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Hospice Access for Individuals With Dementia

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Involvement in a hospice program is important because it may allow individuals with dementia to delay or prevent institutionalization as well as provide psychosocial support for their families. Once used mostly by patients with a terminal cancer, now more than one half of the hospice patients have diagnoses other than cancer. Yet hospice is still underused for individuals dying with advanced dementia. We conducted a pilot study of hospice agencies to determine barriers and characteristics of dementia hospice enrollment. Using a mailed questionnaire and interview, we looked at demographics, accessibility, training, referral sources, and marketing. Our analysis divided the agencies based on dementia census and availability to non-Medicare eligible individuals. Results showed hospices having Bridge and Transition programs had on average 4 times higher Alzheimer's disease (AD) and dementia census than hospices without these programs. The highest rated barriers to hospice use for individuals with dementia were prognosis, education, and finance.

Keywords: bridge program; transition program; hospice; dementia; enrollment

Introduction

More than one half of hospice patients have diagnoses other than cancer although hospice was originally used mostly by patients with terminal cancer. Despite this progress, there is still evidence that hospice is underused for individuals dying with advanced dementia. A Michigan study investigated hospice referrals in persons 65 years old or older with advanced dementia that died within 1 year of admission to either a nursing home or the state's publicly funded home and community-based services. The results showed that only 5.7% of nursing home residents and 10.7% of homecare clients dying with advanced dementia were referred to hospice.[1] In long-term care, only 22% of nursing home residents elected Medicare hospice in 2000.[2] This is despite the fact that 67% of dementia-related deaths occur in nursing homes.[3]

Despite improved utilization rates documented in 2000, key barriers to hospice access are inaccurate prognostication in noncancer diagnoses, lack of communication among decision makers, and lack of agreement or implementation of end-of-life (EOL) care plans.[4,5] The determination of 6-month terminality, as required by many states, for persons with the primary diagnosis of dementia is difficult.[6-9] The staging of dementia has traditionally been done with measures that bottom out as the disease enters late stage, exhibiting a floor effect.[8,10] Physicians and clinicians have difficulty knowing when the individual with dementia has entered end stage. The end stage can be quite protracted. This inability to determine terminality results in a high percentage of individuals missing the additional benefits of palliation and hospice enrollment.[11]

Another barrier to hospice utilization for individuals with dementia in nursing homes is a lack of coordination between nursing home and hospice staff.[12] This includes communication gaps between family, hospice, and nursing home staff as well as lack of agreement and implementation of the EOL care plan.[4]

Some hospices appear to be overcoming these barriers as evidenced by their higher percentages of dementia enrollment. The overall percentage of individuals with the primary diagnosis of dementia admitted to hospices is only 10%.[13] However hospice utilization in some programs was reported to be as high as 22%.[14]

The Alzheimer's Association funded this pilot study to more closely look at utilization rates for

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individuals with dementia from a hospice agency perspective. In particular, the study was being funded to provide additional research aimed at policy development. Therefore, we investigated what promotes and prevents involvement of individuals with dementia in a hospice program. The purpose of this article is to suggest which interventions and policy changes would promote access of individuals with dementia to hospice care.

Methods

We surveyed a convenience sample of hospice organizations with a mailed questionnaire and a semistructured telephone or in-person interview. The study was approved by the Institutional Review Board at the University of South Florida. The views expressed in this article are those of the authors and do not necessarily represent the policies of the Alzheimer's Association.

Sample

A convenience sample included hospice organizations that differed in dementia enrollment. The Florida and Maryland hospices have high and low enrollment, respectively. Lower percentage as well as hospices who submitted to the annual Alzheimer's Association conference were included because of their interest in hospice care for individuals with dementia. Of 24 hospices that were contacted, 14 agreed to participate. However, 2 could not be included in most quantitative analyses because of lack of diagnosis information.

