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Strengthening the Dementia Care Triad: Identifying Knowledge Gaps and Linking to Resources

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Abstract

This article describes a project to identify the needs of family caregivers and health care providers caring for persons with dementia. Participants included 128 caregivers, who completed a survey, and 27 health care providers, who participated in a focus group and completed a survey. Caregivers reported their primary source of information about the disease was the doctor; however, the majority also reported they were primarily informed of medications and not about needed resources. Health care providers identified limited time with patients and families, and lack of awareness of community services, as their main challenges. Recommendations include strengthening the partnership between physicians, patients, and caregivers (the dementia care triad) through additional support and training for physicians and caregivers, increasing awareness of the Alzheimer's Association, and utilization of technology for families and professionals to track the needs of persons with dementia.

Keywords

dementia care triad, dementia care management, Alzheimer's Association

Introduction

This investigation was undertaken to determine the needs of health care providers with respect to supporting families caring for relatives with dementia and characterize the needs of family caregivers, as they interact with the care recipient's health care provider. Studies over the past decade have consistently found that caregivers are broadly satisfied with medical care although vague diagnoses and limited information about or referrals to support services are frequently reported, indicating that partners in the dementia care triad continue to be challenged by the management of the disease.[1] The number of individuals with Alzheimer's disease (AD) in the United States is projected to reach 7.1 million by 2025, a 40% increase from current levels, with 17 states expected to experience an increase of 50% or higher in their dementia populations over the next decade.[2] Many family caregivers and care receivers depend on their primary care physician for direction in not only what to expect as the disease progresses but also how to physically and emotionally manage the changing conditions associated with the disease.[3-5] The interaction of the physician, the family caregiver, and the person with dementia is known as the dementia care triad, a 3-way partnership to which all partners bring their unique sociodemographic, cultural, psychological, and health-related characteristics.[1,6,7] Broadly speaking, an information and communication gap appears to exist between family caregivers and the care recipient's primary care physician with respect to treatment plans and support services.[8] Studies exploring these challenges frequently cite the physician's available time per patient, limited knowledge of available community resources and supports, and denial of the disease on the part of the family caregiver or patient as common barriers to meeting the needs of the person with dementia and their caregiver.[9-11] Gibson and Anderson studied the family caregivers' perception of length of time it took for a diagnosis of dementia as well as the resources provided by the physician.[12] They found that more than half of their sample (n = 106) reported the diagnosis took 3 months or longer. And many of these caregivers wanted information about the disease and community resources that they did not receive both at the time of diagnosis and 12 months later. How then are support systems put in place so that caregivers and health care providers can achieve a balance between what is needed and what is provided in order to maintain optimal care throughout the course of the disease?

The Alzheimer's Association's manual, "Partnering with Your Doctor: A Guide for Persons with Memory Problems and Their Care Partners," explains how the diagnosis is made, provides communication strategies for working with the physician,

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and offers a checklist for follow-up visits.[13] This and similar materials, such as the Alzheimer's Association Caregiver's Notebook,[14] place the responsibility for communication with health care professionals on the family caregiver. Most family caregivers have a desire to be advocates for their loved one and thus seek out information to help them navigate through the day-to-day maze of this disease.[15] In fact, several studies have documented that family members are the ones who first raise the issue of memory loss with their loved one's family doctor.[10,16]

Numerous medical books have been published which detail AD, in terms of its causes and techniques for making a diagnosis. However, information is less readily available that provides primary care physicians with recommended steps to follow in ensuring that a treatment plan, including medication and support services, is established once the diagnosis has been made.[4] Two particular challenges impacting both physicians and family caregivers include the time available to spend with patients and caregivers during doctor visits and awareness of available resources, such as the Alzheimer's Association.[17] There are a variety of educational materials made available to physicians (eg, Merck Institute of Aging and Health Toolkits[18] and guidance from the Alzheimer's Association[19]), but little is known about how aware health care professionals are of these resources, and how widely disseminated and used they are by both physicians and their ancillary staff.

