Case 16—A Depressed Caregiver Neglects His Own Health

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JA was an 82-year-old man who was taken by ambulance to the local hospital in the middle of the night, having apparently suffered cardiac arrest. His wife, CA, had summoned help by repeatedly tapping on the floor of their 2nd story condominium with her cane, hoping to attract the neighbor's attention. CA was unable to communicate over the telephone, as she had suffered a devastating stroke in her late 30's, likely as a result of being a heavy smoker and an early adopter of birth control pills. When the neighbors finally heard her call for help, they found JA unconscious on the floor of the bedroom and quickly called 911.

Early the following morning, the neighbors found the name and local phone number of one of JA's brothers and called to alert him about what had happened. JA was the oldest of three brothers; the middle brother, who had received the neighbor's phone call, was spending the winter months locally with his wife. The neighbor told JA's brother what had happened and that an emergency placement in a nearby assisted living facility (ALF) was being arranged for CA by the hospital social worker. The brother called the hospital and was told that JA needed immediate quadruple bypass surgery, and his brother consented to the surgery on his behalf. JA did not have an advance directive nor had he specified a surrogate decision maker. CA was cognitively intact but her difficulties in communicating made her an unlikely surrogate.

JA's middle brother and his wife's daughter (JA's niece, who lived in the same state year- round) drove the 3 h to the hospital to check on him. JA was stable and heavily sedated after the surgery. The family visited CA at the assisted living facility, and found her distraught over her husband's condition and happy to get an update from her extended family. The brother and sister-in-law then visited the couple's condominium and were appalled by what they saw: old, spoiled food stored inappropriately in the dishwasher and in cupboards, dirty dishes spilling over the counters onto all available surfaces, and a urine-soaked sofa. The condominium was a disaster, and it was clear that JA's refusals to get together over the last few years should have been interpreted as calls for help. JA had been his wife's full-time

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caregiver for nearly 50 years. They had no children and no relatives nearby, and they had relied on one another exclusively.

JA's heart surgery was successful and he was finally able to admit to his brother that as a result of his wife's increasing disabilities, he had become unable to care for her and had become depressed as a result. "My greatest fear was that we would be separated," he explained, "that's why I didn't want anyone to see how we were living." JA underwent in-patient cardiac rehabilitation, and CA settled rather comfortably into her new assisted living residence. When JA was ready for discharge, the family worked with the hospital social worker and discharge planner to find a new assisted living facility where JA and CA could be together. Since CA could no longer swallow consistently enough to ensure adequate nutrition, the new ALF required placement of a feeding tube, to which she consented.

After a few relatively uneventful months, CA suffered another catastrophic stroke and died in the ambulance on the way to the hospital. JA's health continued to decline, exacerbated by his grieving. As is common after open-heart surgery, his depression worsened. He had been a life-long stutterer, which became more pronounced with his deepening depression and he also experienced the onset of mild cognitive impairment. JA's middle brother had also died in the interim, and so the youngest of the three brothers was appointed as JA's legal guardian. He lived in California, however, and told his niece in Florida that he trusted her to make whatever medical decisions were necessary for JA's care. JA's niece arranged for him to move closer to her family so that JA would not be so isolated after CA died. The niece also arranged for medical care for JA, assumed the role of health care proxy, and consulted with her other uncle in California only when necessary; the "California" uncle was also experiencing a number of serious medical challenges, and she did not want to add to his burdens. JA's niece was a professor at a major research university and had lived in the area for nearly 20 years. She had a number of contacts in the medical field, and arranged for JA to be a patient with a well-regarded geriatrician with whom she had collaborated on research in the past.

