Communicating with dementia patients on hospice

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Abstract

There are distinct differences in caring for the ‘typical’ hospice patient as opposed to the hospice patient who has Alzheimer’s disease. The entire hospice team, from volunteers to physicians, can benefit from dementia-specific training in this area. This article addresses this topic in terms of what to be aware of in the disease process, understanding and responding to the caregiver’s experience and needs, and, of course, patient care. Particular communication techniques are presented to facilitate interactions with the dementia patient at each of the stages of his or her disease.

Key words: Alzheimer’s disease, caregivers, dementia, hospice

Introduction

Until fairly recently, hospice was not an option for patients with Alzheimer’s disease. Depending on concurrent conditions, Alzheimer’s disease can last from two to 20 years, making a terminal diagnosis difficult. The patient is generally unable to report his or her own symptoms and may have a decreased sensitivity to pain. Medical decisions must be made without input from the patient.

In addition to these barriers, the orientation of hospice has always been a family-based mode of care, which includes enhancing the patient’s life. Because of the nature of Alzheimer’s disease, the patient may seem to the hospice team to be almost inaccessible. Frequently, by the time hospice enters the picture, the patient is not conversant. There is no opportunity to fulfill any of his or her needs or wishes. There is little or no social or personal interaction. In many cases, pain management is not needed. With regard to the family, the hospice team typically assists them in dealing with the shock and anticipatory grief of a terminal diagnosis. The Alzheimer’s family has probably been dealing with this illness and all the issues surrounding it for years. Grieving may have been worked through or set aside. Also, because of the length of this disease, the nursing home staff or family may be resistant to hospice “taking over.”

However, recently, the thinking on this subject has changed. Taking concurrent conditions or illnesses into consideration, patients can be evaluated to determine a terminal prognosis (i.e., survival of six months or less). The physician looks at the stage of Alzheimer’s disease the person has reached in terms of his or her ability to perform activities of daily living (i.e., dressing, feeding, toileting, etc.), as well as speech patterns, mobility, and continence. The individual is rated according to various scales, such as independent to completely dependent or regular to disrupted. Along with these ratings, the physician will also look for concurrent problems, such as susceptibility to infectious illnesses or pneumonia, recurrence of urinary tract infections, decubitus ulcers (bedsores), unexpected weight loss, and difficulty swallowing or eating. Of course, if there is a serious (life-threatening) concurrent illness as well, such as cancer or heart disease, this will be the primary determinant of the person’s eligibility for hospice.

The decision to move a loved one into a hospice program must be made by the family in the absence of the patient’s ability to contribute. The family may need to be counseled as to exactly what hospice will offer their loved one. If they believe this is the right step, the family must also be reassured that they can change their minds at any time and take their loved one out of the program. Subsequent to the six-month prognosis, decisions need to be made by the family and the hospice team (as well as the nursing home staff, if applicable). The family makes the team aware of the patient’s needs and wants, if they were expressed before dementia, as well as
their own ethical requirements. The hospice team contributes the best in palliative care on a case-by-case basis. Hospice and the nursing home should then work together to create a new care plan for the patient, emphasizing comfort care rather than rehabilitation or restorative care.

Following are some of the benefits hospice has to offer the Alzheimer’s family:

- The patient’s own physician remains in charge;
- A licensed hospice nurse will oversee the care of the individual;
- A social worker will be available for the family;
- Pastoral care and counseling are available;
- Medicare coverage is available and includes medical equipment and medications; and
- Volunteers will visit, run errands, offer moral support, sit with the patient, etc.

Ideally, before any of this takes place, the hospice staff should undergo dementia-specific training. All members of the team, from volunteers to physicians, are typically accustomed to dealing with cancer cases, occasionally AIDS, and perhaps heart or renal failure. However, both the dementia patient and the family will in many ways have very different needs from any of these.

The disease process

Alzheimer’s disease begins to manifest itself through random, occasional memory lapses, which are not typical of the individual. These memory lapses become more frequent until concern drives the person or his or her family to seek a diagnosis. For a fairly long period of time, the individual will be quite aware of what is happening because a good part of the time he or she is lucid and capable. Eventually, the occasional memory lapses will become more encompassing and the lucid moments will become random and occasional. In time, the patient moves into that “other world,” where he or she no longer is conscious that there is a problem.

