CHAPTER

5

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Screening and Detection for Asymptomatic Individuals

INTRODUCTION

Improved survival from cancer has been a result of both improved treatment and the earlier detection of cancer. Oncology nurses are becoming increasingly involved in cancer prevention and detection services. This chapter provides an overview of the fundamental principles involved in the early detection of cancer, also referred to as cancer screening. Principles of cancer risk assessment will be addressed as well.

CONCEPTUAL CONSIDERATIONS IN CANCER SCREENING

Intuitively, it makes sense to screen for and detect cancer in its earliest stages. Theoretically, treatment should be the least complicated and least toxic at this point, and there should be the greatest chance for long-term disease-free survival. Nurses are often confronted with questions about prevention, screening modalities, and the early detection of cancer. They need to be able to instruct patients and families on the principles of screening, the rationale for the different recommendations put forth by national agencies, and controversies in screening.

DEFINITIONS

An understanding of commonly used terms for risk assessment and cancer screening is fundamental. Many of these terms are used by the public interchangeably, but there are subtle differences in the meanings of various terms, and oncology nurses should be able to interpret these terms and educate persons about cancer prevention. Oncology nurses need to be able to explain each term accurately to patients when educating about cancer screening. Once patients understand these terms, they find it easier to make appropriate choices regarding cancer screening. **Table 5-1** lists some commonly used terms and their definitions.

Cancer screening is aimed at asymptomatic persons with the goal of finding disease when it is most easily treated. It

TABLE 5-1

Definitions of Terms Used in Cancer Screening

Primary cancer prevention	Measures to avoid carcinogen exposure, improve health practices, and, in some cases, use chemoprevention agents. Primary prevention may also include the use of prophylactic surgery to prevent or significantly reduce the development of a malignancy in persons with extremely elevated risk (usually due to known hereditary risk).
Secondary cancer prevention	The identification of persons at risk for developing malignancy and the implementation of appropriate screening recommendations. Also referred to as early detection and cancer screening.
Tertiary cancer prevention	Efforts aimed at persons with a history of malignancy, which includes monitoring for and preventing recurrence and screening for second primary cancers. In many cases, these individuals have had a diagnosis of cancer or carry a mutation in a cancer susceptibility gene and are known to be at significantly higher risk for developing a second malignancy.
Cancer screening test	The method used to detect a specific target cancer. It may be a single modality, but often is a combination of tests. Laboratory tests of blood or body fluids, imaging tests, physical examination, and invasive procedures are all sometimes used for screening tests.
Asymptomatic	The person being screened and the examiner are unaware of any signs or symptoms of cancer in the individual prior to initiating the screening test.
Diagnostic tests	Tests used in those persons with symptoms of cancer or abnormal screening tests. The purpose of diagnostic testing is to determine the cause of symptoms or abnormal screening tests.
Target population	The number of persons in a defined group who are capable of developing the disease and would be appropriate candidates for screening. *Population* may refer to the general population, or a specific group of people defined by geographic, physical, or social characteristics. For example, nurses who provide cancer genetics counseling need to determine whether a person is of Ashkenazi Jewish background, as this special population of Jewish people is at higher risk for three specific mutations for hereditary breast cancer.
Mortality	The number of persons who die of a particular cancer during a defined period of time such as one year.
Prevalence	The number of cancers that exist in a defined population at a given point in time.
Outcomes	The health and economic results that occur related to screening. Outcomes may include the benefits, harms, and costs of screening or genetic testing, and its incurred diagnostic evaluations. Outcomes may be short or long term in nature.
Cost-effectiveness	A condition in which the costs of the screening program are less than the costs in the unscreened group.

is important for patients to understand that screening is not prevention; the cancer must be measurable and present to be detected on a screening examination. True cancer prevention is aimed at keeping the cancer from ever developing.

Screening tests seek to decrease both the morbidity and the mortality associated with cancer because, theoretically, at an early stage, cancer is most effectively and easily treated. This is the traditional definition of cancer screening. Some also consider screening for genetic mutations or molecular markers, which put an individual at high risk for developing cancer, to be a form of cancer screening. Such screening is a rapidly emerging and targeted means to better quantify risk and offer primary prevention measures (e.g., prophylactic surgery).[1] Genetic testing is providing the capability to more accurately predict risk for developing specific cancer(s) and then offer individualized appropriate recommendations for cancer prevention and early detection based on more accurate assessment of risk. Information on genetic testing is found in detail in Chapter 6. This chapter focuses on cancer screening in the more traditional sense.

OUTCOMES

Short-term outcomes may include measures of the number of persons who are screened or who undergo genetic testing, the number of persons with abnormal screens who have further diagnostic testing, the number of cancers detected, or the cost per cancer detected and risks associated with screening. Often, healthcare providers are most focused on the short-term benefits of screening, when larger gains in decreasing the morbidity and mortality associated with cancer could ultimately be achieved with a focus on more long-term goals and an emphasis on primary prevention behaviors, especially in relation to tobacco and alcohol usage, obesity, poor dietary habits, and sedentary lifestyle.[2,3] Long-term outcomes may include site-specific cancers detected in the screened population, total costs, and the stage distribution of detected cancers during a specific period following an intervention.[4]

Knowledge of outcome measures is important for nurses who provide risk assessments and cancer screening services. Goals of cancer screening are described in **Table 5-2**.[4–7] Nurses need to be able to give detailed information about the risks and benefits that can arise during the screening process and provide patients with the rationale for screening so they understand the importance of the early detection of cancer.

CANCER RISK ASSESSMENT: THE FIRST STEP IN THE CANCER SCREENING PROCESS

A *risk factor* is a trait or characteristic that is associated with a statistically significant and increased likelihood of developing a disease.[5,8,9] It is important to note, however, that having a risk factor does not mean that a person will inevitably develop a disease, such as malignancy, nor does the absence of a risk factor render one immune to developing a disease or malignancy.

Basic elements of a *cancer risk assessment* may include a review of past and present medical history, a history of exposures to carcinogens in daily living, and a detailed family history. The risk assessment may also include genetic testing information and results in families with a significant history of cancer.

Once all information is gathered, the magnitude of the risk must be interpreted to the patient in understandable terms. Often this is accomplished by using various risk calculations such as absolute risk, relative risk, attributable

TABLE 5-2

Goals of Cancer Risk Assessment and Screening Programs

- Provide accurate information on the genetic, biologic, and environmental factors related to the individual's risk for developing a cancer
- Formulate appropriate recommendations for primary and secondary prevention
- Identify individuals and families who might benefit from more extensive genetic assessment, counseling, and possibly genetic testing to better clarify risk
- Offer emotional and psychosocial support to facilitate adjustment to the information regarding risk and promote adherence to recommendations for prevention and early detection
- Increase the number of individuals who are offered screening
- Increase the number of individuals who complete screening
- Assure 100% follow-up of all abnormal screens
- Increase the number of premalignant lesions detected
- Long-term goals: an earlier stage distribution of detected cancer, decreased mortality, improved quality of life, and decreased healthcare costs

Source: Data from Smith et al[4]; Croswell et al[5]; Craft[6]; Hampel.[7]

risk, or specific risk models for various cancers. Lack of uniformity in how to conduct and interpret a cancer risk assessment has been a major barrier to comprehensive cancer risk assessment outside of specialized cancer risk clinics.[5] Further, it is often difficult for the primary care provider to provide comprehensive cancer genetic counseling and testing.[10–12] These families should be referred to a credentialed genetics provider for more in-depth assessment, counseling, and testing when appropriate.

Collecting enough history to construct a comprehensive cancer risk assessment is challenging. The availability of computers could potentially increase opportunities for persons to gather and store the information necessary for a cancer risk assessment. For example, "My Family Health Portrait" (http://www.hhs.gov/familyhistory) provides a tool for individuals to continually gather and update their family history in an organized fashion. The computer, however, cannot replace the judgment of a healthcare professional and interpretation of the risk assessment. With the emergence of electronic medical records, there is the potential to add platforms that can facilitate risk assessment or flag patients who might have increased risk and would benefit from more comprehensive cancer risk or genetic assessment.

The National Cancer Institute's (NCI) Division of Epidemiology and Genetics also has some risk assessment tools that patients and healthcare providers can complete to obtain general information about cancer risk based on a variety of risk factors. Currently, it offers tools to calculate breast, colorectal, and melanoma cancer risk (http://dceg.cancer.gov/research/how-we-study/risk-modeling/risk-modeling).[13–16] Some healthcare providers use tools such as these as a starting point to initiate a conversation about cancer risk.

FAMILY HISTORY

The family history is a critical piece of cancer risk assessment.[17] The more accurate the family history, the more accurate the assessment of the risk of developing cancer, which in turn guides selection of prevention and screening recommendations. A family history should focus on primary and secondary relatives. This includes an assessment of both paternal and maternal sides, as many autosomal dominant syndromes can be passed through either the father or the mother (**Figure 5-1**). First-degree relatives include parents, siblings, and children. Because first-degree relatives share 50% of their genes, these relatives will be the most likely to inherit similar genetic information. Families with hereditary predisposition to cancer often have multiple cases of cancer at an earlier age than would be expected in the general population. Information about second-degree relatives can also prove helpful.