These bi-monthly doctor visits were something that JA and his niece looked forward to. They would rehearse answers to the questions JA knew he would be asked to assess his cognitive function such as "what day is it?" and "what did you have for breakfast today?" Often they would have a quick lunch together after JA's appointment. JA referred to the geriatrician as "Doctor," and even though his stutter and cognitive impairment made conversation difficult, the two nonetheless engaged in a kind of respectful dialogue, often punctuated with good-natured laughter. On one occasion the physician heard an odd heart sound and was relieved and amused to find a paper valentine heart pressed neatly inside JA's shirt pocket. A subsequent examination revealed the presence of cataracts in both eyes. One of his niece's first major responsibilities was to locate an appropriate ophthalmologist, schedule the surgeries, consent to the procedures, and accompany her uncle to the facility on two occasions. JA's improved eyesight contributed greatly to his quality of life. He enjoyed watching television with the other residents and was often found in the fenced backyard garden watching the birds and the squirrels. The new assisted living facility provided good care, served wonderful food, and created a warm and

inviting atmosphere. Unlike many ALFs, this facility was part of a Medicare demonstration project that accepted patients' Social Security checks as sufficient payment for room, board and assistance with activities of daily living. JA participated in holiday parties and outings, and he was able to enjoy being around his niece and her young family.

As would be expected, however, his cognitive impairment increased, and his ability to participate in activities decreased as a result. JA's niece received a call from the ALF informing her that JA had been taken to a local hospital because he had begun to hallucinate and refused to eat. He was diagnosed with a urinary tract infection, which was effectively treated with antibiotics, and he was released after a few days. A few weeks later, the same situation occurred; this time the urologist said benign prostatic hypertrophy (BPH) was the likely cause of JA's repeated infections and occasional incontinence, and he recommended that JA undergo a transurethral resection of the prostate (TUR).

JA's niece consented to the surgery since JA was found to be incompetent by his attending physician. JA was capable of understanding what was happening to him, but it required an attentive listener to decipher was he was saying. His niece asked the urologist to speak to JA and obtain his assent to the procedure; the surgeon agreed to do so, but in fact did not take the time to explain anything to his patient. When his niece explained why he had to stay in the hospital, JA said, "I don't want surgery! Just let me go, I want to see my wife again!" His niece explained that the surgery was necessary in order for him to remain in the assisted living facility—were he to become permanently incontinent, he would have to be moved to a skilled nursing facility (SNF). The surgery proceeded, despite JA's protestations, and was successful. Upon discharge, JA returned to the ALF.

A follow-up appointment was scheduled for 3 weeks post-surgery. JA's niece picked him up at the ALF at 9:30 am. The ALF staff members were able to accommodate this scheduled appointment, and they made sure that JA was up and dressed and had had breakfast before his niece arrived. On the drive, JA became confused and attempted to get out of the car at a red light. Once they were safely at the medical building, the walk from the parking lot to the doctor's office took nearly 30 min. JA was disoriented and anxious, and he did not understand where he was going nor why. The urologist's waiting room was packed with 12 elderly male patients, most of whom were accompanied by a caregiver or relative. When his niece signed him in and asked about the likely waiting time, the receptionist informed her that all surgical follow-up appointments were scheduled for 11:00 am and that they would just have to wait until called. By about 12:30 pm, JA had become agitated, and was hungry and ready to return to the ALF for lunch and his usual afternoon nap. When he was finally called back, the nurse said there was no need for JA's niece to accompany him.

Several minutes later the nurse returned to the waiting room to summon JA's niece. She was red-faced and angry, and said JA refused to comply with her request to provide a urine sample. The nurse led his niece to a bathroom, and said loudly, "Sir, you need to pee in this cup immediately! And since you won't do it for me I brought your niece, and she is going to have to make you do what I say!" JA looked

ashamed; he had no idea what he was expected to do and lacked the ability to comply with the nurse's impatient demands. JA's niece explained that if a urine sample was required, she would have had to make arrangements with the ALF to procure it the day before. JA was incontinent and too demented to be able to produce a urine specimen on demand, especially in a strange and threatening environment. The nurse, clearly annoyed, explained that the follow up visit would be a waste of the doctor's time and that they might as well leave. JA was bewildered by the commotion and disruption to his daily routine, and his niece was frustrated and concerned that her uncle was not receiving the post-surgical care he required.

