

Care for Caregivers- A Mission for Primary Care

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Abstract

Background. The number of elderly people living in the community who are limited in daily activities is increasing worldwide. This generates prolonged care, which usually falls on one family member, the family caregiver. Caregivers sometimes develop psychosocial and physical symptoms. As a result, the World Health Organization (WHO) issued a clear directive to assess and support these caregivers.

The present study focuses on providing preventive solutions by primary care physicians (PCP) to caregivers.

Methods. Data were collected from a convenience sample of 201 PCP interviewed with specifically structured questionnaires.

Results. The participants' mean age was 48.5 ± 11.2 years and 53.5% were female. Only 48.5% were Israel medical graduates and 72% were board-certified family physicians. Nearly 34% had formally been primary caregivers of family members.

Most physicians (83.6%) were aware of the primary caregiver's high-risk for morbidity and mortality, and recommended preventive care. On a multivariate regression, awareness of the risk, country of medical school and board certification were considered to be of great significance in relation to providing preventive care. However, being a primary caregiver for a sick family member neither contributed significantly to the doctors' awareness to caregiving risks nor to their preventive care.

Conclusion. Although a high percentage of physicians were aware and concerned about caregivers' welfare, their preventive care activities were relatively passive. PCPs should take a more active and preventive role.

Background

The increase in life expectancy is particularly significant in western countries with low birth rates. Limitation in daily activities are frequent among this age group, and yet increasing (1). In Israel the recent statistics showed that 11.8% of the general population were elderly (2), 26% of whom were limited in daily activities (21.4% men and 30.2% women) (3). These figures have a significant impact on all health, economy and welfare systems on both national and private levels.

The present Covid 19 pandemic has drastically affected the world health status and has altered the lives of millions of people, especially the older population (4). Unfortunately, the death toll among the sick elderly is the greatest, and many more old people face social isolation, loneliness, depression and fear. In such circumstances, family members are expected to take the role and responsibility as caregivers.

The primary caregiver is responsible for prolonged care for an elderly sick patient at home taking charge and devoting much time to the patient's care (5). Caregivers are mainly women, some of them are elderly

themselves, and others are at essential stages of their own lives and lack the necessary time or skills (6,7).

Caregivers often suffer from psychosocial symptoms such as anxiety and depression (8,9) which occur in 34% to 52%, and is particularly common among the patients' spouses (8). The severity of depression among caregivers is often greater than among the sick patients themselves (10).

Compared to non-caregivers, physical symptoms are more common, too: caregivers suffer from fatigue, digestion problems (11,12) reduced immune system activity, slower wound healing (13), relatively higher blood pressure levels, and multiple sleep problems (14).

The task of caregiving also affects the caregivers' social life, 50% of whom report a decrease in social ties due to the caregiving burden (15). These findings are exacerbated when the caregivers are elderly themselves (16,17).

Elderly caregivers are a group at high risk, termed in the literature as "the hidden victims" (18). Therefore, the World Health Organization (WHO) issued a clear directive calling to support and look after their welfare during the caregiving period and also following the patient's death (19).

These principles direct family doctors to identify the caregivers of their patients, assess their condition regularly, support, treat and refer them to appropriate resources for help (20). A similar call emphasizes the importance of identifying and assessing caregiver burden and distress in order to prevent negative health outcomes (6,9).

To the best of our knowledge, no study to date has assessed the implementation of these guidelines, such as doctors' awareness of the high risk for morbidity and mortality of caregivers, or referral for age-appropriate health screening tests. This concern is especially noteworthy during the current pandemic, when many more elderly people and their caregivers, are isolated at home. A recent study from Italy, found that quarantine induces a rapid increase of behavioral and psychological symptoms in approximately 60% of dementia patients and stress-related symptoms in two-thirds of their caregivers (21).

The present study focuses on the degree of awareness and responses of primary care doctors to caregivers' physical and mental health needs.