Method

This study examined several hypotheses as part of a larger project. The 2 hypotheses addressed here include (1) family caregivers would report there is information they have not received but would find helpful to receive from the care recipient's health care provider and (2) health care professionals, including doctors and nurses, would report certain types of materials and tools that are more helpful to them in working with family caregivers.

Family Caregivers

Primary caregivers (n = 128), defined as those family members providing more than 50% of the needed care for the individual with AD, were surveyed. Needed care was based on caregiver perception and amount of time, care, and companionship provided. In cases where the care recipient has died (n = 12), caregivers were eligible for inclusion in the survey if the care recipient had passed away within the past 12 months. Participants were self-selected and were recruited from the 7400 mile^2 service area of the Southeastern Virginia Alzheimer's Association chapter. In addition, a modified snowball sampling approach was used, as some participants knew other caregivers performing similar duties. Demographic data for the caregivers are presented in Table 1. The mean age of the caregivers was 62.5 years (standard deviation [SD] = 12.5), with a range of 29 to 88 years. Females accounted for 76% of the participants, with 47.6% adult children/children-in-law and 36.5% spouses. The majority (68.3%) of participants reported that they had been caring for their relative for 3 years or longer, with the most common response being "between 3 and 5 years" (38.9%). Nearly 15% of the participants (n = 17) reported they had been serving as the caregiver for 8 or more years. More than half (54%) of the respondents explained that they were involved in caregiving duties for more than 30 hours each week, with the most common response being "more than 79 hours each week" (34.7%).

Table 1. Categorical Descriptive Variables for Caregivers.

	N	%
Ethnicity		
Caucasian	105	82.0
African American	11	8.6
Other	3	2.4
Not reported	9	7.0
Education		
Some high school/high-school degree	17	13.3
Some college	34	26.6
College degree	33	25.8
Some graduate school/graduate degree	33	25.7
Not reported	11	8.6
Marital status		
Married/living with partner	92	71.8
Separated/divorced	15	11.7
Widowed	6	4.7
Single/never married	7	5.5
Not reported	8	6.3
Employment		
Retired	46	35.9
Employed full time	26	20.3
Employed part time	15	11.7
Self-employed	10	7.8
Unemployed/not working outside home	18	14.1
Other	4	3.1
Not reported	9	7.0
Annual household income		
Less than US$15 000	7	5.5
Between US$15 000-US$24 999	6	4.7
Between US$25 000-US$34 999	13	10.2
Between US$35 000-US$49 999	24	18.8
Between US$50 000-US$74 000	23	18.0
Between US$75 000-US$99 999	9	7.0
Between US$100 000-US$149 999	17	13.3
More than US$150 000	3	2.3
Don't know	5	3.9
Not reported	21	16.3
Caregiver's self-rated health		
Excellent or very good	56	43.8
Good	48	37.5
Fair or poor	17	13.3
Not reported	7	5.4

Diagnostic-related characteristics of the care recipients are presented in Table 2. The mean age of the care recipients was 79.3 years (SD = 8.0), with a range of 52 to 98 years. The majority of care recipients resided at home, either on their own or with family, with 18.5% resident at an assisted living facility, and 9.7% at a nursing home. In the case of these latter 2 groups, family caregivers continued their caregiving role,

Table 2. Health-Related Characteristics for Care Recipients.

	N	%
Care recipient's diagnosis		
Alzheimer's disease	68	53.1
Probable Alzheimer's disease	15	11.7
Dementia	33	25.8
Other (eg, Parkinson's disease, unknown)	12	9.4
When diagnosed		
Within the past year	12	9.4
1-3 years ago	41	32.0
4-6 years ago	42	32.8
7-9 years ago	13	10.2
More than 9 years ago	12	9.4
Not reported	8	6.2

oftentimes reporting as much if not more care and companionship provided when compared to prefacility status. Approximately 65% of care receivers had been diagnosed with probable or definite AD.

