Patient Education Regarding Cancer Screening Guidelines

Suzanne M. Mahon, RN, DNSc, AOCN®, APNG

Increased consumerism and health awareness have resulted in greater numbers of asymptomatic individuals inquiring about cancer screening. Furthermore, patients newly diagnosed with cancer often inquire about screening recommendations for healthy relatives. Providing such information is an important component of patient education, and oncology nurses can convey it in a variety of formats. This article provides background information that led to the development of the pull-out reference sheet on cancer screening guidelines, “Risk Factors and Screening Guidelines for the 12 Most Commonly Diagnosed Cancers” (see insert at end of article).

Cancer Screening Guidelines

Screening for cancer is a form of secondary prevention. Other secondary prevention measures include defining and identifying groups at risk for cancer and detecting and diagnosing cancer early. Primary prevention involves reducing cancer risk by avoiding or limiting exposure to cancer-causing agents and promoting protective behaviors (e.g., avoiding sun exposure, wearing sunscreen).

Cancer screening should consist of a series of steps, beginning with detailed cancer risk assessment. Assessment findings should be interpreted for individuals at risk. Once risk is understood, the process of selecting appropriate cancer screening tests can begin. The cancer screening reference sheet at the end of this article, “Risk Factors and Screening Guidelines for the 12 Most Commonly Diagnosed Cancers,” was designed to help patients understand risks for cancer and general cancer screening guidelines and is to be used by individuals at average risk for developing cancer.

Many guidelines are available for cancer screening. Healthcare providers are responsible for explaining the rationale for guidelines to individuals at risk for developing cancer. The reference sheet at the end of this article is based largely on American Cancer Society (ACS) guidelines, which are updated annually (Smith, Cokkinides, & Eyre, 2003).

Controversy exists about the choice of screening tests, recommended intervals for testing, and the populations to be screened for cancer. The confusion stems from differences in populations, different thresholds for acceptance of effectiveness of tests, and the underlying missions of recommending agencies (Foltz, 2000).

A variety of agencies issues cancer screening guidelines, including governmental agencies such as the U.S. Preventive Services Task Force and the Canadian Task Force on Periodic Health Examination. Such governmental agencies issue guidelines for many diseases or conditions, including cancer (New U.S. Preventive Services Task Force, 2003). Disease-related organizations such as ACS or the American Lung Association also issue recommendations for screening. Recently, health maintenance organizations (HMOs), utilization management groups, and private insurers have become active in this area. Healthcare providers also may be members of organizations that issue screening guidelines, such as the American College of Obstetricians and Gynecologists or the American Dermatologic Association.

The source and mission of a group issuing a guideline often affect the choice of test, population, and interval for screening. Governmental agencies usually focus on large public health issues. Their guidelines seek to help the largest number of people and carefully consider cost analysis. Disease-related organizations may analyze data differently and focus on eradication of a disease, even at a higher financial cost. HMOs carefully consider the populations they cover and the pooled financial risks associated with guidelines. Thus, when recommendations are made, clear communication and understanding about the choice of guidelines must exist.

Submitted April 2003. Accepted for publication May 12, 2003.

Digital Object Identifier: 10.1188/03.CJON.581-584
Potential Benefits and Limitations of Guidelines

Ideally, health promotion guidelines improve outcomes by reducing the morbidity and mortality associated with a particular disease. Guidelines also should help to improve consistency in care. When an agency publishes a guideline, it usually promotes that guideline to the public. The recent ACS promotion of Polyp Man™ is an example of how a guideline can be promoted publicly (Islam, 2002). These public service messages use a humorous tone to convey the message that both men and women who are 50 or older must take active roles in preventing and detecting colon cancer by discussing risk factors such as polyps and early detection methods, including colonoscopy, with their healthcare providers. By promoting the guideline, ACS is empowering patients to become more involved in their health care and better understand the potential benefits and risks associated with a particular screening test.

Guidelines also help individuals because they ultimately influence public policy (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). Services that may not have been available previously may become more accessible because of increased recognition of their importance. For example, Medicare now covers reimbursement of colonoscopy beginning at age 50, as do many private insurers.

