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**Strategies for Improving Adherence to Colonoscopy
Screening Guidelines**

Introduction

The Need for More Screening

Colorectal cancer (cancer of the colon and/or rectum) is the second leading cause of cancer-related deaths in the United States, accounting for 10 percent of cancer deaths overall (Ziegler et. al. 2010). In 2010, the disease claimed over 51,000 lives (American Cancer Society 2011), each of which could have been saved by a simple procedure: a colonoscopy. Colonoscopies are considered the gold standard for early detection of colorectal cancer and of polyps which can become malignant if not removed. The U.S. Centers for Disease Control and Prevention (2010) estimates that as many as 60 percent of colorectal cancer related deaths could be prevented each year if all men and women age 50 and older were screened routinely in accordance with national guidelines. Yet, less than one third of Americans in this age group have ever received a colonoscopy (Brody 2005). Furthermore, a mere 20 percent of doctors follow colorectal cancer screening guidelines, either ordering tests too frequently or too seldom (Reinberg 2010). The present paper examines the reasons behind the lack of adherence to colonoscopy screening guidelines and suggests strategies for improving compliance with these quality measures based on a review of the pertinent literature and the author's own opinions.

Different Screening Options

Colonoscopies are the primary focus of this discussion because they are the preferred method of screening, but other less invasive methods of screening are available which can indicate whether a colonoscopy is necessary. If used appropriately, these alternate types of screening can bring a patient into compliance with the guidelines. The American Cancer Society (ACS), the U.S. Preventive Services Taskforce (USPST), and the American Gastroenterological Association (AGA) recommend screening beginning at age 50 for average risk individuals (DeBourcy et. al. 2005). Earlier testing is advised for

those with a family history of the disease. The American Cancer Society (2010) recommends that a flexible sigmoidoscopy, double-contrast barium enema, or CT colonography (virtual colonoscopy) be performed every five years and followed by a colonoscopy if the results are positive, or that a colonoscopy be performed every ten years. All of these tests have the potential to find cancer and detect precancerous polyps, but a colonoscopy is the most thorough procedure since it scans the entire colon. If a colonoscopy reveals polyps or early tumor growth, doctors are advised to schedule a follow up colonoscopy much sooner than the next ten year benchmark. Other tests which primarily find cancer, but cannot detect precancerous polyps include fecal occult blood tests (FOBTs) and fecal immunochemical tests (FITs) which can be performed every year, and stool DNA tests for which screening intervals are uncertain. While many doctors order these tests, the American Cancer Society does not recommend them if one of the more comprehensive tests is available.

Electing to get a colonoscopy eliminates the inconvenience of undergoing screening at frequent intervals, assuming results are negative. That said, colonoscopies are the most invasive of the testing options and require considerable preparation on the patient's part. As a result, compliance with colonoscopy screening is much lower than that of other types of screening even though it is the most effective at detecting polyps and cancer.

Reasons to Recommend Colonoscopies Over Less Invasive Procedures

Whether encouraging patients to get a colonoscopy every ten years or undergo less invasive screening options at frequent intervals is more effective at improving compliance with screening guidelines is a matter of debate in the literature. Some patients resist the prospect of enduring three days of bowel cleansing preparation, being sedated, and having a tube inserted into their large intestine, so these individuals are more likely to prefer a sigmoidoscopy, barium enema, or CT colonography. Then

there are those who do not mind getting a colonoscopy, but cannot secure time off of work or other obligations to follow through with the procedure. Others would rather have the peace of mind a colonoscopy affords and check off colorectal cancer screening from their “to-do list” for the next decade. The present paper takes the position that colonoscopies are the best method of ensuring compliance with screening guidelines.

