

Hospice Care for Alzheimer's Disease: Caring for the Patient, Family, and Caregivers

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Abstract

The purpose of this article is to highlight the benefits of hospice care for the individual with Alzheimer's disease and their families. This article explains the ways hospice supports the patient and families physically, emotionally, and financially. This article provides the information needed to assist health care professionals in guiding patients and caregivers to the appropriate support they need for this progressive illness. This article proves that hospice care is appropriate for Alzheimer's disease and improves outcomes for the families and caregivers after this terminal disease has run its course. It demonstrates that hospice is not only a viable choice for family members dealing with Alzheimer's patients, but why the expertise of hospice personnel is especially well suited to the needs of these patients.

INTRODUCTION

Alzheimer's disease is a chronic, progressive, irreversible degenerative disease that affects approximately four million people today. This number is expected to increase to fourteen million by the year 2050 (Diwan, Hougham, and Sachs, 2004). When a person has Alzheimer's disease, they begin to experience memory impairment and a decreased attention span. This beginning stage usually lasts one to three years. Then the person begins developing memory loss that is more obvious along with confusion, irritability, and impaired motor skills that affect their ability to care for themselves. In this stage, the person may wander or show other signs of impaired judgment. This stage lasts anywhere from two to ten years. In the final stage of the illness, the person loses cognitive abilities such as reading and writing. In this stage it is common for the person to be disoriented to time and place and eventually they will fail to even recognize the people that are closest to them. Physically, the personal motor skills become worse, they experience difficulty eating and swallowing, and lose bowel and bladder continence. In the terminal stage the person is at risk for aspiration, developing pneumonia, and skin breakdown.

The affects of this disease on the patient are apparent. The families and caregivers are also greatly impacted by this disease. The length of the illness and the increased financial and physical burdens create great amounts of stress on the people that are close to the patient. Caregivers need to be

provided with support to deal with the strain of caring for the patient. Many people do not even realize hospice is available for Alzheimer's disease. Health care providers need to become more informed of how this type of care will benefit the patient and caregivers so that they can offer this option to those in need.

LITERATURE REVIEW

Once a person with Alzheimer's disease has reached the advanced stages of the disease, the level of care required is a great demand on caregivers. Alzheimer's disease is considered incurable and terminal, so comfort care and a focus on quality of life is a priority (Haak, 2004). Hospice philosophy recognizes dying as a normal process. People with AD can benefit from hospice in a multitude of ways. Cognitively impaired patients are no longer able to communicate discomfort in traditional ways. Hospice nurses are better trained to recognize non-verbal symptoms of pain (Haak, 2004). The hospice team is also knowledgeable on methods to relieve pain, which is important when the patient is no longer able to swallow and painful shots are not an option. Based on the study conducted by Bekelman, Black, Shore, Kasper, and Rabins (2005), participants in hospice experienced less pain when compared to those who did not elect hospice. With a hospice team involved in the care of the AD patient, the patient gets individualized attention from the healthcare team. Before enrollment in hospice, on average the physician only sees the patient every few

months. Hospice comes to the patient's home at least weekly. Hospice provides needed supplies to the patient that the family may not have the resources to provide, such as shower chairs, bed side commodes, wheelchairs, devices to lift the patient out of bed, and hospital beds just to name a few. Hospice also provides supplies for the incontinent patient and assists with medications related to comfort and the terminal disease process (Haak, 2004).

Patients with AD who reside in long term care facilities can also benefit from hospice care when the disease reaches the late stages. Approximately 70 percent of LTCF residents have a diagnosis of dementia (Haak, 2004). In the LTCF, there is such a high patient to staff ratio, patients often do not get individualized attention. And once the AD patient has reached the late stages of the disease, they can no longer voice their needs. Hospice is intended to supplement the care provided by the LTCF so that the person approaching the end of their life can get the personal attention that is so critical during this time (Murphy and Luchins, 1997). The survey by Volicer, Hurley, and Blasi (2003) also showed that LTCF residents on hospice were less likely to be hospitalized than non-hospice residents with the same diagnosis. Patients in the LTCF were also more likely to receive assistance with eating, drinking, and oral hygiene while under hospice care. Like patients who stayed at home, AD patients with hospice in the LTCF were more likely to be treated for pain and other symptoms (Munn, Zimmerman, Sloane, and Mitchell, 2006).