Questionnaire

The questionnaire collected quantitative data regarding hospice characteristics, criteria used for admission, services provided, sources of referrals, and outreach used. Quantitative data were analyzed by dividing hospices into high and low dementia census groups according to the percentage of Medicare patients enrolled in the hospice that had a primary diagnosis of Alzheimer's disease (AD). The 2 median hospices had percentages that were very close (3.89 vs 3.84) to other hospices with low census and were included in the low census group. Therefore, we compared 5 high census and 7 low census hospices (Table 1). In addition, we compared hospices that provided alternative programs for Medicare hospice ineligible individuals with hospices that did not provide alternative programs. Independent 2-sample t tests and χ^2 statistics were used to test for statistical significance with P values $< .1$.

Hospices were also asked to rank order what they believed were 3 barriers to hospice enrollment for individuals with dementia. The most important barriers were weighted as 3 points, the second in importance were weighted as 2 points, and those listed third were weighted 1 point. A summary score was then computed for each barrier (Figure 1).

Interview

The second data collection instrument was a semistructured interview conducted with the same sample of agencies. Of the 14 agencies interviewed, the interviewees included 3 registered nurses, 6 social workers, and 4 hospice directors. The questions were designed to elicit descriptions of barriers to hospice access and suggestions for access improvement. These included characteristics of care being provided by each agency. The interviewer also asked which dementia-specific care problems hospices encountered when working with hospitals and long-term care facilities, and if the hospice provided services to individuals with the primary diagnosis of AD, who were Medicare hospice ineligible. The interview also explored financial barriers, opinions regarding the most valuable patient and family services, and outreach strategies.

Open-ended interviews were recorded and transcribed. Qualitative analysis listed common themes and unique responses.

Results

Agency Characteristics

The survey included hospices with different characteristics, ranging from a small all-volunteer hospice with an annual census of 500 to a large hospice with an annual census of 22 500 (Table 1). Seven hospices had an annual census of less then 3000 patients, three 7000 to 9000, and two 10 000 or more. There was also a wide range of the number of patients with AD that were included in hospice care, ranging from zero patients having dementia to 25% of patients having AD as their primary diagnosis.

The reported numbers of patients with AD might be an underestimation because we specified AD as a primary diagnosis. This was consistent with the focus of our funding source. It is also justified by the fact that 60% to 80% of dementia is of the Alzheimer's type.[15] However, 1 hospice reported that they had 55 patients with AD as the primary diagnosis, and

Table 1. Differences Between Agencies With High and Low Dementia Participation

Variable		High Alzheimer's Census (n = 5)	Low Alzheimer's Census (n = 7)	Total	*P*
Annual census	All patients	4315 ± 4000 (900-10 000)	6747 ± 7877 (507-22 500)	5734 ± 6420 (507-22 500)	NS
	Patients with Alzheimer's disease, on Medicare	569 ± 811 (59-2000)	128 ± 145 (0-342)	312 ± 550 (0-2000)	NS
	Patients with Alzheimer's disease, without Medicare	6 ± 8 (0-19)	8 ± 17 (0-46)	7 ± 13 (0-46)	NS
	Patients with secondary diagnosis of dementia	763 ± 1277 (1-3000)	29 ± 46 (0-131)	335 ± 859 (0-3000)	NS
	All patients with Alzheimer's disease	575 ± 809 (60-2000)	136 ± 157 (0-388)	319 ± 550 (0-2000)	NS
	All patients with dementia	1338 ± 2085 (61-5000)	165 ± 181 (0-443)	654 ± 1401 (0-5000)	NS
	Patients with Alzheimer's disease discharged alive	94 ± 172 (0-400)	27 ± 40 (0-97)	58 ± 117 (0-400)	NS
Percentage of annual census	Patients with Alzheimer's disease, on Medicare	12.4 ± 10 (4.3-26.3)	1.7 ± 1.2 (0-3.4)	6.2 ± 8.2 (0-26.3)	.017
	Patients with Alzheimer's disease, without Medicare	0.3 ± 0.3 (0-0.9)	0.1 ± 0.2 (0-0.5)	0.2 ± 0.3 (0-0.9)	NS
	All patients with Alzheimer's disease	12.7 ± 10.3 (4.4-27.2)	1.8 ± 1.3 (0-3.9)	6.3 ± 8.4 (0-27.2)	.018
	Patients with secondary diagnosis of dementia	10.2 ± 11.6 (0.1-30)	0.5 ± 0.5 (0-1.2)	4.6 ± 8.6 (0-30)	.048
	All patients with dementia	23.0 ± 19.0 (4.5-50)	2.3 ± 1.4 (0-3.9)	10.9 ± 15.7 (0-50.0)	.015
Percentage of patients with Alzheimer's disease discharged alive		9.7 ± 8.1 (0-20)	14.4 ± 11.1 (0.6-31.1)	12.0 ± 9.5 (0-31.1)	NS
Length of stay for patients with Alzheimer's disease	Average	130.6 ± 56.8 (68-222)	96.0 ± 48.5 (11-137)	111.7 ± 52.8 (11-222)	NS
	Median	62.8 ± 69.9 (10-182)	64.8 ± 32.4 (25-90)	63.8 ± 51.4 (10-182)	NS

