

Developing a Rural Colorectal Screening Program

by James N. Frame, M.D., F.A.C.P., Carrol Klinker, R.N., Gladys Kuhn, R.N., Todd A. Witsberger, M.D., Joe J. White, M.D., and Shelley Johns, Psy.D.

About 135,400 new cases of colorectal cancer (CRC) are expected in the United States this year, and 56,700 people will die from the disease.¹ Among U.S. men and women, CRC mortality ranks second only to that of cancer of the lung and bronchus and exceeds mortality estimates from either breast or prostate cancer.

The good news is that from 1990 to 1996, mortality from CRC

James N. Frame, M.D., F.A.C.P., is medical director, Oncology Services, Charleston Area Medical Center and David Lee Outpatient Cancer Center. He is also clinical associate professor, Robert C. Byrd Health Sciences Center, West Virginia University School of Medicine, Charleston, W.Va., Carrol Klinker, R.N., is cancer center outreach nurse, Charleston Area Medical Center, Charleston, W.Va., Gladys Kuhn, R.N., is oncology corporate director, Charleston Area Medical Center. Todd A. Witsberger, M.D., is a general surgeon with the Charleston Surgical Group. Joe J. White, M.D., is a gastroenterologist with Charleston Gastroenterology Associates. Shelley Johns, Psy.D., is oncology clinical psychologist, Charleston Area Medical Center, Charleston, W.Va. Address comments to James N. Frame, M.D., F.A.C.P., Charleston Area Medical Center, Oncology Administration, 3200 MacCorkle Avenue, S.E., Charleston, WV 25304. E-mail: james.frame@camcare.com.

declined an average 1.7 percent per year.¹ Furthermore, among all races in the United States, five-year relative cancer survivor rates from 1974-1976 to 1989-1995 have increased by 12 percent and 11 percent for colon and rectal cancers, respectively.¹

Although CRC screening recommendations have been published for more than a decade, current evidence suggests insufficient public awareness and underutilization of CRC screening in the U.S. In a population survey presented at the kickoff of the first National Colorectal Cancer Awareness Month (March 2000), 99 percent of those questioned did not mention CRC when asked to name a serious life-threatening disease, 63 percent older than age 50 were not receiving CRC screening, 25 percent could not name one method of CRC screening, and 90 percent believed it was the physician's responsibility to recommend CRC screening.² Additionally, respondent data from the Center for Disease Control's 1997 Behavioral Risk Factor Surveillance System (BRFSS) showed that home-administered fecal occult blood testing (FOBT) was performed in only 19.8 percent of U.S. adults ages 50 years and older in the preceding one year.³ In this same population, just 30.4 percent received sigmoidoscopy/proctoscopy during the preceding five years.

Recognizing the potential benefits of increasing community CRC awareness and the importance of screening, the Cancer Committee of the Charleston Area Medical Center (CAMC) developed a pilot CRC screening project to serve our

predominantly rural service population base. The pilot project would serve as a base from which to develop a formalized CRC screening program. Impetus for this effort was reinforced by BRFSS data in 1997 for the state of West Virginia, which showed that only 11.9 percent of respondents ages 50 years or older had completed FOBT in the preceding year.³

PHASE I: BACKGROUND AND PLANNING

The Charleston Area Medical Center (CAMC) is a 919-licensed, tertiary care community hospital system with three clinical campuses located in Charleston, W.Va. CAMC is a central component of the non-profit Camcare Health Care System serving the residents of south-central West Virginia. The cancer program has been accredited by the American College of Surgeons since 1957. Today, CAMC's cancer program accesses 1,300 to 1,400 analytical cancer cases per year or approximately 10 percent of West Virginia's new cancer diagnoses. The current CRC screening pilot extends CAMC's core community cancer screening efforts in breast, cervical, prostate, and skin cancer.

In benchmarking at least 10 other cancer programs across the country for their approaches to community CRC screening, the planning team found several sites using educational materials about stool testing in their outreach activities, while some sites had no formal specified educational program for community CRC screening. Although far from a complete program survey, this information

provided further impetus for the planning team to initiate a local strategy to design and implement a pilot CRC education and screening project for our predominantly rural community in south central West Virginia.

