Background

Between 1999 and 2003, the age-adjusted incidence rate for colorectal cancer (CRC) for males and females in Indiana County, respectively, was higher than the national and state rates (chart 1). However, mortality rates for CRC among males and females in Indiana County was higher than the national, but lower than the state rates. The Healthy People 2010 objective is 13.9 deaths per 100,000 (chart 2). According to 2004 Behavioral Risk Factor Surveillance System data, 31.9% of Pennsylvanians aged 50+ have ever had a sigmoidoscopy or colonoscopy while only 26% of those 50+ have had a blood stool test within the past two years.

Purpose

To improve colorectal cancer survivorship and education in Indiana County.

Objective

To reduce the number of deaths from colorectal cancer in Indiana County by raising public and provider awareness of the value of early detection through screening.

Methods

Forming a subcommittee, coalition members aimed to identify resources and discover barriers and gaps experienced by CRC cancer survivors (including family, friends and caregivers) using the following methods:

- Committee members designed a mailed survey influenced by the Lance Armstrong Survivors Survey to determine screening and post-diagnostic problems and concerns.
- Survivors were self-identified at the county fair and targeted through a process of cross-referring survivors known to the ACS with the oncology center’s tumor registry database.
- Phone interviews were conducted with survivors willing to be called after the survey. An incentive was offered to increase survey responses.
- In addition, the medical director of oncology services program, a surgeon, was interviewed to investigate the medical perspective of CRC cancer survivorship.
- The committee completed an inventory of local CRC cancer resources and services.

Evaluation

Results of the returned questionnaires and follow up phone interviews were cataloged and totaled.

Results

Of the 31 mail survey respondents, 20 were CRC survivors while 11 were caregivers. Of those surveyed, 58% agreed to a telephone interview to further investigate barriers and gaps. Barriers discovered through the survey and interview included:

- 64% never had screening prior to diagnosis;
- 85% were not screened because they didn’t think they were at risk or had no symptoms;
- 58% never discussed screening, risk factors or symptoms with their doctor prior to diagnosis;
- 48% identified physical support and/or treatment side effects as problems or concerns after diagnosis.

Other concerns or problems included the lack of prescription and insurance coverage, social, emotional and spiritual support, follow-up care, diet and nutritional information, transportation and information and resources for care following surgery.

The assets inventory found no dedicated colorectal support groups but uncovered new resources including:

- screening (stool blood testing) available at no charge through the hospital;
- other survivor and caregiver support groups;
- American Cancer Society (ACS) Cancer Survivors Network (on-line);
- possible future collaborative opportunities through legislative/advisory groups like the ACS Cancer Action Network, the Hospital and Healthcare Association of Pennsylvania and Indiana County Chapter of the Pennsylvania Medical Society;
- key-informant provider interview showed a lack of compliance with screening.

Conclusions

- Colorectal cancer survivors and caregivers reported a lack of screening prior to diagnosis due to no symptoms and a belief they were not at risk.
- Many never discussed screening, risk factors or symptoms with their doctor prior to diagnosis.
- After diagnosis, survivors reported a variety of concerns and unmet needs.
- Public and healthcare provider education aimed to increase knowledge of screening guidelines may increase early detection of the disease and improve cancer mortality.
- Collaborative partnerships between local cancer center and community organizations may enable more comprehensive support to CRC survivors including a support group and resource directory.

Acknowledgements

American Cancer Society
Northern Appalachia Cancer Network, A Region of the Appalachian Community Cancer Network
Herbert L. Hanna, MD, Center for Oncology Care
Indiana County Cancer Coalition members and community volunteers
Indiana County State Health Center, Pennsylvania Department of Health
Lance Armstrong Foundation
Penn State Cancer Institute
Penn State Cooperative Extension Service
Pennsylvania Department of Health

Indiana County Facts:

- Located in southwest Pennsylvania, approximately 50 miles east of Pittsburgh.
- Population 88,703 (2005 estimate), 96.8% white
- 69% of the county is rural
- Median household income $32,443 with 14% below the poverty level
- Reported new CRC cases 1999-2003: 154 males, 163 females
- One county acute care hospital
- Indiana Regional Medical Center with an affiliated cancer center, Herbert L. Hanna Center for Oncology Care.

Age-adjusted Incidence Rate for Colorectal Cancer in Indiana County 1999-2003

Source: American Cancer Society and Pennsylvania Department of Health

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Age-adjusted Colonorectal Cancer Death Rates in Indiana County

Source: American Cancer Society and Pennsylvania Department of Health

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Improving Colorectal Cancer Survivorship in Indiana County

James Berger, CRC survivor and community volunteer; Jane Coleman, CRC survivor and community volunteer; Lisa Lotito, American Cancer Society; Connie Michaels, Indiana County State Health Center, Pennsylvania Department of Health; Eugene Miller, Indiana County Cancer Coalition; Colleen Musho, Pennsylvania Department of Health; Charles Shoemaker, Indiana Regional Medical Center’s Herbert L. Hanna, MD, Center for Oncology Care