Abbreviation: NS, not significant.

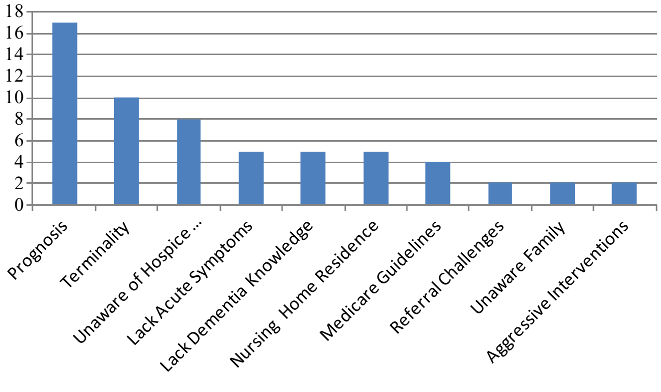

Figure 1. Barriers to hospice enrollment for individuals with advanced dementia.

228 patients with dementia as primary diagnosis. Another hospice wrote on the questionnaire "many more as 'dementia' but not Alzheimer's."

Most patients with AD were on Medicare. An average of 12% was discharged alive from hospice care but this percentage was as high as 31%. The average length of stay for patients with AD was almost 4 months, with a median of approximately 2 months. There were no significant differences in census characteristics or length of stay between high and low census hospices.

Facilitators for Utilization

All hospices involved in this study provided care in the community and long-term care institutions, with two thirds of them providing care in a hospital. All hospices with a high Alzheimer's census hosted an in-patient and/or residential hospice facility, while only 50% of hospices with low Alzheimer's census hosted one.

Study hospices provided care primarily for individuals eligible for the Medicare hospice benefit as well as for eligible individuals covered by private insurance and Medicaid. For individuals at home, 4 hospices reported that they also provided free services supported by fundraising. Most hospices did not provide free services to individuals in long-term care facilities because that could have been seen as enticement for referral.

Six hospices also provided services for individuals with dementia who were not eligible by Medicare criteria. These services included Bridge, Transitions, and palliative care programs. Hospice organizations that included Bridge and Transition programs had 4 times the percentage of individuals with AD and dementia in their census than hospice organizations without these programs (Table 2). Bridge programs are offered to individuals having active treatment or not ready to commit. Transitions are funded by community resources and volunteer-driven services for hospice ineligible. A full description of Bridge, Transitions, and palliative care programs is provided in the Discussion section.

Barriers to Utilization by Individuals With Dementia

Agency ranking of barriers to hospice enrollment listed physician prognosis as the most important barrier (Figure 1). Thirteen of the 14 hospices sampled listed Medicare requirements as an important barrier to hospice enrollment for individuals with dementia. The exception was an all-volunteer hospice that was not Medicare certified.

