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The Needs of Family Caregivers of Persons Living with Dementia Cared for in Primary Care Practices

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Abstract

Rationale: The informal caregivers who provide unpaid support for persons living with dementia (PLWD) are often unprepared to appropriately manage symptoms and navigate health services to support themselves or the PLWD.

Aim: To understand informal caregivers' perceived capabilities of handling dementia symptomology and perceived support from providers.

Methods: We identified and surveyed caregivers of primary care patients in the Mass General Brigham health system. We included a self-efficacy questionnaire to assess caregivers' ability and confidence in access to dementia care, symptom management, and provider support.

Results: Respondents indicated that although their provider had knowledge of dementia and memory care, they were least likely to agree (39.2%) that their provider helped them with these challenging symptoms. Those who live with the care recipient were least likely to receive advice about common symptoms (43.6%) and to access community services (63.8%), and in general felt moderately knowledgeable about the progression of the disease (47.9%).

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Conflicts of Interest

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Conclusions: The findings imply that caregivers are aware of disease progression, dementia symptoms, and do not feel supported by their providers in managing care or accessing support services. There is opportunity to support informal caregivers in a primary care setting by appropriately uptraining providers in dementia care.

Keywords

caregivers; dementia; care delivery; primary care

Introduction

As the population ages, the proportion of persons living with dementia (PLWD) in the US is projected to increase from 5.2% presently to 10.5% by 2050.[1] A majority will be cared for by family caregivers and primary care providers, many of whom do not feel confident in diagnosing and treating patients with dementia.[2] Data from a survey conducted among primary care clinicians in our system revealed that assessment, diagnosis and treatment of individuals with dementia is an area of concern (unpublished data). In response, our health system initiated two pilot programs aiming to improve care management in primary care for PLWD and their caregivers. At baseline, we assessed primary caregiver self-efficacy to identify caregiver challenges (e.g., understanding and managing behaviors, knowledge of available caregiver resources).

Methods

We completed 143 baseline interviews with caregivers of PLWD out of 351 program-eligible patients for whom caregivers were identified. We selected patients from our Medicare ACO beneficiaries, served by 34 primary care practices affiliated with our health system, using a combination of Medicare claims data, patient problem lists, and current medication data to identify PLWD.[3] We identified primary caregivers through electronic health record review and confirmed with care managers. We excluded caregivers of patients living in skilled nursing facilities. We contacted caregivers in English and Spanish by postal mail inviting a telephone interview and then followed with direct telephone outreach by trained interviewers. The survey questionnaire included items on caregiver strain, symptoms of dementia, caregiver relationship with the patient, caregiving tasks, and patient functional status. We also used a 9-item caregiver self-efficacy scale developed by researchers at the University of California at Los Angeles for use in a study of community-dwelling adults with dementia referred to a dementia care management program.[4] No open-ended questions were included about self-efficacy. Full item text is shown in the tables. Chi-square tests assessed self-efficacy by relationship, and whether the caregiver lived with the patient. Data analyses were conducted using Stata/SE (17.0, College Station, TX: StataCorp LLC.).

Results

The total survey response rate was 40.7%. The primary reason for non-response was the inability to contact and interview caregivers. At baseline, we had demographic characterisitics for patients, but not for caregivers in our system records, which precludes an analysis of the characteristics of non-respondent caregivers. We were more successful in reaching caregivers who interacted with our care management programs or attended visits with patients and were identified in clinical notes. Among the 143 respondents, 70.0% were female, and 80.4% were White Non-Hispanic, 55.2% of caregiver respondents were children of the care recipient, and 65.7% lived with the person they care for (Table 1). About half of the caregivers were under 65 (46.2%).

Caregiver self-efficacy items are shown in Table 2. Caregivers were most likely to agree that their doctors understand how memory or behavioral problems complicate health (85.3%) and least likely to agree that they had a health professional who helped them work through dementia care problems (39.2%). Only 45% agreed that they received advice on what problems to expect in the future related to Alzheimer's or dementia. Just over half, 51.8%, agreed that they received advice on handling behavioral problems related to memory loss. Caregivers who lived with the care recipient were significantly less likely to have received advice about common behavioral problems compared to those who did not live with the care recipient (43.6% vs. 68.6%, $P = .005$). Similarly, if a caregiver lived with the family member, they were less likely to know how to access community services that would help in providing care (63.8% vs. 81.3%, $P = .03$). Additional analyses not presented here indicated no significant associations among self-efficacy items and gender, race, or ethnicity.

