analysis show that the stated aspects are significant impact factors for a subjective feeling of satisfaction with the level of support provided by the GP as well as the feeling of being able to manage the care situation.

To date, German-speaking countries in particular have lacked studies that provide general insights into the approaches and strategies adopted by GPs in relation to the family carer target group as well as the challenges experienced. The present study therefore aims to provide a basic status quo analysis of how GPs assess their options for supporting family caregivers, as well as the focal points that they set while doing so in their practice.

1.1 Research interest and aim of study

This work is part of an explorative, multipart study that focuses on the viewpoints of family caregivers and GPs in relation to the potential for support offered by primary care practitioners. By considering various perspectives held by the two groups, the aim is to derive approaches to optimising the level of care offered by GPs. The research interest of this partial study can be expressed primarily as answering the following questions:

- How do GPs see their personal significance as contact persons for caregivers? How would they assess their options for providing effective support to caregivers?
- How can the various support and assistance networks be described in their handling of family caregivers?
- What needs for advice and assistance on the part of family caregivers are perceived by GPs? Which priorities do they set when offering support?
- To what extent do GPs experience challenges in supporting caregivers?
- To what extent do GPs make use of options for standardisation and maximising effectiveness when providing support to caregivers?
- What improvement strategies can be derived for the GP setting?

2 Material and methods

2.1 Study design

The study to be presented here consists of an independent investigation in the wider contextual framework of a model project looking at outpatient medical and nursing dementia care, funded for a period of three years by an innovation fund (*DemStepCare*, Proposal-ID: 01NVF18027) [28, 29]. The primary focus here is on the optimisation of GP-based dementia care. The *DemStepCare* model project has been approved by the Institutional Review Board of the Rhineland-Palatinate State Medical Council (reference number: 2019-14427).

The investigation that is the subject of this article was preceded by the aforementioned online survey of family caregivers [27], which aimed to identify the needs for assistance relating to primary care provision and experience of the same. In comparison, the present work intends to record the approaches and experience of GPs in terms of supporting caregivers, and to assess the extent to which the findings of the preceding survey can be confirmed from a GP perspective. The choice was made to conduct an online survey with a written invitation to participate sent by post.

2.2 Development of survey instrument

An independent survey instrument (see Supplementary file) was developed, supported by a number of elements:

- Preparations for a multipart study series (including interviews with family caregivers in the context of *DemStepCare*, focus group of eight GPs)
- Design and findings of the online survey of family caregivers [27]
- Other preceding studies by the authors on dementia care, in which the topic of family care is accounted for (e.g. [30])
- General literature review

The literature review consulted works whose central point of focus addressed family caregivers and their (potential) support in a GP-based setting [12, 17, 19, 22, 24, 26, 31], including work published by Geschke et al. [19], Greenwood et al. [22, 26] and Joling et al. [17]. Before its use in the field, the questionnaire was also pretested by a group of 20 GPs.

The aim was to partially adapt the questionnaire that had been given to family caregivers, so as to ensure that the findings could be compared with one another. Sociodemographic attributes surveyed included age, gender, general practice type, patients per quarter, practice environment and relevant additional/further qualifications.

With the exception of a number of free-form questions, the online survey worked almost exclusively with required questions, which had to be answered before continuing with the survey. This choice was made to ensure that the dataset obtained would be as complete as possible—something not always assured with a traditional written/postal survey format.

2.3 Recruitment and participants

Between April and November 2022, all 11,133 GPs registered as primary care practitioners in North Rhine-Westphalia received a written invitation by post to participate in the anonymised online survey. North Rhine-Westphalia was chosen not only as the German state with the largest population by a large margin but also because it is highly heterogeneous in terms of the sociodemographic distribution of its GP and patient groups. The letter was a one-shot mailing, in which the GPs to be surveyed were also provided with password-protected credentials for the online survey (no incentives were offered).