The second most important barrier listed was the lack of recognition of dementia as a terminal illness. A lack of knowledge about severe dementia and misconceptions about dementia and hospice care by nursing home staff were also listed. The third category of barriers included the lack of professional and family caregiver awareness of hospice availability for dementia care. The fourth ranked barrier was health management issues, such as the lack of acute symptom management and misunderstanding the decreased efficacy of aggressive interventions in dementia.

Difficulty With Prognosis

The barrier most commonly mentioned by hospice providers during interviews was lack of recognition that advanced dementia is a terminal condition. Families may be unaware of hospice benefits for noncancer diagnoses. Physicians, who are not aware of the characteristics of end-stage dementia, might equate referral to hospice as "giving up" and are afraid of regulatory scrutiny for early referral. Physicians are also hampered by a need for a determination of 6 months survival prognosis (depending on state Centers for Medicare and Medicaid Services [CMS]) which is very difficult in individuals with dementia.

The problem with determination of dementia terminality is reflected in the diversity of criteria that hospices use for certification. The Functional Assessment Staging Tool (FAST)[16] is most commonly used as recommended by the CMS, but 3 organizations did not use it. The main problem with this scale is its ordinal and sequential approach.[8] The requirement of severe speech impairment at stage 7 may not be present even in severe dementia. As 1

Table 2. Impact of Availability of Alternative Programs (Bridge and Transitions)

Variable		Program Present (n = 5)	Program Absent (n = 7)	Total	*P*
Annual census	All patients	4542 ± 4365 (900-10 000)	6585 ± 7800 (507-22 500)	5734 ± 6420 (507-22 500)	NS
	Patients with Alzheimer's disease, on Medicare	508 ± 838 (21-2000)	172 ± 178 (0-420)	312 ± 550 (0-2000)	NS
	Patients with Alzheimer's disease, without Medicare	4 ± 5 (0-10)	10 ± 17 (0-46)	7 ± 13 (0-46)	NS
	All patients with Alzheimer's disease	512 ± 836 (21-2000)	182 ± 190 (0-439)	319 ± 550 (0-2000)	NS
	All patients with dementia	1150 ± 2154 (33-5000)	299 ± 391 (0-1089)	654 ± 1401 (0-5000)	NS
	Patients with secondary diagnosis of dementia	639 ± 1320 (12-3000)	118 ± 239 (0-650)	335 ± 859 (0-3000)	NS
	Patients with Alzheimer's disease, discharged alive	87 ± 175 (1-400)	33 ± 38 (0-97)	58 ± 117 (0-400)	NS
Percentage of annual census	Patients with Alzheimer's disease, on Medicare	11.2 ± 11.3 (1.8-26.3)	2.6 ± 2.1 (0-6)	6.2 ± 8.2 (0-26.3)	.075
	Patients with Alzheimer's disease, without Medicare	0.2 ± 0.4 (0-0.9)	0.1 ± 0.2 (0-0.5)	0.2 ± 0.3 (0-0.9)	NS
	All patients with Alzheimer's disease	11.4 ± 11.5 (1.9-27.2)	2.7 ± 2.2 (0-6.3)	6.3 ± 8.4 (0-27.2)	.078
	Patients with secondary diagnosis of dementia	8.6 ± 12.3 (0.2-30.0)	1.7 ± 3.4 (0-9.3)	4.6 ± 8.6 (0-30)	NS
	All patients with dementia	20.0 ± 21.4 (2.1-50.0)	4.4 ± 5.2 (0-15.6)	10.9 ± 15.7 (0-50.0)	.088
Percentage of patients with Alzheimer's disease, discharged alive		10.1 ± 7.9 (0.6-20.0)	14.0 ± 11.5 (0-31.1)	12.0 ± 9.5 (0-31.1)	NS
Length of stay of patients with Alzheimer's disease	Average	90.2 ± 51.0 (11-137.3)	129.7 ± 51.5 (67-222)	111.7 ± 52.8 (11-222)	NS
	Median	47.0 ± 31.2 (10-90)	80.6 ± 65.2 (21-182)	63.8 ± 51.4 (10-182)	NS

Abbreviation: NS, not significant.

responder stated "We've had very clear speakers, no orientation but bed-bound and dying."

