

When a competent elderly man refuses nursing home placement

CASE

Mr. James is a 98-year-old single gentleman living with his 92-year-old brother in a one-bedroom apartment in a retirement complex. Mr. James grew up in Eastern Europe and immigrated to the United States in 1937. He is from a large family of eight brothers and four sisters. Many family members live nearby, and they visit often. Until recently, Mr. James was in excellent health and able to care for himself.

Recently, however, he fell and fractured a hip. The hip replacement surgery was successful, his recovery was uneventful, and after his rehabilitation, he was able to obtain full ambulation. After he returned home, he developed urinary incontinence; a urinary catheter was placed and maintained without complications. He has become more fragile, however, and his brother is no longer able to care for him.

Mr. James is able to slowly ambulate around the apartment and within the retirement facility, and he can feed himself. He needs assistance in showering and caring for his urinary catheter. He is unable to independently shop for food, clean the apartment, or do his laundry. However, the retirement center provides meals in a common dining room, and there are also laundry services available. He attempts to do his accounting, but this has become less reliable since his hip injury. His brother is able to assist with the accounts. His hearing is intact and, with corrective lenses, his vision is also intact. On the five-item geriatric depression scale,¹ he scores 2 out of 5, indicating the presence of some depression.

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Mr. James' brother and other family members reluctantly want to move him to a nursing home because of his growing frailty. Mr. James has become physically more fragile, although he is mentally proficient and able to make informed decisions. He adamantly refuses to go to the nursing home. The PA has cared for Mr. James for the past 18 years and knows the family and Mr. James well. Mr. James and the PA over the years have reviewed his advance care plan by completing and updating the workbook *Your Life, Your Choices: Planning for Future Medical Decisions*.² Mr. James's brother and another family member have privately asked the PA somehow to get Mr. James placed in a nursing home as soon as possible.

THE ETHICAL QUANDARY

The PA is unsure how to define the ethical issues in this case. The PA's major questions are whether Mr. James should be placed in a nursing home against his will, and if so, how?

DISCUSSION

Medical indications Mr. James is competent and able to make informed decisions, but he is becoming frail and can no longer care for himself fully. The trajectory for a 97-year-old frail male is increased dependency, especially if organ systems begin to weaken.^{3,4}

Patient preference Mr. James has been an independent adult since leaving Germany just before the Holocaust, in which he lost a number of family members. He worked as a successful wine merchant for more than 60 years. He lived in Los Angeles for a majority of his adult life, recently moving to Chicago so that family could care for him. Mr. James and the PA have recently reviewed his advance care plan, and Mr. James completed his advance directive. He is well informed regarding the is-

ssues of dependency and his increased weakness and frailty. He prefers to be cared for in the home of a family member rather than in an "institution."

Quality of life Mr. James feels that his quality of life is acceptable living with his brother. He understands that his body is aging, and he knows that his dependency on others will only increase. His inability to shower by himself is very frustrating. Not being able to do his laundry or shop for food or clothes is very irritating as well. In the past, he was usually impeccably dressed in a suit and tie and rarely seen in other attire. He continues to insist on being dressed in a suit and tie.

Mr. James attends and participates in daily religious services with his brother. He finds his active participation fulfilling and gratifying. His participation includes setting up the chairs, greeting members of the community as they arrive for services, and handing out prayer books. His other activity includes caring for and reading the Torah at services. He has also visited members of his community who were hospitalized with illnesses and comforted those who had a recent death in their family. Although it takes him longer to perform these activities, he finds them essential for a moral and acceptable quality of life. Mr. James adamantly believes his religious activities are the core of his life and that not being able to participate in them would be unacceptable. He believes moving to a nursing home would prevent his participation.

Contextual features Mr. James's family feel they do not have the expertise, time, or ability to care for Mr. James in any of their homes. Financially, Mr. James can afford to stay in a nursing home indefinitely.

As of 2004, there were 16,100 nursing homes in the United States caring for 1,730,000 people with an occupan-

“If the PA overrides this patient’s decision to refuse nursing home placement, is he paternalistic? Is paternalism always bad?”

cy rate of 86.3%.⁵ Quality nursing homes are difficult to find, however, and they are not on the list of places to visit and stay for most elders. In 1997, a study designed “to evaluate patients’ willingness to live permanently in a nursing home and surrogate and physician understanding of that preference” showed that 7% were very willing to live permanently in a nursing home, 19% somewhat willing, 11% somewhat unwilling, 26% very unwilling, and 30% would rather die.⁶ Furthermore, surrogates identified only 35% of patients willing to live permanently in a nursing home, while physicians identified less than 18%.⁶

The reasons for much of the unwillingness may be identified in a qualitative study by Kane, Caplan, and colleagues.⁷ In that study, patients identified as significantly important “choice and control in matters of bedtime, rising time, food, roommates, care routines, use of money, use of the telephone, trips out of the nursing home, and initiating contact with a physician.”⁷ The loss of identity, independence, and dignity is also part of the reluctance to move to nursing homes. Kane also includes “quality-of-life-domains—security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being and functional competence.”⁸

Case analysis and recommendations

Mr. James is frail but competent and able to make informed choices. His family wants him to move to a nursing home. He resolutely refuses. The family has asked the PA to place Mr. James in a nursing home for his safety and health. The major biomedical principles that appear in conflict with one another are beneficence and autonomy. The Jonsen paradigm requires the dia-

logue of these principles take place within the context of this specific case.

Beneficence on the part of the PA in this case is to prevent harm to Mr. James. **Autonomy** is the obligation of the PA to respect Mr. James’ informed choice of care. Beauchamp and Childress believe that “Neither the patient nor the [clinician] has a premier and overriding authority, and no pre-eminent principle exists in biomedical ethics, not even the obligation to act in the patient’s best interest.”⁹ In the past two decades, the medical provider’s authority to make decisions on behalf of the patient has been challenged by the declaration of the rights of patients to make their own decisions about medical matters.

If the PA overrides Mr. James’ decision, is this paternalistic? *Paternalism* is defined as “the intentional overriding of one person’s known preference or actions by another person, where the person that overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preference or actions are overridden.”⁹ Is all paternalism “bad”? Beauchamp and Childress argue the following:

The most plausible justification for paternalistic action places benefit on a scale with autonomy interests and balances both: As a person’s interests in autonomy increase and the benefit for the person decreases, the justification of paternalistic action becomes less cogent. Conversely, as benefits for a person increase and that person’s interest in autonomy decreases, the justification of paternalistic action becomes more plausible. Thus, preventing minor harms or providing minor benefits while deeply disrespecting autonomy lacks plausible justification; but actions that prevent major harms or

provide major benefits while trivially disrespecting autonomy have a highly plausible paternalistic rationale.⁹

Beauchamp and Childress also state that to determine which paternalistic actions are defensible, a provider must have excellent judgment in handling the case within context and the ability to integrate the conditions within the disagreement.⁹

Keeping Mr. James at home endangers his health and welfare. Placing him in a nursing home, given conditions in a vast majority of these facilities, does not accommodate individual autonomy. Balancing the principles of beneficence and autonomy is a challenge in this case. Mr. James’s safety and welfare is the question at hand for the PA. Does protecting his perceived welfare provide major benefits? Or will it deeply disrespect Mr. James’ autonomy? What would you decide? What is the rationale for your decision? What contextual challenges within your community would affect this case? We are interested in your thoughts and comments, and we would be like to share them in a future installment of this column. **JAAPA**

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