2.4 Data analysis

The data were analysed using SPSS 23.0. We used a t-test for independent random samples to analyse for any significant differences between the two groups, assuming significance at values of $p \leq 0.001$. The Likert-scaled scale gradings used were partially consolidated for the presentation of findings. Answers to free-form questions were analysed using a subsequent coding based on a qualitative content analysis [32]. As part of reviewing the responses, a category system was developed, which was iteratively assessed and modified as necessary as analysis proceeded. The following sections also present selected quotes given by GPs as answers to the free-form questions.

3 Results

3.1 Random sample

Of the 5203 surveys processed, 5112 survey forms completed in full were used for the analysis (response quota: 46%). The random sample is structured as follows:

- Gender: 58% male, 42% female
- Average age: 57 (median: 56)
- Practice environment: 50% medium-sized town/city, 50% rural/small town (according to general statistics in the Federal Republic of Germany, a rural town has less than 5000 inhabitants, a small town 5000 to 2000 inhabitants, a medium-sized town 20,000 to 100,000 inhabitants, and a city at least 100,000 inhabitants)
- Practice type: 55% single-handed practice, 45% group practice
- Patients per quarter: 26% < 1500, 35% 1501–2000, 39% > 2000
- Further qualifications/additional qualifications: 8% palliative care, 7% social medicine, 2% psychotherapy, 18% geriatric medicine

3.2 Informational and advisory role for family caregivers

A total of 79% of respondents were of the opinion that GPs play a (highly) significant role as contact persons for issues relating to providing in-home care. As revealed by answers to a free-form question, reasons given for this included the primary care role, combined with long-standing knowledge of patients and their dependants. A total of 70% stated that they are in (very) frequent contact with family caregivers in day-to-day practice (30% 'Occasional'). While 29% stated that the number of family caregivers had increased sharply in recent years, 50% stated that the increase was only moderate (21% 'Stayed the same').

> "Family caregivers always come to us for support in the practice – and their numbers are increasing. This isn't just a result of demographic change. […] Apart from psychosocial support, it seems to me that these individuals are primarily looking for basic guidance here. The German healthcare and nursing system is a bit of a jungle, in which you can easily lose your way." (Response of one GP to a free-form question.)

According to respondents, the dialogue between GPs and family caregivers generally results from the latter broaching the issue with the former because they either need advice or have questions about organising care (90% 'Very often'/'Quite often'). In contrast, 45% state that this initial conversation results from the GP (proactively) approaching caregivers directly (e.g. as a result of identifying a care situation, initiating a medical history interview/assessment of the care situation). Some 58% state that the topic of care often comes up in another context—such as a medical check-up.

> "A systematic approach to dialogue with family caregivers is hardly possible in day-to-day practice. Accordingly, we have to assume that people will approach us and raise the issue themselves. This naturally creates a situation where we do not talk to individuals who remain silent, and do not bring up the worries and problems, etc. that they have about providing care." (Response of one GP to a free-form question.)

According to respondents, the person being cared for is typically a long-standing patient of the practice (84% 'Very often'/'Quite often'). Some 56% also state that the caregiver is often a long-standing patient of theirs. The consultation with the GP about care predominantly involves topics such as changes to care needs (86%), a worsening of the care situation or adaptation to new circumstances (77%) as well as physical and/or psychological complaints (70%). More rarely, caregivers want to talk about changes in the relationship with the person requiring care (50%) and the start of care, including the preparation and planning of in-home care (44%).

3.3 Perceptions and priorities in relation to the needs of family caregivers

Table 1 contrasts the support needs for caregivers as perceived by respondents contrasted with the priorities as expressed by GPs for their own provision of support. In the latter case, respondents were asked to select a maximum of six items, with the aim of clarifying the primary points of focus set by practices. The results indicate that GPs perceive a multidimensional range of needs on the part of caregivers, which are primarily consolidated into an individually tailored, competent and personally calibrated package of support. While GPs with practices in small towns/rural areas see the wishes and expectations of caregivers as being best served by a package of proactive, collaborative and psychosocial support, also including house calls, GPs in urban settings see their role rather more as delegators, referring caregivers to professional support services and consultants. Notably, practices with qualifications in geriatric medicine inform caregivers about advisory/support services or refer them to these services considerably more often.