Second-degree relatives include grandparents, aunts, and uncles. Second-degree relatives have 25% of their genes in common. In particular, older second-degree relatives can provide important information about genetic risk, because they would have been expected to manifest an early-onset cancer if a hereditary trait is present in the family. The pedigree should also include nieces and nephews, because these younger family members can provide information about childhood cancers, which also has implications for the genetic risk assessment.

Third-degree relatives (cousins, great-aunts and great-uncles, and great-grandparents) can be included as well, although the accuracy of reports on these relatives is not always high. These relatives share 12.5% of the same genes.

Once all of this information is documented, it should be stored in a standard pedigree format (Figure 5-1). In families with multiple cases of malignancy, this pedigree can help to teach concepts of genetics, clarify relationships, and provide a quick reference. The availability of software to draw these pedigrees has greatly simplified the process of updating this information. The routine use of electronic medical records in health care also encourages the healthcare provider to collect a family history. Some have the capability to visually represent it in a standardized pedigree as well as to calculate risks mathematically.

Reliability of patient information should be considered both when obtaining and when communicating the risk assessment. Reports suggest that personal recall of a family

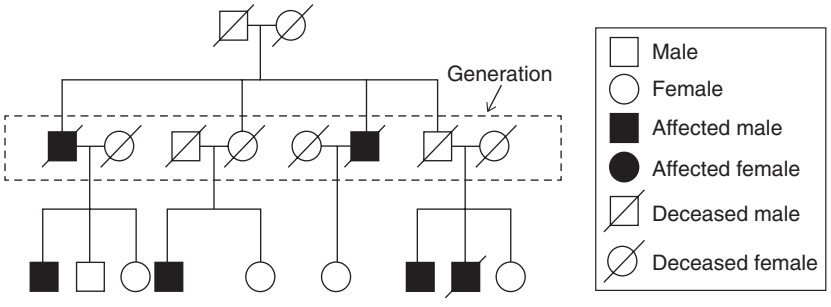


FIGURE 5-1

Common pedigree symbols.

history of malignancy may be inaccurate. Family reports may be inaccurate as much as 26% of the time for first-degree relatives and even more frequently for second- and third-degree relatives.[18] Further, the documentation of family history is variable in primary care settings. Although as many as 97% of all primary care charts may mention family history, the level of detail about this history, such as specific cancer site and age of diagnosis, is insufficient and inadequate in more than 65% of the cases to make an accurate risk assessment or appropriate referral for cancer genetics services.[18] With the ever-increasing number of guidelines for the management of persons at increased risk for cancer because of their genetic background, it is becoming more important for providers to extract a reasonably accurate family history and refer to it accordingly.[19]

Taking a family history in the primary care setting may take 15 to 30 minutes depending on the size of the family and the level of reported detail. Pursuing pathology reports to confirm diagnoses takes additional time, and interpreting that information can take even longer. Tools are being developed for providers to utilize to gather this information more efficiently. Such tools will, however, be effective only if the risk is interpreted to the patient and used to guide screening and prevention recommendations.

The family history provides an organized way to document the risk factors related to heredity, such as whether a relative is alive or dead, age at death if applicable, significant medical diagnoses, or a diagnosis of cancer. Space can be provided to describe in detail the specific type of cancer, age at diagnosis, and other characteristics such as whether a breast cancer was premenopausal or bilateral. Specific knowledge may influence recommendations for screening. Taking a detailed family history is not only useful for cancer risk assessment, but is also the first step in identifying families with a possible hereditary predisposition to malignancy and other illnesses. Healthcare providers should ask patients about specific relatives and their health individually rather than asking a more general question, such as "Have any of your relatives been diagnosed with cancer?" After gathering the family history, it is important to recheck whether any of the patient's relatives have been diagnosed with these cancers. It is amazing how often patients forget to provide this information, and reiterating this question may unearth valuable information. Further, there may be a legal obligation to identify and inform patients and families that they might have a genetic risk for developing cancer and assure that they are referred for comprehensive genetic assessment and counseling with a credentialed genetics professional.[20]

PAST MEDICAL HISTORY/LIFESTYLE FACTORS

Assessment of past medical history and personal history factors that may increase the risk of developing cancer should be documented. Many of these risk factors are not within an individual's control and are not amenable to primary prevention efforts (e.g., age at menarche). In contrast, lifestyle factors complete the risk factor assessment and often can be changed by the individual (e.g., smoking or failing to engage in regular exercise). They provide a framework for providing education about primary prevention efforts, which is discussed in more detail in Chapter 4.

Structuring the interview in more of a traditional medical history format facilitates the information-gathering process. Trying to find risk factors by category or anatomic site can be confusing to the patient, resulting in a disjointed and often redundant interview, and may not be as thorough as a comprehensive health history. Healthcare professionals need to realize that conducting an interview in this fashion demands that the clinician interpret the risk factors to the patient and document recommendations for cancer prevention and early detection somewhere on the chart. For that reason, it may be helpful to include specially designed applications in the electronic medical record that can make documentation of risk factors comprehensive and the information easy to retrieve, update, and interpret to the patient.[21,22]

Past screening activities and findings from such activities contribute to the risk assessment and provide further opportunities to educate the patient about the potential strengths, benefits, and risks associated with screening. Unfortunately, patients' reports of these results may not be accurate. It is important to order pathology reports or actual mammograms for review before determining risk and communicating risk information to the patient. For example, there is a big difference between the risk for development of breast cancer in a woman with a biopsy-proven fibroadenoma and in a woman with biopsy-proven ductal hyperplasia with atypia. Fibrocystic disease or change is a generic term and should not be equated with an increased risk for developing breast cancer. Obtaining accurate information is necessary to develop the most accurate risk assessment possible, correct misconceptions if indicated, and make the best possible recommendations for cancer screening.

Similarly, it is often not enough to rely on an individual to provide accurate information about the last screening examinations. A large meta-analysis demonstrated that self-reported histories are often inaccurate and tend to overestimate cancer screening utilization.[23] Of concern regarding this overestimation is that individual patients will not be referred for cancer screening tests at an appropriate interval. On a national level, such data may not provide an accurate picture of cancer screening utilization and progress toward national goals such as those set by the *Healthy People 2020* program.

After all of the risk data are collected, the clinician must assimilate the risk factors mentally and provide information about them for each of the major cancers to the patient. For example, early menarche, nulliparity, and late menopause are risk factors for both breast and endometrial cancers. The communication of risk, therefore, should include a discussion of the risk for developing both of these cancers.

Risk can be communicated to patients in several different formats. The importance of communicating risk individually to patients should not be underestimated. A Cochrane systematic review of randomized controlled trials found that providing patients with an individualized risk estimate, as opposed to receiving general information about risk, significantly increased the probability that those individuals would participate in a screening program.[24] Often, it is best to use several means, including absolute, relative, and attributable risk.

More recently, there has been great concern that risk assessment opportunities are often missed in primary care where practice is busy and there is limited time for health promotion activities. This may be especially true with uninsured, underinsured, and minority patients, for whom there are multiple barriers associated with health care.[6,8,12,25]

ABSOLUTE RISK

Absolute risk is a measure of the occurrence of cancer, either incidence (new cases) or mortality (deaths), in the general population. It can be expressed either as the number of cases for a specified denominator (e.g., 75 cases per 10,000 people annually) or as a cumulative risk up to a specified age (e.g., 1 in 8 women will develop breast cancer if they live to age 85). Another way to express absolute risk is to discuss average risk of developing breast cancer at a certain age. For example, a woman's risk of developing breast cancer might be 2% at age 50 but 12% at age 85. Risk estimates will be much different for a 50-year-old woman than for an 85-year-old woman, as approximately 50% of all cases of breast cancer occur after the age of 65. Absolute risk factors for the major cancers are shown in **Table 5-3**.[8]

Patients who present for screening need to understand that certain assumptions are made to reach an absolute risk figure. For example, the "1 in 8" figure describes the "average" risk of breast cancer in Caucasian American women and takes into consideration other causes of death over the life span. By necessity, this figure will overestimate breast cancer risk for some women with no risk factors and underestimate the risk for women with several risk factors.[16] These statistics actually mean that the average woman's breast cancer risk is 0.48% to age 39; 3.86% from age 40 to 49; 3.51% from age 50 to 59; 3.21% from age 60 to 69; and 2.24% for age 70 and older.[8] The 13% or "1 in 8" risk is obtained by adding the risk in each age category (0.48 + 3.86 + 3.51 + 3.21 + 2.24 = 13.3%). When a woman who has an average risk reaches age 50 without a diagnosis of breast cancer, she has passed through 4% of her risk, so her risk to age 85 is 13% minus 4%, which equals 9%. When she reaches age 70 without a diagnosis of breast cancer, her risk to age 85 is 13% – (0.48% + 3.86% + 3.51% + 3.21%) = 2.24%. Time must always be considered for the risk figure to be meaningful. For example, the average 50-year-old woman's risk is 6% to age 70 but 9% to age 80.[7]

TABLE 5-3

Lifetime Probability of Developing Invasive Cancers Over Selected Age Intervals by Sex, United States, 2008–2010

Site	Male	Female
All sites	1 in 2	1 in 3
Kidney and renal pelvis	1 in 49	1 in 83
Breast		1 in 8
Colon/rectum	1 in 21	1 in 23
Leukemia	1 in 57	1 in 82
Lung	1 in 14	1 in 17
Melanoma	1 in 33	1 in 52
Prostate	1 in 7	
Ovary		1 in 62
Uterine cervix		1 in 157
Uterine corpus (endometrium)		1 in 36

Source: Data from American Cancer Society.[8]

Absolute risk is helpful when a patient needs to understand the chances for all persons in a population of developing a particular disease. Screening tests often focus on cancers with higher absolute risk because they are more common in certain populations.

