**Case Studies on Ethical Issues in Community-Based Care**

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**Introduction**

This document includes a list of practice issues to consider in working with older adults and persons with disabilities, associated references, and discussion questions for students to address related to five case studies that raise complex ethical dilemmas.

**Practice Issues**

* Lived experience of the elder or person with a disability is central.
* Empowering the caregivers, especially relatives, is also a key factor.
* Ability to have choice and control positively impacts quality of life (and can be cost effective) (Holstein & Mitzen, 2001).
* Issues of competence are complex. “. . . the law presumes every adult is competent. The burden of proof is on the person who would try to take an individual’s right to make decisions away. . . (Although only a judge can actually adjudicate an individual incompetent and appoint a guardian with legal authority to make decisions for the individual).” (Annas, 2004, p. 125).
* Ways must be found to balance all these factors along with issues of safety and organizational rules.
* Important also to consider interdisciplinary approaches (with their various codes of ethics) and work together.
* Cultural differences are important. For example, “In collectivist societies, many decisions are not made by individuals, but by families and groups, presumably with the larger good in mind.” (McLaughlin & Braun, 1998, p. 118).
* We need to remember the growing demographics of elders and people with disabilities as well as the fact that “the United States is a death-denying, age-denying, and disability-denying society.” (Sullivan & Lewin, 1988, p. 112).

**Sources**

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**Discussion Questions for Each Case Study**

1. What is/are the ethical issues here? Whose issues are they primarily?
2. What is involved and what is at risk? What societal values are involved?
3. What alternatives are there for the individual, their family, agency staff, and various kinds of caregivers? What agreements are there?
4. Most important, what is the “client’s” choice?
5. Is competence an issue? By whom & how is this being defined?
6. Are there any clear policy, legal, medical, or ethical (as in codes of ethics) impediments for doing what is agreed upon? If so, what would be the consequences?
7. In what ways does the ethical dilemma relate to costs, waiting lists, lack of availability of adequate competent workers?
8. From a policy point of view, how might these issues best be changed?

**Case Studies**

**Charles and Dorothy**

Charles is now 95 and has lived with his youngest sister Dorothy for many years and provided hands on care for her since his wife died 10 years ago. Dorothy has a different father and has inherited Huntington’s disease from him. She is no longer able to manage cooking, cleaning, or personal care and has never worked outside the home or been able to drive. She is completely dependent on Charles and gets very agitated when he is not there.

They live in rural Vermont and Charles was a farmer for many years. He has had some mild heart problems but is basically in remarkable physical condition. They have had some assistance in the past from some local agencies but would really benefit from more extensive participant-directed care. This was once tried briefly but Charles did not understand how it worked, Dorothy insisted he be there at all times as well provide all care for her, and Charles ended up not paying the caregiver all the money because he was not pleased with what happened and he felt that his housekeeping was being insulted. Their doctor is very traditional and they will listen to him. Some other providers, though, insist that Charles is no longer competent, impossible to work with, and both of them should be put into nursing homes. In addition, there is a shortage of competent, reliable caregivers in their rural area.

**The Dahal Family**

Dahal family members are refugees from a camp in Nepal and came to Vermont 3 years ago, choosing to live together. The family includes a 70-year-old great-grandmother, Maya, a son and his wife, a daughter with her husband, and a 27-year-old grandson. The grandson is married and lives there with his wife and two children, ages 1 & 3. Most of the adults work outside the home, but the son’s wife and the great-grandmother are at home and take care of the two small children and the basic housework. Other family lives close by and everyone in the family is very attentive to the needs of others.

Maya increasingly is not feeling well, having trouble keeping food down, and the daughter and daughter-in-law, who both know some English, took her recently to the Community Health Center. The doctor there urged that she go to the hospital for a few days for tests as they suspect some kind of intestinal cancer. The two women agreed to setting this up but did not tell Maya what it was for. She, in turn, tentatively agreed but awaited her son’s opinion of the tests. While she was in the hospital, a family member was almost always with her. Many doctors and professionals came to her room asking questions and giving information. A Nepali interpreter was called in but still the situation seemed confusing. Finally a social worker came and asked if the son could meet with the doctor and an interpreter and this was set up for the next day. Meanwhile Maya continued not feeling well or eating , and various people tried to talk with the family about having her go to a nursing home or perhaps soon receiving hospice care at home.