Methods

Study population

Data were collected from a sample of primary care physicians (PCPs) who were defined as specialists or trainees in family or internal medicine, or general practitioners with at least six months experience who worked in a variety of clinics in Israel. They were asked to participate in the study either through the

Association of Family Doctors or by direct contact. They then underwent a 40-minute interview conducted by experienced interviewers.

Study type: A cross sectional study.

The study was approved by the Ethics Committee of Ben-Gurion University of the Negev (approval # 21-2014). It was exempted by the Ethics committee from signing informed consent forms.

The study instruments

Since no suitable instruments existed in the literature, we developed dedicated questionnaires for this study. For each item, the doctors were asked to mark the degree to which they agreed, on a Likert scale ranging from 1 (never) to 3 (often) or from 1 (no) to 6 (always). The three questionnaires included the following elements: Awareness of the risks of caregiving for the caregiver (7 items). Recommendations by physicians on preventive care for the caregiver (4 items). Monitoring of the caregiver by the physician (3 items). A factor analysis by Varimax rotation, conducted on the items of each of the questionnaires identified only one factor. For 'awareness' and 'recommendations', the mean of the different items was calculated as a general index of the extent of the element tested, and the sum of the items for 'monitoring'. Internal reliability of the different scales was assessed using Cronbach alpha coefficient and was found satisfactory (Table 1). The questionnaire items appear in Supplementary file 1.

Socio-demographic characteristics of the physicians included age, gender, family status (married/ cohabiting/ single), number of children, country of birth (Israel/other), and religiosity (secular/traditional/religious/ultra-religious).

Professional characteristics included experience as a physician (years), experience as a PCP (years), number of working hours (weekly), medical school (Israel/other), specialist (board-certified, not board-certified), area of specialization (family medicine/other), place of work (HMO clinic, independent clinic, other).

Statistical analysis methods

Initially relations between dependent and independent variables were tested by Pearson, Chi-square, or Spearman as appropriate for the type of variable. Only variables that correlated significantly with the physicians' awareness in the univariate analyses were included as independent variables. Physicians' recommendations on preventive care for the caregiver were examined by a hierarchical multivariate regression analysis: in the first block, professional sociodemographic variables were entered; in the second block, awareness of the risks of caregiving was added. The SPSS software (V. 21) was used for data processing and analyses. Statistical significance was set at $P < 0.05$.

Results

We interviewed 201 physicians for this study. Table 2 indicates the socio-demographic and professional characteristics of the participating physicians. The mean age of the physicians was 48.5 ± 11.2 years and 53.5% were female. About half of the physicians (48.7%) were born and graduated in Israel and most of them (67.2%) defined themselves as secular.

The participants were experienced physicians, with a mean of 18.7 ± 12.2 years of work and 16.2 ± 11.0 years as PCPs. Among the sample, 84.2% were board-certified physicians of whom 85.3% were board certified family physicians, mostly employed in HMO clinics.

Relating to the physicians' own family, 39.1% had dependent elderly family members, and about 34% had been caregivers for severely ill elderly family members with a mean duration of 44.3 ± 57.2 months of caregiving.

Most of the physicians always (47.8%) or often (35.8%) identified that the caregiver in families with a severely ill or disabled member was at high risk for morbidity or mortality and recommended they receive preventive care.

The physicians' recommendations for preventive care for the caregivers included four elements. Most of the physicians recommended treatment for the caregiver often (39.8%), or always (26.0%), to prevent a decline in their health. Regular physical activity was recommended always (41.7%) or often (38.5%) together with good sleep habits. Physicians advocated that the caregiver seek regular help from a social worker or a psychologist (35.7%), or frequently (31.1%),

Many of the physicians (60.5%) stated that they invited caregivers for a follow-up visit on their own initiative. Moreover, regular clinic appointments for the caregiver were initiated by 56.6% of the doctors over the prior six months.