> "The most decisive factor here is our accurate and relevant knowledge of the in-home care situation. Everything depends on this. Ideally, we would then identify the needs of the carer themselves, and put together a suitable package of support and relief services. This might sound simple in theory, but, in day-to-day practice, a reliable assessment of the carer's needs and the provision of suitable services are both rather difficult to achieve." (Response of a GP to a free-form question.)

3.4 Challenges experienced

In providing support to caregivers, GPs see the organisation of timely relief services to avoid care situations turning into crises as challenging; a comparable situation exists in terms of the identification and procurement of appropriate help programmes (cf. Table 2). Also problematic is ensuring enough time can be scheduled to address the often complex stresses experienced by family caregivers, as well as ensuring the early identification of and dialogue with caregivers. Some of the challenges stated are perceived as considerably less burdensome by practices with qualifications in geriatric medicine.

> "To ensure a good level of support for family caregivers, I think it is simply necessary to make used of evidence-based instruments such as guidelines and follow a process of continuing professional development. In a great many cases, this necessarily requires the acquisition of expertise in geriatrics." (Response of a GP to a free-form question.)

3.5 Acting within help and support structures

Respondents were asked to give an estimate of the number of families they had advised in recent years in terms of providing them with information about or a referral to specific help services. Some 18% of respondents stated that they had provided 60% or more of families with information about such services; 30% gave 'about half' as the figure (29%: 33–50%, 8%: 33% or fewer). While 38% of urban GPs stated that they had informed 60% or more of families about support structures, this figure was just 16% for rural GPs ($p < 0.001$). This proportion was 48% for practices with qualifications

Table 1 Perceived needs for support contrasted with support priorities (N = 5112)

Carers think that it is important that their GP…	Very important/quite important Overall (%)	Very important/quite important Urban GP practices vs. rural practices	Very important/quite important GPs with vs. without geriatric medicine qualification	In providing assistance to family carers, I consider it especially important that their GP…	Selected (max. 6 points could be specified) (%)	Urban GP practices vs. rural practices	GPs with vs. without geriatric medicine qualification
…refers the persons giving and receiving care to relevant consultants	98	98%/98%	98%/98%	…refers the persons giving and receiving care to relevant consultants	72	81%/65%*	69%/73%
…offers explanations to the person receiving care so as to clarify their condition and thereby provide further support for the activities of the carer	95	94%/96%	99%/94%	…offers explanations to the person receiving care so as to clarify their condition and thereby provide further support for the activities of the carer	16	14%/18%	10%/18%
…involves the person needing care in decision-making and accommodates their wishes	95	95%/95%	95%/95%	…involves the person needing care in decision-making and accommodates their wishes	22	13%/29%*	21%/22%
…is familiar with their personal caregiving situation	95	90%/99%	99%/94%	…is familiar with the personal caregiving situation	75	75%/75%	53%/80%*
…knows a lot about the day-to-day life and challenges faced by family carers, is well-versed in the subject and has expertise in this field	91	98%/85%	99%/89%	…knows a lot about the day-to-day life and challenges faced by family carers, is well-versed in the subject and has expertise in this field	32	31%/33%	51%/26%*
…not only sees the needs of the person requiring care but also the viewpoints, needs and burden placed on the carer themselves	91	87%/94%	98%/89%	…not only considers the needs of the person requiring care but also the viewpoints, needs and burden placed on the carer themselves	11	8%/12%	5%/12%

Table 1 (continued)