The hospice team also provides support to family and caregivers. When hospice is initiated, there are some difficult topics to discuss that many caregivers have avoided. The hospice team helps the family and caregivers to clarify the plan of care for comfort and to discuss the benefits and disadvantages of aggressive medical intervention for the patient with AD (Head, 2003). Part of the goal of hospice care is to educate the family on the disease process and what will progressively occur. This helps to alleviate misunderstandings and relieve feelings of guilt concerning health care decisions (Albinsson and Stang, 2003). Many times caregivers are exhausted from years of providing total care for the patient with little or no support. Many caregivers report feeling that they are on duty 24 hours a day (Diwan, Hougham, and Sachs, 2004). Respite services are offered to caregivers through hospice, which gives the caregiver a chance to rest or do other things they have not been able to do because of the great needs of their family member (Head, 2003). Hospice staff can also help the caregiver deal with the

strain of handling difficult behaviors.

The greatest benefit provided by hospice for the patient with AD and their families is spiritual and grief counseling. Caregivers have reported that hospice providers were well equipped to assist them with grief (Murphy et al., 1997). Caregivers reported that they frequently wanted more support and reassurance from the patient's health care professionals before beginning hospice, but were afraid to ask (Diwan et al., 2004). In the survey by Murphy, Hanrachan, and Luchins, (1997), LTCF's were asked about grief and bereavement services that were provided by the LTCF where the decedent had resided. Of the 111 homes that responded, 99% of facilities did not give any materials to families about grief or bereavement and 98% of facilities had no further contact at all with the decedent's family once belongings were removed and the final bills were paid (Murphy et al., 1997). When hospice becomes involved in a patient's care, grief counseling begins before the actual patient death. This is especially important with AD since the majority of families experience what is known as "dual dying", the first part of grief occurs as the loved one slowly slips away and then another grief process begins after the actual death of the patient (Murphy et al, 1997). Bereavement services are also offered to the family after the patient's death for at least one year. This service is an important aspect of hospice care since it has been shown that families still have unresolved grief and a need to talk about their loss even a year after the patient has died (Murphy et al, 1997).

Hospice benefits are provided under the Medicare Part A coverage. When hospice is initiated, the patient signs a statement electing hospice and at that point, Medicare will no longer pay for other treatments related to the terminal diagnosis. Medicare still pays for healthcare related to other conditions. Most private insurances also provided a hospice benefit and each of the provisions vary. There have been several studies concerning the cost effectiveness of hospice care. On average, Medicare spends \$21,268 on patients with AD that do not utilize hospice. For AD patients with hospice, the average cost to Medicare is \$16,986 (Pyenson, Connor, Fitch, and Kinzbrunner, 2004). With approximately 4 million people affected by AD today and an average savings of \$4282 per patient that elects hospice care over traditional care, the cost effectiveness is more than apparent.

The positive outcomes that hospice care provides are the most important aspects to take into consideration. With AD, the outcome is death, and even though that cannot be

changed at the present time, the death experience for the patient and caregivers can be improved with the support provided by hospice. The Palliative Excellence in Alzheimer Care Efforts (PEACE) Program has performed a study to identify the strains experienced by caregivers and what caregivers view as valuable resources when the patient is in the terminal phase of illness (Diwan et al, 2004).

Approximately sixty percent of the caregivers interviewed indicated that it was difficult for them to cope emotionally with the changes that occurred as a result of the patient's dementia. Caregivers reported feeling more distressed when the patient's disease symptoms intensified (Diwan et al, 2004). Another study showed that hospice care was associated with more effective symptom management as the time of death approached (Bekelman et al, 2005).