The family caregiver survey was administered both via telephone and online. The purpose of the survey was to provide details regarding the types of information family caregivers reported receiving from their relative's physician with respect to the diagnosis and the disease. Descriptive statistics and frequency distributions were calculated on all variables, and where possible, cross-tabulations were conducted to examine frequencies and percentages of individuals when considering 2 variables. Correlational analyses were conducted to determine the degree of relationship between specific variables (eg, length of time caregiving and caregiver and care recipient's health status). Where qualitative information was obtained (eg, types of information and advice provided by doctor) responses were examined for patterns and themes.

Health Care Providers

The second group of participants included physicians and their nursing staff practicing in the geographic area previously identified. Three focus groups, consisting of 8 to 17 health care providers each, were organized with a total of 37 participants. All focus group participants were invited to complete a brief survey. Demographic data for health care providers are presented in Table 3. Of the 37 participants, 30 health care providers completed the survey. The purpose of the focus groups was to identify the scope of care, challenges in care, and recommendations to strengthen the caregiver–health care provider relationship. One objective of the study was to determine the types of tools and resources doctors and their staff are using in working with persons with dementia. This information was gathered via a brief survey. Handwritten notes and audio recording were utilized at each focus group session to ensure that all responses were accurately documented. Three independent reviewers listened to the audio recordings, reviewed the transcript, and reached consensus on the identified themes. An initial step of the data analysis was the calculation of frequencies among the caregiver and care recipient characteristics identified in the family caregiver survey and from the survey of health care providers. Although a variety of analyses were conducted, the data presented here represent descriptive summaries of the caregivers and the health care providers' experiences and perceptions.

Table 3. Characteristics of Health Care Providers Completing Survey as Part of Focus Groups.

	N	%
Type		
Primary care physician	6	20.0
Specialist	2	6.7
Nurse/nurse practitioner	11	36.7
Office manager	2	6.7
Other (eg, certified medical assistant, scheduler)	9	30.0
Proportion of patients 60 years of age and older		
40% or fewer	3	9.9
Between 50% and 70%	10	33.3
Between 75% and 85%	9	30.1
More than 85%	5	16.6
Not reported	3	10.0
Proportion of patients with dementia		
10% or fewer	9	30.0
Between 20% and 30%	6	20.0
Between 35% and 45%	6	20.0
50% or more	4	13.3
Not reported	5	16.7
Distinguish between dementia and AD diagnosis		
Always	8	26.6
Sometimes	11	36.7
Rarely	4	13.3
Never	2	6.7
Not reported	5	16.7
Tools utilized		
MMSE	27	90.0
Clock drawing test	19	63.3
Referral to specialist/assessment center	9	30.0
The 36-hour day	7	23.3
The Merck Manual of Geriatrics	5	16.7
Schedule additional time with patients with dementia	15	50.0
Schedule additional time with family caregivers	16	53.3

Abbreviations: AD, Alzheimer's disease; MMSE, Mini-Mental State Examination.

Results

Hypothesis 1

Two essential survey items invited caregivers to share any additional comments about their experiences. When reviewing and categorizing the types of responses, the following themes emerged:

- Better awareness of community resources is needed for both family caregivers and health care providers.
- Additional knowledge and training about the disease are needed including:
    - caregiver training;

    - educational programs for health care providers;
    - training for aides in long-term care facilities.
- Caregiving is stressful, and adequate coping skills are important to help with the day-to-day variability of AD.

Caregivers reported that their primary source of information about the disease and community services was their doctor; however, the majority (64.5%) of caregivers reported that the doctor was more likely to provide information about medications than about the course of the disease, available community resources, or long-term care planning. Other sources of information identified by caregivers included the Alzheimer's Association, support groups, books/magazines, and Web sites. When caregivers were asked to identify the resources (eg, adult day services and home health care) they were currently using to assist them in their caregiving role, the Alzheimer's Association (44.5%), the Internet (33.6%), and support groups (35.9%) were the most commonly reported. When asked about information or advice they would like to have been provided about the care recipient's dementia, caregivers reported a variety of items. These items included general information about the disease and disease progression, types of services available (eg, adult day care, support groups), how to handle the care recipient's other health problems, and financing the care over an extended period of time.