Planning for a CRC screening pilot program began in August 1999. Following approval by the Cancer Committee, a planning team was assembled with the goal of developing a CRC screening pilot program for implementation in 2000. The planning team was comprised of the cancer center outreach nurse, cancer committee chairman, a community gastroenterologist, the corporate director for oncology services, and the medical director for oncology services. Ad hoc members of the planning team included the director of marketing and public affairs, a representative from the office of the general counsel, and the vice president for medical services.

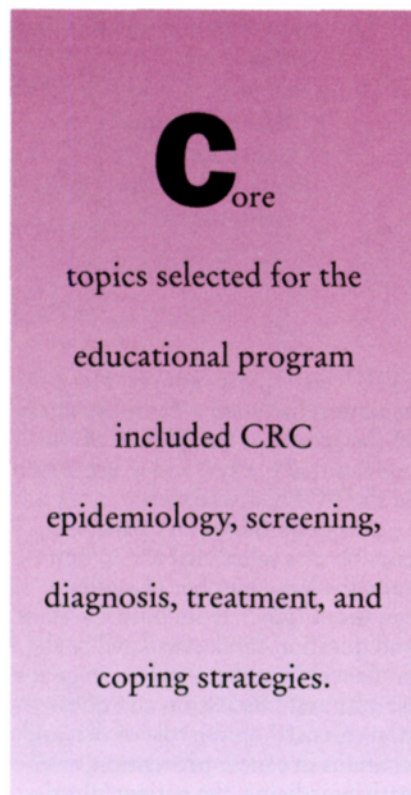
The primary goal of the planning team was to develop an educational strategy and support structure to raise community awareness about CRC screening. Core topics selected for the educational program included CRC epidemiology, screening, diagnosis, treatment, and coping strategies. An additional goal of the project was to examine the feasibility of including Fecal Occult Blood Testing (FOBT) in the screening project.

The planning team developed a list of responsibilities for the cancer center outreach nurse that included:

- coordinating volunteer support among the medical center's "55-Plus" seniors' organization, a health care membership program for anyone age 55 and older sponsored by our health care system
- coordinating screening registration before and during the event
- developing a CRC screening educational packet to include Hemoccult II test kits
- identifying the screening facility site
- preparing grant requests to defray educational costs
- exploring opportunities for pharmaceutical industry support for educational materials
- making arrangements for media coverage via the Office of Public Affairs.

In addition, the planning team compiled a list of responsibilities for the medical and corporate director that included 1) identifying the course faculty, core educational activities, and material support, 2) leadership for the planning team, 3) networking with corporate sponsors for project support when required, and 4) progress reporting to the Cancer Committee.

Early on the planning team confronted the challenge of how to



incorporate FOBT on site.

Numerous questions had to be answered, including the type of FOBT (Hemoccult II vs toilet-based testing "drop in the bowl" technique) most feasible for the conference participants, the mechanism by which screenees would be followed-up post-conference, and the identification of medical/legal ramifications of conducting on-site FOBT for the screenees and how the primary care providers would be notified of FOBT results.

For logistical reasons, the performance of flexible sigmoidoscopy, colonoscopy, and/or barium enema examinations on site were excluded. FOBT on site was excluded due to requirements for pre-course dietary preparations and concerns that the screening program should not assume the

primary oversight for follow-up of patient care or clinical care. The planning team judged this activity as best coordinated by the conference screenee and his or her primary care physician.

After legal consultation, the planning team adopted FOBT screening procedures for the screening participants. These procedures included: 1) distribution of Hemoccult II kits (3 test slides and stool application sticks), 2) instructions for self-FOBT screening with dietary guidelines, and 3) educational materials for CRC awareness. Both written instructions and demonstration in the use of the FOBT kit were to be provided. In addition, a disclaimer information sheet was provided to each screenee that indicated use of the FOBT kit was voluntary, and if self-administered, the participants were instructed to send the slides to their primary care physicians for testing and follow-up. For those participants who had no family physician, a telephone number and contact information for CAMC's Physician Match Program were provided.

