PERSPECTIVE

LESS IS MORE

Looking for Trouble—Patient Preference Misdiagnosis and Overtesting
A Teachable Moment

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Story From the Front Lines

A 74-year-old woman with systemic sclerosis was referred to a rheumatology clinic to reestablish care after a 5-year hiatus. Diagnosed as having scleroderma 30 years earlier, her disease manifestations of sclerodactyly, Raynaud phenomenon, gastroesophageal reflux, and calcinosis were consistent with the limited cutaneous subtype of systemic sclerosis, and she had never required anything more than a proton pump inhibitor to control her symptoms. Over the course of the visit, she made it clear that as long as she felt well enough to spend time with her family and tend to her garden, she wished to avoid invasive medical testing. She mentioned that she discontinued routine cancer screening several years earlier because, "At this stage in my life, I don't want any more uncomfortable tests if I don't really need them. No point in looking for trouble if I feel good."

Although she had no symptoms of cardiopulmonary disease, after learning that pulmonary hypertension and interstitial lung disease are leading causes of death in patients with systemic sclerosis and that it is common practice to screen for these complications at regular intervals,[1] she agreed to undergo an echocardiogram and high-resolution computed tomography (CT) of the chest. These would not be invasive tests, she reasoned, and she did not recall being screened for these conditions previously. There was very little discussion of the potential risks of screening or alternatives. Her echocardiogram was unremarkable, and high-resolution CT did not show evidence of interstitial lung disease; however, it did reveal esophageal dilation and several small pulmonary nodules. Her primary care physician subsequently referred her for upper endoscopy and follow-up chest CT; esophageal biopsy results showed long-term changes consistent with scleroderma, and repeated imaging showed stable pulmonary nodules. Months later, she reflected on how stressful the experience had been and wondered what good, if any, had come of all the testing.

Teachable Moment

Screening tests can result in earlier detection of disease, but they are imperfect. There is always the potential for iatrogenic harm, either directly through performance of the test itself or indirectly via false-positive or false-negative results. Moreover, incidental findings frequently lead to psychological distress and cascades of follow-up tests and procedures.[2] A retrospective cohort study that analyzed 1426 imaging studies from participants in various Mayo Clinic research imaging examinations found that 55% of CT scans of the thorax revealed at least 1 incidental finding of potential clinical significance, and the risk of incidental findings increased with age.[3] Traditional immunosuppressive therapy is associated with significant potential toxic effects and only marginal improvement in outcomes in scleroderma-associated interstitial lung disease,[1] so it seems unlikely that this asymptomatic patient would proceed with treatment even if high-resolution CT had revealed early fibrosis. The decision to screen should never be made lightly, and avoidance of overtesting requires recognizing the point at which the risks of a given test outweigh the benefits for a particular patient. This can be challenging for clinicians, given the financial and legal incentives for increased testing and a prevailing cultural belief that more is better.

Faced with an overwhelming multitude of diagnostic and therapeutic options, patients often feel inadequately equipped to make well-informed health care choices and rely on clinicians for guidance. Mulley et al[4] define "patient preference diagnosis" as "an inference of what a patient would choose if he or she were a fully informed decision maker" that has become central to the delivery of optimal patient care. Unfortunately, evidence suggests that clinicians often fail to accurately identify patient preferences,[4] as is all too apparent in this case. More weight was placed on a routine clinical practice than this patient's individual values, and a course of action was pursued that ultimately led her to undergo precisely what she wished to avoid: an invasive procedure of unclear benefit.

With a vast array of interventions at our fingertips, we have more opportunities than ever to develop individualized plans of care tailored to fit the unique needs and values of our patients. By doing so, not only will we provide care that is more patient centered, we may simultaneously reduce health care costs. Evidence suggests that better-informed, more-engaged patients consume less health care,[5] so it follows that by more accurately assessing and incorporating patient preferences into medical decisions, we may decrease overuse of resources and move toward a higher-value, lower-cost health care system. Consistently and accurately diagnosing patient preferences is no easy feat; clinicians are often under pressure to see large numbers of patients in short periods, making it difficult to fully elicit individual preferences and dis-

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cuss the risks and benefits of every test and treatment option. Nonetheless, it is essential we find ways to overcome this challenge. While we possess more medical knowledge than our patients, they are the experts when it comes to their preferences, and only by engaging in shared decision making will we be able to consistently provide high-value care.

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