

What are the Needs and Experiences of Family Caregivers with Regard to Primary Care?

Findings from a Qualitative Interview Study

Welche Betreuungsbedürfnisse und -erfahrungen haben pflegende Angehörige mit Blick auf die hausärztliche Versorgung?

Befunde einer qualitativen Studie

Julian Wangler, Michael Jansky

Background

Family caregivers face a variety of challenges. Family physicians (FPs) are in an excellent position to provide support and a stabilising influence in addressing the needs and expectations on support in this group. This study was intended to shed light on the attitudes, desires, and experience of family caregivers regarding support from primary care.

Methods

We recruited a total of sixty-eight family caregivers from seventeen German-language online care forums and conducted telephone interviews between August 2020 and June 2021. The investigation was aimed at family caregivers of all kinds. After transcription, a qualitative structuring (deductive) content analysis according to Mayring was conducted.

Results

Most interviewees see FPs as a major source of support with a high level of competence and trust. Family caregivers particularly appreciated the awareness that FPs have for personal care situations, approachability in a variety of issues, and support for patients in care. Nevertheless, in the perception of many interviewees, the FP identified and approached on the issue of family caregiving rather late in the day. From the interviewees' point of view, FPs do not always take the needs of relatives into account to the same degree as they do for those in care. The experience of the sample shows that only some FPs refer family caregivers to advice and support services.

Conclusions

Against the backdrop of the results, it can be stated that, overall, the experiences of family caregivers with FP support are positive and that regular contact with the FP is perceived as helpful and relieving. According to some of the interviewees, however, challenges and grievances occasionally occur, so that there is potential for improvement when it comes to consistently taking into account the needs, wishes and burdens of caregivers.

Keywords

caregivers; family practitioners; family doctors; identification; strain; needs; care; support

Hintergrund

Hausärzt*innen befinden sich in einer günstigen Position, um sich auf die Bedürfnisse und Wünsche Pflegender einzustellen und damit häusliche Pflegesettings zu stabilisieren. Ziel der explorativen Studie ist es, hausärztliche Betreuungsbedürfnisse und -erwartungen pflegender Personen zu beleuchten.

Methoden

Zwischen August 2020 und Juni 2021 wurden 68 telefonische Interviews mit pflegenden Angehörigen geführt, die über 17 deutschsprachige Online-Pflegeforen rekrutiert wurden. Die Studie zielte auf pflegende Angehörige aus allen Bereichen. Im Anschluss an die Transkription wurde eine qualitative strukturierende (deduktive) Inhaltsanalyse nach Mayring durchgeführt.

Ergebnisse

Die meisten Interviewten erachten den Hausarzt als zentrale Unterstützungsinstanz mit hoher Kompetenz- und Vertrauenszuweisung. Pflegende Personen schätzen v.a. das Bewusstsein für individuelle Pflegesituationen, die Zugänglichkeit bei verschiedenen Problemen sowie die Hinwendung zur gepflegten Person. Zugleich kam es in vielen Fällen zu einer deutlich verzögerten Kommunikation über die Pflege, was mit einer verspäteten Identifizierung bzw. Ansprache Pflegender korrespondiert. Zudem nehmen Hausärzt*innen den Interviewten zufolge nicht immer im selben Maße Rücksicht auf die Bedürfnisse von Angehörigen, wie sie auf Gepflegte eingehen. Mit Blick auf die Erfahrungen des Interviewsamples verweist nur ein Teil der Ärzt*innen Angehörige zu Beratungs- und Hilfsangeboten.

Schlussfolgerungen

Vor dem Hintergrund der Ergebnisse lässt sich festhalten, dass in Summe die Erfahrungen pflegender Angehöriger mit der hausärztlichen Unterstützung positiv ausfallen und der regelmäßige Kontakt mit Hausärzt*innen als hilfreich und entlastend empfunden wird. Nach Ansicht eines Teils der Interviewten kommt es gelegentlich aber auch zu Herausforderungen und Missständen, sodass Verbesserungspotenziale bestehen.