PHASE II: IMPLEMENTATION

Our first community CRC screening program was conducted on Saturday, January 22, 2000, and entitled: "Frankly Speaking about Colorectal Cancer." The amphitheater of the Robert C. Byrd Health Sciences Center of West Virginia University - Charleston Division, adjacent to the CAMC clinical campus, was selected for the screening/conference site. Our Office of Public Affairs coordinated the placement of newspaper ads. A full-page article about the screening program and colorectal cancer awareness was published on December 14, 1999, in the "Health Watch" section of the local regional newspaper. The article was facilitated by our Public Affairs Director. One thousand fliers promoting the event were mailed to local churches, civic organizations, and industry. Advertising to the 55-Plus seniors' organization reached 3,000 subscribers. In addition, our outreach nurse conducted health fairs or promotional events in three local churches, the county court house, local malls, and with the 55-Plus seniors' organization. Within CAMC, e-mail distribution

and public fliers for the event were posted. Physician Match, which coordinates new patient requests for identifying an available physician in our health care system, coordinated screening registration activities.

Table 1 outlines the expense categories and costs associated with conducting the CRC screening pilot. A total of \$1,753 in direct costs were incurred and paid for by a grant approved by the Charleston Area Medical Center Foundation, Inc. Industry sponsors and the 55-Plus membership donated supplies at no direct cost to the pilot project. Donated personnel time included six members of 55-Plus who coordinated registration activities on site and five speakers for the conference curriculum. A total of 140 working hours of personnel time was provided by the cancer center outreach nurse and supported from the cancer center's annual budget. Administrative support by the medical and corporate directors for oncology services and legal services were provided by the medical center's budgets for these positions.

All presentations during the one-half day CRC screening curriculum were informal and included time for questions and discussion. Visual aids included slides, overheads, and demonstration in the use of the Hemoccult II kit with developer. Colonoscopic pictures were used to demonstrate the normal colon as well as polyps and carcinomas of the colon and rectum. Pictures of the flexible sigmoidoscope, colonoscope, positive/negative hemoccult test slides, and barium enema radiographs were shown to enhance awareness of these screening tools.

Our commitment to a multidisciplinary approach to CRC was emphasized by having presentations by different members of the oncology team. A general surgeon, gastroenterologist, medical oncologist, clinical psychologist, and outreach nurse presented core topics relevant to CRC screening, as well as the diagnosis and treatment of CRC. Our oncology service-dedicated clinical psychologist addressed coping strategies and mental health support services for the patient undergoing colorectal screening as well as during various phases of the CRC treatment continuum. The cancer center outreach nurse discussed

Table 1. Overview of Expense Categories for the Colorectal Cancer Screening Program

Expense category	Cost
Newspaper ads	\$978
Fliers	38
Poster/program printing	42
Conference video production	130
Refreshments from CAMC Dietary Department	300
Additional educational materials	160
Postage for follow-up	105
Donation of professional time/supplies:	
Speaker fees	0
Hemoccult II kits (n=200)	0
CRC educational kits	0
Facility fee	0
Paper, pencils, note pads	0
Telephone calls	0
TOTAL	\$1,753

FOBT testing procedures. Her presentation included a demonstration of the screening kit, review of the educational packet, and a discussion of the FOBT disclaimer.

Although the faculty panel discussion was scheduled for 30 minutes, the large number of audience questions (taken from both the floor and question cards circulated to the audience) kept the panel on stage for 60 minutes. Discussion and questions focused on the role of diet and vitamins in cancer prevention, alternative medicine, the patient/physician relationship, side effects of chemotherapy, recovery after CRC surgery, and CRC screening of high-risk family pedigrees.

PHASE III: POST-SCREENING FOLLOW-UP

Of 196 individuals registering for the pilot screening event, 101 attended. The attendees ranged in age from 32 to 92 years, with a median age of 70 years. Sixty-one of the participants were female and 40 were male.