Carers think that it is important that their GP…	Very important/quite important Overall (%)	Very important/quite important Urban GP practices vs. rural practices	Very important/quite important GPs with vs. without geriatric medicine qualification	In providing assistance to family carers, I consider it especially important that their GP…	Selected (max. 6 points could be specified) (%)	Urban GP practices vs. rural practices	GPs with vs. without geriatric medicine qualification
… considers themselves an authority for issues faced by family carers, and provides advice and assistance to carers if they encounter difficulties	91	87%/96%	98%/89%	…considers themselves an authority for issues faced by carers, and provides them with advice and assistance if they encounter difficulties	34	32%/36%	20%/37%*
…issues a diagnosis in good time, so as to establish clarity, and so that the persons giving and receiving care can prepare for future developments	90	92%/88%	99%/89%	…issues a diagnosis in good time, so as to establish clarity, and so that the persons giving and receiving care can prepare for future developments	11	9%/13%	5%/12%
…gives the carer time to think about key decisions needing to be taken about caregiving	85	85%/85%	100%/82%*	…gives the carer time to think about key decisions needing to be taken about caregiving	20	24%/16%	21%/19%
…takes decisions together with the carer on the care provided to individuals needing care	85	84%/86%	99%/82%	…takes decisions together with the carer on the care provided to individuals needing care	14	8%/21%*	15%/13%
…encourages the carer to raise the question of their own health needs	85	76%/94%*	100%/82%*	…encourages the carer to raise the question of their own health needs	4	2%/7%	15%/2%

Table 1 (continued)

Carers think that it is important that their GP…	Very important/quite important Overall (%)	Very important/quite important Urban GP practices vs. rural practices	Very important/quite important GPs with vs. without geriatric medicine qualification	In providing assistance to family carers, I consider it especially important that their GP…	Selected (max. 6 points could be specified) (%)	Urban GP practices vs. rural practices	GPs with vs. without geriatric medicine qualification
…advises the carer about local help and assistance programmes for supporting carers (e.g. short-term care, carer support services)	84	96%/72%*	99%/82%	…advises the carer about local help and assistance programmes for supporting carers (e.g. short-term care, carer support services)	29	48%/14%*	58%/21%*
…conducts regular observations over time to determine how the physical and/or psychological condition of the person requiring care develop(s)	81	81%/81%	99%/75%	…conducts regular observations over time to determine how the physical and/or psychological condition of the person requiring care develop(s)	28	28%/28%	15%/30%*
…has the carer 'on their radar' in good time and therefore knows that someone is responsible for caring for the dependant	80	81%/79%	88%/79%	…has the carer 'on their radar' in good time and knows early on that someone is responsible for caring for the dependant	2	4%/1%	9%/1%*
…supports the provision of/actively provides treatment to the carer	75	69%/81%*	92%/73%*	…supports the provision of treatment to the carer, treats the carer	30	23%/40%*	42%/27%*
…provides carers with emotional support for their caregiving, e.g. by giving assurances	74	61%/86%*	96%/69%*	…provides carers with emotional support for their caregiving, e.g. by giving assurance	13	11%/13%	6%/14%

Table 1 (continued)

Carers think that it is important that their GP…	Very important/quite important Overall (%)	Very important/quite important Urban GP practices vs. rural practices	Very important/quite important GPs with vs. without geriatric medicine qualification	In providing assistance to family carers, I consider it especially important that their GP…	Selected (max. 6 points could be specified) (%)	Urban GP practices vs. rural practices	GPs with vs. without geriatric medicine qualification
…conducts house calls to relieve the burden on the carer while also obtaining a picture of the person needing care in their home environment	68	51%/85%*	68%/69%	…conducts house calls to relieve the burden on the carer while also obtaining a picture of the person needing care in their home environment	6	6%/7%	1%/7%
…does not wait until the people providing care raise issues themselves but proactively addresses these topics	67	55%/80%*	99%/59%*	…does not wait until the people providing care raise issues themselves but proactively addresses these topics	3	5%/1%	11%/1%
…advises the carer on legal aspects (e.g. medical proxies, assistance, 'taxi service')	56	65%/47%*	65%/54%	…advises the carer on legal aspects (e.g. medical proxies, assistance, 'taxi service')	3	6%/1%	11%/1%*
…recommends support and assistance programmes to the carer	49	61%/36%*	55%/48%	…recommends support and assistance programmes to the carer	15	26%/6%*	59%/4%*