Enrollment criteria that all study hospices used were comorbidities and frequent hospitalizations. All hospices except for 1 also used incontinence, limited speech, weight loss, and physical decline. The majority of the hospices sampled also used the inability to sit/hold head up, dysphagia, being nonresponsive to nutritional support, and losing the will to live. The Palliative Performance Scale was used by three quarters of the hospices with 3 of them also using the original Karnofsky Scale.[17,18] Serum albumin levels and considerations of caregiver ability and stress were used by half of the hospices.

Three hospices reported that they use the diagnosis "failure to thrive" for individuals with dementia when they are afraid that the eligibility for Medicare hospice benefit may be questioned by fiscal intermediaries.

Communication Difficulties

The second most commonly listed barrier for dementia enrollment in interviews was communication difficulties. Individuals with advanced dementia are often unable to communicate verbally, making care a challenge for hospice organizations. The individuals cannot select hospice care themselves and, therefore, the selection is made by their proxy or next-of-kin. They are unable to communicate effectively with hospice staff regarding their condition. Hospice staff stated that they have to develop skills for nonverbal assessment of pain and other symptoms. One rural organization mentioned that even hospice nurses are initially hesitant to enroll individuals with dementia who have very different symptoms than the more commonly served patients with cancer. Communication with families may become complicated if there is a disagreement about the nature of care interventions among family members. If an individual with advanced dementia resided in a long-term care facility, interstaff communication may also be problematic. Long-term care staff may not believe that their residents would benefit from hospice services because they believe that the facility already provides all the necessary care. Most hospices reported that they improved communication by establishing long-term care teams that provided continuity of care.

Financial Considerations

Hospice providers reported that families may be afraid that hospice involvement will be expensive, not realizing that it may actually decrease their expenses. Families are unaware that hospice pays for some medications and supplies that are not provided free by a long-term care facility. Nursing homes and even individual physicians may be afraid of revenue loss with hospice enrollment. The physicians do not recognize that they may remain the primary care providers even when patients are treated by a hospice organization.

According to hospice agencies, hospice enrollment of a Medicare-eligible individual with dementia represents a loss of nursing home revenue and increased family expenses. The nursing home does not receive the relatively high Medicare reimbursement for patients who are in a hospice program. Hospice pays for medications and treatments but does not pay for room and board for an individual who is eligible for long-term Medicare benefits. This expense, which would be reimbursed by Medicare if the individual was not in a hospice program, has to be covered by the family unless the individual is also Medicaid-eligible.

Institutional Barriers

Hospice staff reported that when individuals with advanced dementia are transferred to a hospital, it may be more difficult to enroll them in a hospice. Hospital treatment often includes invasive interventions, such as insertion of a feeding tube, that are considered curative. Hospitals also have more problems with behavioral symptoms of dementia such as sundowning and wandering that may result in a fall and injury. They are likely to use restraints to prevent wandering that cause deconditioning and development of pressure ulcers. If an individual with dementia is transferred from a long-term care setting to a hospital without a companion, communication problems and elopement are possible.

According to the hospice staff, nursing home personnel are often resistant to hospice care for residents with dementia. They sometimes disagree with the family about the need for palliative care and their desire to terminate invasive interventions such as feeding tubes. They may operate by "rote" and transfer a resident to the hospital at the first sign of a problem. Nursing personnel may not recognize the additional benefit hospice involvement provides. They may disagree with some hospice interventions aimed at increasing patient comfort, such as prescribing medications for agitation. This may be considered chemical restraints. These attitudes may make developing and instituting a combined plan of care difficult.

Hospice staff reported that hospice involvement in assisted living facilities is hampered by a lack of facility supervision. This may result in increased problems with behavioral symptoms as well as problems with administration of medications. Medications ordered "as needed" are often not given and the hospices are forced to order them as scheduled treatments. Proper care in this environment often requires additional supervision provided at family expense. Sometimes the patients are transferred to an inpatient hospice unit to better meet their needs though availability is often limited.