The cancer center outreach nurse coordinated post-course critiques and a follow-up telephone survey of those who had completed CRC screening. All course participants indicated a high score for course content and faculty presentation; many requested to have similar cancer education programs in the future. One hundred percent of attendees

One hundred percent of attendees indicated a marked increase in their understanding of CRC and the need for screening.

indicated a marked increase in their understanding of CRC and the need for screening. Despite cold, icy weather on the morning of the screening event, the audience appeared highly motivated.

Table 2 outlines the results of a telephone survey of the 101 CRC screening program attendees updated as of October 1, 2000. In this surveyed population, 77 (76.2 percent) completed at least one modality of CRC screening: 14 performed within the year prior to the pilot screening program event and 63 performed in the eight-month period following our screening education program.

Table 2. Telephone Survey Follow-up of 101 CRC Screening Program Attendees (October 1, 2000, Update)

	No. Screenees
Pre-conference screening	14
Fecal occult blood test within prior one year	3
Negative	3
Colonoscopy within prior one year	10
Negative	10
Flexible sigmoidoscopy within prior one year	1
Negative	1
Post-conference screening	63
Fecal occult blood test	36
Negative	28
Positive	8
Colonoscopy negative	6
Flexible sigmoidoscopy negative	1
Barium enema negative	1
Colonoscopy	24
Negative	17
Benign polyp	3
Cancerous polyp	2
Diverticulosis	2
Flexible sigmoidoscopy	3
Negative	3
Unscreened to date	24
Planned to be screened	10
No active plan to be screened	14

In the post-pilot screening/education event group of 63 individuals, 36 completed FOBT and 24 had a colonoscopy. Of the 36 individuals who completed FOBT, eight were found to be FOBT-positive. Six subsequently underwent colonoscopy, one had repeat FOBT, and one flexible sigmoidoscopy. Of the 24 individuals having a colonoscopy without a prior reported FOBT, three were found to have benign polyps, two had cancerous polyps, and two, diverticulosis.

Twenty-four attendees (23.7 percent) remain unscreened. Results from the telephone survey indicate that 10 individuals plan to complete colorectal cancer screening in the near future: seven attendees have scheduled a colonoscopy to be performed by year's end, and three individuals plan to undergo

FOBT at their next physician visit.

Fourteen individuals (13.9 percent) have made no active plans for colorectal cancer screening.

LESSONS LEARNED

Our rural-based community CRC screening education pilot incorporating self-administered FOBT stool sampling was both feasible and successfully implemented as outlined. Sixty-three percent of survey screening attendees received one or more modalities of CRC screening in the eight-month period following the educational event. An additional 10 percent plan to review FOBT or colonoscopy within the year or their next physician followup. Variation in the selection of the initial CRC screening modality was observed suggesting further opportunities for professional awareness. The full-page article about CRC awareness

and the screening event in the health section of a local newspaper helped to increase the number of registrants. Mailings to local churches, area businesses, and civic organizations were less successful in pulling in registrants. Additionally, educational grants from our CAMC Foundation and industry proved to be fiscally essential to complement the cancer program's screening budget.

Attendees' critique of faculty mix, presentation format, and course content was uniformly positive. Some participants suggested that future screening events include a presentation by an actual CRC survivor and additional content material about chemotherapy, the role of diet in cancer prevention, genetic screening, side effects of treatment, and alternative and complementary medicine.

We distributed Hemoccult II stool kits to attendees only after professional demonstration and dietary education. The demonstration and educational process for self-directed FOBT sampling helped screenees to enhance their understanding of colorectal cancer screening and motivation to seek CRC screening testing in coordination with their physicians. Self-directed FOBT sampling satisfied legal concerns in the screening process and emphasized the central role of the patient-physician relationship in the screening process.

After reviewing the screening pilot, our Cancer Committee noted the opportunity to better serve minority and other rural populations who might prefer to receive screening education in local sites of worship or in a more conveniently located educational site. Our Cancer Committee members are actively reviewing opportunities to partner with community leaders who represent minority population bases in which to incorporate their suggestions for future community screening events.