Schlüsselwörter

Pflegende Angehörige; Hausarzt; Identifizierung; Belastungen; Bedürfnisse; Betreuung

Background

In the EU 27 more than 20 % of the population is currently at least 65 years old [1], causing a constantly growing need for care. Germany has 4.1 million people formally classified as in need of care [2], or even around 5.5 million after including informal, unpaid support and care into the calculation [3].

Informal care is mostly provided by family caregivers in the domestic setting, and family caregivers play a substantial role in caring for people close to them [4–6]. Nevertheless, caregivers are often overwhelmed if the consequences of the disease have not been dealt with [3, 5, 7–9]. Various support services have been established to avoid these crisis situations and increase resilience amongst caregivers. Even though, studies have shown that only a limited number of caregivers actually use these services [10, 11] and that provision of information on all aspects of care structures was felt to be inadequate [12].

Family physicians (FPs) are held to be in an especially favourable position to provide support specific to family caregivers due to their many years of experience in treating the patients and their awareness of their patients' situations [13–15]. Apart from diagnosing and treating health problems, FPs can provide information and advice as well as psychosocial support to caregivers, and gain insight into the care conditions towards meeting long-term needs in a timely fashion. FPs can lay the foundations for long-term successful care and arrange for suitable services to help give patients relief and balance by arranging the appropriate services such as self-help groups, information on care advice and contact persons as well as basic legal consultation [10].

The distinction between formal and informal caregivers can be blurred, so identifying family caregivers early may pose a challenge in primary care [4, 14]. Difficulties may arise when a caregiver and the person in care do not share the same family practitioner [13, 16, 17].

A survey concluded that 60 % of family caregivers in Germany consult FPs on their care responsibilities [15]. An online survey focused on care was

carried out in 2020 on a total of 612 family caregivers recruited from 17 online forums [18]; the survey demonstrated that a clear majority of respondents gave positive ratings for their FPs' awareness of the care situation, responsiveness to care-related issues, and focus on the caregiver. Around half the respondents stated that their FPs had suggested advice and support services; a similarly high number indicated that their FPs immediately acknowledged them as caregivers and felt that they were involved. Regression analysis on these aspects shows the results to be significant as influencing factors on subjective satisfaction with support provided by FPs and the feeling of being able to cope with the care situation.

Research interest

This study was intended to shed light on the attitudes, needs, desires, and experience of family caregivers regarding support from primary care. The research interest focuses on the following issues:

- The importance of support from FPs for family caregivers
- Primary care needs and desires of family caregivers
- The extent to which caregivers consulted FPs on their care activities
- How to describe caregivers' experiences with support from FPs regarding needs they had articulated
- Resulting approaches towards improving the primary care setting

Methods

Study design and setting

The study is part of a broader context, *DemStepCare*, a model project for outpatient medical and nursing care in dementia, itself part of a the broader innovation fund project.

The above online survey [18] intended to determine the broad range of care needs from primary care preceded the current study. The aim of the qualitative study was to go into the subject in greater depth using interviews with family caregivers. In the course of this, individual facets should be worked out and the level of detail should be increased. A qualitative study offers the opportunity to specifically address certain aspects

and connections, to ask questions and to record possible problems more precisely with the help of the subjective view.

Investigation tools

Since this is a multi-part series of studies, the previous quantitative work was used in the preparation of the semi-structured interview guideline. Ergo, the conception of the instrument was closely based on the questionnaire [18]. In some cases, questions from the survey with predefined answers were converted into open questions in order to enable broad exploration. In addition, we used general literature research [9, 10, 14, 17].

Our guideline focused on the following factors: meaning of primary care setting in own care activity; initiation and frequency of consultation on care activity; expectations and needs on support from primary care; support experienced and its assessment; suggestions and desires for improving general practitioner care (see eAppendix 1).

In order to pretest the guideline, three sample interviews were conducted with family caregivers.

Recruitment and sampling

The investigation was aimed at family caregivers of all kinds. Participants were recruited from German-language internet discussion forums dedicated to or aimed towards family caregivers. The decision in favor of recruiting via Internet forums is based on a potentially large pool of caregivers and the possibility of approaching potential study participants as anonymously as possible on this sensitive topic.