Discussion

Increasing enrollment for individuals with dementia has the potential of improving EOL care for not only the individual but also the family and community. The percentage of enrollment remains low despite the increasing number of individuals with end-stage dementia. This study's focus on AD as a primary diagnosis limited the enrollment data for those with a general dementia diagnosis rather than an AD diagnosis.

Nonetheless, the small sample size of this pilot study has served to reinforce the previous research findings on barriers to utilization. Prognosis constraints continue to be a primary barrier in this small sample. Centers for Medicare and Medicaid Services constraints are reiterated as part of this barrier. Previous research showing communication and education as barriers is affirmed in this study. The misunderstanding of hospice's purpose and intent as well as public distrust and ignorance is echoed in this study. The affirmation of the primary barriers leads the authors to suggest the following policy considerations. There were 2 main strategies identified that would improve access.

First, the adverse effect of Medicare regulations may be decreased by establishing different eligibility criteria. Policy initiatives would include support for the development of alternative programs for individuals with AD and other dementias who are not strictly eligible for Medicare hospice benefit. The second strategy to improve access would be the initiation of more intensive education.

Policy Initiatives

Current Medicare regulations have adverse impact on hospice access for individuals with AD because of the requirement of a 6-month survival prognosis certified by 2 physicians. The most common causes of mortality in advanced AD are intercurrent infections, which occur and recover at unpredictable rates. Therefore, the determination of a 6-month survival prognosis cannot be made with a high degree of certainty. The current Medicare guidelines are difficult to apply and are not valid predictors of survival in hospice patients with dementia. The commonly used FAST score is an inaccurate tool for prognosis with research validating its inadequacy in predicting 6-month mortality.[19]

A more accurate estimation of prognosis based on the Minimum Data Set evaluations has been the percentage of individuals who die within 6 months. The Palliative Performance Scale is used by many hospices and found to be useful in a heterogeneous hospice population.[17] Another policy initiative that would eliminate the family financial burden due to hospice enrollment is a hospice benefit that will include room and board of individuals transferred from a hospital to a nursing home who are Medicare hospice eligible. Alternatively, hospices could be allowed to provide free hospice care for these individuals.

Support for development of alternative programs such as the Bridge, Transitions, and palliative care programs highlighted in the results show improved access to hospice care for individuals with dementia.

Bridge Programs

A Bridge program is "a program that is provided by a hospice in collaboration with a home health agency or another health care provider that offers pain and symptom management as well as emotional support during a period when a patient with life-limiting condition may still be pursuing active treatment, or is not yet ready to elect the hospice benefit."[20] Earlier identification of patients who are appropriate for hospice care is the goal.[21] The bridge program can be provided in 1 of 2 models: The Dual Model and the Consultative Model.

The Dual Model is a program offered by a hospice that is formally associated with a home health agency/visiting nurse association. The patient has to meet home health regulatory requirements, including having a skilled need and being homebound. The home health agency staff receives education regarding pain management, EOL issues, and how to initiate discussion regarding transition to hospice.

The Consultative Model is a program offered by a hospice that is not formally affiliated with a home health agency. When the home health agency staff identifies a patient as having a limited prognosis, a hospice nurse is provided through a contractual arrangement. The patient remains on the home health nurse's caseload. Subsequent visits by the hospice nurse evaluate the effectiveness of recommendations and allow the development of a relationship between the patient and hospice nurse. The Home Health Aide may transition with the patient by a contractual arrangement.

The limitation of a bridge program is the eligibility requirement for home health care. Some individuals with advanced dementia may be homebound but not require skilled services unless they have other comorbidities or develop some complications, such as pressure ulcers. However, a bridge program may still provide services for a significant number of individuals with dementia. Incentives for hospices to offer bridge programs would positively affect utilization for individuals with dementia.