In a randomized population-based survey of 1,223 residents of two communities in southwestern Pennsylvania, Robert Schoen et. al. (2002) found that colonoscopies are an effective way to improve compliance with colorectal cancer screening guidelines for the reasons discussed above. Study participants were selected from lists of 65- to 79 year old Medicare beneficiaries and 50- to 64 year old licensed automobile drivers. 496 of those sampled completed a telephone interview in which they were asked about their past screening behavior. Among the 377 respondents with average risk (no family history of colorectal cancer), 50 percent, 19.6 percent, 39.8 percent, and 17.5 percent reported ever having had FOBT, FS, barium enema, and colonoscopy, respectively. Despite the overall low rate of colonoscopy screening in this sample, including TCE within the previous 5 years increased the measured compliance to 39.7 percent. Self-reports of recent colonoscopy were verified in 29 of 35 instances (83 percent).

In Schoen’s study, colonoscopy screening rates for individuals with a family history of colorectal cancer were much higher at 62.9 percent (p. 446), demonstrating that a personal connection to the disease improves screening compliance. Only 17.1 percent of those with family histories of colorectal cancer in first degree relatives reported no prior testing (p. 448). Yet, given that 80 percent of colorectal cancer cases occur in people without a family history (Moran 2002) there need to be better strategies for improving screening rates among individuals with no overt risk factors.

Reasons for Non-Compliance

Lack of Education and Patient Anxiety

Lack of education about colonoscopies on the part of both patients and physicians as well as patient anxiety about the procedure itself are key reasons for low compliance with screening guidelines, not only in the United States, but also in Europe. These two reasons are inter-related because patient anxiety is often caused by a lack of knowledge or misguided information. Many people are reluctant to undergo a colonoscopy because they do not understand its value, they are unaware of the guidelines, or they have false schemas of what a colonoscopy is like based on unattractive portrayals in the media.

In a structured survey of 239 individuals aged 55 to 89 years of age in Germany, Matthias Ziegler et. al. found that attitudes toward secondary prevention and concerns about colonoscopy are the most important predictors of participation in colonoscopy screening. Ziegler examined the differences in perceptions about colonoscopies among patients who had undergone screening in the past and those who had not. He found that bowel preparation was a major concern among both groups, but in general, perception of colonoscopy was worse in the non-screened group than in the screened group. 36 percent of the non-screened group and 4 percent of the screened group reported to be afraid of discomfort or complications caused by the colonoscopy. The two groups also differed significantly ($p < 0.001$ for both) in their attitudes toward secondary prevention. 80 percent of the screened compared to 46 percent of the non-screened individuals rated “screening examinations and consultations with a physician concerning screening as important” (p. 122). The authors note that 50 percent of the non-screened group had the misconception that screening should only be performed for symptomatic patients, indicating that more needs to be done via public awareness campaigns and primary care physicians to educate people about the preventive purpose of colonoscopies. Ziegler’s findings also reveal that while the experience of

having a colonoscopy decreases fear of the unknown, even patients who have had a colonoscopy in the past are still prone to anxiety, especially regarding the bowel preparation. Such anxiety may cause someone to skip a follow up colonoscopy or deter a friend or relative from having the procedure.

Ziegler found that the typical colonoscopy patient in his sample was unemployed or retired and had a lower degree of education. These findings stand in contrast to the bulk of the literature which points to a correlation between higher education and higher participation rates in screening programs. Ziegler suspects that the reason for this discrepancy is the limited representativeness of all available studies. He reasons that his findings can be explained by the fact that “people with a higher education and those with a better health status tend to work longer during their lifetimes and might therefore never be in need nor have the time to regularly see a doctor and to undergo a screening colonoscopy” (p. 124). However, in the United States, the working poor are probably the ones least likely to be screened since they may not qualify for Medicaid and cannot afford private health insurance. In Germany, one can be unemployed without sacrificing health coverage. Also, the American working poor may not have access to paid benefits such as sick leave to afford them time off of work to get a colonoscopy.