A month later, the ALF called JA's niece to say he had been taken to the hospital by ambulance because he had vomited blood. The ER physicians diagnosed him as having diverticulitis.[1] JA's treatment involved keeping the stomach empty by sucking out the contents through a tube passed up his nose and down his throat into his stomach (nasogastric or NG tube). JA was thus able to avoid surgery, but his hospital stay proved difficult. He again experienced hallucinations, and was extremely confused about where he was. When his niece visited he explained that he needed to get up to feed the cats who he said were crouched under his hospital bed. JA had been a life-long animal lover, and a favorite family story was about the winter in Michigan when JA had fed 20 stray cats he found huddled in an abandoned warehouse. He became frightened when anyone came near him, and he eventually needed to be restrained to prevent him from pulling out his NG tube or IV. The restraints increased his terror and confusion, and his niece intervened. Instead of requiring physical restraints, the hospital installed a "watcher," a volunteer who sat quietly in his room in order to provide a comforting presence. After discharge to the assisted living facility, JA told his niece that he did not ever want to return to the hospital. The next time the ALF called to report that JA had once again been taken to the hospital because of hallucinations and a probable infection of some sort, his niece requested a hospice evaluation; the hospital did not have a palliative care service.

A nurse from the local hospice agency came to JA's hospital room to evaluate his eligibility for hospice services. She said that although JA did not have a terminal or end-stage disease, he was hospice-eligible under the general diagnosis of "failure to thrive." He was thus able to return to the ALF under the care of hospice upon discharge from the hospital. A hospice nurse visited him twice each week at the ALF. The hospice nurse was also able to spend time with the certified nursing assistants who provided most of the care at the ALF, and as a result, the care of all residents, including JA, was enhanced. After 3 months JA's case was re-evaluated by the hospice care team, and because of his improved mood and functional status, JA was found to no longer meet the hospice criterion of "expected death within 6 months," which was required in order for the ALF to be reimbursed for JA's care through the Medicare Hospice Benefit.

After the hospice nurse's visits stopped, JA's condition predictably deteriorated. His niece requested another hospice evaluation after 6 weeks, and JA was readmitted to hospice care. His condition improved to the point at which the hospice

found him ineligible after another 3 months. His condition deteriorated again, and the ALF administrator sent him to the local hospital when his aides were unable to get him up and dressed for breakfast. By now JA was incontinent, moderately cognitively impaired and unable to effectively communicate. When the hospital was not able to diagnose any condition requiring in-patient acute care, JA was discharged to a skilled nursing facility, since the ALF was no longer willing to accommodate his incontinence and repeated needs for hospitalization.

JA spent 2 weeks in the nursing home and was then admitted to the hospital due to his inability to ingest sufficient calories by mouth. His niece met with the attending physician, who asked if she would consent to feeding tube placement. JA was only intermittently conscious and unable to communicate and had been diagnosed with bilateral pneumonia. Knowing her uncle's wishes for no further hospitalizations, his niece refused to provide consent for the feeding tube or for antibiotics. JA died peacefully two days later, with his niece at his bedside.

Discussion Questions

1. Under what circumstances should a proxy's decision making authority be questioned?
2. What are some ways to include incapacitated patients in decision making?
3. How can caregivers be supported so as not to neglect their own health?
4. In what ways does the Medicare Hospice Benefit limit hospice agencies from being able to fulfill their mission of providing high quality end-of-life care?

A Bioethicist Responds

The case of JA appears to be similar to so many others involving elderly patients who have become incapacitated, who have left no advance directives and who have not designated specific surrogate decision-makers. Yet consideration of four specific issues will yield a rather interesting analysis of this situation:

1. The presumed "authority" of JA's niece as health care proxy;
2. The role of his niece as advocate (proxy) for JA;
3. The urologist's office environment, including staff;
4. Prudential decision making on the part of JA's niece.

