

The case of Mr. S.

F.J. Gianola, PA

In previous columns, using the Jonsen four-box approach to clinical bioethics,¹ we focused on the issues of medical indications and contextual features. In this case, we will explore patient preference. I would like to thank my student Letitia McCully for presenting this case.

Case

Mr. S. is a 74-year-old man who is a new patient to our family practice. His major concern at the initial visit is an occasional cough that started about 2 months previously while he was on vacation. A month ago, he started feeling tired all the time, and 2 weeks ago, his legs began to “swell up.” Mr. S. has had some dyspnea, dyspnea on exertion, orthopnea, and cough without sputum production or hemoptysis.

Mr. S. believes he may have the flu, which his wife had 2 weeks ago. He has not had any chronic medical condition such as diabetes, hypertension, or cancer. He has no family history of such conditions. He has no allergies to medication or the environment.

He is a well-developed, well-nourished, tanned man in no apparent acute distress who appears younger than his stated age. He is oriented to time, place, and person. His respiratory exam reveals regular breathing, with bilateral crackles at the bases of both lungs that do not clear with cough. The remainder of the respiratory exam is noncontributory. His cardiovascular exam, including auscultation, discloses an irregular heartbeat at a rate of 120 beats per minute. He has 3+ bilaterally equal peripheral pulses. No murmurs or other abnormal heart sounds are noted. Mr. S. has 2+ pitting edema from groin to ankles bilaterally. The remainder of his physical examination is unremarkable. An ECG confirms the suspicion of atrial fibrillation (AF). The chest film reveals cardiomegaly and pulmonary edema.

Mr. S. and his wife are informed of the ECG and chest film results. He does not want further medical tests or a referral for further work-up or treatment. His wife concurs with the decision.

The author is on the faculty of the MEDEX Northwest Division of Physician Assistant Studies, School of Medicine and Center for Health Sciences Interprofessional Education and Research, University of Washington, Seattle. He has indicated no relationships to disclose relating to the content of this article.

The ethical question

The ethical predicament, and the PA's concern, is the patient's refusal to undergo further medical evaluation and to accept treatment.

Discussion

Medical indications (beneficence and nonmaleficence) This section includes diagnosis, prognosis, and the goals of treatment. Approximately 2.3 million people in this country have AF; in the next 45 years, the rate of AF for those older than 80 years will more than double.² The American College of Cardiology, American Heart Association, and European Society of Cardiology have proposed a classification of AF as follows:

- Paroxysmal (self-terminating) AF episodes lasting less than 7 days (frequently less than 24 hours) and potentially recurrent
- Persistent AF, which fails to self-terminate and lasts longer than 7 days
- Permanent AF, which lasts longer than 1 year
- Lone AF, which is present in paroxysmal, persistent, or permanent AF without structural heart disease.³

The guidelines recommend a minimal work-up, including a compulsory history and physical examination, to define the symptoms associated with AF and to clarify the clinical type.³ The historical information needed to identify the type of AF includes the onset of the first symptomatic attack, its frequency and duration, precipitating factors, and how it stopped, if indeed it did. The clinician should also ask whether any previous medication for AF was administered and whether there was a response. Is there any underlying heart disease or other reversible condition? An ECG, chest radiograph, echocardiogram, and blood tests for thyroid function should be ordered. The data gathered may indicate the need for other tests.

The major causes of AF are hypertension, heart failure, heart valve disease, surgery, alcohol use or binge drinking, hypothyroidism, and use of theophylline, digoxin, and caffeine. The risks associated with AF include stroke and heart failure, with a significant number of deaths attributed to underlying disease.³ Treatment aims to prevent systemic embolization and maintain normal sinus rhythm.

Patient preference (autonomy) This section addresses the patient's right to choose within the law and

ethics. What is the patient's preference? How does the principle of autonomy affect Mr. S's right to decline treatment for AF?

In the fifth edition of *Principles of Biomedical Ethics*, Beauchamp and Childress responded to criticism about the order of presentation of the four principles of bioethics. One concern was that they had stressed autonomy over the other principles. They responded, "Although we begin our discussion of the principles of biomedical ethics with respect for autonomy, our order does not imply that this principle has priority over all other principles."⁴

The principle of autonomy allows a competent person to make an informed choice about treatment.

Autonomy can be defined as "self-rule, free from controlling influence of others and from inadequate understanding that prevents meaningful choice."⁴ In the United States, informed consent typically requires that full information be presented to the patient, including the relevant benefits, adverse effects, and risks of treatment or research. The person must be legally competent and understand the information presented. The choice to undergo treatment must be voluntary and free of undue influence or coercion.⁴ However, if the patient has the right to agree to treatment, he or she also has the right to refuse treatment or information. The PA's respect for autonomy requires restraint in providing information or treatment if that is the patient's choice. How does the PA provide enough information for the patient to make an informed decision, yet to know when to stop providing information if the patient asks for no more information and/or makes a choice for no further treatment?

Quality of life (nonmaleficence, beneficence, and autonomy) The third section reviews the issues of restoration, maintenance, or improvement of Mr. S.'s quality of life. Information needed includes the likelihood of the return to a normal life with or without treatment and what, if any, deficits (physical, mental, or social) Mr. S. may experience if treatment is successful. Does the PA have any preconceived notions that may prejudice the assessment of Mr. S.'s quality of life?

Mr. S. believes his quality of life right now is good. From the PA's view, Mr. S.'s quality of life has decreased over the past few months with progressive shortness of breath, the ability to walk only short distances, and the inability to lie flat in bed.

The treatments that could be offered to Mr. S.—electrical cardioversion and medication—should not have any negative long-term effects. Without treatment, he has a significant risk of stroke. His lungs will continue to accumulate fluid, causing increased shortness of breath and increasing the strain on his already enlarged heart, which in turn increases the risk of heart failure and death. Mr. S. may well have an underlying treatable disease.

Contextual features (justice) This segment considers the external forces that come into play when evaluating the case. These external forces include economic, legal, social, and institutional matters that influence the case. The patient-provider relationship is affected by the society in which they live and their duties to the social order.

Mr. S. does not have religious reasons for declining treatment. He has a loving wife and family. He has adequate insurance to cover health costs.

Recommendations

The PA caring for Mr. S. believes that further workup is indicated and that the underlying disease may be treatable. The PA thinks that Mr. S.'s persistent AF and symptoms could be treated with minimal side effects, providing a much better quality and length of life. The PA believes that without proper diagnosis and treatment, Mr. S.'s death could be hastened.

The principle of autonomy allows a competent person to make an informed choice for or against treatment. This is the person's right.⁴ In this case, the PA should respect Mr. S.'s right to make his choice. However, the principle of beneficence creates a professional obligation to offer continued palliative care and, as symptoms progress, symptomatic treatment if Mr. S. so desires.⁵

Autonomy seems to trump all other ethical principles in the United States today. Stiggelbout and colleagues have developed the Ideal Patient Autonomy Scale to help assess and quantify the patient's and clinician's view in clinical decision-making.⁶ These authors are attempting to identify, in a quantitative manner, evidence-based patient choice in decision making. The tension between beneficence and autonomy is a constant struggle for clinicians. Quality of life will be discussed at length in the next installment of "PA Quandaries." □

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