The most important outcome for the patient with AD is to have a good death. A good death is achieved when physical symptoms are controlled, spiritual needs are met, and emotional support is provided. A good death is highly individual and based on the perspective of the patient and caregivers (Kehl, 2006). The hospice team is able to assist caregivers by educating them on the signs of impending death. When the caregiver knows what to expect, their anxiety is lessened (Kehl, 2006). The hospice team treats physical symptoms of distress to ensure the patient's comfort. Spiritual counseling is an important aspect of the dying process. Hospice offers counseling before the acute dying phase occurs, while the patient is actively dying, and after death has occurred.

Many barriers exist that prevent patients with AD from getting the palliative care they need. Caregivers have a difficult time when making health care decisions for the patient with AD. The patient is no longer able to make decisions because of their decreased cognitive ability and caregivers feel guilty if they decide to forgo life-extending treatments (Jennings, 2003). With appropriate education about hospice in the beginning stages of the illness, the patient can make their health care decisions in advance. Health care professionals should not delay discussions concerning end of life care. To do so may deprive the patient and caregivers of much needed emotional, physical, and spiritual support (Modi and Moore, 2005).

Hospice is centered on meaningful life closure. Health care professionals feel that this cannot occur with AD since the patient loses cognitive function (Jennings, 2003). The lack of AD patient access to hospice services is partially due to health care professionals that are not adequately informed of

the many benefits hospice provides to AD patients and caregivers. Often physicians do not realize that hospice can improve the quality of life of the AD patient. The hospice team is trained to recognize non-verbal signs of distress, anxiety, and agitation. When these symptoms occur or exacerbate, hospice team members can inform the physician so that appropriate interventions can be made to keep the patient's discomfort controlled (Kehl, 2006).

A current Medicare eligibility criterion also creates a barrier to needed palliative care. Physicians are leery to refer to hospice because of the Medicare requirement to certify the patient's life expectancy to be six months or less if the disease runs its normal course. AD is highly unpredictable and progresses at many different paces, making it difficult to determine life expectancy. The National Hospice Organization (NHO) has designated certain guidelines to assist with the determination of life expectancy by using the Functional Assessment Staging Scale (FAST). FAST stage 7a is the guideline used to determine the life expectancy of patients with AD. At stage 7a, the patient is only able to speak a few intelligible words, is incontinent, and is dependent in activities of daily living (Modi et al, 2005). Medicare utilization reviews usually pick AD patient charts to review, causing many hospice organizations to shy away from taking referrals for patients with AD (Jennings, 2003).

Certain misconceptions concerning the care provided by hospice can also interfere with AD patients obtaining palliative care. Many people view hospice as a sign of impending death. Caregivers report feelings of failure and betrayal when hospice care is recommended. Caregiver's also report a fear that hospice will hasten the patient's death (Haak et al, 2004). Studies have shown that individuals with AD that received hospice services actually live longer than other AD patients who forgo hospice care (Pyenson et al, 2004). Caregivers also fear that the patient will be starved and suffer. Hospice staff members can help to alleviate this misconception with education about the dying process. A decreased desire and need for food and fluids is a natural part of the dying process. Dehydration decreases the sensations of pain. When food and water are forced into the dying body it causes greater discomfort and prolongs suffering.

CONCLUSION

In order for AD patients to receive appropriate palliative care, the public needs to be educated on the benefits of hospice services and myths need to be dispelled. Health care

providers need to be aware of the variety of support an AD patient can receive from hospice. Caregivers are burdened emotionally, physically, and financially simply because of a lack of knowledge. Based on a study conducted by Murphy and Luchins (1997), 90 percent of healthcare professionals and family members who were interviewed prefer the hospice approach for end stage AD. Once caregivers are educated, they will better appreciate the importance and benefits of hospice care instead of treatments that extend the dying process. Life extending treatments create avoidable suffering and the most compassionate decision for patients with advanced AD is a focus on palliative care.

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