**Emily Jones**

Emily Jones is a 78-year-old widow with no children who worked most of her life as a cook in an elementary school. She was very dependent on her husband who worked for the state highway department and they enjoyed going with a small camper on trips to Canada. Her only sibling, a sister, lives in Canada, is 82, also has no children, and is not well either. Emily’s husband died six years ago. She retired soon after that and lives on a meager pension plus Social Security and has been able to stay in their modest rent-controlled apartment. She visited her sister several times and thought of moving to Canada but never got around to it. She is very active in her church and has a will to donate almost everything to them.

Two years ago she was diagnosed with breast cancer, received a mastectomy, radiation, and chemotherapy. The cancer has now returned and her very nice woman doctor has recommended hospice. This frightens Emily a lot but she has also heard about the state Death with Dignity Law from a friend, thinks she would consider that, and wants to discuss it with her doctor as well. She has several caretakers and a social worker who helps her from a local agency; she has decided to give her favorite caretaker, Jane, her wedding ring and some pieces of jewelry she inherited from her mother and wants to do this now while she is clear of mind. Her husband’s two nieces, who “never paid any attention” to Emily, are coming around and “bothering her” and she thinks it’s because she is dying. She is very hurt that Jane is hesitant about the gift and afraid she will stop visiting and has called her social worker to help work this out. He will visit her tomorrow.

**Jim**

An 86-year-old gentleman, Jim, is to be discharged home from the hospital after a serious bout with pneumonia. He lives alone in a second floor apartment with only stairs from the first floor. His doctor and physical therapists think he should go to a nursing home for a while instead of directly home, but he refuses. A social worker helped with discharge planning and feels caught in the middle. Since the 1970s, he has lived with a disability from a leg injury during active duty and has had difficulty going upstairs. He insists that this time he will rely on the ambulance crew to carry him up and then – in an emergency – would slide down the stairs himself. Jim has and will use a walker and cane.

He is a veteran and has some financial benefits from them but refuses to go to VA facilities (“Because their treatment isn’t good.”). His family is not involved, thinks he is “too stubborn,” and all live out of state. His landlady downstairs will bring up the mail and church members are willing to help him with shopping. He enjoys watching TV and doing crossword puzzles and he says he can wash dishes and sweep his floor. He has some history of drinking a lot but he insists that is over. He would accept having a caregiver of his choice coming in but some agencies are uncomfortable with what they see as the lack of safety in his housing situation. A few people have questioned his competence but others think he is fine in that respect.

**The Pojinsky Family**

The three-generational Pojinsky family lives in a small house in the Old North End of Burlington. The grandmother, Mara, is 85 and a widow who has worked hard all her life cleaning for others and is now failing from a long struggle with Parkinson’s disease. She was widowed at 35, lost two sons in a mining accident, and her only daughter went off to Australia with a sailor and has never come back and mostly lost touch with the family. The remaining and youngest son, Jacob, has been in and out of prison for drug dealing and Mara has been a long-time kinship caregiver for his two daughters (now 12 & 14) through the Department of Children and Families.

Jacob’s wife is not permitted near the children due to addiction issues. However, Jacob has had extensive treatment, earned his GED, and is officially clear of his various addictions and able to visit the family regularly. Although the state is unaware, in reality, he is living there, and now has a part-time job. Mara receives Supplemental Security Income (SSI), a child-only grant from Temporary Assistance to Needy Families (TANF), and is on the Supplemental Nutrition Assistance Program (SNAP, also known as food stamps), all which barely cover expenses. The granddaughters are doing OK in school and do help their grandmother some at home. Jacob tends to be impatient at times with his mother’s care, is sometimes verbally aggressive, and often wants to “borrow” money from her which she always refuses. Sometimes he thinks paid help would be good, as does his mother, but at other times she is very scared that if someone comes in, the children will be taken away and/or her son will be put back in prison for some reason (like yelling at her occasionally). So far she has refused all help suggested by her doctor or nurses at the Community Health Center.