The forums were already selected for the online survey [18], which mainly involved search engine searches using keywords such as *caregivers*, and *family caregivers* (a total of twenty-nine forums were used in research). After that, we contacted the forum admins and asked for formal permission to recruit for the survey in each respective forum. Based on the number of registered members that can be viewed for each forum, the authors assume that the forums theoretically reach up to 11,000 caregivers.

Once the forum admins had given their approval, we posted a thread with information on the general topic in July 2020. Forum participants ready to be available for an interview (no incentives) were given an e-mail address to reply to by the beginning of 2021. After voluntary reporting (68 people in total from all seventeen forums), several general characteristics were collected in advance (gender, age, academic qualification, occupation, general living environment, duration of care activity). Forum participants were only enrolled if they had been providing care or support for a person close to them during the past six months.

Interviews were finally performed on all 68 family caregivers. Two of the participants had already taken part in the online survey. A genuine sampling strategy (e.g. purposive sampling) was not used. Due to the approach of exploring broadly and the possibility of obtaining a broad sample from the 68 volunteers, the decision was made to conduct interviews with all the people who were willing to participate and to carry out no further selection.

The authors – two researchers in general medical healthcare services – performed the interviews alternately by telephone between August 2020 and June 2021. The interviews lasted between 20 and 65 minutes.

Interviewees were sent an explanation of the topic and declaration of consent to sign before the interview; this included assurance of strict pseudonymisation and deletion of call recordings after evaluation. As all interviews were conducted in German, the quotes were translated into English for publication by the first author.

Data analysis

All interviews were included in the analysis. After transcription, the first author conducted a qualitative structuring (deductive) content analysis according to Mayring [19] using MAXQDA (VERBI Software). With this method, the categories are essentially set up and defined prior to the analysis of the data material. The goal is to extract specified elements from the material. There is a run

Age	Mean 51 years (Range: 15)
Gender	(60) women, (8) men
Academic qualification:	(8) Volks-/Hauptschulabschluss (lower secondary), (12) Mittlere Reife/Realschulabschluss (upper secondary), (24) (Fach)Abitur (high school matriculation grade), (17) university graduation, (7) other academic qualification
Occupation	(9) in full-time employment, (28) in part-time employment, (22) retired, (9) not in employment
Living environment	(31) in a large city or town (37) in a small town or rural area
Duration of care activity	(14) 6–12 months, (19) 1–3 years, (20) 3–5 years, (15) 5 years or longer
Care setting	Of the 68 interviewees, 30 provided care alone whereas 38 shared their care responsibilities with others
Person in care had been given a care level (officially classified as in need of care)	(35) yes, (33) no
Person in care	(33) parent or parent-in-law, (19) husband, wife or life partner, (8) own child, foster child, godchild or child-in-law, (8) another relative
Living in the same household as the person in care	(34) yes, (34) no
Condition of the person in care	(55) judged as (very) highly restricted, (45) reported (very) heavy cognitive impairment
Care activities focused on	(65) assistance and mental stimulation during everyday life, (60) household chores and assistance in household chores, (57) assistance in personal care, nutrition, and mobility, (48) arranging for assistance and care such as filling out and submitting applications and managing appointments with authorities or doctors, (34) activities related to medical nursing
Burden of the caregiver	(51) described their personal burden as caregivers as (very) great, (17) less great

Table 1 Description of the sample (N = 68)

through the entire data with regard to previously decided structures. The basic form, the profile of the material, is to be assessed on the basis of these classification criteria [19: 65]. The procedure is useful if researchers already have extensive prior knowledge of their research subject. The categories can then be formed based on important aspects from the literature or based on the data collection instrument used. Therefore, the categorical system (see eAppendix 2) created was structured closely to the guideline and repeatedly reviewed and modified as necessary during evaluation. In preparation, the written consultations were summarised with the essential information to gain an overview of the fundamental material. No global analysis was carried out using the interviews con-

ducted; similarly, there was no detailed analysis of a subsample. Data saturation became apparent after 50 interviews.

Results

Table 1 shows the sample gained.

Importance of FP support

A clear majority of those interviewed consider their FPs to be an important source of information and support. A majority of those interviewed reported that they discussed care matters with their own or another FP more often or occasionally. Many interviewees emphasised the central importance of their FP's familiarity with their own situation in accepting advice and following recommendations.