The association of the study indices with socio-demographic characteristics varied. Female physicians were more likely to recommend preventive care than males ($p = 0.04$). Israeli medical graduates were more aware of preventive care than those who studied abroad, but abroad medical graduates were more likely to recommend preventive care than those who studied in Israel ($p = 0.005$). Specialists were more liable to make recommendations for preventive care than non-specialists, and family doctors were more likely to do so than their colleagues ($p = 0.001$).

Physicians who experienced being caregivers themselves were more likely to recommend preventive care than those who were not ($p = 0.03$). There were no statistically significant differences in physicians' awareness, recommendations for preventive care, and in the treatment follow-up related to religiosity or place of work. (Table 1).

We conducted a multivariate linear regression analysis to identify the unique contribution of the study variables to the explanation of physicians' awareness of the risks of caregiving (Table 3). Since the variable "duration of caregiving" for a sick family member was significantly associated with risk awareness in the univariate analyses, and only one third of the study physicians answered this item, it

was added to the multiple regression analysis as a dichotomous variable referring to whether the physician himself was a caregiver for a severely ill family member. The model for the regression analysis on physicians' awareness was found to be significant ($F[3,172]=6.65, P<0.000$). Only two variables made a unique contribution to physicians' awareness: Board certified family physicians and physicians who graduated medical schools in Israel were more aware of the risks of caregiving compared to the others. In total, these disparities explained a relatively low percentage (11%) of the variance of this dependent variable. Surprisingly, being a caregiver for a sick family member did not contribute significantly to physicians' awareness of the risks of caregiving.

Table 4 shows the multivariate linear regression analysis to identify variables that explain physicians' recommendations for preventive treatment. These variables were introduced into this analysis in two steps. In the first step, we entered the socio-demographic and professional variables (sex, country of medical school graduation, specialist/non-specialist, primary caregiver). Only variables that were significantly associated with the dependent variable in the univariate analysis were considered.

Board certification emerged significant. Country of medical school graduation was considered to be of statistical significance ($F=0.13, P=0.08$).

In the second step, we added the variable "physician's awareness of the risks of caregiving". This variable explained another 8% of the variance of the dependent variable and was statistically significant ($F[1,185]=17.6, P<0.000$). Thus, physician's awareness represents a substantial contribution to the 16.5% percentage of the stated variance. Three variables made a significant contribution: physician's awareness of the risks of caregiving, country of medical school graduation and board certification (Table 4).

We did not conduct a multivariate analysis on "treatment & follow-up" because no independent variable was significantly associated with it in the univariate analysis.

Discussion

The aims of the present study were to evaluate the extent to which PCPs are aware of family caregivers' risks, and whether they take preventive measures to maintain caregivers' health.

The results showed that, while a high percentage of physicians reported that they were aware of the caregivers' higher risk for physical and mental impairments, they did not initiate interventions to address this vulnerable group. The reason for these inconsistent findings could stem from barriers such as lack of time, lack of knowledge, a different outlook, or other obstacles. Nonetheless, doctors were aware of this issue, especially board-certified family physicians, so this could be a first stage in promoting appropriate treatment of caregivers in primary care medicine.

The professional literature focuses particular attention on caregivers for patients with dementia, since this large group of patients in the community places a heavy and prolonged burden on family members. For example, a Belgian study investigated the attitudes of PCPs to family caregivers for Alzheimer's

disease patients. They found that doctors had a high level of skills and awareness of their role. The doctors expressed difficulty in reporting the diagnosis of dementia to patients and their family and identified implementation barriers, especially lack of time and lack of appropriate remuneration. Despite their high level of awareness of the importance of treating caregivers, the same Belgian study found that caregivers were dissatisfied with the provision of home care (22).

Another study, conducted in Montreal, Canada, assessed the attitudes of family doctors to the family members of elderly patients. They found that over 90% thought that their role was to address the requests and concerns of patients' family members and felt that they fulfilled this role appropriately. However, 81% reported that this role caused work stress, deriving from the risk of diagnostic errors, conflict between the benefit of the patient and that of the family caregiver, or refusal on the part of the patient or family member to accept help from community organizations (23).

