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Difficult Diagnoses: Family Caregivers' Experiences During and Following the Diagnostic Process for Dementia

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Abstract

Diagnosing Alzheimer's disease and related dementias (ADRD) and adequately connecting families with information and supportive services continue to be challenging processes. Definitive diagnoses can take months and there is often little in place to systematically link families with community organizations. In this brief descriptive study, the researchers examined family caregivers' (N = 106) experiences with these processes. While specialists and sophisticated tests were often used, 58% of caregivers reported that a definitive diagnosis still took 3 months or longer, with 12% waiting more than 1 year. Caregivers also indicated that they were not provided with adequate information about the disease or about community resources both at the time of diagnosis and 1-year following the diagnosis. These findings suggest that there is ample opportunity to improve services offered to families affected by ADRD and that additional training, coordination, and cooperation may enhance our ability to help during and following the diagnosis.

Keywords

Alzheimer's disease, dementia, diagnosis, family caregivers

The process of receiving a diagnosis of Alzheimer's disease or related dementias (ADRD) can be overwhelming and often times frustrating for families. In addition to dealing with a devastating diagnosis, information and support that individuals and families receive during and following such diagnoses are often incomplete and inadequate. In some cases, individuals and families can wait years to finally receive a definitive diagnosis, thus delaying their ability to connect to available support resources.[1] While many caregivers are interested in receiving information about providing care and available resources, they often do not receive it in a timely fashion.[2] Without education and information, caregivers are left to fend for themselves in learning about the disease, locating community support, and obtaining assistance in managing their care. The purpose of this study was to further understand the experiences of family caregivers during the diagnostic process, specifically the process of receiving the diagnosis, the length of time to receive a definitive diagnosis, and the process by which they become connected with community resources. While a handful of past studies have also explored this topic, it is critical to continue to try to understand the diagnostic process, particularly in light of recent advances in diagnostic testing for ADRD. Additionally, it is important to understand family caregivers' point of view as they are typically the primary source of support for individuals diagnosed with ADRD.

While criteria and clinical guidelines for diagnosing ADRD exist, many physicians struggle with providing definitive diagnoses in an expedient manner. Researchers have found a variety of reasons why physicians, especially primary care physicians, have such difficulties with the diagnostic process, most notably limited training in ADRD and illnesses associated with aging and the complexity and variability of ADRD. Given the fact that many ADRD are progressive and not reversible, physicians may also feel that it is futile to provide a diagnosis for a virtually untreatable disease.[1,3–5] Failure to provide a diagnosis in a timely manner can be problematic for individuals and families. The National Institute of Aging[6] suggests having an early diagnosis and starting treatment in the early stages of ADRD can help preserve functioning abilities from months to years, even though the underlying process cannot be changed. When diagnosis of ADRD occurs earlier in the disease process, there is more time available for treatment aimed to enhance patient functioning and delaying decline, and for family education about the disease and its management.[7] Without a diagnosis, individuals and family members may also be reluctant to seek out community resources. Essentially, why contact the Alzheimer's Association if you *don't have* AD?

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Once a diagnosis of ADRD is provided, there is evidence[1,8–10] to suggest that physicians often fail to adequately educate individuals and families about the disease and to establish connections with community resources. In the most recent of these studies, researchers found that less than 30% of primary care physicians referred their clients with dementia to the Alzheimer's association and less that 35% referred their clients to local Area Agencies on Aging, a clearinghouse of information and support. In another recent study using focus groups, primary care physicians acknowledged that they lacked an understanding of the services available to individuals and families, simply stating, "We have not referred any patients; it's usually family members who find these services."[11] It appears that this lack of connection between physicians and community resources is not necessarily a one-way street. Community resources, such as the Alzheimer's Association, have acknowledged this failure and have made recent efforts to strengthen the ties between medical providers and the community.[12,13] While these programs have promise, it appears that many caregivers are still left with simply a diagnosis and a wish of good luck.

In the current study, the researchers explored the diagnostic process for ADRD from the caregiver's perspective—a view that has received sparse attention in the literature. In addition, it is important to periodically gauge the effectiveness of health care professionals and supportive services involved with ADRD as advances in diagnostic techniques continue to evolve. To guide the study, the following 2 specific aims were developed:

1. To learn from family caregivers about the diagnostic process (eg, diagnosing physician and diagnostic tests utilized) and the length of time that it took to receive a definitive diagnosis of ADRD.
2. To determine whether family caregivers were provided with adequate information about disease processes and community resources.

The findings from this study will allow us to gauge the progress of the medical community in diagnosing ADRD and the degree to which physicians and associated health care professionals are effective in linking individuals and families with community resources.