“That’s the only readily available source of medical advice for me. Our

doctor is someone who can easily understand my situation." (I-17f)

In most cases, caregivers stated that they approached their FPs for consultation on their care activities. A smaller number reported being approached by their FPs about the care situation or that the topic came up while seeing their FP for a preventive medical check-up. Some interviewees expressed regret that the consultation on caring activities did not initially take place, which they attributed to feeling "a deep sense of uncertainty" (I-2m) as to whether it was appropriate to talk about their private care situation and take up the FP's time with the topic.

"I wasn't sure whether I really had the right to 'bother' my FP with these problems." (I-11f)

"It does make a difference whether FPs send out signals that it would be appropriate to address the topic of family care with them." (I-7m)

Even after the perceived occasional delay, most caregivers stated that they raised the topic of care with their FPs reported that these consultations were now taking place on a regular basis. Some interviewees thought "separate consultations specifically for care" (I-15m) were important, but others responded that the topic was raised as needed while seeing their FPs.

Care needs

Beyond taking enough time for consultation and "making decisions by mutual agreement" (I-19f), interviewees expressed a desire for FPs to "really deal with my personal care situation" (I-36f), "feel competent in dealing with issues facing caregivers" (I-33m), and "not wait too long for me to raise an issue myself" (I-17f) in discussing needs and expectations.

Most of the interviewees that consulted with their FPs on care saw great importance in the FP's role as a source of information. A large part of the sample said they would like to have their FPs "suggest options for further advice and support at an early stage" (I-30f) and "specific services available nearby that could provide support in planning effective care" (I-33m). Most caregivers were satisfied with general options for support services such as

by issuing leaflets, but a minority did express a desire to be referred to specific support services.

One group addressed the importance of legal aspects of care and thought it would be beneficial if FPs could give some guidance on the matter. Around the same number of interviewees would have liked "something like emotional support" (I-14f) or "a doctor that just listens and encourages you to see the bright side of this situation". (I-22f)

Satisfaction with FP support

Most of the interviewees that consulted with their FPs on their care activities were (very) satisfied with the support they received. Particularly positive emphasis was placed on the trusting relationship in the consultation about care work and personal awareness of the care situation. Psychosocial aspects of support were also mentioned and were experienced as motivating factors.

"I've been seeing my FP for years, and she has a solid understanding of my everyday life. That plays a role in her advice and suggestions." (I-27f)

Many also positively emphasised the point that their FPs were also treating the person in care for health and mental needs, interests and in decision-making, and securing their agreement through explanation.

Even though, the interviewees did address weaknesses in the support they had been receiving. For example, the desires of caregivers for a proactive role from FPs in recognising and anticipating care issues on time were not always fulfilled.

"It took too long to develop into a regular topic. That was because my FP didn't initiate the consultation on my caring activity even through both my family member and I see the same doctor." (I-19f)

Various interviewees addressed the problem that FPs often focused exclusively on the people in care and their situations and far less on the needs and burdens of family caregivers.

"Our doctor often only looks at my husband, who is in my care, and I mostly get left out. The thing is that it can only work with both involved." (I-28f)

Several interviewees reported that their FPs had told them about support services on at least one occasion, most frequently referring to care services and welfare centres, day or short-term care, and everyday support services. The caregivers said that this made life easier for them in the long term. Nevertheless, many family caregivers often found the support from their FPs to be rather weak in this specific point. Many caregivers would like to have seen their FPs play a more advisory role in organising the general planning for their care activities.

"I was a little disappointed that my doctor didn't suggest any support options." (I-20m)

"I had to find out more or less on my own and with help from the health insurance, which didn't go all that well." (I-35f)

Some interviewees were also unhappy about their FPs not advising them on legal aspects (especially power of attorney, care, 'driving a car').

Optimisation approaches

Finally, interviewees were asked what primary care interventions they thought could improve support for caregivers in the future and more specifically address their needs and problems. Some interviewees suggested a comprehensive standardised checklist that FPs could work through together with family caregivers towards taking the necessary preparations for constant home care to be effective.