Note on significance: *p = 0.001

Table 2 As a GP, providing support to family caregivers can involve a number of challenges

	Very severe/ severe Overall (%)	Very severe/ severe Urban GP practices vs. rural practices	Very severe/severe GPs with vs. without geriatric medicine qualification
Prompt availability of relief programmes (e.g. short-term/daytime care, psychosocial programmes)	87	80%/93%	72%/93%*
In the event of a sudden deterioration in the condition of the person receiving care, offering relief options promptly to avoid any destabilisation of the care situation	86	82%/90%	81%/89%
Locating individual, tailor-made support, assistance and relief programmes in the local environment	80	70%/90%*	54%/86%*
Allowing sufficient time for providing advice to family caregivers	70	76%/65%	44%/76%*
Early identification of and communication with caregivers	60	58%/62%	43%/65%*
Provision of legal advice to caregivers	55	53%/57%	24%/61%*
Ensuring the needs and wishes of the persons giving and receiving care are catered to equally	44	46%/42%	12%/55%*
Ensuring regular dialogue (e.g. because the person receiving care is registered with another GP and there is thus no automatic occasion for dialogue)	43	47%/38%	26%/47%*
Ensuring assessments of the concrete needs/problems of the person requiring care are made as promptly as possible	26	23%/30%	6%/31%*
Ensuring caregivers know about compliance	10	12%/8%	2%/10%

Please specify in each case the severity of the following challenges, in your opinion (N = 5112)

Note on significance: *p = 0.001

in geriatric medicine and 24% for other practices ($p < 0.001$). Services most commonly the subject of referrals included first and foremost care and nursing homes (74%), and local daytime/short-term care services (65%), followed by general care services and community centres (58%), programmes for day-to-day support (47%), and care counselling and carer support services (42%).

Some 42% of GPs stated that they were familiar with the interdisciplinary S3 guideline 'Family caregivers' (published by the German College of General Practitioners and Family Physicians, DEGAM), which focuses on providing GP-compliant, evidence-based support for this target group (58% not familiar). Of these, 55% stated that they applied the guideline on a frequent or occasional basis (44% 'Rarely'). Some 28% of rural GPs stated they were familiar with the 'Family caregivers' guideline, with the figure being 55% for urban GPs ($p < 0.001$).

Some 48% of respondents have staff in their own practice who are not part of the medical practice team, who nonetheless provide routine support to GPs in assisting family caregivers (e.g. as a result of having attended relevant further training courses). Of this group, 84% state that these individuals help with the identification of caregivers and initiating dialogue; 43% state that they provide general advice, e.g. with questions of organising care ($p < 0.001$). Some 82% of practices with qualifications in geriatric medicine state that they involve practice staff in support provided to family caregivers, compared with 39% of other respondents ($p < 0.001$).

> "It all comes down to our practice team: my staff are my eyes and ears, and can really help to reduce my workload. This is why I invest in my staff by providing them with a range of further training. If you then add good practice management into the mix, you can set things up so that family caregivers and their needs can be better identified—and also provided with a better level of support." (Response of a GP to a free-form question.)

