

Virtual Mentor

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Clinical Case Informed Refusal

Commentaries by Howard Brody, MD, PhD, and Ruth Jepson, PhD

Dr Michaels looked at his clinic schedule for the day and immediately felt uneasy. The first person on his roster was Frank Elgie, a 56-year-old man coming in for his annual physical. Mr Elgie is generally healthy and takes one medication for hypertension and several vitamins.

Dr Michaels keeps up with the medical literature, has an MPH, and thinks that screening tests help to improve outcomes for individual patients as well as society by decreasing costs and the burden of disease. Dr Michaels recommends screening tests to his patients based on a combination of their medical history, age, risk factors, and clinical indication. As he stares at his patient list, he remembers his last visit with Mr Elgie a year ago because of their heated argument that upset Dr Michaels for days.

Last year, Dr Michaels told Mr Elgie that he needed a colonoscopy, and several other screening tests. Mr Elgie responded by saying, "I'm not going through that. Besides, I'm not at risk. No one in my family's ever had cancer." Dr Michaels tried to explain to Mr Elgie that the colonoscopy would be done with sedation so that the discomfort would be minimal. More importantly, Dr Michaels stressed that colon cancer was common enough in those without a family history to warrant screening. Mr Elgie said "Look, doc, I know my body and I'll know if I have a problem." Frustrated and running out of patience, Dr Michaels reprimanded Mr Elgie for not taking his health seriously enough. He even went so far as to ask Mr Elgie why he came to the doctor if he didn't intend to follow professional advice. Mr Elgie had not returned the rest of the year, but now he was back for his annual visit.

Dr Michaels does not want to get into another debate, but he strongly believes that screening is important. As he enters the exam room, he is still contemplating whether or not to mention any screening tests to Mr Elgie.

Commentary 1 by Howard Brody, MD, PhD

Dr Michaels should take 2 aspirin, lie down, and call me in the morning.

Dr Michaels has experienced the unfortunate shift that has occurred for many in our society (both physicians and the general public)—the turning of "preventive screening" from science into religion. The shift from science to religion may have resulted in part

from the zealous overselling of screening by patient advocacy groups, but I suspect it is due, at least in part, to the pervasive death phobia in our culture and the desire to convince ourselves that we can become immortal through the proper application of medical technology. Dr Michaels is now concerned because he cannot convert Mr Elgie to his own religious sect. But that is not his job. As a physician he should ensure that Mr Elgie is well informed about the pros and cons of all screening tests. He should also attempt to dissuade Mr Elgie whenever it appears that ill-founded fears or concerns might be swaying him toward a decision that he would later regret. Once Mr Elgie has understood Dr Michaels' point of view and has made up his mind, and Dr Michaels has documented the conversation in the record, Dr Michaels' job is done until the following year when he can ask Mr Elgie if he would like to reopen the conversation. Perhaps in the intervening year a good friend of Mr Elgie's will have been diagnosed with colon cancer, and he will then be in a totally different frame of mind. An important "law" from the novel *The House of God* states: "The patient is the one with the disease" [1]. The patient is also the one with the risks. Dr Michaels should never allow Mr Elgie's risks or decisions to make him, Dr Michaels, feel ill.

Since Dr Michaels has both a medical and an MPH degree, he presumably knows that it is now common to view a medical journal article as seriously lacking unless it reports its findings in terms of number needed to treat (NNT). Reporting the statistics as NNT is the best way to introduce healthy skepticism among readers when a new therapy is being recommended on relatively weak grounds. For example, imagine that after 10 years, 2 percent of subjects die in the control group, while 1 percent dies in the treatment group. These results would often be reported as a "50 percent reduction in mortality." It is much less impressive to report the NNT—that 100 patients would have to be treated with this drug for 10 years to prevent 1 death.