RELATIVE RISK

The term *relative risk* refers to a comparison of the incidence or deaths among those with a particular risk factor and those without the risk factor. By using relative risk factors, an individual can determine his or her risk factors and, therefore, better understand his or her personal chance of developing a specific cancer as compared to individuals without such risk factors. If the risk for a person with no known risk factors is 1.0, the nurse can evaluate the risk of individuals with risk factors in relation to this figure. For example, for a woman whose mother had breast cancer in both breasts before age 40, the relative risk would be approximately 8.5 over her lifetime. In other words, she has eight and a half times the chance of developing breast cancer of a woman without a known family history of breast cancer.

Relative risk factors can confuse some patients. If a nurse plans to give an individual information about his or her relative risk, it is important to specify exactly which

comparison is being made. Often percentages are confusing when used with risk. If a news report states that there is a 30% to 50% increase in breast cancer risk in women who take a particular hormone therapy after menopause, it means, in absolute numerical terms, that there will be 0.6 more cases of breast cancer per 100 women from ages 50 to 70. The same concept applies if a person is informed that he or she has a 1% chance of developing cancer. This statement simply means that the risk has increased from 1 in 10,000 to 1.3 in 10,000.[26]

Nurses need to remember that the relative risk statistic is helpful only if it is clear what the baseline risk is. Unless the risk to the baseline group is clearly known, a comparison risk is not useful and can even prove misleading.

Relative risk can be very helpful when selecting screening recommendations. If a person's relative risk is significantly higher than that of most members of the general population, it will probably be necessary to modify the screening recommendation usually given for the general population.

ATTRIBUTABLE RISK

Attributable risk is the amount of disease within the population that could be prevented by alteration of a risk factor. Although historically this component of risk assessment has not received much attention, assessment of attributable risk has important implications for public health policy. A risk factor could convey a very large relative risk, yet be restricted to a few individuals; as a consequence, changing it would benefit only a small group. Conversely, some risk factors that can be altered (such as cigarette smoking) could potentially decrease the morbidity and mortality associated with malignancy in a large number of people.

One clinical example involves the use of attributable risk related to smoking and lung cancers. Attributable risk could be calculated to determine how many lung cancer cases could be prevented if everyone stopped or never started smoking. Another example is the number of cases of breast cancer that might develop in women taking a particular birth control pill. A package insert might report a relative risk for developing breast cancer of 2.35 in women younger than age 35 whose first exposure to the drug was within the previous four years. Because the annual incidence rate (absolute risk) for women aged 30 to 34 is 26.7 cases per 100,000, a relative risk of 2.35 increases the possible risk from 26.7 to 62.75 cases per 100,000 women. The attributable risk of breast cancer is calculated to be 3.38 cases per 10,000 additional women per year. This slight increase in the number of cases may possibly be associated with the use of the contraceptive.

EXPLANATION OF RISK WITH CLINICAL MODELS

More recently, models have become available with which to calculate risk for developing a specific cancer. This is a rapidly growing area of research, especially with the increasing availability of genetic tests. Models are used to calculate not only the risk of developing a particular cancer, but also the risk of having a genetic mutation associated with hereditary risk. Most of the current models have been developed for use in women with a risk for developing breast cancer.[27,28] A list of models, the measurements they provide, and appropriate references can be found in **Table 5-4**.

Note that some of these models are used to calculate risk for developing a disease, whereas others are used to calculate risk of having a cancer susceptibility mutation. It is important to be careful to distinguish to patients whether the model predicts risk of developing a particular cancer or risk of having a mutation. In most cases, there will be a range of risk figures. The clinician must then explain what the range means, emphasizing that it is not an absolute figure for whether an individual has a mutation or will develop a cancer; rather, it is an estimation of risk to guide decisions about genetic testing or screening modalities.

Each model has its own strengths and weaknesses, which must be presented to the patient. A major limitation of most of the breast cancer models is that they rarely account for

TABLE 5-4

Models That Predict Risk of Developing a Particular Cancer or Having a Mutation for Developing a Particular Cancer

Parameter	Model	References
Risk of developing breast cancer	Gail	16, 19, 29
	Claus	30, 31
	Tyrer-Cuzick	18, 28
Risk of a *BRCA1/2* mutation	Couch	32
	Shattuck-Eidens	33
	Berry	34
	Frank	35
	Family History Assessment Tool	36
	PENN2 Model	37
Risk of hereditary colorectal cancer mutation	Bethesda	38
	Wijnen	39
	PREMM	39, 40
Risk of developing melanoma	NCI Melanoma Risk Prediction Model	13
Risk of having a hereditary melanoma mutation	MELPREDICT	41
	GenoMEL	42

mammographic density, which is a significant risk factor as well as a barrier to interpreting mammograms.[9] Some models better calculate risk at a single moment in time and others provide more cumulative risk data.[29] Many clinicians will use two or three models and give the individual a range of figures; this calculation communicates that no model is perfect and may provide a better estimate of risk.[28]

The purpose of using these models is to guide or modify screening recommendations for each individual. Other commonly cited purposes for using risk models is to stratify individuals in clinical trials, estimate the cost of the disease in a population, design prevention trials, and improve decision making about genetic testing or a potential screening or prevention measure (such as prophylactic surgery) following the determination that an individual has a mutation.[28,43,44] For many of the major cancers, no models are available and risk assessment is less accurate.

PRINCIPLES OF CANCER RISK COMMUNICATION

Cancer risk communication has many goals. These goals are not limited to helping people understand the risks they face.[45] Other goals include building trust, influencing public policy, fulfilling legal obligations, denying responsibility for undesirable outcomes, and justifying past actions.

Risks can be communicated to patients in numerous ways. Nurses need to be aware of the strengths and limitations of the various forms of risk communication and provide each patient with a balanced discussion of risks. Most risk discussions will include, at a minimum, a discussion of absolute risks and relative risks; in some cases, discussion of genetic risk assessment models may also be warranted.

There is no perfect model that completely and accurately explains an individual's risk for developing a particular cancer.[24] Indeed, for most cancers, a portion of those cases diagnosed cannot be explained by recognized risk factors. For example, approximately 41% of breast cancer cases are attributable to later age at first birth, nulliparity, and family history of breast cancer.[9,46] Ideally, knowledge of risk factors should guide primary prevention efforts. In the case of breast cancer, however, the inability to readily alter these risk factors has limited their relevance for primary prevention. In some cancers, such as breast cancer, the central role of risk factor identification at this point is to identify women at higher risk, particularly those with a potential genetic susceptibility to breast cancer, and to screen them more aggressively. For example, women from these families may be advised to undergo mammography at a younger age than usually recommended, or to have a clinical breast examination (CBE) twice a year instead of annually.[8,9,47]

Sharing risk information is a central component of all screening and genetic counseling programs—a task that is much more difficult than it might appear at first glance. Risk assessment is a complex discipline that is often not fully understood by healthcare professionals and is even less clear to the lay public.[24] For professionals who practice risk assessment on a daily basis, debate persists regarding the best terminology and techniques.

Of course, decisions and behavior are not determined by knowledge of risk alone.[48] Being well educated about risk and other issues offers no guarantee that good decisions will be made. Other factors may play even more powerful roles in decision making about risk, including emotions, personal values, social pressures, environmental barriers, and economic constraints.

The transmission of information about risk is also often influenced by professional judgment.[26] Many professional groups have standards of practice or position statements that influence how risks are communicated to patients. For example, guidelines for management of average risk and hereditary risk are provided and promoted by the American Cancer Society (ACS), National Comprehensive Cancer Network (NCCN), United States Preventive Service Task Force (USPSTF), American Society of Clinical Oncology (ASCO), Centers for Disease Control and Prevention (CDC), and a wide range of subspecialty organizations. Current guidelines can be accessed at http://www.guidelines.gov. The background for each recommendation is provided, and guidelines can be compared, at this clearinghouse.

In addition, professional opinions about emotionally charged issues such as genetic testing probably influence how risk information is communicated. These biases are probably apparent no matter how nonjudgmental a professional tries to be during a risk communication session.