The case narrative makes clear that JA's niece assumed total responsibility for her uncle's health care, effectively becoming his proxy, once JA's wife and his middle brother are deceased, and once JA's youngest brother in California, who had been appointed his legal guardian, has entrusted "whatever medical decisions were necessary" into her care. Yet this immediately raises an important issue: There is no evidence that his niece had been legally appointed as health care proxy, or that this authority should fall to her automatically as provided in Florida law. F.S. 765.401 lists in priority order those persons who may act as proxies for incapacitated or developmentally disabled patients who have not executed advance directives or

designated surrogates to execute an advance directive.[2] Nowhere in that statute does it say anything about nieces or nephews. However, part of this statute does provide that "An adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs;…" may act as health care proxy or surrogate. One might argue that JA's niece exhibited special care and concern for her uncle as well as familiarity with his activities, health and religious or moral beliefs. Nonetheless, his niece picked up the mantle of proxy by virtue of JA's youngest brother having merely handed it over to her absent any formal legal action or documentation. And, she is apparently never questioned by anyone charged with the responsibility for providing health care for her uncle as to whether or not she has authority to act as proxy.

It may nevertheless be unsurprising that JA's niece has little trouble stepping into this role unchallenged. She had arranged to have her uncle moved closer to her and her family so that he not be isolated after the death of his wife, and no doubt those familiar with JA and his health problems at that time were only too happy to have someone with initiative and the apparent resources come to his rescue, and move him from their area of responsibility. It can also safely be assumed that JA's niece would have introduced herself to all health care, hospital, physician's office, ALF, SNF and insurance office personnel as "Dr. X", as would be customary for a university professor in dealing with others in a business or professional setting. It is not to suggest that JA's niece would in any way have attempted to masquerade as a physician in order to somehow intimidate persons accustomed never to question the authority, statements or actions of those addressed as "Doctor," but the foregoing is to suggest that her professionalism, self-possession and willingness to assume the advocacy role, especially in the absence of challenges to her doing so, goes a long way to explaining the health care community's apparent ready acceptance of the patient's niece as legitimate proxy without insisting upon documentary evidence.

Her continuing concern and attention to her uncle's needs served only to underscore her good intentions and wise choices surrounding his overall health care. This was demonstrated not only by her choice of ALF, but also her guarantee of proper geriatric, ophthalmological and urological care for him, signing consents as necessary. She would later also ensure that a hospice nurse visit him at his ALF. JA's niece clearly filled the role of the advocate with the best interests of the patient in mind and, therefore, acting as health care proxy appropriately. It was not all easy going, however.

JA's condition deteriorated somewhat rapidly after the TUR, particularly with regard to confusion and dementia, as is seen most dramatically in the three-week post-operative office visit to the urologist. It is here that his niece experiences the worst of the medical establishment's elitist mentality or behavior that can sometimes be used to intimidate patients and let them know who the most important, the most central figure in the healing relationship really is. This urologist's office had done what many surgical specialists have been known to do, that is schedule all post-operative office follow-ups for the same hour, thus ensuring that a queue of patients will be ready to be ushered into the next available examining room as soon

as one has been vacated such that the physician can be assured of having absolutely no delay in moving from one patient to the next—at her or his own speed. The fact that this may require some patients to wait virtually hours to be seen, not to mention that this type of scheduling is nothing short of misleading, says a great deal about who the physician believes is the more important in the physician-patient dyad, whose time is more valuable, and who is in "control" in this relationship. None of this could have been lost on JA's niece, who had to have already been frustrated in just getting her uncle to the doctor's office that day, but the nurse's behavior, after attempting to obtain a urine specimen from JA, only added insult to injury. Such treatment of patients or family members by any professional is unconscionable.[3]