As a point of comparison with Ziegler’s findings, a U.S. based study by A.L. DeBourcey et. al. found that ethnic minorities and people with lower educational attainment are more likely to choose a less invasive procedure when given the choice between that and a colonoscopy. In a diverse sample of 323 colonoscopy-naïve supermarket shoppers in Denver, Colorado, DeBourcy found that 53 percent preferred FOBT and 47 percent preferred colonoscopy for colorectal cancer screening when given a detailed side-by-side comparison of the two procedures (DeBourcey et. al., 2007). Individuals of Latino ethnicity and those with less education were more likely to prefer FOBT than non-Latino whites and those with at least some college. In addition, almost half of the respondents felt “very strongly” about their preferences, and one third said they would not change their mind regardless of physician

recommendation. DeBourcy's study raises the question of whether negative attitudes about colonoscopy are so engrained in society that physician referral will have a limited impact on compliance, especially among underserved populations. What this study does not show is whether individuals who prefer FOBT over colonoscopies would change their mind if they knew that the former is not even recommended by the American Cancer Society.

Poor Patient Attendance for Colonoscopy Appointments

Poor patient attendance to scheduled colonoscopies is another reason for low compliance with screening guidelines. Using computerized scheduling data for 23 sites performing endoscopic procedures in the University of Pennsylvania health system, Barbara J. Turner et. al. found that "physician appointment-keeping behavior predicted attendance to colorectal endoscopic studies and may help identify persons who need interventions to promote adherence" (Turner et. al. 2004, p. 528). In Turner's study, almost 40 percent of nearly 12,000 patients did not keep their first scheduled colonoscopy or sigmoidoscopy. Roughly 1,000 persons in this cohort failed to keep two sequential appointments, and nearly 18,000 additional patients did not reschedule. Of patients in the lowest quartile of physician visit adherence, roughly 50 percent attended their first colon study compared with 70 percent of those in the highest quartile for adherence. Consistent with other literature, women, blacks, those with incomes below \$25,000 and those with Medicaid or unknown insurance were less likely than whites, males, those with higher incomes and those with private insurance to keep their first or reschedule their colon study appointment. The authors suggest that patients are reluctant to keep colonoscopy appointments because they find them to be "violating" and "painful" and that patients do not appreciate the risk for colon cancer (p. 530).

The fact that so many patients fail to keep their colonoscopy appointments has implications for non-compliance not just for the no-shows, but for other patients who are on waiting lists and cannot receive a colonoscopy because slots have been claimed by people who are missing appointments. Statistics on the exact number of patients on waiting lists for every colonoscopy that is missed are not available, but the number is undoubtedly high. Colonoscopies require considerable resources including equipment, a physician, anesthesiologist, and other hospital staff, so missed appointments contribute to the rising cost of health care which in turn makes colonoscopies more inaccessible for those who need and want them. In a study of patients attending an outpatient clinic in Spain, Javier Sola-Vera et. al. found that a longer time on the waiting list and referral by a general practitioner as opposed to a specialist are associated with patients failing to keep their endoscopy appointment (Sola-Vera 2008). Poor compliance with scheduled colonoscopy appointments is both a symptom of a larger underlying problem about patient attitudes toward colonoscopies and is also a problem in and of itself.

Over and Under- Referral for Colonoscopies

As previously noted, many physicians are uneducated about screening guidelines and tend to either over or under-refer patients for colonoscopies. When it comes to compliance, over-referral is just as much of an issue as under-referral because patients who do not need colonoscopies are taking appointment slots that could be used by patients who need them, resulting in the same problem created by no-shows. At the same time, many patients who need colonoscopies are uneducated about the screening guidelines and are not being informed by their doctors.

In a study of 155 VA primary care clinics, Elizabeth Yano et. al. found that patients cite lack of physician recommendation as the primary reason for not being up-to-date on their colonoscopy screenings. Lack of education and the organizational structure of primary care offices are factors she

examines in her analysis. Yano's study shows that nearly one third of primary care physicians rely on single sample, in-office FOBT tests to determine if a patient is at risk for colon cancer, even though this is the least accurate method of colorectal cancer screening. Another third only recommend repeat FOBT after a positive test. Yano also found that the organizational structure and processes of primary care offices influence the quality of care, demonstrating the largest effect on prevention performance including colon cancer screening. Primary care practices that have greater autonomy over the internal structure of care delivery ($p < 0.04$), more clinical arrangements ($p < 0.03$), and smaller size ($p < 0.001$) are more likely to refer patients for colonoscopies (Yano et. al. 2006).