The most important limitation of a particular clinical guideline is that it might be wrong (Woolf et al., 1999). This is not deliberate but occurs because of human error. Perhaps not enough accurate science exists to support a particular recommendation. An issuing body may have a bias, and that bias might be reflected in the guideline, regardless of underlying scientific evidence. Other factors also are considered when applying guidelines, including cost, public safety, societal needs, and special interests, such as those of healthcare providers, risk managers, or politicians. These issues might lead to less-than-optimal screening guidelines.

Guideline Selection and Evaluation

Healthcare providers and patients must not simply accept guidelines because they come from certain organizations. They should consider some basic evaluation criteria and determine what threshold of accuracy is acceptable before adopting a particular guideline. The development of usable, evidence-based guidelines is an extremely difficult and complex task (Zinberg, 1998). Cost may be one of the biggest considerations in guideline development because increased screening translates into increased healthcare costs. The annual healthcare expenditure in the United States exceeds $1 trillion, which is more than 13% of the gross domestic product (Levit, Lazenby, Braden, & National Health Accounts Team, 1998). However, increased costs associated with screening ultimately may result in a reduction in healthcare spending if screening leads to earlier detection of disease.

The agenda of the author, organization, or entity issuing a particular guideline often is the driving force behind the guideline. For third-party payors, the agenda may be cost. For healthcare providers, it may be quality of care; for employers, it may be efficiency. However, these are not always mutually compatible. For example, decreasing cost may decrease quality and increase liability (Zinberg, 1998).

The emergence of evidence-based practice has helped healthcare professionals focus on the scientific process of guideline development. The guidelines published annually by ACS reflect the increased scrutiny. Beginning in 2000, ACS began issuing a yearly report on its guidelines (Smith, Mettlin, Davis, & Eyre, 2000), which includes the protocol for how each guideline was developed. Since the 1980s, guidelines from ACS have considered test efficacy, medical benefit-to-risk ratios, costs of tests compared to expected benefits, and practicality and feasibility of tests. The ACS guidelines also have emphasized that they are intended to help individual healthcare providers and their patients select the best tests to meet their particular needs. In a number of cases recommendations for those at higher risk are made. As Smith et al. (2000) noted, an important distinction exists between a guideline designed to assist patients and healthcare professionals in selecting screening and a recommendation intended for mass public screening. Other considerations for evaluating guidelines are shown in Table 1. Healthcare providers should think about these issues and decide what is most important when selecting guidelines and counseling patients. Guidelines are not perfect. Healthcare providers continually must remind patients that they are, in fact, guidelines, to consider when designing personal programs for health promotion.

Guidelines continually are updated and revised. Although changes may be a source of confusion for healthcare providers, they help to ensure the best possible care for patients. In general, guidelines and the evidence supporting them should be reviewed at least every three years and more frequently if research findings identify significant new developments (Shekelle et al., 2001).

Implementing Guidelines: Patient Education

When using screening guidelines, healthcare providers should emphasize repeatedly that they are recommendations that patients should discuss with their healthcare providers. This is important for several reasons. First, it encourages dialogue between patients and their healthcare providers. Second, it encourages healthcare providers to make or update comprehensive cancer risk assessments. Third, it encourages the process of informed decision making. Any discussions of screening recommendations should include the expected benefits and potential risks associated with accepting or declining particular tests. Too often, more emphasis is placed on undergoing cancer screening than on the option of declining tests. The ACS guidelines regarding prostate cancer screening are an illustrative example. They recommend that a prostate-specific antigen (PSA) test and a digital rectal examination (DRE) are offered beginning at age 50 to men who have life expectancies of at least 10 years. The guidelines further state that information should be provided to men about the benefits and limitations of testing (Smith et al., 2003). Therefore, in terms of prostate cancer screening, healthcare providers play an important role in providing the information that men who are elderly or have limited life expectancies need to make informed decisions about whether to undergo PSA testing and DRE.

Guidelines often offer several options, allowing healthcare providers to tailor screening to best suit the needs of individual patients. This also can be a source of confusion for patients and healthcare providers. The current ACS guidelines for the early detection of colorectal cancer are a good example (Smith et al., 2003). ACS recommends that adults of average risk choose one of five options beginning at age 50: annual fecal occult blood test (FOBT), flexible sigmoidoscopy every five years, annual FOBT plus flexible sigmoidoscopy every five years, double contrast barium enema every five years, or colonoscopy every 10 years. Clearly, healthcare providers need to provide some insight in interpreting these guidelines for their patients. Patients need to comprehend the sensitivity and specificity of FOBT. They need to understand that flexible sigmoidoscopy only examines the lower third of the colon. They should know that colonoscopy requires more extensive preparation and sedation but that if a polyp is found, it can be removed at that time. They need to know that if a polyp is found on barium enema, they...
have to undergo complete preparation for colonoscopy so that the polyp can be removed.