Risk factor assessment is an ongoing part of oncology nursing practice. Risk factor profiles should be reviewed at least annually. Patients should be questioned about any change in their family history since the last assessment, development of any new health problems that may be associated with increased risk (e.g., abnormal Pap test, a change in breast examination), and initiation of any new medications that may change the risk profile (e.g., started estrogen replacement therapy or tamoxifen therapy). If significant changes have occurred, screening recommendations may need to be modified. If no significant changes have occurred, an annual review of the risk factor assessment offers an excellent opportunity to reinforce information on cancer prevention and early detection. It also communicates an ongoing concern for the patient as a dynamic individual and identifies the nurse as a resource for further information, should a problem develop in the future.

ORAL COMMUNICATION OF RISK

Communication of cancer risk can be challenging because it includes both qualitative and quantitative components.[24] The quantitative component is usually relatively straightforward: It typically involves sharing risk figures such

as absolute or relative risk, or the probability of having a mutation in a cancer susceptibility gene. Numerical data can be presented with the understanding that some individuals have a greater capacity than others to comprehend the meaning of such data. Qualitative information should follow the presentation of quantitative data; it includes a discussion of what the quantitative data specifically mean for the individual patient. Many experts in risk communication believe that all discussions of risk should include both qualitative and quantitative components.[24,43]

People often hold an inaccurate assessment of their personal risk for developing cancer.[49] In other words, patients may perceive their risk to be lower or higher than it actually is. These biases may occur because persons have inaccurate information; are unable to comprehend complex, technical information; or have developed a psychologically protective coping mechanism.

An awareness of the individual's anxiety is important, because it can limit an individual's ability to actually understand his or her risk for developing cancer. The thought of cancer can be so anxiety provoking in some individuals that they fail to understand their actual risk for cancer.

Communication of risk information should reflect how much the patient or family wishes to know.[50] Timing may be important as well. Messages suggesting increased susceptibility to breast cancer may be less effective if delivered too soon after the breast cancer diagnosis of a close relative, for example, but they might be appropriate several months after the diagnosis.[49]

Communication of a cancer risk assessment should be viewed as an information-sharing interview. **Table 5-5** summarizes the steps involved. The manner in which the information is communicated (sometimes referred to as "framing") is also important.[45] If material is presented in a negative fashion, patients may assume that the risk is greater than it actually is. If the discussion is too positive, the magnitude of risk may be underestimated or minimized. Framing occurs with statistics, too. If an individual is told that he or she has a risk of a particular cancer of 1.4 in 10,000 compared to the general population's risk of 1 in 10,000, that difference will not be particularly impressive to most people. If the same risk is communicated using the format that the individual has a 40% greater risk than the general population, the situation is likely to be seen as "riskier" even though the two situations are equivalent.[25] Clearly, this is the most challenging aspect of cancer risk assessment communication. The goal is not to frighten a patient unnecessarily; conversely, if the risk is minimized too much, the patient may not see the value in recommended cancer prevention and screening activities.[24,25,45]

Recently there has been an emphasis on shared decision making about participation in cancer screening practices following an honest risk appraisal. The ACS clearly recommends that all men be informed about the potential risks and benefits of prostate screening and that women be offered information about the strengths and limitations of breast self-examination.[8] To ensure that patients' perspectives and concerns are elicited and considered, patient decision-making approaches should be implemented.[49,51] Decision aids may be an effective tool to help patients understand their risk of developing a particular cancer, the screening options available (including the alternative of not screening), and recommended screening time intervals, and to help them better identify their own values and preferences for a particular option and outcome.[52] Such aids are not meant to replace the discussion between the patient and the clinician, but rather to complement it.

TABLE 5-5

Steps in Cancer Risk Communication

1. Communication of the risk information should begin by reminding the patient of the strengths and limitations as well as the purpose of a cancer risk assessment. The patient should clearly understand that the assessment will be only as accurate as the information that the patient provides.
2. Provide information on the risk factors for the cancer(s) for which the person desires screening.
3. Provide basic information on the cancer for which the person is at risk (e.g., number of people affected annually, average age at diagnosis, clinical presentation). Information about the general population can serve as a baseline against which individuals can measure the magnitude of their increased risk.
4. Review basic anatomy and physiology using diagrams and models, as appropriate, to provide necessary background information.
5. Depending on the magnitude of the risk and the ability and desire of the patient to understand the content, expand the discussion to include a more detailed discussion of absolute or relative risk. Care should be given to distinguish between absolute and relative risk and reinforce the fact that risk factors do not combine in a simple mathematical fashion.
6. Provide information about lifestyle factors amenable to changes.
7. Provide information about the strengths and limitations of screening tools.
8. Provide an adequate opportunity for the patient to ask questions and express concerns; this step is essential to make the cancer risk assessment process effective and the interview truly information-sharing.

Ideally, healthcare providers will become more proficient and comfortable in promoting a discussion that includes options as well as risks and benefits of a particular test in light of the individual's risk, so that patients are aware that choices can be made and they have enough information to make an informed choice. Conveying a better understanding of the individual's risk for developing a particular cancer is part of this informed consent process. For example, ensuring true informed consent can directly—and sometimes negatively—affect the patient's interest and desire to undergo cancer screening. Conversely, giving more information about the benefits of a screening test when accompanied by information about personal risk may increase interest in participating in a specific screening.

Thus, the importance of communicating the risk individually should not be underestimated. A meta-analysis found that individualized risk communication generally leads to increased use of screening modalities.[52] Individualized counseling makes the risk more realistic to the individual.

TECHNOLOGICAL COMMUNICATION OF RISK

Today, technology is affecting the means of communication of cancer risk. The use of computers in educating people about cancer risk and the management of cancer risk is relatively new, but more such programs are rapidly becoming available for both the public and health professionals to utilize. Little is known about the effectiveness of these programs. An advantage of using some of the newer technologies and multimedia options is that by accessing the medium, patients have active—rather than passive—involvement.[53] A multimedia approach also offers the advantage of being able to deliver a consistent message to a large number of persons at a relatively low cost. Disadvantages include the difficulty of ensuring that the individual understands the meaning and implications of the risk assessment.

VISUAL AIDS IN RISK COMMUNICATION

Graphics can be a very effective means to communicate risk, and they can be especially effective in communicating numerical risk.[21,54] Graphics can often reveal data patterns that might otherwise go undetected. They also hold people's attention for longer periods of time, which might increase the understanding of data. To be truly useful, these visual aids must communicate the magnitude of risk, relative risk, cumulative risk, uncertainty, and interactions among risk factors. Despite the popularity of using graphics, little research has focused on their impact in communicating risk data. In many cases, a combination of formats is used to present risk information, including numerical, visual, and explanatory presentations.[24]

Several considerations do enhance the usefulness of graphs. The graph should decrease the number of mathematical computations that the user must make. In some cases, it may be best to avoid communicating small-probability events with graphs.[54] Although most persons can understand a flip of the coin (0.5 chance), it is often very difficult for persons to understand the magnitude of a small-probability event such as a 0.0003 chance. A solution to this problem is to change the probabilities to frequencies (3 out of 10,000).

A risk ladder is often used to describe environmental hazards. It displays a range of risk magnitudes by showing increasing risks as being higher on the ladder. Perceptions of risk are, therefore, influenced by the location on the ladder. This type of graphic helps people to anchor risk to upper and lower reference points.

Pie charts are commonly and effectively used to communicate information about proportions. Most individuals are able to understand a pie chart. These graphics can sometimes be combined to explain subcategories of data.

Histograms are also commonly used. Most individuals have some understanding of how to read a simple histogram. These illustrations will often convey the magnitude of the risk more clearly than just using numbers.[54,55]

PSYCHOLOGICAL CONCERNS

Risk assessment and giving patients information about risk factors do not directly affect the risk of developing cancer. Nevertheless, such information about risk may influence patients' choices regarding screening and may change the way in which some people think about their lives. A risk factor assessment can potentially improve patients' health care and ultimately their quality of life if it results in engagement with primary prevention practices and regular screenings and possibly the prevention or early detection of a malignancy. Conversely, if a person becomes distressed or upset by the information conveyed in a risk assessment, recommendations for screening may be ignored or the person may experience psychological harm and possibly increased morbidity if a malignancy is not detected early.

The psychosocial effects of risk factor communication have not received much attention in the literature.[55,56] Some degree of concern or anxiety about cancer might heighten an individual's vigilance and motivation to seek reassurance through repetitive screenings. Conversely, such notification may result in anxiety and cancer worries with a reduction in recommended screening. Of concern would be the potential for inappropriate decisions about the use of prophylactic surgery in persons who overestimate their risk for developing breast cancer or endometrial cancer.

Clearly, the overall impact of risk assessment on quality of life is poorly understood. Similarly, it is not clear why two women with similar risk factors for developing breast cancer who receive risk factor information in a similar format can respond so differently to the information.

DOCUMENTATION OF RISK ASSESSMENT

Documentation of a risk assessment is important and may enhance the risk communication process. The first time a patient is seen for risk assessment and screening services, information should be gathered about family history, pertinent medical background, and lifestyle factors. This information is necessary for the initial risk assessment as well as for any subsequent reevaluation and update of the assessment. The choice of the format for documentation and risk factors to be included ultimately affect the risk assessment. For example, in a mammography center, a woman may be queried regarding risk factors for breast cancer. Some of the same risk factors may place the woman at higher risk for endometrial, ovarian, or colorectal cancer.

