Colon Cancer
Prevention Project

June 9, 2016

National Challenge to Improve On Time Screenings

Introduction

The primary goal of this communication is to challenge the colorectal cancer (CRC) community to improve adherence to the current guidelines for screening and early diagnosis as recommended by the American Cancer Society (ACS), the US Preventative Services Task Force (USPSTF) and the National Colorectal Cancer Round Table (NCCRT).

Great organizations are marked by self-reflection and adaptation, and there great organizations in the CRC community. Within the CRC world, the ACS and the NCCRT have provided steady and forward-thinking guidance. These organizations, their members, and their supporters should rightly claim a bulk of the responsibility for the dramatic lowering of CRC incidence and mortality, a trend which continues today.

Process improvement involves taking a hard look at the data, then developing plans. These plans should be based on the input and consensus of experts, (as well as advocates), and address opportunities to increase compliance with current screening guidelines or even changing guidelines. Many of these opportunities have been identified and subsequently addressed including disparities among various racial and ethnic groups, non-invasive fecal screening options, engaging with low performing screening states by helping them incorporate the process, and finally, focusing within the realm of the community health center networks. It can be represented with the OODA loop in our war on cancer: observe, orient, decide then act.

In short, by self-correcting our course, while remaining steadfast to the goal, we have made remarkable progress. Yet at the time this is written, the CRC community has the opportunity to consider an additional strategy to increase compliance within the current guidelines, further promoting the goal of reducing unnecessary suffering and premature deaths from CRC.

The bottom line is this: lead time messaging = on time screening

There are three subsets of the population we currently serve that are underperforming on screening or diagnostics and have tremendous opportunities for improvement:

1. The 10-15% of the at risk population with a family history of colon cancer or family history of colon adenomas or genetic syndromes who require colonoscopy-based initial screening before the age of 50, are too frequently unidentified, unscreened or screened too late.

2. Those under age 50 with signs and symptoms suggesting sporadic CRC for whom prompt self-referral, and appropriate diagnostic evaluation by providers is often delayed due to the knowledge gap surrounding the 13% (and climbing) of CRC which develop under the age of 50.

3. The 46% of asymptomatic normal risk persons who are not receiving any colon screenings during the entirety of their 5th decade.

The three areas identified above may at first glance seem disparate; however, they share a common solution which can be addressed with a simple, actionable and rapidly implementable strategy. That factor is ***lead time messaging*** for providing actionable accurate and relevant information. This strategy will invariably lead to more ***on time*** risk appropriate screenings as well as symptom evaluation and potentially even further upstream risk factor modification. By providing current, evidence-based information to people about colon cancer by at least age 40 we can hypothesize a broad set of results including:

1. Dramatic improvement of the majority of "on-time" screening for high risk individuals requiring screening before age 50.

2. More broad and rapid recognition of, self-referral, and timely accurate diagnostic testing for those who develop signs or symptoms of colon cancer before age 50.

3. An improvement in the percentage of asymptomatic normal risk individuals screened at age 50 (on time) rather than significantly later than age 50 (as is the case now).

We have an obligation to ensure high level, systematic, evidence-based information and education around CRC and specifically CRC screening be delivered at the time when it can have the greatest impact. ***Therefore, we advocate for insertion of a hard stop educational intervention to the entire population by at least age 40*** to achieve the 3 major beneficial outcomes as briefly outlined above and to further improve and accelerate the remarkable progress we have made so far on the road to 80% x 2108.

First, the high risk population represents around 10-15% of the entire population yet we sorely lack a process for timely identification and referral for screenings or to track and improve their "on time" screening rate statistics. How strange to have the least attention or planning to those most at risk. In addition, in the over 50 year old age group genetic plus familial CRC accounts for 20% of CRC, while in the under 50 age group genetic plus familial CRC is responsible for a significantly higher percentage of Early Age Onset (EAO) CRC. ***An on time and thorough family cancer history is critical to saving lives through prevention.*** Identifying a genetic carrier state only after a cancer diagnosis has been made should be considered a failure of our current system.

The incidences of both EAO colon and rectal cancers have almost doubled in the last decade and by all studies continue to rise. As far as we can tell, it's not going away anytime soon. People must know their CRC risks on time when appropriate screening will make the difference. Fifty is too late to find out you should have been screened at an earlier age. ***A well designed, consistently implemented systematic communication strategy designed to better support the current guidelines should improve or pick up the almost 75% of the EAO CRC which presents between age 40 and 50.***

The second opportunity by the CRC community is to address the perception that CRC only affects those 50 and over. This invariably leads to a toxic and lethal combination of delays for the patient. Lack of awareness leads to delays in self-referral to the health system, and then all too often followed by a lack of awareness on behalf of the provider by not making the timely appropriate referral for specific diagnostic testing to exclude CRC. ***People must recognize their CRC symptoms on time when a rapid diagnosis will theoretically allow for down-staging of disease resulting in reduced morbidity and mortality.*** Fifty is too late to know about the signs and symptoms of CRC.

Third, there is a roaring paucity of attention given to the percentage of asymptomatic normal risk individuals who fail to undergone on time screening at age 50. In fact, only 54% of this population actually completes their first screening in their 50's. Some lesser fraction of these is actually screened on time. This is unacceptable. The screening rates reported nationally overstate the number who are "on time" with initial screening. No doubt this is the major reason why there has been little if any improvement of morbidity or mortality in the 50-55 age group because at minimum, less than half have been screened. If that's ok then perhaps we should change the recommendation to ".....sometime after 50 or before 60?" At 50 should mean at 50.