Caregivers shared their experiences of interacting with the medical community in the dementia care triad. One husband, caring for his wife, explained, "I think the medical community takes a hands-off approach. I have some experience with this as I have lost two sisters with memory problems. There aren't even any geriatricians in our area. I've really had trouble getting any reports or information from the doctors she has seen. Another thing that concerns me is the change in administration in the long-term care facility where my wife is." Another caregiver responded, "I guess I really didn't expect the doctor to have a lot of resource information to deal with things on a day-to-day basis. The support group has provided a wealth of information on how to cope and keep your loved one safe." Another caregiver explained her situation with the following: "I think generally the doctors do a very poor job of the dynamics of the disease on the family. There is very little advice or even what to expect given to the family. I have even had doctors be a little flippant saying everyone is different. It has been a major source of frustration that you are left out there hanging." The views of these caregivers vividly highlight their desire for more support to manage the effects of the unfolding disease process.

Hypothesis 2

Physicians and nurses who participated in the focus groups and completed the survey reported that time to spend with patients, and their families, and awareness of community services were their biggest challenges. Health care providers who completed the survey detailed ways in which the primary care physician's staff (eg, nurses and nurse practitioners) could provide support to families including:

- making sure that patients are referred to a specialist in a timely fashion;
- communicating with family members about the disease and available resources;
- assessing the caregiver's level of understanding about the disease in order to aid the physician in the treatment;
- being a good listener;
- providing encouragement, support, and explaining what to expect.

Nearly 40% of health care providers responded that they have tools or resources that are routinely distributed to assist family caregivers, including books (eg, The 36-Hour Day[20]), handouts, brochures, and Web sites. Other resources included referrals to an assessment center or the Alzheimer's Association and the Association-sponsored support groups. The materials and tools most commonly used are documented in Table 3 and include the Mini-Mental State Examination (MMSE), the clock drawing test, referrals to specialists, and The 36-Hour Day. Table 4 identifies health care providers' perceptions of the helpfulness of tools they use when treating their patients with dementia. More than two-thirds of the respondents identified these screening tools and books as "very helpful" in delivering care from diagnosis to treatment, including communication with the patient and/or family. It should be noted that since this research was undertaken, enforcement of the MMSE copyright has increased with the result that clinicians are increasingly using alternative screening tools for cognitive impairment (eg, Montreal Cognitive Assessment and St Louis University Mental Status) in place of the MMSE. Other than The 36-Hour Day, there was no 1 specific tool recognized that was being routinely distributed. A large majority (80%) of health care providers identified their interest in a checklist, similar to an order set, which could be available to offer to family caregivers. The checklist might include referrals, reminders, and itemized steps in a treatment plan.

Discussion

Persons with dementia continue to see their primary care physician for managing other health issues as well as their dementia. Physicians fulfill numerous roles in treating patients with dementia, including treating psychological and behavioral symptoms, counseling them, and planning for the future.[6] However, dementia care is not profitable, and reimbursement does not adequately cover many critical elements of care, including coordination with community services and education and support of caregivers.[21,22] This issue of low reimbursement is clearly at odds with the amount of time many physicians report they need to adequately diagnose and treat a person with AD. This was evident from the results of the health care provider survey and focus groups. Interestingly, 50% of health care providers responding to the survey reported that they allow

Table 4. Degree of Helpfulness of Tools Utilized in Providing Treatment to Persons With Dementia.

	Not at All Helpful, % (n)	Somewhat Helpful, % (n)	Very Helpful, % (n)	N/A, % (n)
Establishing the diagnosis		17.9 (5)	78.6 (22)	3.6 (1)
Providing a treatment plan	3.4 (1)	13.8 (4)	79.3 (23)	3.4 (1)
Prescribing medication	3.7 (1)	22.2 (6)	66.7 (18)	7.4 (2)
Communicating with the patient and/or family		20.0 (5)	76.0 (19)	4.0 (1)

extra time to meet with their patients with memory loss and 53.3% reported additional time was scheduled for meeting with family members. These percentages indicate a positive development in that physicians and their staff are acknowledging the need for, and attempting to incorporate, additional time to meet with patients and families. Several participants in the focus groups explained that they meet with family members outside of regular business hours, where there is no opportunity for reimbursement.

