

Research Letter

Informal Caregivers and How Primary Care Physicians Can Support Them

An estimated five million people in Germany care for relatives in their home environment (1). The various consequences of such informal care work on health include general states of exhaustion, deficits in sleep quality, back pain, and in many cases psychological stress (1, 2). The physical and psychological stress seemed to increase during the COVID-19 pandemic due to the lack of services and support structures in the residential area (3). Primary care physicians are important contact persons and a source of advice for informal caregivers. This was already evident in the survey of insured persons conducted by the German National Association of Statutory Health Insurance Physicians (KBV; *Kassenärztlichen Bundesvereinigung*) in 2018.

The aim of this study was to identify possible inequalities in the support provided by primary care physicians to informal caregivers based on the socio-demographic characteristics of caregivers. The results are based on a sub-sample of 355 informal caregivers, which was taken from data of the KBV insurance survey for 2020 (N = 2 036). A telephone survey of randomly selected insured persons took place at the beginning of the COVID-19 pandemic, from 16–25 March 2020. A regionally stratified, two-fold random selection was used. The results are representative for the adult German-speaking resident population (4). Statistical analyses were carried out using multiple logistic regressions, using a significance level set to 5%. Evaluations were carried out using IBM SPSS Statistics for Windows, Version 25.0 (IBM Corp., Armonk, NY, USA).

Results

Informal Caregivers

Informal caregivers were predominantly female (61.4%), 40–64 years old (51.3%), and either in full-time employment (39.2%) or retired (31.1%) (Table 1). Overall, 78.3% of caregivers described their state of health as good or very good; more than half reported having a chronic illness (55.5%). Around 30.3% of the respondents stated that they care for relatives with dementia.

Contact and Support of Primary Care Physicians

Of the caregivers, 68.5% visited a primary care physician in the year before the survey, and most of these visited one to five times (75.7%) (Table 1). Around three-quarters of the caregivers who went to a primary care physician also discussed their care situation (77.0%). Specifically, caregivers who belonged to a vulnerable group, such as older persons (≥ 65 years, odds ratio [OR]: 5.56; 95% confidence interval: [1.24; 25.02]), those with self-assessed poor health (OR: 8.19 [2.21; 30.35]), or those with a chronic illness (OR: 5.78 [2.11; 15.83]), consulted their primary care physician more often than their respective reference groups (Table 2). With respect to educational levels, the opposite effect can be seen: persons who contacted their primary care physicians particularly often to discuss their care situation were more likely to be in a group with a medium level (OR: 4.03 [1.19; 13.68]) or high level (OR: 3.27 [0.99; 10.72]) of formal education than to be in a group of the most vulnerable with a low level of formal education (Table 2).

TABLE 1

Characteristics of randomly-sampled informal caregivers

	N* = 355	% [95% CI]
<b>Gender</b>		
Male	137	38.6 [33.9; 44.0]
Female	218	61.4 [56.3; 66.4]
<b>Age (years)</b>		
18–39	73	20.5 [16.6; 25.0]
40–64	182	51.3 [45.1; 56.4]
65+	100	28.2 [23.7; 33.0]
<b>Education level</b>		
General secondary school	108	32.1 [27.3; 37.3]
Intermediate secondary school	119	35.4 [30.4; 40.6]
University entrance certificate	109	32.4 [27.6; 37.6]
<b>Occupation</b>		
Employed full-time	136	39.2 [34.2; 44.4]
Employed part-time	53	15.3 [11.8; 19.3]
Retired	108	31.1 [26.4; 36.1]
Other (short-time work, unemployed, parental leave)	50	14.4 [11.0; 18.4]
<b>Subjective health status</b>		
Very good	107	30.1 [25.5; 35.1]
Good	171	48.2 [43.0; 53.4]
Poor	77	21.7 [17.6; 26.2]
<b>Chronic illness</b>	197	55.5 [50.3; 60.6]
<b>Frequency PCP visit in 12 months</b>		
1 or 2 times	72	29.6 [24.2; 35.6]
3 to 5 times	112	46.1 [39.9; 52.4]
6 or more times	59	24.3 [19.2; 30.0]
<b>Caring for someone with dementia</b>	106	30.3 [25.7; 35.3]
<b>Has discussed care situation with PCP: 77% (187 of 243)</b>	187	56.0 [50.6; 61.2]
<b>Has discussed care situation and received support</b>	142	75.9 [69.4; 81.6]

\* Difference to N = 355: no data or data not applicable  
95% CI, 95% confidence interval; PCP, primary care physician

Discussion

Primary care physicians are an important part of the support network for informal caregivers. In order to maintain this function, primary care physicians not only need advanced training on all aspects of caregiving (5) but also reliable margins to exercise their advisory function. It is necessary that the urgently needed advisory function is appropriately remunerated. On the other hand, caregivers require preventive medical expertise when it comes to maintaining their own health despite the stressful care situation. As these results show, caregivers with poor health especially have a high need for support. In particular, it is advisable that the stressful care situation is taken into account, as it could further impair their health. The extent to which the poor health of caregivers had already been influenced by the care situation could not be investigated on the basis of the data available and requires further investigation.

TABLE 2

**Selection: informal caregiver visits to PCP in past year**

	Discussed care situation with primary care physician	
	OR [95% CI]	p
<b>Age (years)</b>		
18–39	1	
40–64	3.98 [1.30; 12.23]	0.02
65+	5.56 [1.24; 25.02]	0.03
<b>Education level</b>		
General secondary school	1	
Intermediate secondary school	4.03 [1.19; 13.68]	0.03
University entrance certificate	3.27 [0.99; 10.72]	0.04
<b>Subjective health status</b>		
Very good	1	
Good	0.94 [0.32; 2.79]	0.91
Poor	8.19 [2.21; 30.35]	0.00
<b>Chronic illness</b>	5.78 [2.11; 15.83]	0.01

Multiple logistic regressions: talked to primary care physician (0 = no; 1 = yes)  
 The following variables were taken into account in the regressions:  
 gender, age, school leaving certificate, subjective health, chronic illness, perceived  
 greatest challenges for health care (shortage of physicians, lack of infrastructure, coronavirus  
 virus/infections).  
 Variables are <0.05.  
 95% CI, 95% confidence interval; OR, odds ratio

Based on the available results, it seems advisable for primary care physicians to speak to their patients with a low level of formal education about a possible care situation and its associated burdens. A possible reason why this group discusses their care situation less often than the groups of person with higher formal levels of education could be the strong asymmetry of the physician–patient relationship and a lower level of health literacy. Future studies should shed more light on the identified inequalities, using qualitative studies to be able to determine the underlying attitudes of both patients and physicians.

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**Conflict of interest statement:**

Prof. Dr. Kuhlmei and PD Dr. Schnitzer have served as unpaid consultants for the German National Association of Statutory Health Insurance Physicians (KBV) with respect to their survey for insured persons.

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