Other results show that, in some cases, practices who integrate their personnel into the handling of the topics involved may then experience fewer challenges in providing support to caregivers. Of the GPs who adopt this collaborative approach, 49% consider it a major challenge to identify caregivers at an early stage—compared with 67% of GPs who do not adopt this approach ($p < 0.001$). Of those who include practice staff in the process of providing support to caregivers, 32% describe ensuring a continuous dialogue with caregivers as demanding—compared with 52% of other practices ($p < 0.001$). Some 9% of collaborative-minded GPs experience making a prompt and immediate estimation of caregivers' problems and needs as fairly challenging—compared with 42% of other respondents ($p < 0.001$).

3.6 Summary of support offered to family caregivers and proposed optimisations

In summary, 49% of respondents state that their accommodation of the needs of family caregivers in day-to-day practice is (very) good (51% 'Not so good' and 'Not good at all'). Within healthcare as a sector, the options and structures made available to GPs for providing high-quality support to family caregivers are rated positive by 42% and negative by 54% of respondents. A frequent point of criticism expressed in answers to free-form questions was the lack of adequate inter-professional structures (interdisciplinary dialogue, inpatient facilities for palliative care) as well as red tape.

> "In our healthcare sector, doctors and other medical practitioners are all at each other's throats. In the case of an interface topics such as care or organising care, this immediately becomes noticeable—to the detriment of the family caregivers. […] We need overarching structures—not only patients but we as GPs need to be more aware of whom we can turn to, and, naturally, the relevant processes need to work more quickly and more smoothly as well. But take a look at the rural situation: no matter where you look, there is nowhere and no-one to whom I can send family caregivers for advice and support." (Response of a GP to a free-form question.)

At the end of the survey, participants were presented with two statements that had been articulated in the course of preparing the multipart study, in the context of a focus group of GPs (cf. Table 3). In the sense of providing an overall assessment, it was observed that the vast majority of respondents did consider the GP setting as the primary point of contact for the needs of caregivers. However, many respondents felt restricted by the current general circumstances when it came to taking a more active and present role for the abovementioned target group.

Responding to a free-form question on this topic, some respondents expressed a wish to strengthen the involvement of GPs in community healthcare structures, and for closer cooperation within the inter-professional network, which would make it easier to see the bigger picture and make referrals. Respondents also expressed an interest in health insurers providing systematic and consistent support for family caregivers, and therefore underpinning the work done by GPs. Interest was also expressed in the creation of a formal support programme, in which family caregivers could be

Table 3 Here are two statements that were made by GPs in the course of an earlier interview study

	Yes, absolutely/yes, more or less Overall (%)	Yes, absolutely/yes, more or less Urban GP practices vs. rural practices	Yes, absolutely/yes, more or less GPs with vs. without geriatric medicine qualification
"GPs should be considered the primary point of contact for handling the needs of caregivers and should systematically coordinate the provision of care."	75	72%/84%	76%/78%
"I would like to have a more significant and participative role for family caregivers but cannot do so as a result of the general circumstances at the moment."	61	52%/69%*	52%/68%*

Would you agree with these statements? (N = 5112)

Note on significance: *p = 0.001

registered by GPs, and which would secure the continuous provision of information and advice—and, where necessary, intervention measures—by means of an individual risk stratification system.

> "We need corresponding structures on a local basis in order to provide family caregivers with a consistent system of advice and help. In some regions, there are the dementia networks, for example, and I have enjoyed working with these. But we are very far away from having these kinds of structures—and even less so in rural regions. And even when we have them in place, we GPs need to know to whom we can refer our patients and dependants. So this means we need background knowledge and a good overview of the topic." (Response of a GP to a free-form question.)

4 Discussion

4.1 Principal findings and comparison with prior work

The results of the survey show that GPs consider the general practice setting to be a central support and care instance for family caregivers. A large majority of respondents state that they frequently encounter individuals providing care in day-to-day practice and that numbers have risen in recent years. Often, GP-caregiver relationships arise as a result of family caregivers broaching the topic with the GP of the person requiring care; other dialogue initiation situations are rarer. The most common topics raised here involve a worsening of the care situation and changes in the level of care needed; in comparison, consultations are less commonly sought in the initial and preparatory phase of care.

