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Case Study: Ethical Concerns in the Care of Individuals with Alzheimer's Disease

by Jeanne Sorrell, RN, Ph.D.

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Educational Objectives

1. Identify important ethical concerns in the care of individuals with Alzheimer's Disease.
2. Describe the use of the Fairhill Guidelines as a frame-work for study of ethical issues related to the care of individuals with Alzheimer's Disease.
3. Discuss interventions to assist individuals with dementia and their family members in exploring ethical concerns.

Background

The approximately four million individuals with Alzheimer's Disease in the United States reflect a critical problem in our society. It is estimated that Alzheimer's Disease affects one-third to one-half of persons over 85 years; the numbers increase still higher when persons with other types of dementia are included (Post, 1995). A national survey concluded that caregivers provide an average of 70 - 100 hours of care per week for individuals with Alzheimer's Disease, often referred to as AD persons. Many of these caregivers are family members and most have been providing this care for an average of four years (Alzheimer's Association National Newsletter, 1996). The overall national cost for this condition is estimated to be as high as \$120 billion annually (U.S. Department of Health and Human Services, 1996). The emotional cost to AD persons and family members seems beyond estimation.

Surprisingly little has been written about the ethics of caring for these individuals (Sorrell, 1997). The prevalence of this condition in our society, the economic and emotional cost, and the vulnerability of AD persons, however, suggest that the ethics of dementia is a critical issue to consider. Post (1995) proposes that we must develop an ethics of dementia that attaches no moral relevance to mental acuity or decline. Our society's traditional focus on the "authenticity" of the self excludes those whose self is increasingly fragmented and scattered. Post suggests that an ethics of dementia be developed not merely through moral abstractions or ethical principles, but through active listening to AD persons, caregivers, and families as they describe the reality of living with dementia.

The following case study is intended to encourage reflection on how, through listening to stories of AD individuals, caregivers, and families, we can begin to understand their unique experiences and to identify interventions for ensuring that the care of AD persons embodies respect and dignity.

Case Study

In the following true case study (names and identifying circumstances have been altered), Robert discusses with a nurse specific ethical concerns related to the care of his wife with Alzheimer's Disease:

It's really strange in my case because some of the ones in our support group, they actually knew, they were told point blank, that their loved one had Alzheimer's. Josie just kind of evolved into the whole thing. She was only 47 when she started becoming symptomatic, and they really didn't know what it was. We actually went to four different neurologists. One thing led to another, and the next thing I know, I'm in an Alzheimer's study. But no one's actually come out and said, "Yes, she has Alzheimer's." I really denied it for awhile. But when she had to retire, I started going to the Alzheimer's support group and started comparing notes with others.

The first thing that she lost was her ability to pay the bills. She'd get so confused, and I couldn't figure out what was going on. Everything just happened so gradually that little by little I found myself, like doing the driving, 'cause she used to do all the driving, even when we went on vacation. She didn't verbalize it, but I think she was having a problem herself and so every time I took over something, it was actually a relief to her.

One hard thing is that Josie was always such a gentle person, and now sometimes when she wants to resist things, it's like looking into the eyes of the devil. It's scary. I had never seen such hate and anger. I just try to keep things on an even keel and not worry about things that aren't really issues. She went to bed with her clothes on -- well, so what? You have to deal with it that way. Once she got real upset when watching "Seinfeld" - she didn't like the way that crazy guy Kramer was acting. I mean she was about ready to kill somebody. But once we got her on the anti-depressants, it modified her behavior problems.

One concern that I have now that Josie is in assisted living is about emergency measures. I'm Catholic, and I have to see how much ethically I can do or not do. I mean I want to do anything within what's ethically correct but I wouldn't want to go to any extreme measures. I don't think, given the dynamics of the disease, that I'd want to prolong it any more than it already has been prolonged. I think some kind of a course would be good where you really think through what would be most important. Because a lot of times I think once they start something, then it's hard to undo it. I took ethics like 100 years ago, but I don't remember all the implications. Until we started talking today I hadn't really thought of it that much. I guess I should go to the priest and see what I can and can't do. I think Alzheimer's [Association] may even offer some of those kinds of programs. I've found that once you start talking to people you find there are lots of resources out there. That could be my full social life, going to programs and all!

Intellectually for me, I still feel that Josie is a human being and I've tried to ensure that she has a quality of life. When I go visit her sometimes she slips in and out of being normal. I would always hope that she's still treated with the dignity that she should have as a human being. I guess what I'm saying is that, even though it seems weird, there's still a human being in there sometimes, there really is, and it's important to remember that. I can enjoy Josie now more than I could when I had her 24 hours a day. That was a nerve-wracking experience, especially when there were behavior problems. She's still the love of my life.

Discussion

Robert informally outlined many of the ethical issues that have been framed in the Fairhill Guidelines on Ethics and the Care of People with Alzheimer's Disease (Post & Whitehouse, 1995). These guidelines evolved from discussions among a diverse group of professionals, including nurses, physicians, lawyers, ethicists, and administrators, who gathered regularly from 1993 to 1994 to listen to stories of family caregivers and individuals with mild dementia of the Alzheimer's type. The overall purpose of these sessions was to explore ethical concerns related to dementia care. Individuals with dementia and their caregivers were encouraged to bring forward "real life" issues that otherwise might be missed with a reliance only on ethical theory and solitary reflection.