Over a span of two to 20 years, besides losing intellectual function, the individual will also gradually lose the ability to carry out routine activities, and his or her physical mobility will be lost. At the point in time when hospice enters the patient’s life, he or she may be unable to speak and may be bedridden and in a semifetal position. On first observation, one would assume that death is imminent. Surprisingly, this “stage” of Alzheimer’s disease can last for two or three years. The Alzheimer’s patient functionally regresses through the stages of childhood, babyhood, and infancy. Eventually, as the brain shuts down, various bodily systems, the body is no longer able to function, and, eventually, the lungs and heart will give out. Fortunately, in most cases that reach this stage of the disease, little or no pain is experienced. The person just appears to weaken with each day and dies fairly peacefully.

The caregiving experience

By the time the Alzheimer’s family opts for hospice, the caregivers have experienced an entire range of reactions:

- Physical—initial verbal or touch cues have become total hands-on care, exhaustion;
- Emotional—shock of diagnosis, coping with “36-hour days,” anticipatory grief as loved one disappears, anger, guilt, fear;
- Financial—especially difficult in spousal situations; and
- Social—isoilation, misunderstanding (early on, patient looks normal), people do not visit (“She won’t know me, anyway.”), etc.

The family has experienced all the various stages of grief, perhaps many times over: shock, denial, anger, depression, sleeplessness, guilt, and anticipated loss. This is compounded by the ongoing situation and losses. The family is misunderstood, their difficulties minimized, and there may be little tolerance or sustenance for their grief. The community cannot sustain someone’s grief over such a long period and neither can the individual. Placement in a nursing home can represent “permanent severing of attachment bonds. There are no rituals, no public acknowledgment, no expressions of sympathy to support feelings of loss.” This is most keenly felt by spouses. As a result, one needs to “normalize” the situation. The family will have reached some level of acceptance by this time; this life has become the “norm.” There will be some fear of the loss of routine when hospice comes into the picture.

In spite of the length of time this illness has continued, or perhaps because of it, the caregiver may have a sense of disbelief and shock. The first couple of years of coping with Alzheimer’s disease entail a lot of anger, guilt, and denial. In time, the caregiver recognizes that this is an unbeatable disease and their loved one will die, probably soon; certainly within another year or two. When the situation becomes normalized, he or she eventually assumes that it will always be this way. It will never change, although the patient may change in terms of physical and mental status. There is typically a calm acceptance at this point, and the relationship between the caregiver and patient moves to a new
and different level. The caregiver puts the past totally away and lives in the present reality, caring for and about the patient in a much truer way.

Once hospice is suggested, the caregiver has to reorient his or her thinking. Suddenly, he or she again must realize that, in fact, this person is going to die—and perhaps soon. The hospice team can be a crucial help at this point. The team must be sensitive to the fact that this individual (or family) needs to start a new kind of grieving. The caregiver has lost touch with normal life and may not realize what his or her needs are. “Validate the fact that she is engulfed in pathological circumstances not of her own making.” Such validation will help to relieve her sense of disenfranchisement and free her to grieve openly. He or she needs to let go of the loved one and the caregiving experience. This will leave a major gap in his or her life.

The caregiver can use much encouragement and discussion about what he or she will do with the extra time. When the hospice workers recognize that the caregiver has accepted the imminent nature of the patient’s death, it is time to help the caregiver start bringing back the past. The hospice team should ask about this patient, who he or she was, what he or she did, and what he or she was like. Gradually, the hospice team can help caregivers return to the place where they lost themselves in the avalanche of this disease. They have lost the person their loved one was before. They have lost the social aspects of their former life. They have lost themselves as spouse, daughter, sister, etc. When the loved one has died and the caregiving role is suddenly removed, there can be an overwhelming emotional vacuum. All the members of the hospice team can help minimize this by assisting the person to think through where he or she will go from here, where he or she was before Alzheimer’s disease, and how to put the pieces of his or her life back together.

Also, recognize the unique stresses that exist for the family in the nursing home setting. These are very specific needs that can be fulfilled by various members of the hospice team. The nursing home may employ one social worker for 100 patients or more. Little individual attention is given to the family. The family needs more attention in end-stages, and nursing home staff is stretched to the maximum as it is. For an older spouse or family member, driving, shopping, and visiting are all greatly appreciated.

If this patient has been in a facility for quite a length of time, also empathize with staff. The staff have become like family members and will be grieving this loss as well. Ask them about the patient’s past and his or her life since residing in the nursing home.

Patient care

Hospice staff and volunteers who are not familiar with dementia patients may become frustrated by the seeming lack of response when using familiar skills. They may not give the patient credit for thoughts or feelings if they do not know how to recognize responses. As an Alzheimer’s patient regresses through this disease, he or she follows, in reverse order, the stages of growth of an infant, baby, toddler, and child. While one does not treat the patient as a child, caring for the patient on the basis of his or her equivalent developmental age can be beneficial to the patient as well as the hospice worker.