While respondents perceive a complex constellation of needs on the part of family caregivers, differences in priorities are observable between GPs in urban and rural environments. Accordingly, rural practices place a greater emphasis on proactive, collaborative and psychosocial support, while urban practices focus more on the consultant/support network that is more accessible in these regions. Notably, practices with qualifications in geriatric medicine are likely to refer caregivers to advisory/support services more often.

In answering questions about the various challenges faced, respondents state that the provision of comprehensive support to family caregivers can be demanding in day-to-day general practice, especially in consideration of the organisation of prompt relief services to avoid crises in care provision, in procuring appropriate help services or in the early identification of informal caregivers. Significantly, many challenges are perceived as less burdensome by practices with qualifications in geriatric medicine. This can be seen in the context of the fact that appropriately qualified GPs seek out cooperation with inter-professional actors for both caregivers and those receiving care to a significantly higher degree, and involve their practice staff more closely in the provision of support to family caregivers.

Overall, the study findings reflect the results of the preceding online survey [27] as well as other surveys, which indicate that GPs play a significant role for family caregivers as a group [6, 20–22, 25, 33–35]. Both family caregivers and GPs themselves view the general practice setting as offering major potential for addressing the problems that are faced by caregivers [7, 14, 23, 24, 33]. In Ireland, for example, an interview study completed with caregivers emphasised the primary role played by GPs in situations involving the development of longer-term coping and resilience strategies within in-home care settings [34]. For their part, Greenwood et al. [26] were able to establish that the general practice setting can assume the role of a central provider in terms of supporting specific groups of caregivers and can effectively coordinate the procurement of other care services.

As the present study has also shown, other studies conducted on the topic have highlighted weaknesses in the provision of primary care. Qualitative survey studies have shown that GPs consider the provision of support to family caregivers as being an important part of their work—although, owing to a lack of time and resources, GPs are not always able to comprehensively accommodate the needs of these in-home care situations [6, 36]. As Höppner et al. [31] and others have shown, GPs do fulfil their roles as advisors on the organisation of care in particular, and as primary sources of information about illness and outcomes. In contrast, the physical and psychological stress experienced by family caregivers is less of a priority for discussion or treatment [21, 25, 26]. In this regard, the research literature notes a tendency to view family caregivers primarily in the context of the person receiving care, whereby the psychosocial impacts become marginalised [31, 37]. As several authors have noted, achieving effective support for successful care depends on catering equally to the needs and stresses of the persons giving and receiving care as part of the caregiver-care receiver-GP triad [24–26, 33, 38].

Another problem that is reflected in the survey results concerns the identification of persons providing care [36]. The findings of the qualitative investigations conducted by Burridge et al. also reveal that caregivers do not always have the confidence to raise these issues if GPs do not advertise themselves as a contact point for such problems [25, 39, 40]. GPs, in turn, are often unsure of being able to accurately identify informal caregivers as such in their practice [22]. For family caregivers to be able to articulate their issues and problems, they need to be informed at an early stage that their GP is indeed qualified to give them the support that they need.

Furthermore, only some of the GPs surveyed were familiar with guidelines on the topic; in addition, only some of the practices surveyed involve their staff in the support provided to caregivers. A focus group study from Krug et al. [41] shows that practice staff are often not systematic in identifying dependants and the burdens they are dealing with but merely respond to symptoms of being unable to cope—this is therefore related to factors such as further training and practice organisation [31].