Few published reports describe documentation of a risk factor assessment.[7] A checklist form containing the major risk factors for the various cancers can be completed after an interview, with space being provided to encourage documentation specific to the risk factor, such as number of years of estrogen replacement therapy or number of years and packs of cigarettes a patient has smoked. Other items that should be documented are a pedigree and any numerical risk assessments that have been calculated. Components of patient education should be documented as well.[21]

MEASURES OF THE ACCURACY OF SCREENING TESTS

In addition to conveying information about cancer risk, nurses must communicate to patients the accuracy of screening tests. It is not enough to simply recommend a screening test—patients need to understand what the possibilities are regarding a truly positive or a truly negative test result.

ACCURACY

The *accuracy* of screening tests is described using a number of terms.

1. A *true-positive test* (TP) is a normal test for cancer in an individual who actually has cancer. In **Table 5-6**, the number of true-positive tests is 75.
2. A *true-negative test* (TN) is a normal or negative screen for cancer in an individual who is subsequently found not to have cancer within a defined period after the last test. In Table 5-6, the number of true-negative tests is 775.
3. A *false-negative test* (FN) is a normal test for cancer in an individual who actually has cancer. In Table 5-6, the number of false-negative tests is 25.
4. A *false-positive test* (FP) is an abnormal test for cancer screening in an individual who actually does not have cancer. In Table 5-6, the number of false-positive tests is 225.

An understanding of true and false test results is necessary to calculate information about sensitivity and specificity

TABLE 5-6

Accuracy of Cancer Screening Tests

Results of Screening Test	Population Who Actually Have the Disease	Population Who Actually Do Not Have the Disease
Positive test	75	225
Negative test	25	775
Total	100	1000
True positives = 75		
True negatives = 775		
False positives = 225		
False negatives = 25		
Sensitivity = 75/(75 + 25) = 0.75		
Specificity = 775/(775 + 225) = 0.78		
Positive predictive value = 75/(75 + 225) = 0.25		
Negative predictive value = 775/(775 + 25) = 0.97		

(Table 5-6). Other information about the accuracy of screening tests can be found in **Table 5-7**.[3]

SENSITIVITY

The *sensitivity* of a screening test is its ability to detect those individuals with cancer. It is calculated by taking the number of TPs and dividing it by the total number of cancer cases (TP + FN). For the data in Table 5-6, sensitivity would be calculated as 75/(75 + 25) = 0.75. Most people are unwilling to accept a test with a high false-negative rate because many cancers will be missed.

SPECIFICITY

The *specificity* of a test is its ability to identify those individuals who actually do not have cancer. It is calculated by dividing the TN by the sum of the TN and FP cases. For the data in Table 5-6, specificity is calculated as 775/(775 + 225) = 0.78. A high false-positive test rate can result in unnecessary follow-up testing and anxiety in persons who have a positive screen.

POSITIVE PREDICTIVE VALUE

The *positive predictive value* is a measure of the validity of a positive test; it is the proportion of positive tests that are TP cases. The predictive value of a test depends on the disease prevalence. As the prevalence of a cancer increases in the population, the positive predictive value of the screening tests increases, even though its sensitivity and specificity remain unchanged.[8]

NEGATIVE PREDICTIVE VALUE

The *negative predictive value* is a measure of the validity of a negative test. It refers to the proportion of negative tests that are TNs.

IMPROVING THE ACCURACY OF SCREENING

Healthcare providers can take several steps to improve the accuracy of screening tests.[8] Attaining certification and following federal guidelines in the area of radiology and laboratory services, for example, are key means to ensure better screening. Guidelines are now in place for mammography centers and laboratories providing cancer screening services to ensure that a minimum acceptable standard is met. Certification from relevant agencies should be publicly displayed.

The person conducting the exam or interpreting the laboratory or radiological test results profoundly affects the effectiveness of a cancer screening test. For example, some healthcare professionals are clearly better at performing CBEs than others and are more likely to detect a subtle breast change. Monitoring the quality of clinical examinations is

TABLE 5-7

Principles in Developing Cancer Screening Tests

- **The disease should be an important health problem.** There is little doubt that cancer is a significant health problem, but cancer is not just one disease. Some types of cancer are more significant health problems than other types. For example, the incidence of breast cancer is an estimated 232,670 new cases annually and that of lung cancer is an estimated 224,210 new cases; thus both of these cancers are very significant.[8] The mortality associated with these cancers is also high, with an estimated 40,000 deaths annually from breast cancer and an estimated 159,260 deaths annually from lung cancer.[8] Clearly, both of these cancers are significant health problems.
- **The disease should have a preclinical stage before symptoms become obvious.** In breast cancer, mammography is able to detect breast cancers before the cancer is palpable. Although lung cancer has a high incidence, at present there is not an obvious preclinical stage.
- **The test should be treatable.** There should be a recognized treatment for lesions identified following screening. Breast cancer is a disease that responds to surgery, chemotherapy, and radiation therapy, especially when the disease is detected early. Even more important, when breast cancer is detected early, it can often be treated with less radical surgery, such as lumpectomy. The same is not as true of cancers such as ovarian or lung cancer.
- **The test must be clinically relevant.** The test must be able to detect a condition for which intervention at a preclinical stage can improve the outcome. The test must be accurate. The sensitivity and specificity must be acceptable.
- **The test must be acceptable to individuals being screened.** Highly invasive, painful, or risky procedures are generally unacceptable.
- **The test must be widely available and easily accessible.** Technology has made mammography readily available. Colonoscopy is becoming increasingly available. Medicare and insurance coverage of these screening tests makes them more financially accessible to a larger group of people.
- **The test must be cost-effective.** Measuring cost-effectiveness can be difficult. Different groups have different thresholds for what they consider to be cost-effective.

important. Monitoring and improving the quality of physical examinations in the clinical setting is far more challenging, but is nevertheless important to improve the sensitivity and specificity of the examination.[50] More recently, attention has been directed toward improving the quality of colorectal examinations, especially those involving colonoscopy.[57]

Screening quality may also be improved by developing standardized instructions for patient preparation. This may not only improve patient compliance, but also help obtain the best possible screen. An example might be scheduling a breast screening a week after the menses begin, avoiding the use of deodorant prior to mammography, or instructing a patient to avoid douching for 24 hours prior to a Pap smear. The quality of the bowel preparation directly impacts the accuracy of any endoscopic evaluation of the colon.

Providers need to be continually updated on the newest guidelines and techniques for cancer screening; such training should include a staff competency evaluation. Moreover, new equipment is constantly being developed to enhance screening and diagnostic procedures. Agencies that provide screening services need to not just review such equipment, but also develop policies on how they will test and possibly adapt such equipment to their specific needs. Most recently, the introduction of breast magnetic resonance imaging (MRI) for the detection of breast cancer has raised questions about the type of equipment used in breast MRI, the ability to provide biopsies, and the skill of the radiologist interpreting the examination.

IMPLEMENTING CANCER SCREENING

A screening protocol or recommendation defines how cancer screening tests should be used. **Table 5-8** provides the ACS recommendations for the early detection of cancer in asymptomatic individuals[8]; it is an example of a screening protocol. Such recommendations can vary among organizations and practitioners. A recommendation generally describes the target population to be served, the screening to be applied, and the intervals at which the test should be performed.

TABLE 5-8

American Cancer Society Recommendations for the Early Detection of Cancer

Breast Cancer

1. Yearly mammograms are recommended starting at age 40 and continuing for as long as a woman is in good health.
2. Clinical breast exam (CBE) should be part of a periodic health exam, about every 3 years for women in their 20s and 30s and every year for women 40 and older.
3. It is acceptable for women to do breast self-exam (BSE) on a monthly basis, regularly, or irregularly. In her early 20s, a woman should be informed about the benefits, limitations, and risks associated with BSE. All women should be instructed on signs and symptoms that warrant immediate evaluation. If a woman chooses to practice BSE, she should receive instruction and have her technique checked during a routine health examination.
4. Women at high risk (greater than 20% lifetime risk) should get magnetic resonance imaging (MRI) and a mammogram every year. Women at moderately increased risk (15% to 20% lifetime risk) should talk with their doctors about the benefits and limitations of adding MRI screening to their yearly mammogram. Yearly MRI screening is not recommended for women whose lifetime risk of breast cancer is less than 15%.

Colorectal Cancer

1. Beginning at age 50, both men and women at average risk for developing colorectal cancer should use one of the following screening tests. The tests that are designed to find both early cancer and polyps are preferred. Any abnormality must be further evaluated with colonoscopy. Individuals with risk factors will need more frequent screening.