Some suggested that it would make sense to give caregivers an early and consistent overview of advice and support services. Local or regional summaries for FPs to pass on to the caregivers and the people in care would be useful. Other interviewees thought it would make sense if FPs and other professionals were to combine forces in healthcare networks at community level. This form of collaboration would allow faster and smoother referrals to psychosocial and health-promoting services.

Another proposal was a kind of loose, low-threshold support programme for family caregivers with health insurance companies with FPs signing the corresponding caregivers

up for them. This might ensure that health insurance companies take the initiative in contacting caregivers in a more proactive information approach.

Discussion

The expectations that family caregivers have towards FP support relate strongly to taking enough time for consultation, knowledge of the personal care situation, proactively addressing care needs and making decisions by mutual agreement. Most of the interviewees that consulted with their FPs see great importance in the FP's role as a source of information, advice and support. Indeed, many interviewees consulted with their doctors (regularly) about their care activities; their FPs' awareness of individual care situations, availability for a wide variety of issues and focus on the person in care were particularly valued.

Nevertheless, not all expectations seem to be met in everyday practice. Some interviewees reported a noticeable delay in addressing the topic of care in many cases – that is, caregivers were identified and spoken to rather late in the day. FPs do not always seem to consider the needs of relatives to the same extent as those of people in need of care. The interviews also indicated that only some FPs suggested advice and support services for family caregivers.

Comparison with prior work

The findings from the present study reflect not only the central findings of the previous online survey [18], but also other studies emphasising the importance of support for caregivers in primary care [4, 7, 15, 20]. Several international qualitative studies have also yielded similar results to the current study. One study in Ireland highlighted the primary role of FPs in developing long-term coping and resilience strategies in home care situations [21]. This also showed a need for continuous proactive support by a constant medical advisor as well as an in-depth understanding of family care and the need for bespoke care solutions. In their qualitative work, Greenwood et al. [17] established that the primary care

setting could perform a central role by supporting specific groups of family caregivers while coordinating additional support effectively and collaboratively.

Other studies have also pinpointed weak points in support provided by FPs as has this current study. As an example, qualitative studies by Burrige et al. showed that caregivers did not always build up the courage to explain their problems if FPs did not give the appropriate signals as someone to consult on the issue [16, 22]. FPs signalling willingness to pro-



Dr. Julian Wangler ...

... ist wissenschaftlicher Mitarbeiter (Postdoc) in der Abteilung Allgemeinmedizin des Zentrums für Allgemeinmedizin und Geriatrie der Universitätsmedizin Mainz. Sein Forschungsschwerpunkt liegt im Bereich der empirischen Versorgungsforschung unter besonderer Berücksichtigung der hausärztlichen Versorgung sowie der Auswirkungen von eHealth und mHealth auf die allgemeinmedizinische Tätigkeit und das Gesundheitssystem.

Foto: privat

vide support at an early stage is important for family caregivers to voice their concerns and issues. Ideal opportunities for FPs to raise these issues proactively include routine check-ups and vaccinations. There have been cases where FPs have not given the same degree of support to caregivers as they have to the people in care. Research literature has addressed a tendency to focus on care recipients while marginalising the psychosocial effects of providing care [13, 14]. Effective support for successful care depends on taking the needs and challenges of family caregivers and those in care into account in a health-

care triad approach as various studies have already emphasised [16, 20].

In addition, studies such as those by Kiceniuk et al. have shown the need for FPs to provide early, consistent, and regular recommendations for advice and support services to caregivers, and that not all FPs address this need. Referring caregivers to these support services gives the caregivers timely access to information on organising their care activities [5, 20], and allows caregivers to stay at home for longer periods without care crises such as hospitalisations [23].

The perception that FPs do not always consistently refer patients to offers of help and support corresponds to other findings. For example, FPs often do not have a sufficient overview of external forms of support for caregivers [10] and are rarely involved in local health networks [24]. This is where formal and informal cooperation networks could be very helpful. For this reason, only some caregivers request advice and assistance such as from care support centres and dementia networks [10, 11]; there is also a lack of relief and prevention services in rural regions. Another issue is the failure of FP's staff members to identify family caregivers immediately [18]. These challenges were already apparent during the online survey. Bernard et al. have already shown that FPs often do not provide the time and resources to do full justice to caregivers [25], an observation that could give some bearing on the issue at hand. In addition, Carduff et al. [26] found that FPs often show wide divergence in how they interpret their roles in dealing with caregivers.