The resolution to what essentially becomes a hopeless situation for JA occurred when his niece refused consent to feeding tube placement, and refused antibiotics on her uncle's behalf when he contracted pneumonia. She had now made a health care decision that she believed was in her uncle's best interest, given that he had become semi-conscious and unable to communicate, was unable to take in adequate nutrition by mouth, had expressed to her his unwillingness to endure further medical interventions, and had been going through a revolving door between the SNF and the hospital. There are undoubtedly those who would argue that she effectively abandoned her uncle, withheld life-sustaining care and thus "killed" him, albeit a view the present writer cannot share.[4] In any case, it had become increasingly clear that JA's progressive decline was unlikely to be reversed. He could be seen to appreciate virtually no quality of life at that point. Moreover, it must be remembered that he had said he was ready to die so that he could be reunited with CA, his wife. It would appear from what is known of him that JA has experienced what he wanted and what he could expect from life at that point, that he viewed his life story as complete, and that his niece would be doing more harm than good by forcing additional treatment upon him. It was not the withdrawal of treatment that brought about JA's death; it was rather the natural result of the disease process. We may assert, therefore, that his niece made a careful assessment of his situation and took the prudential decision that yielded the most desirable result for this particular patient, while also producing the greatest amount of good along with the least amount of harm. A difficult decision to be sure, particularly insofar as it must be made for a family member, but there was nothing in the case narrative to suggest that there was any ulterior motive or conflict of interest on the part of JA's niece.[5] There is every reason to believe that no matter how difficult it would be for anyone in her position to maintain any sense of objectivity in such a situation, she had succeeded in employing the requisite measure of *phronesis* in order to resolve her uncle's situation ethically.[6]

A Health Communication Scholar Responds

This is, unfortunately, a fairly typical story. It lacks some of the emergent ethical issues of previous cases, but is included here to highlight the unique vulnerabilities of elderly male caregivers, the despair felt by those in failing health whose health

status is poor but who are not yet fully eligible for hospice care, and the steady resistance to advance care planning that occurs in many families.

Unlike the caregiving relationship between JA and CA, but characteristic of the later caregiving relationships between JA and his niece, most caregiving falls to women. Daughters, wives, mothers, sisters, daughters-in-law, and other female family members provide most of the world's caregiving to the vulnerable and needy members of the family and the community. But the number of men caring for an older adult has doubled in the past 15 years, from 19% of caregivers in 1996 to 40% by 2009, according to data from the Alzheimer's Association[7] and the National Alliance for Caregiving (NAC).[8] Men face different obstacles and stressors in providing care than do women.[9] Sheer inexperience can raise stress levels. Men are less prepared for the caregiving role, and have less experience in dealing with problems like incontinence, bathing, or feeding, and less practice managing household tasks like cleaning and food preparation. Men tend to be less likely to ask for help, or to be embedded in social networks that provide support such as a shoulder to cry on, information about available resources, or instrumental support like help with meals or transportation. Men who are married tend to rely on their spouse to remind them about important self- and preventive care—regular doctor and dentist appointments, a healthy diet, adherence to medication regimens—and may be unfamiliar or uneasy taking on these health maintenance tasks for themselves and others. Nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should and 55% say they skip doctor appointments for themselves.[10] Men have also traditionally been socialized to keep their emotions to themselves, and tend to view mental health problems like depression or anxiety as personal failings rather than medical conditions, at least among older cohorts.

Depression can be a serious side effect of prolonged caregiving among both men and women. It is estimated that 40–70% of family caregivers have clinically significant symptoms of depression and approximately a quarter to half of these caregivers meet the diagnostic criteria for major depression (Cohen 2000). An older man whose wife is dependent on him for care may develop serious depression after years of caregiving, coupled with increasing isolation. Heart disease and cardiac surgery also increase the incidence and severity of depression; JA was both a long-time caregiver and a cardiac patient (Malphurs and Roscoe 2001). In extreme instances, depression and isolation produce hopelessness in the male caregiver and may trigger acts as desperate as homicide-suicide: murdering one's dependent spouse, and then taking one's own life. An analysis of homicide-suicides in West Central Florida revealed that approximately 40% of the perpetrators (male caregivers) had depression or other psychiatric problems (Cohen 2000). A common feature that precipitates these violent acts is a perception by the older man of an unacceptable threat to the integrity of the relationship (such as impending institutionalization), or a real or perceived threat to the caregiver's health. The present situation did not include violence, but clearly demonstrates to what extremes an older caregiver may go to maintain the current caregiving arrangement, even if it meant ignoring one's own health status, accepting a less than ideal standard of

living, and refusing to accept the interference of even the most well-meaning family members.