This study evaluated whether PCPs reported providing recommendations to family caregivers in terms of preventive care. We found a low level of doctor-initiated interventions to monitor the caregivers' health. A review paper, published in 2016, assessed the effectiveness of intervention programs for family caregivers of patients with dementia. The study concluded that there was no proof of the effectiveness of intervention programs in improving the physical and social conditions of the primary caregiver (24).

A surprising finding in our study was that physicians who were themselves caregivers for elderly or sick family members demonstrated a lower level of awareness of the needs of caregivers as the period of treatment increased. A possible explanation for this finding might be the doctor's denial of the problem, or that, from the physician's perspective, the role of the caregiver is considered as a "normal", "natural" task that does not necessitate special attention. It is also possible that as the time of looking after a sick family member lengthened, the caregiver-physicians adapted and found ways to relieve their own burden.

Although the issue of the physician's relationship with caregivers is important, it has not been the focus of previous studies. A measuring tool, the Physician Caregiver Relationship Scales (PCRS) (25), was developed in the United States, but it addresses parents of sick children. We believe that a scale should be adapted or developed for caregivers of elderly family members.

The present study was an observational study based on one-time interviews with a convenient sample of PCPs. It is possible that those who agreed to participate were already more aware of the study issues or had a higher degree of interest and self-efficacy. Support for this assumption is that they were older and more experienced physicians, many were board-certified family doctors and had personal experiences as caregivers. Although the physicians were chosen from all regions, it is not clear that the findings can be generalized to the entire population of physicians. Interviews might also reflect a social-professional desirability bias that could lead to answering as "was expected". This could become particularly salient in questions on the extent of awareness and less on actual implementation of actions. Despite this potential tendency, we believe that the results of the study are valid, and that, to a similar degree, this bias exists among all physicians.

As the population ages, especially in times of "viral lockdown", as we experience globally in the last year, the number of family members fulfilling the role of caregivers is expected to increase. A recent research in the UK found higher rates of depression among family caregivers compared to non-caregivers, during the COVID 19 epidemic, with loneliness a significant contributor to depressive symptomatology (26). However, the majority of caregivers did not access any online or phone psychiatric support. This makes the front-line primary care physicians and staff even more significant as a support system.

Conclusions

Medical and welfare services should be aware of the risks inherent in caregiving and should allocate support resources, such as the development of interventions at the community level. Special attention should address the most vulnerable groups such as female caregivers, elderly partners of patients, and caregivers who themselves have poor health. Furthermore, we recommend the development of a measurement instrument for the evaluation of the relationship between physicians and family members who are caregivers as well as for the assessment of the effect of interventions on their physical and emotional conditions. Intervention programs, such as skills training for family caregivers (27), are mainly aimed for the caregivers, but we suggest that such training should complement with courses for physicians to support the caregivers, enhance their wellbeing, enrich possible resources, and reduce the burden and costs for the healthcare services and for society as a whole.

Abbreviations

WHO - World Health Organization

PCP - Primary Care Physician

PCRS - Physician Caregiver Relationship Scales

Declarations

Ethics approval and consent to participate: The study was approved by the Ethics Committee of Ben-Gurion University of the Negev (approval # 21-2014). It was exempted by the Ethics committee from signing informed consent forms.

All methods were performed in accordance with the relevant guidelines and regulations.

Consent for publication: Not applicable.

Availability of data and materials: The datasets generated during and analyzed during the current study are not publicly available due to the sensitivity of the data but are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions:

AB: acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript, final approval of the version to be published. SC: study concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript, final approval of the version to be published. SA: analysis and interpretation of data, preparation of manuscript, final approval of the version to be published. YGB: study concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript, final approval of the version to be published.