Strengths and limitations

The study design showed a series of limitations. First of all, it should be pointed out that very different groups of caregivers were considered as a whole, so that specifics of certain groups (e.g. caregiving relatives of people with dementia) could only be dealt with insufficiently. It can be assumed that the possibility of gaining new insights beyond the quantitative study was limited in the present qualitative work. This is due to the fact that the quantitative survey

instrument was used to a large extent to develop the guideline. This also includes the transfer of formerly standardized questions into open questions. Therefore, it must be critically objected that more openness could have better grasped new facets. Consequently, one valid objection to the guideline would be that it included several quantitative assessment questions that seriously limited the range of possibilities for personal accounts and interpretations. Narrative interviews may provide caregivers with extended opportunities to express their own opinions, experiences, and feelings as they talk and explain.

Unlike in qualitative research, the transcription, coding and categorization was carried out by a single evaluator who, however, has extensive research experience. In addition, the results are the verbalized views of the interviewees. The type of FP support the interviewees actually received was not recorded. There is also the possibility that answers were given out of social desirability so there could be a bias in the results.

Online recruitment from web forums generally leads to the real risk of only a certain group of interviewees with specific needs for information and communication being enrolled into the sample. It would be safe to assume that recruiting caregivers from other settings – such as waiting rooms in FP practices – may lead to results that are more generalizable for caregivers. Telephone interviews may also have led to a lower willingness for interviewees to provide information compared to face-to-face interviews. However, studies show that telephone interviews are not fundamentally less suitable than face-to-face interviews [27].

Conclusions

Family caregivers consider FPs to be an important source of support and advice and attributed a high level of competence and trust to them. Nevertheless, the results show that, from the perception of those interviewed, occasional problems occur in everyday practice with regard to identifying, addressing and supporting caring relatives. Consequently, there is potential for improvement when it comes to consistently taking into account the needs, wishes and burdens of caregivers.

Declarations

Funding

This article was created in the broader context of *DemStepCare*, a model project for outpatient medical and nursing care in dementia, which receives financing from the Joint Federal Committee (“Gemeinsamer Bundesausschuss” G-BA) innovation fund for three years. Proposal-ID: 01NVF18027. The funding body had no role in the design of the study, nor in the collection, analysis, or interpretation of study data, nor did they play a role in the writing of the manuscript or the submission of the manuscript for publication.

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Authors' contributions

The authors alone are responsible for the content and the writing of the paper. JW prepared, coordinated and implemented the project. Both JW and MJ contributed to the project design, analysis of transcripts and drafting of the manuscript and approved the final manuscript.

Ethics approval and consent to participate

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, FPs, 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. All methods were carried out in accordance with relevant guidelines and regulations. During the present study, no sensitive patient data was gathered or clinical tests performed. All sixty-eight interviews with family caregivers were strictly anonymized. Written informed consent was obtained from all participants.

Zusatzmaterial im Internet (www.online-zfa.de)

eAppendix 1 Interview guideline

eAppendix 2 Categorical system

Competing interests

The authors declare that they have no competing interests.

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In der Online-Version des Artikels unter www.online-zfa.de/

Corresponding Author

Dr. Julian Wangler
Research Associate, Centre for General Practice and Geriatric Medicine
University Medical Center, Johannes Gutenberg University Mainz
Am Pulverturm 13, 55131 Mainz
julian.wangler@unimedizin-mainz.de

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eAppendix 1: Interview guideline

Formal questions on care setting

Have you provided this support or care on your own or shared the responsibility with others?

(Not including care services and welfare centres such as those provided by care insurance)

Has the person in your care been given a care level?

How long have you been supporting this person?

What is the relationship between you and the person in your care?

In your opinion: How far does disability affect the person in your care? What do the main restrictions involve?

Are you currently living in the same household as the person in your care?

What kind of support do you give your family member?

How much of a burden is it for you to provide support for the person in your care?

