

How Should We Manage Incidentalomas?

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The patient-centered medical home model advocates that diagnostic testing be performed based on shared decision making between the patient and physician.¹ This goal can be challenging when findings are uncertain or incidental to the original reason for ordering the test. For this reason, it would be useful for physicians to have guidelines to help address the ethical, practical, and legal implications of incidental findings.

The Presidential Commission for the Study of Bioethical Issues published guidelines on this topic in 2013.² The report acknowledges that technologic advances in medicine are leading to more incidental findings on imaging studies, genetic sequencing, and laboratory testing. Such findings range from lifesaving to unnecessarily costly, harmful, and anxiety-provoking. For instance, the frequency of abnormal findings on brain magnetic resonance imaging in research studies may be as high as 20%, whereas the percentage of serious findings is closer to 3%.³

The commission made five key recommendations for the ethical management of incidental findings in the clinical, research, and direct-to-consumer settings. First, a discussion about potential expected and unexpected findings should occur before testing, and the clinician should explain how these are generally handled. Evidence-based guidelines can be used to guide these discussions, such as those summarized by Hitzeman and Cotton in this issue of *American Family Physician*.⁴ Second, professional and public health organizations should determine best practices for managing incidental findings and incorporating them into their guidelines. For example, the American College of Radiology has produced a series of white papers about incidental findings from computed tomography and magnetic resonance imaging.^{5,6}

Third, more research is needed to investigate potential outcomes and best practices. Fourth, educational materials about the impact of incidental findings should be produced to inform patients, clinicians, researchers, and institutional review boards. The fifth recommendation describes the principle of justice and fairness, which necessitates access for all individuals to information, guidance, and support before and after testing. The guidelines make specific recommendations for clinical settings that further emphasize shared decision making, respect for patient preferences, the use of decision aids and graphic displays, the need for more studies of the benefits and cost-effectiveness of bundled testing vs. sequential diagnostic testing, and the role of medical education in encouraging selective diagnostic testing.

Even with these guidelines in mind, the conundrum of the incidentaloma boils down to communication between the physician and patient and the lingering question: how much information is enough, and when might this information be harmful? In general, the likelihood that an incidental finding on a radiology study translates to a deadly cancer is less than 1%.⁷ Despite the rarity of this outcome, there are many reasons incidental findings are reported: fear of litigation, desire for full disclosure, clinical experience, and financial incentives.⁸

Using the information at hand, physicians must decide if shared decision making means applying the principle of autonomy or beneficence—or both. In the interest of autonomy for our patients, we should disclose all available information to help with decision making. The principle of beneficence means we do what we think is best for our patients in a way that avoids harm. Disclosing too much information may distract a patient from a more serious health issue. In addition, detailed discussions about incidental findings can take precious time away from the agenda of an already short office visit.

Some general rules can help navigate this complex discussion.⁹ First, we should try ►

to understand our patients, including their cognitive abilities, literacy, values, and desire for information. We should try to overcome our personal biases about the test and focus on the patient as an individual. If a patient asks for information, we should provide it. If we are nervous about withholding some information, we should share it or discuss the situation with a trusted colleague. Family physicians, with our rich knowledge of the patient and his or her family over time, are in a good position to apply these principles while we await more evidence-based guidance on how to manage incidentalomas.

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