Six primary concerns are addressed in the Fairhill Guidelines: truth-telling and diagnosis; driving privileges; respecting choice: autonomy, capacity, and competence; dilemmas of behavior control; issues in death and dying; and quality of life and treatment decisions. Each of these six categories can be seen in the case study.

Truth-telling and Diagnosis

Robert's statement that he never actually received a diagnosis of Alzheimer's Disease for his wife is not unusual. It is important for health care professionals, AD persons, and family members to consider ethical concerns in "truth-telling" related to a diagnosis. Furthermore, although family members may object to the AD person being present, it is important to recognize that cognitive deficits do not waive an individual's moral and legal right to be present. The diversity of cultural values and traditions in our society should also be considered. In conjunction with diagnostic disclosure, health care professionals have a responsibility to assist AD persons and their families in accessing available resources, including counseling and support group interventions.

Driving Privileges

As Robert noted, the limitation of driving privileges is often an early and sensitive problem faced by AD persons and family members. A diagnosis of Alzheimer's Disease, in itself, is not sufficient reason to prevent the AD person from driving. Driving is often viewed as an important symbol of freedom and independence; withholding this privilege unnecessarily can be perceived as unfair and demeaning. Families need guidance in informed decision-making related to driving privileges and in identifying appropriate alternatives.

Respecting Choice: Autonomy, Capacity, and Competence

Understandably, AD persons who are still capable of making reasoned decisions are distressed when they are not allowed to make reasonable choices. Robert described how he allowed Josie to make choices that would not interfere with her or others' safety, such as going to bed with her clothes on. It is important to recognize that the terms "competence" and "incompetence" refer to a person's legal status; the terms "capacity" and "incapacity" are increasingly being used to describe one's ability to make informed choices (Post & Whitehouse, 1995). Even AD persons with fairly advanced dementia may have periodic periods of lucidity, especially in the early part of the day when they are less

fatigued. Caregivers need education and guidance in how to help AD persons feel that they have as much control as possible over their lives (Noyes, 1998).

Dilemmas of Behavior Control

Creative forms of care are often needed to ensure respect and dignity when attempting to control undesirable behaviors such as wandering and agitation. Robert described how he struggled with these behaviors that Josie exhibited. As he suggested, the cautious use of appropriate medications can aid in controlling undesirable behaviors. On the other hand, physical restraints are likely to increase agitation and may actually decrease safety. A calm environment and activities that creatively incorporate remaining abilities of the AD person can decrease problems with behavior control.

Issues in Death and Dying

One can feel the tension as Robert described his thoughts of making decisions related to death and dying for Josie. Often, AD persons with mild dementia can discuss appropriately their wishes regarding end-of-life choices; doing this early can help to avoid later disagreements between themselves and family members. Family members need to recognize their obligation to honor wishes of the AD person and may need help - a "course," as Robert described it - to better understand ethical options and implementation of appropriate advance directives.

Quality of Life and Treatment Decisions

Too often, we equate the loss of cognition with hopelessness and uselessness. This perception leads to what Post (1995) refers to as "exclusionary ethics": too high a value placed on rationality and memory excludes individuals with dementia from the sphere of human dignity and respect and leaves them socially marginalized. Robert described Josie as still "the love of my life." Families of AD persons often express the joy that their loved ones find in simple daily activities. It is important to recognize that any "measurement" of quality of life includes a subjectivity that is not easily quantified.

Implications of a Focus on the Ethics of Dementia

Recognition of the difficulties in "measuring" quality of life, as well as the need to question our assumptions of how cognitive ability and productivity relate to quality of life, implies that we need to identify interventions with AD persons and their families to ensure that ethical concerns are addressed. Participants in the Fairhill Guidelines discussions sometimes used the phrase "quality of lives" rather than "quality of life," suggesting that an important aspect of quality is being connected to others in supportive ways (Post & Whitehouse, 1995). As we become connected with AD persons and their caregivers, we can better understand and interpret their highly individual experiences. Stephen Post summarizes this perspective: *Care, building on the foundation of solicitude, includes joy, compassion, commitment and respect: care rejoices in the existence of the person with dementia, although it need not strive to prolong that existence; care responds supportively to the needs of the person with dementia, although these needs may be largely emotional; care is loyal even as the loved one fades from the sphere of familiar self-identity and becomes almost unknowing and therefore unknown, but still remembered* (Post, 1995, pp. 8-9).

Through listening to narratives of lived experiences, we can reshape our image of persons with dementia. Through focusing on interpretation of the experience of dementia, we can help to establish an ethic of respect for the subjectivity and dignity of those affected.

Study Questions

1. Think about the kind of ethical issues you have experienced in interactions with AD persons and their family members. Would these fit within the framework of the Fairhill Guidelines? If not, what new category do you think would be appropriate to consider?
2. What are appropriate interventions for AD persons and family members to ensure that ethical concerns are addressed?

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