Methods

Sampling

The population for this cross-sectional study consisted of caregivers (e.g. spouses and adult children) of individuals with a diagnosis of ADRD. For the purposes of the current study, caregivers were defined as individuals who provide care or assist with the activities of daily living for an individual with dementia, at home, in the community, or in an institution (eg, nursing home). Convenience sampling was used to recruit participants. The primary author presented information about the study to family caregivers at educational support meetings run through the Alzheimer's Association Central Ohio chapter. Family caregivers who expressed an interest in participating were given the option of either completing a self-administered paper copy of the survey or completing the survey online. As certain items in the survey pertained to current caregiving situations, caregivers whose care recipients were deceased were excluded from this study.

Measures

Measures included in the survey instrument were primarily descriptive. The survey was developed based upon the following: (*a*) our understanding of the existing literature on the diagnostic process; (*b*) questions and ideas that have arose from the authors experience in clinical settings; and (*c*) questions that arose in discussions with support providers, such as the Alzheimer's Association. The authors intentionally limited the number of items to increase participation and to decrease time demands on caregivers. Dichotomous and categorical measures were utilized to explore the experiences and possible needs of caregivers during and following diagnosis. The survey instrument contained items focused on the following: demographic and contextual variables; length of time to diagnosis; diagnosing physician/health care professional; type of diagnosis; and the provision of information about dementia and community resources during and 1 year following diagnosis.

Statistical Analysis

Frequencies, descriptive statistics, and inferential statistics (*t*-tests) were computed for the quantitative data using SPSS 17.0. The survey instrument also contained open-ended questions asking caregivers what would have been helpful to them during and following the diagnosis. The qualitative data from the open-ended questions was minimal and, as such, were not formally analyzed. The statements made by caregivers are used in an illustrative role to support and enrich the understanding and interpretation of the quantitative findings.

Results

The final sample consisted of 106 family caregivers to persons with a dementia diagnosis ($N = 106$). Family caregivers were primarily spouses or partners (50.9%) and adult children (39.6%). Most of the family caregivers were white (89.6%) and lived in urban areas (63.3%). Almost half of the family caregivers were male (49.1%). In terms of the care recipients, the mean age for diagnosis was approximately 77 years of age ($M = 77.60$; $SD = 10.31$). The most common diagnoses included AD (53%), dementia unspecified (16%), and vascular dementia (8%). Sample demographic characteristics are summarized in Table 1.

In terms of the diagnostic process, the majority of families had received the diagnosis from either a neurologist (69.8%)

Table 1. Demographic Characteristics (N = 106)

Characteristic	%
Gender of care recipient	
Female	*50.0*
Male	*49.1*
Race/ethnicity of caregiver	
White	*89.6*
African American	*9.4*
Asian	*0.9*
County where caregiver is located	
Urban	*63.3*
Rural	*37.7*
Relationship to the care recipient	
Spouse or partner	*50.9*
Adult child	*39.6*
Other (e.g., sibling, grandchild)	*9.4*
Current diagnosis of care recipient	
Alzheimer's disease	*52.9*
Dementia unspecified	*16.3*
Frontotemporal dementia	*13.5*
Vascular dementia	*7.7*
Lewy body dementia	*3.8*
Multi-infarct dementia	*1.9*
No diagnosis	*1.9*
Other (eg, Parkinson's disease)	*1.9*

Table 2. Characteristics of the Diagnostic Process (N = 106)

Characteristic	%
Type of doctor who gave current diagnosis	
Neurologist	69.8
Primary care physician	21.7
Other (eg, psychologist, psychiatrist)	7.5
Types of diagnostic tests used for diagnosis	
Neuropsychological test	95.3
Brain imaging test	77.4
Combination of neuropsychological, brain imaging, and lab testing	57.0
Testing unknown	3.8
Length of time it took to receive diagnosis	
First doctor's visit	14.2
1–3 months of testing	27.4
4–6 months of testing	23.6
7–12 months of testing	17.9
1–2 years of testing	9.4
More than 2 years of testing	2.8
Caregiver suspected dementia prior to physician confirming the diagnosis	
Yes	77.4
No	19.8
Family given a different diagnosis during diagnostic testing	
Yes	30.2
No	68.9

or a primary care physician (21.7%). Family caregivers reported that a variety of tests were conducted during the diagnostic process, primarily neuropsychological testing (95.3%), brain imaging (77.4%), or a combination of tests (57%). There was a wide range in the length of time before a definitive diagnosis of dementia was provided. Interestingly, 14.2% reported that they received the diagnosis on the first visit to the physician and another 27.4% received the diagnosis in less than 3 months. Unfortunately, 30.1% of caregivers reported that it took 6 months or more to receive the definitive diagnosis. Independent sample *t*-tests revealed that there were no significant differences between the length of time for a diagnosis of AD, typically one of the most complicated dementia-related diseases to diagnose, and the length of time for a diagnosis of other types of dementia (eg, vascular dementia and dementia unspecified). The location of the diagnosing physician (ie, urban vs suburban/rural) also did not have a significant impact on the length of time for diagnosis. Diagnostic process statistics are reported in Table 2.