Tests That Find Polyps and Cancer

Flexible sigmoidoscopy every 5 years

Colonoscopy every 10 years

Double contrast barium enema every 5 years

Computed tomography (CT) colonography (virtual colonoscopy) every 5 years

Tests That Mainly Find Cancer

Fecal occult blood test (FOBT) every year

Fecal immunochemical test (FIT) every year

Stool DNA test (sDNA), interval uncertain

(continues)

TABLE 5-8

American Cancer Society Recommendations for the Early Detection of Cancer (*continued*)

Cervical Cancer

1. All women should begin cervical cancer screening at age 21.
2. For women ages 21–29, screening should be done every 3 years with conventional liquid-based Pap tests.
3. For women ages 30–65, screening should be done every 5 years with both the human papillomavirus (HPV) test and the Pap test (preferred), or every 3 years with the Pap smear alone (acceptable).
4. Women ages 65 and older who have had three or more consecutive negative Pap tests or two or more consecutive negative HPV and Pap tests within the past 10 years, with the most recent test occurring within 5 years, and women who have had a total hysterectomy should stop cervical cancer screening.

Endometrial Cancer

1. At menopause, all women should be informed about the risks and symptoms of endometrial cancer, and strongly encouraged to report any unexpected bleeding or spotting to their doctors.
2. For women with or at high risk for hereditary non-polyposis colon cancer (HNPCC), annual screening should be offered for endometrial cancer with endometrial biopsy beginning at age 35.

Prostate Cancer

1. Both the prostate-specific antigen (PSA) blood test and digital rectal examination (DRE) should be offered annually, beginning at age 50, to men who have at least a 10-year life expectancy.
2. Men at high risk (African American men and men with a strong family of one or more first-degree relatives diagnosed before age 65) should begin testing at age 45.
3. Information should be provided to all men about what is known and what is uncertain about the benefits, limitations, and harms of early detection and treatment of prostate cancer so that they can make an informed decision about testing.

Lung

1. Current or former smokers ages 55–74 in good health who have 30 pack years or more smoking history, who currently smoke, or who have quit smoking in the last 15 years should be counseled about low-dose helical CT (LDCT). A process of informed and shared decision making with a clinician related to the potential benefits, limitations, and harms associated with screening for lung cancer with LDCT should occur before any decision is made to initiate lung cancer screening.
2. Smoking cessation counseling should continue as a high priority for clinical attention in discussions with current smokers, who should be informed of their continuing risk of lung cancer. Screening should not be viewed as an alternative to smoking cessation.

Risk Education and General Screening

For people aged 20 or older having periodic health exams, a cancer-related checkup should include health counseling and, depending on a person's age and gender, might include exams for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries, as well as for some nonmalignant (noncancerous) diseases.

Source: Data from American Cancer Society.[8]

DEVELOPMENT OF SCREENING GUIDELINES

Screening guidelines change over time. The ACS, for example, has been publishing guidelines for the early detection of cancer for more than 20 years.[8] Some of its guidelines have been revised, added, and eliminated during this time frame. Such changes are a source of confusion for both patients and healthcare providers. For example, in the past, the ACS has recommended screening for lung cancer using sputum cytology, but currently it does recommend LDCT in individuals with a long history of smoking. In addition, efforts are being focused on prevention of smoking and smoking cessation.[8] Although specific guidelines may have changed over the years, the focus of the guidelines has remained largely constant: Healthcare providers are expected to use the guidelines to select the best screening tests for an individual and to modify the guidelines in certain cases, such as if an individual has a particularly high risk for developing a specific malignancy.

Clinicians must remember that screening protocols are merely guidelines—not practice standards to be used blindly with every individual.[4] Many guidelines require risk assessment

to apply them correctly. This is certainly the case with colorectal cancer screening. The recommendations for screening vary depending on the risk of the individual.[58–60] The focus of the organizations creating the guidelines also varies. For example, the goal of the ACS standards is the detection of malignancy based on effectiveness. The U.S. Preventive Services Task Force uses very strict criteria for assessing evidence of effectiveness; cost-effectiveness of the screening recommendations is an important consideration for this group, for example. When providing information on cancer screening recommendations, nurses need to inform the individual why a certain recommendation is being made in his or her case.

Nurses will often make recommendations for various screening or detection measures, especially for persons who have a higher risk for developing a particular cancer, based on their family history and genetic background. Nurses need to be able to accurately explain the risks and benefits of these screening tools to their patients. Doing so requires an understanding of the measures of validity of a screening test. Specific recommendations for a screening test often vary among organizations such as the ACS, the USPSTF, ASCO, or NCI. The specific criteria that each organization uses to make recommendations may vary, which is why the recommendations are not universal and can prove very confusing to the general public. In many cases, tests are combined to compensate for the limitations of any one test.[47] Sometimes patients must also make a choice as to what they are trying to detect. In terms of colorectal cancer screening, there are recommendations for tests that mainly detect polyps and potentially prevent cancer (such as colonoscopy) and recommendations for tests that may detect colorectal cancer (such as fecal occult blood testing).[58]

There are, however, generally agreed-upon requirements and characteristics of acceptable screening tests. When presenting screening recommendations to individuals, it is important to include the rationale and the strengths and limitations of each test and to present this information in light of the individual's own risk for developing cancer. The following issues are frequently considered before organizations make recommendations for screening for the general public. Individuals with a genetic susceptibility, however, often need recommendations that are more rigorous than those for persons with an average risk.

First, nurses need to review the scientific basis for each guideline. Each agency that promulgates a guideline should make this information available. An excellent place to obtain information about the scientific basis and the review process for a guideline is from the individual agency that generates the guideline or at the National Guideline Clearinghouse (http://www.guideline.gov). For some guidelines, the data may support implementation only to a certain age or health parameter; such is the case with mammography, for example. The ACS guidelines do not give an age at which to stop mammography, but rather encourage the clinician to consider the overall health of the woman when recommending the screening.[8,9]

Second, nurses play a key role in interpreting these data to patients. Nurses need to explain why a particular set of guidelines is being used for an individual patient. They need to remind each patient that these recommendations are guidelines and that some modifications may be made based on personal risk factor assessment and findings on a clinical examination. With some persons in failing health, it is appropriate to discuss stopping cancer screening, although few of the guidelines provide specific direction in this area. Clearly, the benefits, risks, and potential limitations of each screening test need to be discussed individually and tailored to the risk factor assessment.

Many individuals will choose to undergo a screening examination, even if a test has a lower sensitivity and specificity, in hopes that it will prove effective for them. Screening for ovarian cancer is an excellent example. Highly specific and sensitive screening tests are currently unavailable for the early detection of ovarian cancer. Many women, however, still want an annual pelvic examination to assess for ovarian masses. This test is relatively inexpensive to perform and is usually tolerated fairly well by women. Some clinicians are better at detecting ovarian masses than others. Nevertheless, many ovarian cancers cannot be detected using this examination, even when it is performed by skilled clinicians. As long as a woman realizes that the test may fail to detect ovarian cancer and is willing to accept this limitation, utilizing the pelvic examination may be effective. Often women at higher risk for ovarian cancer will choose to have CA-125 antigen testing and a transvaginal ultrasound in hopes of finding early ovarian cancer. Neither of these tests has been proved effective in reducing the morbidity and mortality associated with ovarian cancer, yet women at higher risk continue to undergo these screening tests.

INFORMED CONSENT

After the risk assessment is complete and its information is interpreted and shared with the patient, a consent form should be signed for the screening procedures that the patient intends to undergo. The consent form states who will provide the screening procedure, notes that not all cancers may be detected during a screening examination, and, if the patient declines recommended screening, specifies a waiver of which recommended procedures are being declined. This consent also helps to reinforce the recommendations for screening. **Table 5-9** highlights the basic elements of an individual cancer screening session.

Clearly, cancer risk communication influences decisions to undergo cancer screening examinations.[24,25] When a healthcare provider recommends a particular screening examination, there is an increased likelihood that the

TABLE 5-9

Steps in a Basic Individual Cancer Screening Session

- Complete a comprehensive health history and risk assessment. Refer for genetic testing if appropriate.
- Communicate the risk assessment to the patient.
- Complete a physical examination of all or selected at-risk sites. This may include the skin, head and neck area, breasts, abdomen, prostrate, rectum, and gynecologic organs, and a survey of lymph nodes.
- Provide patient education that includes information about anatomy, physiology, risks, strengths and benefits of available screening tests, primary prevention strategies, sources for genetic counseling and testing when appropriate, early signs and symptoms of cancer, and self-examination techniques.
- Schedule and obtain appropriate laboratory and radiologic studies, including Pap test cytology and mammography. Schedule and obtain other screening tests, such as colonoscopy or endometrial biopsy.
- Ensure that the patient receives follow-up. All patients should receive the results of screening, whether they are positive or negative. Patients with abnormalities should receive information about why follow-up is necessary. Those with normal screens should receive a reminder for follow-up screening in one year.

individual will actually go on to have the recommended screening. Health providers can make good recommendations for screening based on the myriad of guidelines available only if they understand the biases of various guidelines and have completed an accurate assessment of risk.[51] In addition, decisions to undergo screening are influenced by how much benefit is perceived to result from undergoing the screening procedure. Such a decision must be balanced with a discussion of the risks associated with screening. Providing individuals with information about the sensitivity and specificity of a screening procedure is, indeed, challenging.