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Tables

Table 1. Description of the three research indices, internal reliability of the different scales (Cronbach alpha coefficient) among 201 physicians (2016)

α	Median	Mean (SD)	Range*	No. of items	Index measured*
79.	4.71	4.53(0.82)	1-6	7	Physicians' awareness of caregiving risks [^]
65.	5.00	4.77(0.98)	1-6	4	Physicians' recommendations for preventive care [^]
74.	6.00	5.67(1.58)	3-9	3	Monitoring of the primary caregiver ⁺

* In all indices the scale direction is from lowest to highest, all three study elements had a high mean value relative to the index scale

[^] Calculated as the average score of the items

⁺ Calculated as the sum of the items

Table 2. The 201 primary care physicians' socio demographic and professional characteristics (2016)

Variable	Result
Age (years) Mean±SD Range	48.5±11.2 28-77
Number of children Mean±SD Range	2.4±1.8 0-12
Gender [n (%)] Males Females	93 (46.5) 107 (53.5)
Family status [n (%)] Married/cohabits Other	93 (46.7) 107 (53.5)
Country of birth [n (%)] Israel Other	97 (48.5) 107 (53.5)
Degree of religiousness [n (%)] Secular Traditional Religious/ultra-religious	135 (67.2) 28 (13.9) 38 (18.9)
Experience as a doctor (years) Mean±SD Range	18.7±12.2 0.5-44
Experience as a primary care doctor (years) Mean±SD Range	16.2±11.0 0-44
Number of weekly work hours Mean±SD Range	38.6±15.9 10-65
Country of medical school graduation [n (%)] Israel Other	96 (48.5) 102 (51.5)
Specialist [n (%)] No Yes	31 (15.8) 165 (84.2)
Field of specialization [n (%)] Family medicine Other	151 (85.3) 26 (14.7)
Place of work [n (%)] Independent clinic HMO clinic Other	48 (23.9) 138 (68.7) 14 (7.0)

Table 3. Results of multivariate linear regression analysis to identify variables that predicted 201 physicians' awareness of the risks of caregiving (2016)

B	S.E	β	t	Variable measured
00.34.-	14.	00.	0.01	Being a primary caregiver^^
52.-	13.	20.-	**2.59-	Country of medical school graduation +
	17.	22.-	**3.05-	Field of specialization++

R² 11% =

* p<0.05, ** p<0.01

^^ Being a primary caregiver – 1-Yes. 2-No

+ Country of medical school graduation – 1-Israel, 2-Other

++ area of specialization -1-Family, 2-Other

Table 4. Results of multivariate linear regression analysis for explaining 201 physicians' recommendation for preventive treatment (2016)

B	S.E	β	t	R ²	Variable
<u>First block</u>					
49.	20.	18.	**2.46	085.	Specialist +
26.	15.	13.	1.71		Country of medical school graduation ++
22.	14.	11.	1.57		Gender^
16.-	16.	07.-	1.00-		Being a primary caregiver ^^
<u>Second block</u>					
38.	19.	14.	*2.00	16.5	Specialist +
39.	15.	19.	**2.61		Country of medical school graduation ++
15.	14.	07.	1.07		Gender^
17.-	15.	08.-	1.12-		Being a primary caregiver ^^
36.	09.	29.	4.19***		Awareness of the risks of caregiving

The results of this hierarchical regression showed that the model is statistically significant ($F[5,184]=7.25$, $P<0.000$) and explains 16.5% of the variance. The model from this first step is statistically significant ($F[4,185]=4.27$, $P<0.001$) and explains 8.5% of the discrepancy in the dependent variable

* $p<0.05$, ** $p<0.01$, *** $p<0.001$

+ Specialist – 1-No, 2- Yes

++ Country of medical school graduation – 1-Israel, 2-Other

^ Gender – 1- Male, 2 - Female

^^ Being a primary caregiver – 1-Yes. 2-No

Supplementary Files

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