Caregivers were also asked if they had been given enough information about the disease and how to care for the care recipient (*a*) at the time of diagnosis and (*b*) 1 year following the diagnosis. A considerable percentage of caregivers reported that they had not received enough information at the time of diagnosis (84.0%) nor had they received enough information 1 year following the diagnosis (49.1%). The caregivers were then asked if they had been given enough information about community resources to help them care for their family members. Again, a considerable percentage of caregivers reported that they had not received enough information about community resources either at the time of diagnosis (93.4%) or 1 year following the diagnosis (62.3%). Finally, caregivers were asked if the diagnosing physician had referred them to any type of support program. Almost two thirds (63.2%) of the sample of caregivers reported that the diagnosing physician had failed to do so. Responses are summarized in Table 3.

Discussion

Using the perspective of family members, this study explored the experiences of family caregivers during and after the diagnosis of ADRD. The first specific aim of the study was to gain insight into the diagnostic process and the length of time that it took for family caregivers to receive a definitive diagnosis of ADRD. Somewhat contrary to expectations, the majority of diagnosing physicians were neurologists rather than primary care physicians. It has been reported that primary care physicians often struggle with diagnosing ADRD and the findings in the current study may indicate that primary care physicians are referring patients with memory loss to specialists.[10] As this study was conducted in an area with a university-operated memory disorders clinic, local primary care physicians have the ability to refer patients—a resource that may not be available in other areas of the country. In terms of the diagnostic tests utilized, it again appears that the presence of the memory disorders clinic may have skewed the results. The vast majority of family caregivers reported that brain imaging was used alone or in combination to diagnose ADRD. This finding is promising as technological advances are improving the ability to diagnose ADRD accurately. New tests for ADRD (eg, spinal fluid testing) should increase the ability of physicians to make

Table 3. Provision of Information and Referral (N = 106)

Question/Item	%
At the time of diagnosis, do you feel you were given enough information about the disease and how to care for your loved one?	
Yes	14.2
No	84.0
One year following the time of diagnosis, do you feel you have been given enough information about the disease and how to care for your loved one?	
Yes	44.3
No	49.1
Not applicable, has not been one year from diagnosis	4.7
At the time of diagnosis, do you feel you were given enough information about community resources to help care for your loved one?	
Yes	6.6
No	93.4
One year following the time of diagnosis, did you feel you have been given enough information about community resources to help care for your loved one?	
Yes	28.3
No	62.3
Not applicable, has not been one year from diagnosis	4.7
Were you referred to any support programs by the doctor who diagnosed the care recipient?	
Yes	35.8
No	63.2

definitive diagnoses without the use of expensive technologies such as brain imaging.[14] It will be interesting to see the impact of these new technologies on the diagnostic process.

As previously mentioned, an expeditious diagnosis of ADRD is critical as it allows individuals and family members to begin treatment, seek support, and plan for the future.[6,15,16] In terms of the length of time for diagnosis, the results indicate improvement but also reveal that the diagnostic process remains lengthy for many. Recent research found that family members waited an average of approximately 1½ years for a definitive diagnosis of ADRD from their first visit to a physician.[1] In the current study, over 40% of family caregivers reported that they received a definitive diagnosis of ADRD within 3 months of seeing a physician. Despite this improvement, it should be recognized that over 30% of family caregivers reportedly waited over 6 months for a definitive diagnosis and over 12% waited 1 year or more. This is a substantially shorter length of time for diagnosis than what families were seeing 10 years ago,[1] but despite these gains, caregivers reported difficulties in obtaining the diagnosis. Some participants stated that the "doctor seemed reluctant to give diagnosis." Others reported difficulties long wait times in setting appointments and accessing services. Interestingly, a few family members indicated that regulations led to delays in learning about a diagnosis. "Dad didn't give me permission to talk to the doctors, and so I had to send letters in before his appointment to talk to the doctor. It was extremely difficult to find out what was going on." In addition to monitoring the impact of new diagnostic techniques on the length of diagnosis, researchers should also examine the impact of government privacy regulations (eg, in the United States, the Health Insurance Portability and Accountability Act or HIPAA) on communications between physicians, patients, and family members.