ACS also recommends annual cancer-related checkups that include case-finding examinations for cancers of the thyroid, testicles, ovaries, lymph nodes, oral cavity, and skin. This differs from past guidelines in that cancer-related checkups should be included with periodic health examinations rather than conducted during separate examinations (Smith et al., 2003). This recommendation also helps start dialogue between patients and healthcare providers. It also includes health counseling about issues such as smoking cessation, diet, exercise, and the risks and benefits of screening tests. It provides a directive to offer and instruct patients on self-examination. It also encourages head-to-toe assessment to identify other health issues that merit further evaluation.

**Potential Uses for the Pull-Out Reference Sheet**

The pull-out reference sheet at the end of this article was developed based on the current recommendations for cancer screening from ACS (Smith et al., 2003). It includes a list of controllable and uncontrollable risk factors. By identifying risk factors in this way, healthcare providers have an opportunity to teach patients how they might modify their lifestyles to prevent or reduce their risk of developing cancer. Uncontrollable risk factors are not included to frighten or depress patients; they help patients understand the magnitude of their risk. Patients with uncontrollable risk factors are encouraged to inform their healthcare providers about them.

When educating patients about screening guidelines, healthcare professionals should review special circumstances or other detailed information. For example, the latest guidelines that ACS issued for the early detection of colorectal cancer are presented for those at average risk; more detail is provided for those at higher risk. If an individual is found to have a polyp greater than 1 cm, the recommendation is for colonoscopy within three years of initial colonoscopy. If that examination is normal, another colonoscopy is indicated in three years. If that examination is normal, the individual can be screened according to the recommendation for people at average risk. For a person at moderate risk, colonoscopy is recommended and the interval depends on previous colonoscopy findings. For an individual with a known cancer predisposition mutation, the interval for screening is even more frequent and begins at an earlier age (Smith et al., 2003). Therefore, oncology nurses should focus their efforts on educating individuals with respect to their special circumstances.
Much has been written on ways to remove barriers to screening. Participation in screening activities can be increased when healthcare providers simply suggest cancer screening examinations to patients. They also can encourage patients to undergo screening examinations by having them review cancer screening guidelines in take-home booklets or reference sheets. Healthcare providers can highlight risk factors and circle recommended screening activities in such publications. If a guideline suggests that an individual’s recommendation should be modified because of hereditary predisposition or other risk, such information can be noted directly in handouts and supplemented with other materials if needed. Cancer screening guidelines and similar health promotion materials can be kept in cancer resource areas where patients and families may stop and get additional cancer information. The information also may be posted on the walls in clinic waiting rooms or distributed at health fairs. All health promotion materials should encourage people to call for more specific information or clarification if they do not understand the material or need additional information.

**Summary**

The purpose of a guideline depends on its author. Ideally, guidelines should be flexible enough to be modified as individual circumstances dictate. Before healthcare providers discuss guidelines with patients, providers need to understand the guidelines’ scientific basis and be able to articulate in understandable terms their strengths and limitations. No guidelines should be implemented without careful individual risk assessment. Healthcare providers must remember that guidelines should be used to guide practice; they are not absolute (Goolsby, 2001). Most importantly, guidelines should open dialogue between patients and healthcare providers that is aimed at designing appropriate and reasonable plans for health promotion.

**Author Contact:** Suzanne M. Mahon, RN, DNSc, AOCN®, APNG, can be reached at mahonsm@slu.edu.

**References**


---

**Rapid Recap**

**Patient Education Regarding Cancer Screening Guidelines**

- Screening for cancer is a form of secondary prevention.
- Healthcare providers must complete accurate cancer risk assessments prior to implementing recommendations or guidelines for the early detection of cancer.
- The source and mission of the entity issuing cancer screening guidelines often influence the entity’s choice of test, population to screen, and interval for screening.
- Cancer screening recommendations are evolving continually, and healthcare providers must stay informed of these changes and associated research.
- Healthcare providers should disclose the strengths, limitations, and risks associated with screening recommendations so that patients can make informed decisions about what is best for their individual situations.