Healthcare professionals must also clarify issues when there are choices about screening. For example, one of the most challenging screening recommendations deals with colorectal cancer screening. The ACS now distinguishes between tests that are likely to prevent cancer (through the removal of polyps) and tests that are likely to detect cancer. Patients must be informed of all the options. The test that prevents cancer is colonoscopy, but some people are unwilling to go through the test and its preparation process. As long as patients are willing to accept the fact that a screening test to detect colorectal cancer—such as a fecal occult blood test—may not detect cancer early, they can make a decision that is congruent with their needs. Healthcare providers have a big role in providing enough information about the risks, benefits, and limitations of recommended screening tests.

FOLLOW-UP

If the intended benefits of screening are to be realized, individuals need to have a clear understanding of the implications of tests both before they are screened and after they receive the results. The potential benefits of screening are lost if individuals are never informed of the test results or the meaning of those results. Providing patients with information about screening results generates another opportunity to reinforce the information included in the risk factor assessment. After screening tests are completed, risk may be more apparent and screening recommendations may need to be revised. For example, a 50-year-old woman may have a baseline colonoscopy examination that demonstrates a polyp, which is subsequently biopsied and shows hyperplasia. Based on this result, her risk for developing colon cancer is higher than initially perceived. She should be informed of this risk and be counseled about ACS's guidelines for colonoscopy following polyp removal.[8,58]

Nurses must also consider the various types of screening programs and identify the one that will best work in a particular environment. These options include mass screening and individual screening. To be successful, either mass screening or individual screening needs to include a strategy to follow up on both normal and abnormal test results. Procedures need to be in place to ensure that patients receive results in a timely fashion. In particular, recommendations for further follow-up or follow-up screening need to be clearly communicated to the patient.

Mass screening generally refers to screening programs in which large numbers of persons undergo screening, usually under fairly impersonal circumstances. An example would be screening 150 persons on two consecutive days for skin cancer. Workplace programs may be an effective means to increase cancer awareness and offer cancer screening to a large group of individuals.[5,61–63] This approach may be especially helpful in self-insured companies, which have an obvious financial incentive to keep employees healthy. The workplace may also be an effective venue for mass screening because it can provide access to large numbers of persons who are potentially a captive audience.

Individual screening typically involves a more traditional approach. It might include risk assessment, education about primary and secondary cancer prevention strategies, screening tests, and results-based health recommendations.

NURSING IMPLICATIONS

EDUCATION OF HEALTHCARE PROFESSIONALS

Risk assessment is the responsibility of many different healthcare professionals, including physicians, nurses, psychologists, and genetic counselors. Formal and clinical education regarding risk assessment is often limited in many professions.[4,24] Risk factor assessment, by contrast, has received scant attention in the formal educational setting. Education of healthcare professionals on techniques and tasks of risk assessment is important because healthcare professionals make initial recommendations for screening.

Many oncology professionals have learned about genetics through self-study and clinical practice.[64–66] Although these professionals may understand oncology well, principles of risk communication may be less clear to them.

Statistics is one of the most challenging courses and a source of frustration for many nurses, both at the undergraduate level and especially at the graduate level. Many nurses, however, do not recognize that this course has numerous ramifications for clinical practice. The challenge is for nurses to understand various statistical measures well enough to accurately critique and use the existing literature and research and—more importantly—to interpret this information to patients and their families.

Educators need to consider adding information about risk factor assessment to both undergraduate and graduate curricula. In particular, these programs need to emphasize the fact that a cancer risk assessment does not merely consist of collecting data, but rather also entails communicating the meaning of those data to a patient, so that he or she can ultimately make informed decisions about cancer prevention and early detection behaviors. Specific content regarding cancer risk assessment that should be incorporated into a curriculum includes basic epidemiologic concepts, specific types of risk (absolute, relative), risk factors for specific cancers and etiologic factors (if known), basic statistics, information about cancer prevention and early detection measures, and counseling techniques.

ADMINISTRATIVE CONSIDERATIONS

Administrators who want to introduce cancer risk assessments into a program of cancer screening or other oncology programs need to consider a number of issues. First, they must look at the rationale for implementing such a program. Often, the goal is just to increase awareness of cancer screening or to promote a particular program. Increasing recruitment to health promotion programs is regarded as a major benefit of completing a health risk assessment. Screening programs that include risk assessments also can be incorporated into outreach programs to work-site settings. Ultimately, the success of most screening programs depends on the effort taken at the beginning to completely assess the unique needs of the population or community being served.

Other important considerations include where services will be provided, marketing of services, and reimbursement issues. If the institution is unable to provide the screening that will be recommended following a risk factor assessment (e.g., genetic testing), which arrangements will be made for patients who desire such services? Administrators cannot overlook the need to hire nursing or other personnel who have the expertise and skills needed to provide this essential and comprehensive service. Barriers to consider are described in **Table 5-10**.[50,52,67–70]

Many innovative secondary cancer screening programs are described elsewhere.[62] The importance of targeting interventions that are culturally sensitive also cannot be overestimated. People choose to engage in cancer screening interventions. If an intervention is not culturally sensitive or makes an individual uncomfortable, an opportunity for screening or increasing cancer awareness may be missed.[69]

ECONOMIC CONSIDERATIONS

At the clinical level, the delivery of cancer risk information takes time, and how people who provide such information should be reimbursed for their risk assessment and

TABLE 5-10

Barriers to Cancer Screening

Patient Factors
Patient does not understand the magnitude of risk
Patient does not understand benefits of screening
Inadequate social support
Patient distress or misconceptions related to screening
Lack of financial resources to pay for screening or follow-up care
Lack of transportation to get to screening
Screening considered too uncomfortable or embarrassing
Screening considered culturally inappropriate
Service System Factors
Lack of a wellness focus in healthcare system
Low awareness of the benefits of screening by some providers
Conflicting recommendations about screening
Lack of time to perform a comprehensive examination or risk assessment
Failure to recommend a screening procedure
Facilities may have access that is difficult or inconvenient

Source: Data from Mahon[50]; Jimbo et al[52]; Greco and Mahon[66]; Escoffery et al[67]; Plutynski[68]; Tkatch et al[69]; Liss and Baker.[70]

counseling services is unclear. Such charges may be bundled with other service charges such as mammography. Without adequate reimbursement, however, risk assessment services are unlikely to be given adequate attention or provided by people with sufficient background and expertise. When providing genetic services, many providers report that a standard protocol states that individuals or families should be seen for two visits, with each session lasting about 90 to 120 minutes. In the setting of genetic risk counseling, the use of multidisciplinary teams and multiple interactions is emphasized. The underlying concern is that individuals may be "overwhelmed" by all the information provided in a single one-hour visit.[11,66,71] Such attention usually is not given to people with an average risk for developing malignancy.

Much debate focuses on how much should be spent on cancer screening. Controversy continues regarding the threshold necessary to deem a screening or treatment as cost-effective. It is difficult to find a measure that allows comparisons between healthcare interventions that save lives and those that improve quality of life.[8]

Clearly, disparities exist in cancer prevention and early detection utilization. Research continues to demonstrate that a direct consequence of lack of insurance or underinsurance is lower screening rates and limited access to primary care for prompt evaluation of symptoms. In turn, members of this population are much more likely than those persons with private insurance to be diagnosed at later stages of tumor development, when treatment is less likely to be effective, and when the condition is associated with increased morbidity, mortality, and economic costs.

For example, data show that 55% of women older than 40 with insurance have had a mammogram in the last year and 71% have had a mammogram in the last two years; by comparison, only 17% of women without insurance have had a mammogram in the last year and 32% have had a mammogram in the past two years.[9] Even when programs such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) administered by the CDC are available to these groups, promoting access to these programs remains a significant challenge. Results indicate that the NBCCEDP may have contributed to reducing cervical cancer mortality in underserved, hard-to-reach, low-income women who otherwise may have not received or had access to such preventive health services. Although the estimated benefits measured in terms of deaths averted by the NBCCEDP appear small, unfortunately the program reaches only approximately 10% of the eligible population.[72]

Recently, patient navigation has been implemented especially in populations likely to be lost to follow-up, including minorities and uninsured and underinsured individuals. Results from a cost-effectiveness study indicate that navigation yields a small but significant increase in the probability of diagnostic resolution after 180 days and 270 days after an abnormal cancer screening test, at an added incremental cost of $275 per person compared with usual care.[62] However, the added costs of navigation services did not translate into down-staging of cancer among the 11% to 12% of patients with abnormal test results who were diagnosed with cancer.

Given the very modest effects of navigation programs, other strategies to improve the timeliness of and access to follow-up care in underserved populations should be considered. For example, focusing navigation programs toward individuals who have no record of follow-up care 180 days after an abnormal screening test result or those with potentially more seriously abnormal findings could reduce costs while targeting those patients who might benefit most from the services. More research is needed to understand if navigation results in more timely early detection of malignancy.[62]

PRACTICE CONSIDERATIONS

The cancer risk assessment begins the educational process related to cancer prevention and early detection. Without an accurate and comprehensive risk assessment, it is impossible to provide the individual with appropriate and reasonable recommendations for primary and secondary cancer prevention. The risk factor assessment provides the oncology nurse with an opportunity to teach individuals about the epidemiology, risk factors, and signs and symptoms associated with the various cancers. It transmits the framework that individuals need so that they can understand the importance and rationale for primary and secondary cancer prevention strategies as well as information about those signs and symptoms that merit further evaluation.

