

## Medical Ethics



By Jonathan Evans, MD, CMD

# When Perceptions of Morals Cloud Ethics

### The Case

A 74-year-old woman with moderately severe Alzheimer's disease was admitted to a skilled nursing facility for long-term care. She had been cared for at home by her husband for 4 years until he was hospitalized for a heart attack and upon going home was suddenly unable to continue that role despite his intention to do so.

Over subsequent months, the patient's husband struggled with feelings of guilt, loneliness, and worthlessness because of his wife's nursing-facility placement. In response, his daughter encouraged him to spend time with friends. In particular, she encouraged him to spend time with a longtime family friend, a woman who was recently widowed herself after caring for her husband at home for several years.

In the months that ensued, the husband and his female friend grew closer, his mood improved, and ultimately, they decided to live together, much to the distress of his daughter. The relationship between the husband and his daughter worsened as his relationship with his female companion grew.

At the nursing facility, the daughter was very involved, often providing direct care to her mother. The husband visited less and less often but insisted upon making medical decisions on his wife's behalf. He was legally empowered to do so as her power of attorney.

The daughter was extremely interested in being involved in her mother's care. At times, however, following arguments with her father, he would instruct the facility that his daughter was forbidden from receiving any information about his wife and from being involved in medical decision making. He threatened to have her banned from the facility if she continued to "interfere."

For the patient's daughter in this case, her father's affair with another woman while her mother still lived was unacceptable and morally distressing. It permanently damaged her relationship with

her father and in turn threatened his relationship with his grandchildren. What was all the more galling to the daughter was what she perceived as her father's hypocrisy, he having always railed against sex between unmarried partners.

Her father's relationship with another woman also caused the daughter to doubt whether he could function effectively as her mother's surrogate in medical decisions. The daughter worried that her father would put his interests above his wife's.

However, at no time did he make medical decisions for his wife that were contrary to her best interests. He did frequently remark that his wife "had suffered enough" and that he hoped "the good Lord would take her soon."

In response to the overall situation, several meetings ensued between the patient's husband and facility staff, including the medical director, ostensibly to clarify questions about communication between facility staff and the patient's daughter and to discuss goals of care.

The ultimate goal for staff was to provide family support and to help the husband and his daughter mend their broken relationship. The patient continued to live in the facility for 2 years and died there comfortably with her daughter at her side.

### Discussion

This particular case illustrates a number of issues for families struggling to care for a chronically ill loved one with dementia. In addition to caregiver stress and surrogate decision making, the case also touches on issues related to marriage.

Recently, the national religious figure Pat Robertson, a former presidential candidate and the founder and chairman of the Christian Broadcasting Network Inc., grabbed headlines when he announced to viewers on his television program that, in his opinion, divorcing a spouse with Alzheimer's disease is justified. The

reason, he said, is that Alzheimer's is "a kind of death." His comments generated a fair amount of controversy and conversation.

Is Alzheimer's a kind of death? If so, what kind of death is it? What other kinds are there? What else is a kind of death, among the many other conditions that our patients experience? Do we treat them as if they are dead? Which should it be? Do we pass judgment upon our patients and their families? If so, how does that affect our treatment of the family? How does it affect the patient's care?

It is hard to agree that Alzheimer's dis-

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ease is the same as death of a human body. It may on the other hand represent or symbolize death of another sort: death of the mind, death of vitality, death of independence, death of a relationship, death of the "life we had together," death of identity, or perhaps even death of a marriage in the world according to Pat Robertson.

But if Alzheimer's is a kind of death, then what does it mean to be alive? What does it mean to *be*? If Alzheimer's itself is a kind of death, couldn't the same thing be said for all stages of life? After all, isn't life a series of deaths as time passes? There is death of childhood, death of adolescence, and deaths of all the lives that exist only in memory as we grow older. In that sense, each of us dies and is reborn continually as an older, different self.

Perhaps Alzheimer's is a kind of death, but it is also a kind of new life –

a second childhood of sorts. Loving relationships change as roles change from partner to parent. We live on in a new form.

Medical professionals have an obligation to do good for our patients (beneficence): to advocate for them to make sure they get the care they want and need. We also have an obligation to protect patients from harm (nonmaleficence): to do no harm ourselves and to prevent others from causing harm. When surrogate decision makers are involved, we must ensure that such surrogates honor the previously expressed wishes of patients, if known, or otherwise act in the patients' best interests.

Although our primary focus must always be the patient, our ability to do good is not limited to the patient. Therefore, we should do all the good that we can for everyone around us. We have the ability to alleviate a great deal of suffering with our words and simply by being there for patients and their families.

Although it may be human nature, making moral judgments about patients and their families generally serves no good purpose. It does not help us do good for our patients but can undermine our objectivity and our ability to act in their best interests.

As human beings, and as a society, we need others to care for. They give us our humanity. They teach us how to live. What we do for the least among us defines who we are as a person and, collectively, as a people.

DR. EVANS is a full-time long-term care physician in Charlottesville, Va., and medical director of two skilled nursing facilities. He serves on AMDA's board of directors and CARING FOR THE AGES' editorial advisory board.

*Continued from previous page*

**MR. MINNIX:** That idea has been kicked around for years. Others have suggested that the Medicaid program be expanded. I don't think anyone in today's economic environment thinks that either of those ideas will be acted upon. What CLASS would have done was allow people to insure themselves. We already know they're spending money on these things.

Therefore, if there was a large pool of self-insurance that allowed people to spend the benefit as they needed, that is a much more viable option than another centralized Medicare or Medicaid program.

**CARING FOR THE AGES:** The CLASS program was voluntary. Is that why it ended up being financial unsustainable, and would a mandatory program a better option?

**MR. MINNIX:** Mandate vs. choice was central in the formation of the CLASS Act by Congress. We did our own study at LeadingAge and looked at the options industrialized countries have chosen to deal with this issue. Germany is probably the closest to our situation.

About 15-20 years ago, they had the same problem we do and they tried to punt the problem to their states through their equivalent to Medicaid. That didn't work because the states couldn't handle it. German officials

finally came up with a mandated long-term care tax. It effectively cut their previous Medicaid-type expenditures for long-term care in half. In our own study, we showed that if a plan like CLASS were in place today and all working people were mandated to participate in it, Medicaid expenditures for long-term care would be about 50%. Politically, everyone says you'll never get a mandate. But the truth is that a program like CLASS is just plain less expensive than the expansion of existing entitlement programs.

Mary Ellen Schneider is with the New York bureau of Elsevier Global Medical News.