To complement our ongoing cancer outreach activities, the Cancer Committee is planning to use our pilot project to model a CRC screening curriculum on an annual basis for our community. This educational program has the potential to involve a volunteer professional faculty that can travel to host sites in our service region. Alternatively, the

Follow-Up for Colorectal Cancer Screening Programs

by Ronald D. Deisher, M.P.A.H.

The Cancer Institute of Health Midwest (TCI/HM) has been conducting and coordinating major community colorectal cancer (CRC) screening programs since 1989. From 1991, when complete records were first kept, through 2000, one or more major campaigns have been conducted each year. During this period, more than 77,000 asymptomatic people throughout the Kansas City metropolitan area have been screened by requesting a fecal occult blood test (FOBT) kit, completing all six slides as instructed, and returning the slides in a special foil-lined envelope to TCI/HM. An experienced laboratory technologist in one of our affiliated clinical laboratories then processes the FOBT slides.

These CRC screening activities have resulted in more than 650 follow-up referrals by TCI nurses to participating physicians, and the eventual detection of more than 120 colorectal cancers, the vast majority of which have been early-stage cancers. Educational materials on all aspects of CRC have been distributed to more than 230,000 households. In addition, volunteers have donated more than 33,500 hours of help with assembling and mailing the FOBT kits. Without volunteer support, these programs would not have been feasible finan-

cially or logistically in terms of volumes of kits, mailing, and processing. Additional support includes more than \$38,000 of voluntary cash donations received from participants.

Over the past 10 years of CRC screenings, our experience has shown that a reasonable return of mailed FOBT kits is between 35 to 50 percent. Any program achieving greater than 50 percent returns is considered very good; and greater than 60 percent is considered excellent. We target asymptomatic groups older than 60 years of age because of their increased risk (more than 90 percent of colorectal cancers are diagnosed after age 60) and because of increased returns and compliance. Returns from age groups under 50 have been disappointing.

Of those kits returned for processing, the positive rates typically run between 4 to 7 percent using rehydrated slides. Of those screenings shown to be positive, between 1 to 3 percent eventually are diagnosed with colorectal cancer. However, when all pathology (such as benign polyps, diverticulosis and diverticulitis, and other colorectal and stomach conditions) from follow-up is included, more than 32 percent of positives turn out to have pathology requiring follow-up care.

Our most effective marketing

in terms of requests for FOBT kits has been TV exposure done consistently in brief 10- to 20-second spots over a week to several weeks. Most of our TV promotion has been done through cosponsorship with a local major TV station at no cost in return for the extremely positive community visibility. TCI/HM handles all purchasing and distribution of kits and follow-up services.

Our most effective promotion in terms of reaching potentially higher risk individuals by age has been through targeted direct-mail campaigns. Radio and newspaper advertising have been less effective in generating requests for kits.

We have kept our screening costs down via cosponsorship, use of trained volunteers, and bulk purchasing of generic FOBT kits. Each kit distributed costs us slightly under \$1. Kits that are returned and processed, and that are positive and followed up by oncology nurses, cost slightly more than \$3.20 each.

MULTIPLE BENEFITS OF FOLLOW-UP

Along with their FOBT screening kit and instructions about diet and completion of the test, everyone who is screened receives two educational pamphlets about colorectal cancer, recommended dietary facts and screening guidelines, and

use of our video production from the colorectal cancer screening project may serve to complement activities of our outreach nurse, providing economies of scale.

Additional review of the screening pilot has identified further screening opportunities:

- Continue targeting the medical center's 55-Plus seniors' program to enhance CRC screening awareness among its 3,000-plus membership
- Optimize use of the Public Affairs' Department to increase TV

and radio exposure. Build partnerships with community leaders to increase interest and support for CRC screening.

- Partner with the county American Cancer Society leadership during Colorectal Cancer Awareness Month
- Integrate the "Screen for Life: National Colorectal Cancer Action Campaign," developed by the Centers for Disease Control, into our next screening. This campaign offers screening materials and guid-

ance (www.cdc.gov/cancer/screenforlife).