Questions about support from primary care

How important is the GP as a contact person for questions about caring for your family member?

Do you consult your own GP or another GP on the care you are giving to your family member?

(This does not necessarily mean your own GP, but the GP you consult in caring for your family member.)

How did you begin consulting your GP on caring for your loved one?

How often do you consult your own or another GP about the care you are giving to your family member? How regular are your visits to the GP about this?

People caring for family members sometimes have very different needs and expectations on how a GP should support them. What do you as a family caregiver feel is important to you in dealing with primary care? What kind of support would you like to see most?

We've just touched on your wishes and expectations. How do you actually experience support from a GP in your role as a family caregiver? What kind of support have you already received from a GP? What things are going well, what are you satisfied with? Where would you like more support from a GP? What are you dissatisfied with, if anything?

In general, in what ways would you as a caregiver expect more in the way of support from your GP?

Someone recently said: "My GP can usually help me out when I ask about care for my family member." How far does this apply to your GP? Please state any reasons why or why not.

What role does your GP play when you are looking for information on care, such as which services are available or who you can ask for further advice?

How often has your GP suggested supportive help or advice in organising care? (By this, we don't necessarily mean specific local services but more generally pointing out that these services exist.) Which services has your GP specifically mentioned to you?

Have you acted on any of these suggestions? How did you benefit, how much did it make it easier for you to care for your family member? Do you think you would have benefited more if your family doctor had referred you to specific support and care services?

On balance: How would you rate the support that your GP has given you in caring for your family member?

Have you ever changed your GP out of dissatisfaction with his or her support for you as a family caregiver?

What do you think could or should be done or improved to provide better support for family caregivers and address their needs and problems more effectively? How could general practitioners in particular help or help more?

eAppendix 2: Categorical system

1. **Family physician as a potential and basic point of contact with regard to family caregiving**
 - a) Family physician as a source of information and advice
 - b) Family physician as mediator for offers of help and support
 - c) Family physician as therapist
 - d) Family physician as psychosocial contact person
2. **Significance of the family physician setting for the support of personal care work**
 - a) Family physician as a source of information and advice
 - b) Family physician as mediator for offers of help and support
 - c) Family physician as therapist
 - d) Family physician as psychosocial contact person
3. **Establishment of a (regular) conversation about the caregiving activities**
 - a) Own and/or other family physician
 - b) Caregivers approach the family physician with questions or problems
 - c) Caregivers were proactively approached by the family physician with regard to family caregiving
 - d) Reason or initial situation
4. **Manner of conversation about the caregiving activities**
 - a) Own and/or other family physician
 - b) Frequency or regularity
 - c) Content and focus
5. **Reference to offers of help and advice**
 - a) General desire for reference and mediation
 - b) One-time or repeated referrals or mediation by the family physician
 - c) Concrete offers
 - d) Use and readiness for use of the offers
 - e) Benefits for personal care work
6. **Expectations and needs with regard to family physician support**
7. **Most important needs (family physician support) from personal perception or experience**
 - a) Making decisions by consensus
 - b) Preoccupation with personal care situation and type of dealing with it
 - c) Family physician feels responsible for problems of caregivers or approaches caregivers proactively
 - d) Early reference to information and advice offers
 - e) Psychosocial or emotional support
 - f) Provision of legal orientation knowledge
8. **Overall satisfaction with family physician support**
9. **Type of support actually experienced as well as its assessment**
 - a) Perceived support versus needs or expectations
10. **Aspects of family physician support – experienced positively**
 - a) Relationship of trust
 - b) Personal knowledge of the care situation
 - c) Psychosocial support or stabilization
 - d) Therapeutic and psychosocial attention to the patient
11. **Aspects of family physician support – experienced negatively**
 - a) No timely response to care situation
 - b) Missing identification of family caregivers
 - c) Hesitant or late reference to offers of help and support
 - d) One-sided focus on the person in need of care, neglect of the caring relative
12. **Change of family physician due to negative experiences with support in terms of family caregiving**
13. **Wishes and suggestions for improving family physician support**
 - a) Standardized checklist
 - b) Overview of help and support offers
 - c) Cooperation networks at municipal level
 - d) Structured support programs for family caregivers