One could logically argue that information that helps physicians is also good for patients [2]. One systematic review concluded that we would have to screen 1173 people a year for colon cancer for 10 years to prevent 1 death [3]. If we told Mr Elgie these statistics, would he be more or less likely to accept the recommended screening? If we do not tell him these statistics, are we adequately informing him? The unfortunate fact is that the number of people who need to be screened for many commonly recommended tests in order to save 1 life runs into the thousands and tens of thousands. It is very likely that if patients were informed and truly understood the meaning of these statistics, enthusiasm for screening would wane rather than grow.

Being adequately informed about preventive screening requires that one know the disadvantages as well as the advantages of the tests. Did Dr Michaels, in his enthusiasm to convince Mr Elgie to have a colonoscopy, frankly discuss the risks of perforation and death from the procedure? Did he disclose the rate of false positive and false negative results?

It is also rather odd that Dr Michaels is ready to go to the mat with Mr Elgie over a colonoscopy, when he ought to know that the US Preventive Services Task Force (USPSTF) has been unable to discover compelling evidence that colonoscopy is superior to other alternatives for colon cancer screening. Indeed, the USPSTF found "good"

evidence that fecal occult blood testing is effective, but “did not find direct evidence” that screening colonoscopy is effective [4]. Did Dr Michaels offer Mr Elgie an annual fecal occult blood test instead of demanding the colonoscopy? It is possible that Dr Michaels may have become confused when the different specialty societies produced practice guidelines with different recommendations, making it very difficult for the well-intentioned physician to sort out the evidence.

The ethical model for preventive screening, as for most other encounters in medical practice, ought to be shared decision making. According to this model, Mr Elgie and Dr Michaels should be partners in deciding whether and how to screen for colon cancer. Different partnerships work differently; some are 50-50 and some are 80-20. Mr Elgie should have a say in the extent to which he wishes to meet Dr Michaels; will it be half way? Will he defer to Dr Michaels’ well-informed clinical recommendations? Or will Mr Elgie demand veto rights over any and all decisions? Whatever level of participation Mr Elgie chooses, he should emerge from the encounter feeling that he has been as involved as he wished to be in whatever decisions have been made. Dr Michaels should also recall that there is nothing about “shared decision making” that makes it wrong for him to try to persuade Mr Elgie that he might be making a mistake. This is especially true if Mr Elgie’s refusal seems to be based on a misunderstanding of his actual level of risk because he has had no relatives with colon cancer. The persuasion should be grounded, however, in genuine respect for Mr Elgie and his right to make his own decision and not in fervor to “tick off” another colonoscopy referral on the scoreboard.

If Dr Michaels remembers that the goal of this encounter ought to be shared decision making and not religious conversion, it is much less likely that either he or Mr Elgie will emerge from the visit with dyspepsia.

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Commentary 2

by Ruth Jepson, PhD

Doctors have an obligation to disclose relevant information (particularly with regard to risk), so that patients can make autonomous decisions; that is, decisions that are neither controlled nor coerced. Because of Dr Michaels’ enthusiasm for screening, he is

(wittingly or unwittingly) failing to disclose all of the known limitations and negative consequences of screening. Current clinical practice emphasizes shared decision making in which doctor and patient reveal treatment (or screening) preferences and agree on how to proceed [1]. In this case, it appears that Dr Michaels is not adhering to the principles of shared decision making and is failing to respect both Mr Elgie's wishes and his right to make an autonomous choice.

Dr Michaels and Mr Elgie need to find a way to move forward so that each believes his views are respected, patient autonomy is protected, and the patient-physician relationship remains strong. Dr Michaels may wish to consider alternative ways of improving Mr Elgie's health outcomes that are acceptable to both.

Benefits and Risk of Screening

Screening stands apart from traditional medicine in that it seeks to detect disease in individuals before they present with symptoms. Benefits of screening include improved prognosis for some illnesses because of early diagnosis, the possibility that less radical treatment is needed to cure the early-stage case, resource savings, and reassurance for those with negative test results. Unintended adverse effects of screening include longer morbidity for cases where the prognosis is unaltered by the early diagnosis, overtreatment of questionable abnormalities, resource costs, false reassurance for those with false-negative results, anxiety and sometimes morbidity for those with false-positive results, and the process hazards of screening tests [2].