In summary, our rural-based community CRC screening education pilot, coupled with self-administered FOBT stool sampling reviewed by the screenees' primary care physician, enhanced CRC awareness and compliance with subsequent CRC screening modalities in this cohort of screenees. Two individuals were incidentally found to have malignant polyps

information on the importance of early detection for best treatment outcomes.

Those who are screened and have negative findings are informed of their results by postcard. We also stress the limitations of FOBT screening and the need to be ever vigilant for signs and symptoms. We are always concerned about false negatives and false positives.

Those with positive results are contacted initially by letter informing them of their results, including the number of slides positive, what these results could mean, and the need for follow-up with their primary physician or a gastrointestinal specialist to determine the actual cause of occult blood in their stool. Subsequent contacts with those with positive screening results are at scheduled intervals over several months by letters and phone calls from an oncology nurse. How many contacts often depends on the number of slides positive, with a greater number of positive slides indicating the potential for significant bleeding and pathology, as well as the individual's need for education, support, and motivation to ensure appropriate follow-up.

All those with positive screening results are initially referred to their primary care physician. However, about 21 to 23 percent of individuals being screened say they do not have or will not identify a primary physician. More than 20 gastroenterologists (GI physicians) affiliated with our hospitals have agreed to accept referrals of those individuals with positive screening results. A standard rota-

W
e
have kept our
screening costs down
via cosponsorship,
use of trained
volunteers, and bulk
purchasing of generic
FOBT kits.

tion among these physicians is followed to ensure equity in referrals.

In general, all those screened with positive findings, especially those older than age 50 or with a family history of cancer, who have never had a complete evaluation of the colon, or at least not in the past three to five years, are recom-

mended to have a colonoscopy.

Careful, complete follow-up is one of the keys to successful CRC screening programs. In fact, such follow-up may be the most important aspect of screening. Community screening programs without an earnest, complete attempt at follow-up, with success in educating, supporting, and motivating appropriate referrals, may be as much disservice as benefit to the community.

Comprehensive follow-up services in any community CRC screening program provide multiple benefits to the individuals participating, to the community, and to the organization conducting the screening. Follow-up helps to increase community awareness of CRC as well as screening, dietary, and other guidelines. Furthermore, early detection of colorectal cancers contributes to significant financial savings to the individual, community, and health insurers and organizations.

Comprehensive follow-up is the only way to collect complete information on the results and success of CRC screenings as well as the best method for tracking spin-off referrals and activities and the financial results from these spin-off activities. ☐

Ronald D. Deisher, M.P.A.H., is executive director of The Cancer Institute of Health Midwest in Kansas City, Mo. The Cancer Institute represents and assists in the coordination of 12 hospital cancer programs throughout the 10-county Kansas City metropolitan area.

from their screening procedures. We are continuing our efforts to further enhance CRC awareness and screening mechanisms in our service population. ☐

REFERENCES

¹Greenlee RT, Hill-Harmon M, Murray T, et al. Cancer Statistics, 2001. *CA Cancer J Clin.* 2001;51:15-36.

²Fromer MJ. New emphasis on colorectal cancer screening with launch of last month's national colorectal cancer

awareness month. *Oncol Times.* 2000;22(4):40-41.

³Screening for colorectal cancer—United States, 1997. *MMWR.* February 19, 1999;48(06):116-121.

ACKNOWLEDGMENTS

The authors wish to recognize the Cancer Committee members of the Charleston Area Medical Center, Office of the General Counsel; Sally Llewellyn, administrator, Women & Children's Hospital; the Offices of Public Affairs and

Marketing and Corporate Development/55-Plus organization; CAMC Foundation, Inc.; Beckman Coulter Corporation; Bristol Myers Squibb, and Roche Pharmaceuticals for their insightful contributions to this project. A special thanks to the attendees and their community physicians whose participation permitted the development of a CRC screening program to better serve our community and to Linda Khummark for manuscript preparation.