The external validity of Yano's study is questionable since she only looked at primary care clinics utilized by veterans, but her findings could probably be generalized to non-VA settings. It is also possible that the low rate of compensation for VA doctors and the overcrowding of these clinics is a contributing factor to poor physician compliance with preventive quality measures in a setting that offers affordable access to care (VA clinics are free), but may be forced to make tradeoffs so that care can be affordable. A fascinating follow-up study might look at the same variables in a smaller, traditional fee-for-service setting to see how the results compare.

While under-referrals for colonoscopies are much more discussed than over-referrals in the literature, some researchers do consider the over-referral problem to be equally deserving of attention. In a National Cancer Institute survey of 1,266 primary care physicians in the U.S., Robin Yabroff et. al. found that 44.3 percent of physicians recommended colonoscopies too frequently (Yabroff 2007). This statistic is surprising given the high number of people who die from colon cancer annually. If so many people are being referred for colonoscopies, even outside of the guidelines, why are there so many deaths from colon cancer? One possibility is that the wrong people are being referred. Also, Yabroff's study does not track how many of these physicians' patients actually followed through on the referral.

Strategies for Improving Compliance

Some strategies for improving compliance with colonoscopy screening guidelines are better communication between patients and physicians, including follow up to ensure that patients arrive for their scheduled colonoscopies; continuing education programs for physicians so that they are informed of changes in guidelines; use of checklists to remind primary care physicians when a patient should be screened; and public awareness campaigns to reduce stigma and reinforce the perception that a colonoscopy is a very safe, low risk procedure. The present discussion will focus on communication tools and education programs for physicians because these are the most important for achieving compliance.

Improved Communication between Patients and Physicians

In a pilot study of 154 screening-eligible, but non-adherent primary care patients at an urban, federally qualified health center, Kishore Khankari et. al. found that the following interventions appeared to be a “feasible means” to improve colorectal cancer screening rates among patients served by community health centers: 1) manually tracking screening-eligible patients, 2) mailing patients a physician letter and brochure before medical visits, 3) health literacy training to help physicians improve their communication with patients to work to resolution, and 4) establishing a "feedback loop" to routinely monitor patient compliance (Khankari et. al. 2007). The baseline pre-study screening rate was 11.5 percent with 31.6 percent of patients having received a recommendation from their physician. At a 1 year follow-up of the study, the screening rate had increased to 27.9 percent ($p < 0.001$) and physician recommendation had increased to 92.9 percent ($p < 0.001$). Although the physician referral rate and actual rate of screening tripled respectively, Khankari’s study appears to have had more influence on rates of physician recommendation than it did on rates of patient compliance with screening guidelines, for at the

end of the study almost all physicians had recommended colonoscopy whereas over 60 percent of patients who had been referred for colonoscopies were still not getting them. The authors acknowledge that “more attention to patient decision making and education may be needed to further increase screening rates” (p. 1410). While communication is central to ensuring compliance, patient attitudes also need to change.

Other studies have compared the impact of one communication tool over another on compliance. In a follow up to her earlier study on patients who miss scheduled colonoscopy appointments, Turner et. al. used the same health systems data to conduct a randomized control trial to see if receiving an educational brochure in the mail or peer coach support was a more effective intervention for improving attendance. (Turner et. al. 2007). 275 patients were randomly assigned to a control group which did not receive any intervention or one of two “treatment groups,” where they either received a brochure or a call from a coach.¹ In a model with the groups that received support, the peer coach group had over two-fold higher adjusted odd-ratios of keeping the colonoscopy appointment compared with the brochure group. These findings also held true in a model of all patients including those in the control group. The peer coach was endorsed by 80 percent as “very helpful.” Patients in that group appreciated being able to hear about another person’s experience with colonoscopy and cited dissatisfaction with their doctor for not addressing their concerns.