Information Needed for Informed Decisions about Colorectal Screening

Dr Michaels is convinced of the benefits of screening, but has failed to disclose all of the unintended consequences and limitations of colonoscopy. A *Cochrane* review concluded that harmful effects of colorectal screening include the physical complications of colonoscopy such as perforation and haemorrhage, disruption to lifestyle, and stress and discomfort from testing and follow-up investigations [3–5]. In addition, whilst colonoscopies will only detect a few cancers, they will detect and remove a large number of polyps. This detection can be seen as a part of the benefit of screening or part of the harm. Part of the benefit of screening will come from removal of the small proportion of polyps that would have progressed to invasive cancer. Part of the harm of screening will come from regular colonoscopies that are recommended for people who have benign or inconsequential polyps removed [6].

Patient Autonomy within the Medical Encounter

Over the last few decades, the public in general, and bioethicists in particular, have become concerned about the rights of patients, including the right to give informed consent and the right to control one's health care choices [7]. It has been argued that whether or not the benefits of screening outweigh harmful consequences is essentially a value judgment, and one which until now has been made by "paternalistic agents of the state" (physicians) rather than by those invited for screening (the patients) [8]. The patients' rights model seeks to give patients information about the risks and consequences so that they can then make informed choices and judgments themselves.

The goal of enhancing choice—eg, by providing evidence-based information—should not be to encourage a *specific* choice [9]. Approaches to communication of risk information are based on the assumption that individuals will review the evidence rationally and choose the course of action that will maximise benefit to their health. However, rationality is not the only component in decision making; irrational influences and considerations can also exert strong pressures [10]. Whilst information provided by the physician may contribute to more rational decision making, its primary aim is to enhance patient choice and autonomy. In this case, Dr Michaels is convinced that the “right” choice is for Mr Elgie to be screened, but he is not taking into account Mr Elgie’s preferences and what the “right” choice is for him based on these preferences.

The doctrine of informed consent emerged in response to the perception that patients were not being given sufficient information and were thus powerless in health care (ie, without autonomy). One way to redress this imbalance was to better inform patients. Alongside the doctrine of informed consent evolved the complementary patient right to refuse treatment. The right to refuse, combined with the ethos of informed consent, enables patients to retain control over their lives and their health care [11]. Thus a shift took place from paternalism and beneficence in medicine (however benign) towards a partnership between patient and physician. In our case, Dr Michaels is angry because he feels that his professional opinion is not respected by Mr Elgie. But Dr Michaels is not respecting Mr Elgie’s attitudes, beliefs and values, and right to autonomy. Patient autonomy is a relatively new concept and, as such, may be uncomfortable for physicians like Dr Michaels who are used to having their professional views followed unquestioningly.

In shared decision making—“decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient-specific characteristics and values” [12]—both the health professional and the patient are assumed to have a legitimate investment in the treatment decisions [13]. It is this model that Dr Michaels needs to think about and adopt in his encounter with Mr Elgie.

Conclusion

If Dr Michaels decides to talk to Mr Elgie about screening, he needs to give him more complete information, including the limitations and possible consequences of colonoscopy. It appears unlikely that Mr Elgie will change his mind, but at least he will have made a more educated choice. If he continues to refuse screening, both men may wish to discuss other ways of improving Mr Elgie’s health outcomes. For example, Dr Michaels could offer advice on the risk factors for colorectal cancer and provide information on how to modify such risk factors (eg, by diet and exercise). He will also need to provide information on the signs and symptoms of bowel cancer and encourage Mr Elgie to come and see him if he is worried or changes his mind about having a colonoscopy. Mr Elgie may choose to ignore this advice, but Dr Michaels can be assured that he has performed his obligations to disclose, that there has been some element of shared decision making, and that Mr Elgie has made an autonomous, informed choice.

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