JA's situation also highlights the dilemma faced by patients who truly do not want medical interventions that will prolong their lives, but who are not close enough to death to qualify for hospice care without interruption. JA did not perceive he had an acceptable quality of life, even though his basic needs were accommodated. He had difficulty communicating and keenly missed the intimate companionship he enjoyed with his wife of so many years. Because he was unable to meet the standards of capacity for informed consent in the hospitals providing his care, his niece was put in the uneasy position of forcing her uncle to allow procedures that he did not want to undergo. The uncomfortable truth here is that we do not have a health care system that can honor such a request. If a patient is receiving life-sustaining procedures like ventilators or feeding tubes and wants them discontinued, then either the patient or his or her surrogate can make the decision to withdraw these life-supportive measures and allow the patient to die. If a patient is believed to be within 6 months of dying, then hospice care provides a means of providing comfort and support during the dying process while forgoing procedures that might prolong life.

Unfortunately, the lines between terminally and seriously ill are not always easy to draw, and institutional requirements dictate certain rules and regulations be followed. JA did not want the TUR, nor did he want to be hospitalized for treatment for diverticulitis. However, few if any assisted living facilities or nursing homes are willing to care for a patient who is hallucinating due to repeated urinary tract infections, nor one who is at risk of bleeding out because of complications from diverticulitis. The indicated procedures had to be performed if JA was to continue to sustain the quality of life he enjoyed as a resident of the assisted living facility. Returning to the nursing home would have required feeding tube placement along with antibiotic therapy.

Hospice care was deemed appropriate, not appropriate, appropriate yet again—also due to the institutional regulations that govern the use of the Medicare Hospice Benefit. The hospice that provided JA's care had recently been audited by Medicare and had been accused and fined for having too many patients who outlived a 6-month journey to death. And indeed, JA fit the profile of just such a patient—someone whose physical and mental status improved rather dramatically with the addition of skilled hospice nursing care, which addressed pain and symptom management and quality of life specifically. Once he improved to the point of being perceived as no longer having a terminal "failure to thrive" prognosis, those services were removed, and his health declined. This is a deplorable situation. One must assume that if patients who are close to death and who do not want to have aggressive or really any curative medical treatment will improve if their pain and other symptoms are expertly addressed. Such patients deserve to receive hospice benefits no matter if their prognosis exceeds an anticipated 6-month time frame. In several instances JA's hospice eligibility was terminated before having reached the 6-month time line.

Other evidence of the need to revise Medicare Hospice Benefit guidelines can be found in studies that examine the factors that encouraged Jack Kevorkian's clients to seek his aid in dying. Kevorkian was a retired pathologist who assisted in the deaths of over 100 people in Oakland County, Michigan between 1990 and 1997 (Roscoe et al. 2000, 2001). Kevorkian provided illegal assistance in dying to patients who responded to his advertisements in a local newspaper and his growing infamy. The majority of his clients—75%—were not seen as terminally ill (i.e., within 6 months of dying) and were thus unable to access hospice care. In fact, only 3% of the 69 cases included in this study were under the care of hospice. For the most part, these men and women fell into a black hole in our medical care system: too sick to truly benefit from additional surgeries, rounds of chemotherapy, or other potentially curative treatments, and too well to be admitted to hospice care. In their extreme desperation, they sought Kevorkian's illegal help in ending their lives, either with the aid of his intravenous "suicide machine," or if lethal drugs were not available, through the time-tested method of carbon monoxide inhalation. Kevorkian eventually, after 4 jury trials and the enactment of a Michigan law that specifically forbade his acts of assistance in dying, was convicted of second degree murder and served prison time; he died shortly after his release.

The final issue to consider in the case of JA concerns reluctance to engage in advance care planning. The rates of completion of advance directives continue to be low. It will be interesting to see if the new billing codes for conversations and documentation of end-of-life preferences will result in higher rates of completion.[11] We hope that our family members will look out for our medical and other needs, and will make decisions that best represent what we would have wanted if we were able to make our own decisions. It is usually easier for family members to make decisions for their loved ones if they have some documented evidence of their treatment preferences; doubtless JA's niece would have felt a slight bit less alone in making the decision to withhold antibiotics during his last hospitalization if her uncle's advance directive had directed her to do so. Even though they were not documented in an advance directive, JA's preferences were clear to his niece, and perhaps clear to her alone. It was fortuitous in some ways that the hospitals and doctors who cared for JA were so lax in insuring that she had either the legal right to represent his decisions, or had his best interests at heart. At its best, the notion of advanced care planning would encompass more than preferences for medical treatment. Conversations between family members and with physicians should also investigate the preferences and plans older adults have for their living situations, financial interests, and quality of life overall, especially since in many cases prolonged needs for care and multiple medical decisions are likely.