Turner’s study reveals the importance of interpersonal communication in changing behavior. A brochure can easily be thrown away, but an engaging conversation with a well-trained coach who can empathize with the patient’s anxiety may be more influential. The fact that the peer coach support in Turner’s study achieved better compliance than the physician referral in Khankari’s study indicates that

¹ The peer coaches were patients themselves who had previously undergone a colonoscopy and were nominated by their physicians on the basis of being strong communicators. All coaches received training which included viewing Katie Couric’s colonoscopy video.

physicians need to do a better job of listening to patient concerns instead of simply mailing letters or reminding patients about screening procedures during a rushed office visit.

The fee-for-service culture of medicine in the U.S. makes it difficult for physicians to spend sufficient time with patients because they are compensated for the number of hours they can bill, not their quality of performance. That said, insurance companies would be wise to reward physicians for the time they spend on patient education. Even moving a physician to a higher tier in a provider network if they convince enough of their patients to follow through with colonoscopies might be enough of an incentive for physicians to spend more time coaching patients through their concerns. Greater emphasis on pay-for-performance (P4P) measures such as giving physicians a bonus if they get a certain percentage of their patients to comply with colorectal cancer screening guidelines is another idea. If a peer coach is not available and the physician is pressed for time, a nurse, physician assistant, or other qualified health professional could fill the role.

Continuing Education Programs for Physicians

As discussed above, many physicians are unaware of colorectal cancer screening guidelines and either order tests too frequently or too seldom. In a study looking at primary care physicians' familiarity of colorectal cancer screening guidelines, Ami Schattner and Avi Gilad found that only 8 percent of these physicians recommended colonoscopies and sigmoidoscopies at the proper intervals. Schattner concludes that primary care physicians endorse screening, but are unaware of the guidelines and do very little to implement them (Schattner 2002). In order to address this problem, state licensing boards should require physicians to take a course or workshop on preventive screening guidelines every few years. Since the problem is mostly among physicians over 40 (Yabroff 2007), programs should be targeted toward physicians who have been out of medical school for at least five years. Medical schools should

also require a similar training for students entering primary care or gastroenterology so that new physicians are informed of the proper guidelines.

In her study discussed above, Yabroff found that doctors who followed the guidelines were more likely to use electronic medical records and take patient preferences into account. In addition, physicians in single-specialty or multi-specialty practices were more likely to follow guidelines than those in solo practices. This could be because physicians who work with others are exposed to sources of medical information from their colleagues. Therefore, the U.S. Preventive Services Taskforce and the American Cancer Society should hold more conferences to encourage dialogue between physicians with a focus on preventive measures.

Conclusion

Compliance with colonoscopy screening is dismal at best. Physicians are not compensated or in any way rewarded for time they spend endorsing preventive measures or educating patients about the importance of screening. They are also given no incentive to pursue continuing education programs. Even when physicians do properly refer patients for colonoscopies within the guidelines, many factors prevent compliance such as socio-economic status, lack of education about the importance of colonoscopies, and fear and anxiety about the procedure. In order to improve compliance, all of these issues must be addressed.

Federal legislation is currently underway to improve compliance with colonoscopies. If passed, the “Colorectal Cancer Prevention, Early Detection and Treatment Act” of 2011 (H.R. 912/S.494) would “amend the Public Health Service Act to establish a national screening program at the U.S. Centers for Disease Control and Prevention and to amend Title XIX of the Social Security Act to provide States the option to increase screening in the United States population for the prevention, early detection, and

timely treatment of cancer” (GovTrack). Sponsored by Senator Joe Lieberman (I-CT) and Representative Kay Kranger (R-TX), the bill has been read twice and on March 7 it was referred to the Committee on Health, Education, Labor, and Pensions. The bill is especially focused on increasing access to colonoscopies for individuals who are over age 50, but too young to qualify for Medicare. This legislation is a major step forward in the road toward compliance, but even with the best resources and access to care, compliance will not improve unless physicians are aware of the guidelines and patients’ attitudes change.

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