The Council on Scientific Affairs of the American Medical Association has recommended that physicians be reimbursed for time spent providing education to and counseling caregivers, acknowledging that an effective relationship model would identify the key linkages and interdependence between primary care physicians and family caregivers.[23] This view supports the shift from a biomedical to a psychosocial approach to dementia care within a triadic partnership, which has increasingly been recognized as instrumental to effective care.[24,25] This partnership demands that physicians take both time and skill in effectively communicating complex information[26] and linking patients and caregivers to available resources for education and support.[27,28] Hunsaker et al confirm the value caregivers place on support and information provided by the primary care physician.[29] However, they also note that physicians are reluctant to offer advice and input about dementia-related behaviors, which family caregivers express is a particular challenge. Caregivers seek guidance on how to recognize and manage these behaviors. In this sample (n = 25), 80% of caregivers identified they deal with disruptive behaviors; yet, this challenge was addressed in fewer than 25% of the medical visits.

Limitations

There are several limitations to the present study that should be addressed. First, the caregivers who completed the family caregiver survey were a self-selected sample of caregivers. They may have been more motivated to seek out information about memory loss, ways to care for their loved one, and accessing specialty care than nonresponders. A second limitation of the study was the small number of physicians who participated in the focus groups and completed the health care provider survey. The majority of participants were nurses, nurse practitioners, and office managers. Perhaps the participation of these health care professionals is more telling in that nurses and other ancillary staff may be more available and accessible than physicians when it comes to educating and counseling family caregivers.

Recommendations

Simply put, it appears that there are knowledge and communication gaps impacting the current delivery of dementia care. These knowledge gaps may prevent caregivers from "consuming" the information physicians present and communication gaps may make it more challenging both for the physician to convey and the patient and caregiver to receive necessary information. Second, a lack of knowledge about AD and related dementias, community resources, and support services for caregivers appears to exist among physicians. Several of the most feasible options for addressing these knowledge and communication gaps are identified subsequently.

Education and Training

A variety of educational programs are needed to support both the family caregiver and the primary care physician in managing the course of AD. Training programs for family caregivers exist, including ones delivered by the Alzheimer's Association and the National Family Caregivers Association[28]; however, more emphasis needs to be placed on interactive training and colearning environments, where caregivers can be more than passive recipients of information about dementia. Many participants in the caregiver survey responded that their attendance at support groups was beneficial. The Alzheimer's Association's EASE program, available in many states, provides an opportunity over the course of 8 weeks for dyads of individuals newly diagnosed with dementia and their caregivers to meet with and learn alongside others about how to manage the disease and what to expect.[30] The "Caring for You, Caring for Me" Education and Support program of the Rosalynn Carter Institute for Caregiving, also being offered in a number of states, is a 10-hour education and skills building program for families, professionals, and volunteers who are serving as caregivers for older individuals.[31] The program is organized around five 2-hour modules, and participants meet weekly for 5 weeks. A unique feature of this program is that family caregivers and professionals participate together to discuss coping mechanisms; local, state, and national resources and identify key issues, concerns, and ways to work together to enhance the quality of life for the care recipients and the caregivers. These types of interactive educational forums should be more widely available. There is also scope for supporting caregivers through new technology, including handheld devices through which caregivers can communicate with health care professionals in respect of emotional and behavioral changes they observe, in order to receive guidance, recommendations, and reminders from them between appointments.[32]