Once given a diagnosis of ADRD, the vast majority of caregivers (84%) stated that they were not provided with enough information about the disease nor adequately informed of how to care for a person with ADRD. Additionally, very few caregivers (less than 7%) were provided with adequate information regarding available community resources and only about 1/3 of caregivers were referred to support programs. This lack of information and support persisted for caregivers and many reported deficiencies in these areas 1 year following the diagnosis of ADRD. As one caregiver stated, "Anything would have been helpful. We didn't have anything." Another caregiver stated that she learned about the disease and caregiving by "the school of hard knocks." This finding is particularly troubling as the time of diagnosis is a critical juncture where information is vital and all parties are present to exchange information. For some families, the progressive and virtually untreatable nature of many dementia-related diseases (eg, AD) may preclude them from ever visiting the physician again. Again, early support in terms of information about disease processes, counseling and coaching, and access to community resources has been identified as a benchmark in excellent dementia care.[15] Past studies have found that physicians often have inadequate knowledge of community resources, poor connections with community agencies, and a lack of time to facilitate connections between individuals, families, and community support.[3,10,17] Additionally, many caregivers feel this information should come from the physician at diagnosis, which is often not the case.[18] While this study did not test the knowledge of physicians, the results do indicate that the communication and referral processes during and after the diagnostic phase could be improved from the caregivers' point of view. Certainly, these results are not intended to impugn the work of physicians in addressing this complicated and troubling diagnosis. Rather the results suggest that physicians and family caregivers could benefit from collaborative efforts between physicians, other health care professionals, and community support organizations both during and after the diagnosis of ADRD.

Limitations

This study has several limitations that should be considered when interpreting the findings. First, the study was retrospective and required caregivers to recall information that occurred in the past. Caregivers may not have been able to accurately recall details with the passage of time. Additionally, we did not ascertain whether the participants were the primary caregivers at the time of diagnosis. While this can be assumed in most cases, it was not verified in the sampling. Other characteristics of the sample for this study may have also impacted the findings. Participants in this study were actively involved with their local chapter of the Alzheimer's Association. Including family caregivers who were not associated with formal community support agencies may have yielded different results. Indeed, the findings in the current study may overstate the degree to which family caregivers are connected with community support agencies. Additionally, the presence of a university-operated memory disorders clinic may have skewed the percentage of neurologists providing diagnoses of ADRD. Areas without such resources may rely more heavily on primary care physicians in diagnosing ADRD and diagnostic may be qualitatively different. Our measures may have been overly simplistic, as well. For instance, it would have been more informative to use a Likert scale to measure the adequacy of the information and support received by caregivers rather than using a dichotomous variable. Finally, the sample in the current study was relatively small and not diverse in terms of ethnicity and race. This should be noted in generalizing this sample to the overall population of family caregivers. Future studies should consider different and more sophisticated sampling methods to obtain larger and more diverse samples of this population (eg, oversampling of minority populations).

Practical Implications

This study provides an up-to-date status report on how well the health care community and support organizations are addressing the needs of family caregivers to individuals diagnosed with ADRD. The information is critical given the rapidly changing health care system in the United States and the advances that are being made in diagnosing ADRD. While the findings from this study indicate that there are many shortcomings in the diagnostic process for ADRD, they also suggest that opportunities exist to improve this process for individuals and families. First and foremost, primary care physicians need specific training on the diagnosis and care for dementia. As this study and other research[1,19,20] have shown, primary care physicians do not appear to be comfortable or particularly adept at the diagnosis of ADRD. Recent research[21] suggests that the use of evidence-based guidelines, diagnostic toolkits, and creative educational approaches may be effective in facilitating efficiency and accuracy in the ADRD diagnostic process. A key element within these programs[22,23] is the acknowledgement of time constraints for primary care physicians and the use of interdisciplinary teams during and after the diagnostic process. For instance, 1 study[24] found that using care management support from social workers in conjunction with the work and expertise of physicians resulted in higher satisfaction rates for both providers and caregivers, as well as higher rates of compliance with evidence-based guidelines for dementia care. The findings from the present study suggest that physicians could benefit from ancillary support from health care professionals specifically trained to help caregivers connect with resources, such as social workers or nurse case managers. Such collaborations may make the most of physicians' time and provide caregivers with ongoing support well past the diagnosis.

Forming stronger and more effective connections with community agencies, such as the Alzheimer's Association, have also been recommended to help support individuals with ADRD and their caregivers following diagnosis. As the results of this study indicate, family caregivers struggle to obtain the information and support that they need to provide care. Collaborations between health care professionals and community support agencies may be an important bridge mechanism as caregivers move from diagnosis to prolonged care. For example, a recent randomized control trial[25] found that structured care counseling done through collaborative efforts between primary care physicians and Alzheimer's Association chapters resulted in higher satisfaction with care and lower levels of nursing home placement. The onus is not solely on the health care community in building these relationships. Agencies that provide support for individuals with ADRD and their caregivers should also work to build relationships with physicians to enhance quality of care.[11,12] In the long run, caring for individuals with ADRD is a community responsibility. Approaches that use a comprehensive web of care resources may be the most effective way to help families during and after this most difficult diagnosis.

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