In addition, lead time messaging also allows us to recommend earlier risk factor modification for important behaviors such as weight loss, smoking cessation, dietary changes, or exercise, for all who can may benefit.

<u>Optimizing messaging though lead time</u>

The best way to increase the % of the asymptomatic normal risk population for on time screening is a well-designed, consistently implemented, repetitive message in advance of the desired date for the screening intervention. Earlier communication to patients will assuredly increase the dialogue and decision making process around options for on time CRC screening, particularly noninvasive fecal testing such as FIT, sDNA, in addition to colonoscopy.

At the national level we have disproportionately focused on only 1 of the 3 essential components of marketing known as "the message", i.e. "for your wife, for your kids, prevention works etc." The series of messages generated through the ACS and NCCRT collaboration are outstanding. However, the current communication strategy has not taken full advantage of the other two essential elements of marketing toward a time sensitive event.

First and most importantly, the timing of a message must be optimized to have the greatest likelihood of a screening event occurring at the recommended time. The CRC network can be

assured that if one is told at age 50, the intervention will come after age 50. Too many 50-55 year old CRC patients did not get, hear or act on the current recommendations. And a message delivered at 50 will certainly not help anyone who needed screening at age 40. Since the rise in CRC occurs in the early 4th decade, particularly rectal cancers, this seems like the optimal lead time to provide information as persons enter the hot zone for CRC.

The second critical marketing tool impacted by our too late current communication strategy is message frequency. If one must hear a message on average 7 times before an action is it any wonder that the average of first time screenings for CRC is around age 56? McDonald's tells you ten times to change your behavior (eat a Big Mac) and a Big Mac is a much easier and tastier option than a colon cancer screening for sure.

There have been concerns voiced regarding potential behavioral consequences to earlier messaging including the potential risks of inappropriate too early screenings and their associated morbidity, costs to the system and even mortality. We have yet to see a randomized controlled trial, a pilot intervention, social or behavioral modeling that proves or disproves this self-evident proposal with regards to CRC. If this concern is the major barrier to earlier messaging strategies we should demand that it be vigorously studied ASAP to fully vet the risk benefit ratio...

Collateral improvement to the early age onset (EAO)-CRC

Upon returning from the second annual EAO CRC summit, there is frustration around this topic given the lack of vigorous debate or tangible action on the national level. Our organization, The Colon Cancer Prevention Project, is implementing both patient and provider awareness and education promoting the current ACS/USPTFS colon cancer screening guidelines across the state of Kentucky be discussed with patients by age 40. To be clear, not screening for all at age 40, but awareness for all by age 40 of their personal risk, symptom awareness, their screening options and their own individualized “on time" date.

In the state with the highest incidence of CRC in the nation, for 14 years since becoming advocates, we have heard the tragic stories of an ignored or unknown family history, the duration of obvious signs or symptoms of colon cancer ignored or blown off or misinterpreted. Young parents with children in hands, people cut down in the prime of their life changing their lifetime goals to the goal of seeing their own next birthday.

We have heard from the most preeminent scientists and epidemiologists that this trend is real and progressing around the western world. The explanations...diet, genetics, familial, sporadic, unknown cause..... how about unnecessary? Every day there is not a black box warning from the CDC about the alarming rise in rectal cancers (now over 20% of all rectal cancer cases) in the under age 50 population we are shocked.

Of critical importance, we do not yet need to fully understand the why of this phenomenon before we act to reduce the negative impact of EAO CRC, much like we do not require an in depth knowledge of meteorology to seek cover in a hailstorm. We can develop and implement an augmented and updated communication strategy to deal with the younger, earlier changing face of EAO CRC while we strive to understand, manage and overcome the underlying

pathophysiology. Again, an incomplete understanding of EAO CRC should not be allowed to restrain us from action to address this trend.

Call to action

Add the following paragraph to the existing resources for the ACS and NCCRT supported by a vigorous marketing program targeted at primary care providers, providers of screening services, and patients.

"At age 40, both patient and providers should engage in the initial discussion regarding individualized CRC prevention and early detection. The intervention should include four parts: 1) a review of pertinent family history regarding CRC, adenomas, other associated cancers or conditions which may require CRC screening earlier age than age 50, 2) a review of signs and symptoms of CRC, emphasizing the extreme importance of prompt evaluation, 3) review the importance of on time screening at age 50 and discuss the menu of screening options available, and 4) promote evidence based lifestyle modifications to reduce CRC risk including weight loss, smoking cessation, increased exercise and dietary changes."

We challenge the great national reservoir of knowledge and experience - lead by ACS and the NCCRT - to a vigorous and fast-tracked dialogue designed to address these three critical opportunities for improvement via any route. We have proposed a simple, implementable solution with few moving parts as described in this document and welcome feedback comments and criticism to the plan. We also challenge all of our colleagues to develop alternatives or improvements to this simple and actionable plan to increase on time screening. Our vision is a rapidly and broadly implemented communication paradigm shift to achieve our common goals of preventing unnecessary suffering and premature deaths from CRC. The timeline should be short and draft recommendations possible by year's end 2016.

Respectfully submitted and disseminated,

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