Primary care physicians can benefit from additional support, including redesigning the organizational structure of care practices and care protocols to increase collaboration and interdisciplinary team effectiveness in managing dementia care[33,34] as well as using decision support technology to assist with diagnosis and treatment management.[35] However, these are resource-intensive interventions, which may be out of reach for many physician practices. There are more basic responses that do not require substantial reorganization or dedication of resources but which also have the capacity to improve dementia care significantly, especially those which assist physicians to link caregivers to community resources. The Family Caregiver Alliance National Center on Caregiving online toolkit entitled, "Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers" is one example.[36] Further study is needed to understand how this toolkit is shared with medical professionals and how they incorporate the caregiver assessment into their delivery of care. It is also evident from the focus group discussions and the health care provider survey responses that more attention needs to be given to training programs in disease recognition and management for ancillary staff (eg, nurses, office managers, and schedulers). "Especially lacking are explorations of how issues specific to AD or dementia occur among provider–patient triads"[(p.248),29] Importantly, Hunsaker and colleagues acknowledge that not all professional support can or should be provided by the physician and that other clinical staff including nurses and social workers should be an area of focus. Perhaps a nurse well versed in dementia care could become a shared resource and serve as a dementia care coordinator who travels to family practice offices within a specified geographic region.

As more and more physicians take advantage of technological advances to support their delivery of care, it seems a favorable time to introduce prompts into clinical standards following an AD or related dementia diagnosis. The Veterans Administration has already established clinical standards whereby physicians, by use of electronic medical records, are prompted to ask about driving and gun safety when a diagnosis of dementia is documented. Once a diagnosis is established, it would be extremely beneficial to the patient and the family if the primary care physician, specialist, or nurse would direct them to the Alzheimer's Association. Reuben et al[17] designed a simple referral form that can be integrated into the electronic health record and e-faxed to the Alzheimer's Association at the conclusion of a patient visit, in response to focus groups of physicians who indicated this would increase the likelihood of them making such a referral. Once connections are established with the local chapter of the Alzheimer's Association, support for both the caregiver and the person with dementia becomes more accessible. The process also results in a smooth hand off to a well-established community resource. As a variant of this, the research team recommends the development and distribution of a "just in time" aid, which would essentially serve as a discharge/standing order for the primary care physicians and their staff to use. Due to the overwhelming concerns regarding lack of the physician's time documented in this study and others,[5,6,10,37] it is clear that physicians are in need of a checklist that could be provided to families caring for relatives with dementia, and there was considerable interest in such a checklist among the health care provider participants of this research. This checklist might include items such as (1) additional information on the treatment plan; (2) reminders about medical appointments; (3) referral to specific resources, such as the Alzheimer's Association; and (4) reminders to keep a log documenting changes in the care recipient's cognitive status.

Marketing and Promotion of the Alzheimer's Association

As reported by caregivers, physicians were making some referrals to community services. However, a clear need exists for increased awareness of the local Alzheimer's Association chapter and its support services. Because it is more likely that families will seek out these services during times of crisis, and that these times of crisis likely include a visit to the physician, referrals to the Alzheimer's Association should be more routinely incorporated. The research team has been collaborating with the Alzheimer's Association to establish a "When You Run Out of Time" campaign to encourage physicians to make referrals. This campaign would recognize that many physicians are overburdened and do not have the time needed to adequately explain to persons with dementia and their families what types of resources are available, both in the near and long terms. Physicians and their staff would refer their patients to a family orientation, whereby the person with dementia and their family would learn about the available community services and how to access them, including support groups and long-term care planning.

Conclusions

More and more families are being affected by AD. Care recipients, and their families, depend upon their doctor to be a resource for information about medications, the course of the disease, and community services. This study has identified a number of practical changes that may be incorporated to address the knowledge and communication gaps documented. Recognizing the value of triads in dementia care as well as the role of ancillary staff will prove beneficial to caregivers and medical professionals alike. Finding creative ways to enhance knowledge of dementia and of the resources available through the Alzheimer's Association will also be supportive of those providing care. Through greater use of technology, there are many opportunities to assess the experiences of caregivers via online surveys and to support dementia care (eg, clinical prompts and reminders) delivered by medical professionals. Ultimately, the goal in dementia care should be to enhance the triadic partnership. Strengthening this partnership enables care providers to access the resources needed to maintain the dignity and quality of life for persons with dementia while maintaining their own.

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