Notes

[1]Diverticulosis occurs when pouches (diverticula) form in the wall of the colon. If these pouches get inflamed or infected, the condition is called diverticulitis, which can be very painful.

[2]The following rank-ordered list is provided on F.S. 765.401 (abbreviated here):

(a) The judicially appointed guardian of the patient of the guardian advocate of the person having a developmental disability…;
(b) The patient's spouse;
(c) An adult child of the patient, or if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation;
(d) A parent of the patient;
(e) The adult sibling of the patient, or if the patient has more than one adult sibling, a majority of the adult siblings who are reasonably available for consultation;
(f) An adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs; or
(g) A close friend of the patient.
(h) A clinical social worker licensed pursuant to chapter 491, or who is a graduate of a court-approved guardianship program. Such a proxy must be selected by the provider's bioethics committee and must not be employed by the provider.

[3]In fairness, there are two sides to this issue: optimizing effective use of the physician's time with each patient while minimizing patient waiting time. There is considerable literature on the issue of office and clinic scheduling, one of the oldest and most well-known of which is the Bailey-Welch rule of double-booking the first appointment slot and then assigning a single patient to each succeeding slot. See Bailey, Norman. 1952. A study of queues and appointment systems in hospital outpatient departments with special reference to waiting times. *Journal of the Royal Statistical Society* 14: 185–199; and Welch, J. D. 1964. Appointment systems in hospital outpatient departments. *Operational Research Quarterly* 15: 224–232. More recent articles discuss systems derived from mathematical and/or statistical models that account for variables not considered by Bailey and Welch (e.g., low complexity cases, high complexity cases, patient time with nurse, patient time with physician). See especially Oh, H. J., et al. 2013. Guidelines for scheduling in primary care under different patient types and stochastic nurse and provider service times. *IIE Transactions on Healthcare Systems Engineering* 3: 263–279. The practice of scheduling all post-op visits at the same time, however, is quite another thing.

[4]This debate will not be taken up here. Readers interested in delving into this subject will find a wealth of information in any good bioethics textbook, or in journals such as *Bioethics, Journal of Medical Ethics, The Journal of Clinical Ethics, The Journal of Medicine and Philosophy, Cambridge Quarterly of Healthcare Ethics, Kennedy Institute of Ethics Journal, American Journal of Bioethics* and *American Journal of Hospice and Palliative Medicine*, among others.

[5]To clarify, JA's niece did not inherit anything from her uncle upon his death. His condominium, car and other assets were left to his younger brother in payment for his service as executor of the estate.

[6]One of the best treatments of phronesis in the field of biomedical ethics can be found in Pellegrino, Edmund D., & David C. Thomasma. 1993. *Virtues in medical practice*. New York: Oxford University Press.

[7]Refer to Alzheimer's Association (www.alz.org) for more information.

[8]See National Alliance for Caregiving, Caregiving in the U.S. 2015. (www.caregiving.org/caregiving2015/)

[9]For more information see Scott, P. S. Caregiver stress syndrome: What's different for men. (https://www.caring.com/articles/caregiver-stress-syndrome-different-for-men)

[10]Refer to Caregiver Action Network (http://caregiveraction.org/resources/caregiver-statistics)

[11]For more information, consult the Centers for Medicare and Medicaid Services (CMS) website: https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2015-Press-releases-items/2015-10-30.html

Two Medicare billing codes were added in 2015 to allow physicians to bill Medicare for conversations about end-of-life care preferences, and can include the completion of advance directives or any other relevant legal forms (Living Wills, Health Care Proxy, Health Care Durable Power of Attorney, and Medical Orders for Life Sustaining Treatment) if applicable.

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