Discussion

Our survey of family caregivers for PLWD served by our health system underscores the confidence caregivers have in system clinicians' expertise, but also demonstrates significant gaps in caregiver preparedness to care for their family members. Consistent with one other clinic study[5] caregivers who lived with the patient were less likely to have received guidance on how to manage more advanced symptoms of the illness and did not know what to expect in the future. These care gaps highlight the need to provide effective training to clinicians on dementia care, with a particular emphasis on management of behavioral symptoms and community resources.[6] Limitations include inconsistent documentation of caregivers in electronic health records of some patients, challenges in accessing accurate contact information for family members who did not reside with patients which affected our response rate, and variability of practice settings with respect to staffing and patient panel size, and a small sample size of patients studied within a single health system. System innovations to support caregivers should tailor information to help caregivers of and PLWD to prepare for course of illness including treatment and management of behavioral symptoms of dementia. In addition, systems should encourage the identification and documentation of caregivers and underscore the importance of ongoing communication and support as dementia progresses.

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Table 1.

Characteristics of Caregiver Respondents, n = 143

Characteristic	n (%)
Age	
54 & under	28 (19.6)
55–64	38 (26.6)
65–74	36 (25.2)
75+	37 (25.9)
Not reported	4 (2.8)
Race/Ethnicity	
White Non-Hispanic	115 (80.4)
Hispanic/Latino/Other	28 (19.6)
Gender	
Male	39 (27.3)
Female	100 (70.0)
Nonbinary	3 (2.1)
Not reported	1 (0.7)
Relationship to Care Recipient	
Spouse	53 (37.1)
Child, child-in-law	79 (55.2)
Other	11 (7.70)
Not reported	0 (0.00)
Caregiver lives with the care recipient	
Yes	94 (65.7)
No	48 (33.6)
Not reported	1 (0.7)
Care recipient lives alone	
Yes	16 (11.2)
No	122 (85.3)
Not reported	5 (3.5)
Care recipient living Arrangement	
Home/apartment	120 (84.0)
Senior living community/Assisted living	23 (16.0)

Table 2.

Proportion of Agree/Strongly Agree Responses for Self-Efficacy Survey Items Among Combined Cohorts by Living Arrangement and Relationship to Care Recipient, n = 143

	Agree or Strongly Agree with self-efficacy item, n (%)	**Lives with care recipient n (%) of those who agree with statement**			**Relationship with care recipient n (%) of those who agree with statement**			
Self-Efficacy Item	**Agree/ Strongly Agree**	**Yes**	**No**	***P* Value**	**Spouse**	**Child**	**Other**	***P* Value**
The patient’s regular doctor understands how memory or behavior problems complicate other health conditions.	122 (85.3)	79 (84.0)	42 (87.5)	.58	44 (83.0)	68 (86.1)	10 (91.0)	.76
I have received advice about handling problems like the patient’s memory loss, wandering, or behavior problems.	74 (51.8)	41 (43.6)	33 (68.6)	.005	23 (43.4)	44 (55.7)	7 (63.6)	.27
I have received advice about what problems to expect in the future related to Alzheimer’s or dementia.	65 (45.5)	41 (43.6)	23 (47.9)	.62	21 (39.6)	36 (45.2)	8 (72.7)	.13
I am aware of services available to me to help me provide care.	95 (66.4)	60 (63.8)	34 (70.8)	.40	33 (62.7)	55 (69.6)	7 (63.6)	.66
I feel confident that I can handle problems like the patient’s memory loss, wandering or behavior problems.	93 (65.0)	66 (70.2)	26 (54.2)	.05	34 (64.2)	52 (65.8)	7 (63.6)	.97
I know where to turn to get answers to questions about problems like the patient’s memory loss, wandering, or behavior problems.	106 (74.1)	68 (72.3)	38 (79.2)	.37	37 (69.8)	60 (76.0)	9 (81.8)	.60
I know how to get community services that will help me provide care.	100 (70.0)	60 (63.8)	39 (81.3)	.03	31 (58.5)	60 (76.0)	9 (81.8)	.06
I feel confident that I can deal with the frustrations of caregiving.	403 (72.0)	69 (73.4)	33 (68.8)	.56	36 (67.9)	59 (74.7)	8 (72.7)	.69
I have a healthcare professional who helps me work through dementia care problems.	56 (39.2)	35 (37.2)	20 (41.7)	.60	16 (30.2)	35 (44.3)	5 (45.5)	.24