Transitions

Equally beneficial is *Transitions*. This is a program that enables hospices to provide services to people with life-limiting illnesses when they are not eligible for hospice care. It is a volunteer-driven service funded by community resources that is provided for both community-dwelling patients and in long-term care facilities. There are currently more than 80 programs in the United States, and training for initiation and management of this program is offered by Transitions PreHospice, Inc.[21] This program provides friendship and visitation, food preparation, volunteer transportation, assistance with correspondence, and respite breaks. The transition-like program was evaluated by the Office of Inspector General (OIG) and found not to violate the antikickback statute. Because the services provided were from unpaid volunteers, the benefits of the program were primarily intangible and psychic, the program provided a substantial benefit to a vulnerable patient group, and there were substantial barriers to a beneficiary's election of hospice care.[22] Although OIG limited this opinion to 1 hospice organization, it is used by Transition PreHospice Inc in their materials. To date, no Transition program has been challenged by OIG. Incentive to encourage *Transitions* or similar programs would positively influence hospice utilization for dementia as evidenced by this study.

Palliative Care Services

Palliative care services may either involve a treatment team or hospice physician visit. Only 1 hospice in our sample reported such a program but the benefit to the family's education was reiterated. That program was limited to the collaboration of a hospice physician with a primary physician and the hospice physician speaking to the family about goals of care. In this type of palliative care program, the physician "helps the family shift modes." The hospice does not pay for prescriptions for these patients.

Availability of Bridges or Transitions resulted in a significantly higher percentage of patients with the primary diagnosis of AD enrolled in the hospice population. Availability of these programs is equally important for patients who are being discharged alive from a hospice. According to our survey, up to 30% of patients with AD enrolled in a hospice may be considered at 1 point no longer eligible for Medicare hospice benefit and are discharged. These individuals and their families lose all their support if there is no alternative program available.

All 3 of these alternative programs offer some form of free care to the individual with dementia and their family members. Therefore, policy strategies that support their development would optimize utilization for individuals with dementia.

Education

Survey results suggested that more intensive education is needed for everybody involved in the care of individuals with AD. Education should include families of patients with Alzheimer's disease and the wider community: physicians, hospital, and long-term care, and hospice staff. The themes for the education should include general knowledge about severe dementia and recognition of advanced AD as a terminal condition in long-term care staff and families. Improved awareness of the social support provided to the families during a residential hospice stay and during bereavement is needed. Hospice staff training on the unique needs of individuals with AD including how to communicate with them and how to manage behavioral symptoms of dementia is necessary. Overall public education of the terminality of AD and the benefits of hospice care needs to continue to be encouraged from both the Alzheimer's Association and hospice agencies.

Hospice organizations need to access the Alzheimer's Association as a resource. Only 9 of 14 hospices in our sample were already using resources provided by the Alzheimer Association for education of their staff. Alzheimer Association chapters could also encourage hospices to develop alternative programs for individuals with AD, such as Bridge, Transitions, or palliative programs.

Equally important is educational outreach to nursing homes and assisted livings. Long term care staff should be educated about the advantages of hospice enrollment for their residents with AD. They should actively seek hospice care by requesting a hospice informational visit for residents with terminal dementia.

Limitations

The survey has several weaknesses. The number of hospices surveyed was quite small, which may account for the lack of significant differences observed between hospices with high and low Alzheimer's census. Each agency was contacted an average of 7 times before refusal or agreement of participation. The availability of hospice staff time to complete the surveys was a key reason for declining to participate. The criteria of AD as a primary diagnosis limited our sample, excluding some individuals with the primary diagnosis of dementia and those whose diagnosis of "failure to thrive" may have referred to a dementia diagnosis. Another limitation was that participating hospice agencies were nonprofit. Three for-profit hospices that were contacted refused participation. Equally limiting was the lack of generalizability. The hospices were located in Florida and Maryland and do not represent a national sample. Future research should also include a look at palliative care received by individuals with dementia in the presence or absence of hospice enrollment.

In summary, we found several avenues to improve hospice utilization for individuals with dementia as well as the need for continued research into how each avenue can best address the defined needs. National hospice agency research as well as Alzheimer's Association research should focus on both selection criteria for end-stage dementia and on education of both caregivers and agencies.

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