A key to communicating is that you must try to go where the patient is. You cannot get him or her to come to you. If the person tells you he or she is standing on the street corner and waiting for the trolley, that is where you go to meet him or her. You will not convince the patient that he or she is in the hallway of a nursing home. There are four probable states in which you will find your patients: alert and talking (with more or less sense); verbalizing, but without sensible words; alert, but nonverbal; or even less responsive.

If the individual is still talking, ask about his or her past: What kind of car did he drive, what kind of work did he do; how many people are in his family; or where did they live? When you are talking to the person, if he or she goes back in time, go there as well and ask questions in the present tense. A person with Alzheimer’s disease appreciates nothing so much as someone who acknowledges his or her reality. Trying to convince him or her of what is currently happening will only cause frustration and stress on the patient’s part and yours. Throw your reality out the window and affirm what he or she is feeling. You can do this without agreeing with the patient. Suppose you have a fellow who angrily tells you that someone has stolen from him. Your best bet is to try empathizing with his feelings. “It must be frustrating to think someone might do that.” Or, suggest that you can help him fill out a “complaint form.” If you start out this way, the person is relieved about not being contradicted, pleased that someone understands his or her feelings, and may be willing to talk it out until you get him or her onto another subject. Take a simpler, far more common circumstance: the patient asks you to take him home. First, try a quick response, such as “You know, I would, but I’m not going home right now. Maybe we could go tomorrow.” Or, ask where “home” is, what does it look like, who is there, and what did you do there? Frequently, just getting people to talk about what they are feeling and thinking will waylay their urgency to go someplace.

If the patient’s speech pattern is nonsensical, mirror the feelings he or she has. Assume his or her tone and expression so that the person realizes you empathize with him or her. A person’s emotional makeup does not
diminish or change with dementia; neither does the need to be understood. Consider a woman who is given to little spells of anger or distress. She cannot speak intelligibly, but walks around grumbling, shaking her fist, and gritting her teeth. Get right in front of her where she can see you and ask what is wrong. If she grumbles something, imitate the scowl on her face and say “That’s terrible!” or “I guess I’d be angry, too!” After a bit of this back and forth, the creases will gradually leave her face and she will calm down, glad for your understanding.

However, one emotion you do not want to imitate is anxiety. If a person is very anxious or frightened, you need to respond with calm reassurance. Maintain a friendly facial expression and move carefully and deliberately so as not to startle the person and throw him or her off balance.

If patients are no longer speaking, but awake and alert most of the time, read to them or speak in soothing tones. Pray with or for them, using prayers familiar to their religious background. You might want to collect a set of prayers to say for Jewish, Catholic, Protestant, and Muslim persons. Show the person colorful pictures of pets, babies, cars, construction vehicles, or flowers. Take the patient for a ride in a wheelchair, always moving slowly so that objects and people do not go by too quickly for him or her to see. Consider a person walking by you: as he passes, he touches you briefly, says “Hi!” and walks on, never stopping.

Once you have spent time with Alzheimer's patients, you begin to see that they do, indeed, respond to your presence and whatever you bring into their lives. It may be a smile, shaking a finger at you, or grabbing your identification badge. It may be a deeper and more restful sleep as you sit by the bedside reading or playing music. It may be incoherent speech, but with a facial expression that tells you there is meaning there. You will undoubtedly miss these subtle signs if you are just passing by. You have to go where they are to “hear” what they are trying to tell you.

Alzheimer's patients cannot tell you what hurts, but, for instance, you can see that something hurts in his or her expression when you try to move them or do mouth care. Alzheimer's patients cannot ask you for special favors, but you will know by their subtle responses when you have fulfilled their needs. Alzheimer’s patients cannot tell you about issues or relationships that need mending, but they may tell you what good things or painful things they experienced as a young person or child. (I read of an instance where a daughter found herself as caregiver to a father with whom she did not get along. As he regressed in time, he spoke with the greatest joy about his newborn baby girl. This was an unexpected healing for both father and daughter). Alzheimer’s patients cannot prepare themselves for death, but as their body gets weaker and their spirit gets stronger, getting ready to be free, I believe that for a brief time, before the body dies, the spirit is very present to the family and it hears and knows all that they are trying to tell their loved one. This is a gift that you can give to the Alzheimer’s family. As they near the end, tell them of their loved one’s life and that now he or she knows who they are.

References
3. Ibid.: 90.