The online survey of family caregivers [27] has shown that caregivers wish to see general practice taking a more significant role as a source of information and referrals for help services. This corresponds with the findings of the present survey, since only some of the GPs there make use of systematic referrals to services intended to provide caregivers with support or relief. These results are confirmed by Parmar et al., for example, who conclude that the needs of persons both giving and receiving care for early and systematic referrals to professional support and relief services are not always addressed by their GPs [42]. In cases where family caregivers are referred to these kinds of support programmes, they receive timely access to information about organising care [8, 33], which enable the persons being cared for to remain in a home environment for longer without care crises (e.g. hospitalisations) arising [19, 40, 43]. This lack of a consistent practice of referrals to help networks corresponds with the finding that GPs often lack an adequate overview of external support formats for caregivers [19, 24] and are rarely integrated as part of community-run, structured healthcare networks [35, 44]. In light of this fact, it is important to strengthen interdisciplinary, cross-sectoral communication and to establish (in)formal corporative networks.

4.2 Strengths and limitations

The study exhibits several limitations, which should be borne in mind accordingly:

- Limited sample size and limited response rate
- Regional recruitment focus, namely in three districts (Westphalia, the northern part of the Rhineland, and East-Westphalia Lippe)
- Possibility that the GPs participating in the interviews are more tech-savvy and/or have an interest in the topic itself (this is suggested by the high proportion of GPs with qualifications in geriatric medicine)
- Although we have recruited the GPs in a region of a heterogenous population, the possible impact of this factor was not explored (GPs characteristics do not include the question e.g. about socially deprived populations or ethnical minorities)

Even so, the selected method approach and heterogeneous random sample permit statements to be made that reflect the broader GP population. With 5,112 completed survey forms, a considerable response rate of 46% was reached (e.g., a recent meta-analysis concerning response rates of online surveys by Wu and colleagues reported an average response rate of 44%, see [45]).

5 Conclusion

GPs can play a vital role in providing support to family caregivers, providing them with both encouragement and assurance in relation to the organisation of in-home care. The majority of GPs surveyed value the support provided to caregivers and are aware of the key role that they play in providing assistance to this target group. Even so, there are several challenges that arise, which result in GPs not always being able to fully address the needs of caregivers as part of day-to-day practice [44]. These challenges include the organisation of prompt relief services to avoid care situations developing into crises, the procurement of appropriate help services and the early identification of informal caregivers.

By catering to the needs of caregivers, GPs are capable of stabilising in-home care settings over the long term and preventing cases of 'burnout' affecting these caregivers. To this end, family caregivers need to be identified and engaged with at an early stage. In addition, it is important to cater equally to the needs, wishes and burdens of the persons giving and receiving care as part of the caregiver-care receiver-GP triad.

Alongside the active involvement of practice staff, a key instrument for increasing the effectiveness of GP-based support for family caregivers consists of an improved and more systematic intermeshing of GPs with professional advisory and support services, such as carer support services, outpatient psychiatric services and dementia networks. Ensuring that patients and dependants are introduced to these kinds of help networks in good time decisively promotes the maintenance of a good quality of life for all concerned.

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Data availability All major data generated or analysed during this study are included in this published article. Additional information can be provided on request made to the corresponding author.

Code availability Not applicable.

Declarations

Ethics approval and consent to participate All methods were carried out in accordance with relevant guidelines and regulations. Since this is an anonymous survey of GPs on the status of the topic under discussion, the Ethics Commission of the State of Rhineland-Palatinate, Germany, informed us that approval by an ethics committee was not necessary. Written informed consent for participation was obtained from all participants before the start of the study. The respondents received information about the aim and purpose of the study and were informed that it was an anonymous survey in accordance with the existing data protection standards. Furthermore, it was made clear that the data will only be used for scientific purposes. The *DemStepCare* study received approval by the Ethics Committee of the State Chamber of Physicians of Rhineland-Palatinate (Reference number: 2019–14427). All participants (patients, caregivers, GPs, case managers) give written informed consent before any data is collected for the study. If there is a legal guardian, the legal guardian must give written consent in addition to the patient. All patients require a basic competency to consent, otherwise they cannot participate. This paper contains no data from tests conducted on humans or animals.

Consent for publication Not applicable.

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