Empowering patients with enough information in understandable terms so that they can make an informed choice about cancer screening is the ultimate goal of cancer risk counseling. When a healthcare provider simply recommends a screening test or tries to scare a patient into undergoing a screening test or genetic test by telling a poignant or compelling story, the patient may select (or fail to select) a screening test for the wrong reasons. Thus, it is important that providers offer balanced and accurate information. The downside of conveying a risk assessment in a manner such that the individual has enough information to make an informed decision is that it is extremely labor intensive for the healthcare provider.[50]

Although several practice guidelines give general recommendations for screening, many do not address specific issues of concern for older adults in this age range. This issue is complex because the rate of cancer increases among older adults, but routine cancer screening is not always recommended or even appropriate in this population.[6] Cancer screening in an older adult with serious comorbidities and

limited life expectancy may cause more harm than projected good. With such patients, it is important to consider the individual's current health, life expectancy, and understanding of the personal benefit of screening when offering guidance. Having this conversation with patients may be difficult and may also be time consuming. It is also important to consider the risks of the treatments that would be recommended if the patient is found to have a cancer and if the patient would be able to tolerate such treatment.

Staff nurses can serve as case finders to identify individuals at increased risk (especially hereditary risk) for developing cancer who might benefit from a more detailed risk assessment, and possibly cancer genetic counseling.[6] Indeed, many staff nurses who work with patients and get to know their families are the best persons to initiate referrals and begin the cancer risk assessment process. To be an effective case finder, the nurse must understand basic cancer incidence, epidemiology, and the importance of an accurate family history.

Nurses with advanced practice degrees can perform more in-depth risk assessments, recommend cancer screening procedures, explain the risks and benefits of a particular screening examination, and, in many cases, actually carry out the screening examination. They are well suited to perform professional breast examinations, teach breast self-examination, do rectal examinations, perform a skin examination, or complete a pelvic exam and take a Pap smear. Some advanced practice nurses with additional subspecialty training are able to perform flexible endoscopy examinations.

Oncology nurses have a major responsibility to teach the public about cancer detection and screening. Individuals need to realize that cancer screening differs from diagnostic examinations for cancer. They also need to recognize that cancer screening is not perfect and, even when conducted properly, will still fail to detect some malignancies because of the strengths and limitations associated with different screening tests.

Research continues to suggest that the single most important factor in whether an individual has ever had a screening test, or has recently had a screening test, is a recommendation from the healthcare provider.[4] When nurses recommend screening to an individual, there is a far greater chance that the individual will actually go on to have appropriate screening. This recommendation can easily come in the form of patient education about cancer prevention and early detection.

Every cancer screening program should include a significant patient education component. Increasing cancer awareness is the first step in getting individuals to engage in cancer screening. Thus care needs to be taken in gathering appropriate and useful materials for this purpose.[21,54] These materials may include brochures that may come from cancer-related organizations or documents that are developed specifically for an agency's population.

Tailored print communication is better remembered, read, and perceived as more relevant than generic materials.[55] Using computers to develop these documents can facilitate the creation of more detailed tailored materials. Electronic medical records often have the capability to deliver such messages.

Posters can be obtained to provide additional education and be displayed in waiting and examination areas. Bulletin boards are a relatively simple means to provide brief public education specific to a population or topic. They have the advantage of being relatively easy to produce and change to promote different cancers, risk factors, or screening events. In addition, flip charts can be used for individual education; these can be either purchased or developed specifically for the group being served. Other educational aids might include anatomic charts and models, computer-assisted education, and professional samples (e.g., sunscreen or smoking cessation kits).

When providing patients with information on cancer prevention and early detection, it is important to use educational materials that focus on wellness. More of these resources are becoming available. The NCI and the ACS, for example, offer many resources for patient education that are aimed at cancer prevention and early detection. It is inappropriate to provide materials that focus on disease and treatment unless the person requests such information. In fact, some persons find these kinds of materials distressing. The message conveyed by educational programs and materials should be that when detected early, cancer is associated with decreased morbidity and mortality and improved quality of life.

Health literacy is yet another practice consideration. Likewise, patients' proficiency in the language in which risk information is communicated can significantly impact accuracy in the understanding of cancer risk.[54] Immigrant populations may have limitations in their non-native language proficiency, resulting in inaccurate risk perception. With such patients, using plain language is very important. Ideally, materials should be written in a simplified manner so that people of low literacy (eighth grade or lower level of education) can read them and process the information. This can be achieved in part through reduction or elimination of clinical and statistical terms and medical jargon and increasing the use of graphics, including more white space, and using subheadings.[45]

How long a person can retain information after counseling about cancer risk factors is unclear. Information about risk and recommended screening can be reinforced by sending patients a post-visit letter that summarizes the discussion of risk and recommendations for screening or other follow-up. Consideration needs to be given to how individuals will be retained in cancer screening programs and genetic counseling programs so that risk assessments can be updated, recommendations for screening modified if necessary, and

regular routine screening completed. Some type of reminder is generally necessary to facilitate yearly follow-up for cancer screening in healthy individuals.

LEGAL CONSIDERATIONS

Once cancer risks and screening recommendations are identified and communicated to the patient, the patient must make a decision as to which screening tests he or she desires. If a patient declines a recommended screening test, a waiver should be signed on a consent form that acknowledges the patient was informed of the recommendation and is declining the recommended screening at that time. Information about cancer screening recommendations can be reinforced in a post-visit letter that summarizes the discussion of risk, informs the patient of the results of his or her screening tests, reiterates any recommended follow-up, and summarizes the recommendations for cancer prevention and early detection.

INTERACTIONS WITH THE MEDIA

Given that new risk factors seem to emerge every day, an important educational role for nurses is to help patients understand which risks they should take seriously. Most people accept a wide variety of risks (e.g., driving at the posted speed limit, crossing a busy parking lot, riding a bike, flying across the country in an airplane) on a daily basis with little thought. Because news coverage of screening recommendations can potentially influence screening behaviors, it is important that such information be presented accurately and in an understandable format.[73] For some reason, brief news segments about cancer risk seem to conjure up more fear. Nurses need to be aware of public news reports and go to the primary sources when new risk factors are publicized so that they can interpret this information accurately to their patients. They also need to communicate concepts related to cancer risks carefully when providing information to the media. This effort may include providing the media with primary sources and reports and more integrated state-of-the-art information. Both the ACS and the other resources should be consulted prior to speaking with the media, to ensure that accurate statistics and figures are provided.

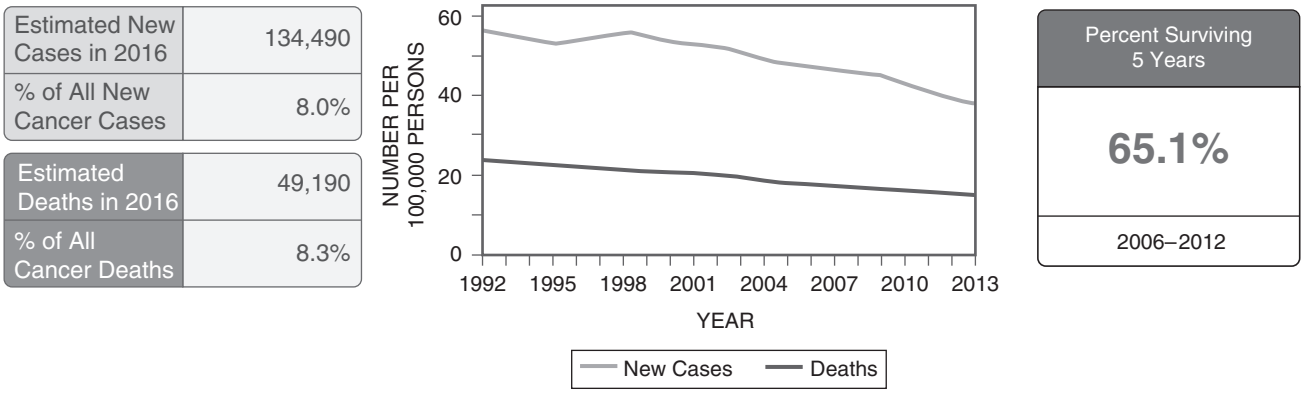
Each year the ACS publishes *Cancer Facts and Figures*.[3,8,9,58,74] Nurses can use this helpful reference to quickly gather incidence data about estimated cancer cases. The information is presented in several formats, including the estimated projected number of new cases of specific cancer (incidence) and estimated mortality rates. The incidence rates are also given by state and geographic region. Oncology nurses can obtain this publication free of charge from the local unit of the ACS and may find it helpful to review so as to better understand the incidence of specific cancers in the geographical area in which they practice. These publications also offer detailed information about primary and secondary cancer prevention of the major tumors as well as projected survival data by stage. Once familiar with the format of the publications, oncology nurses will find them to be an invaluable resource. The ACS also publishes *Facts* & *Figures* documents that deal with specific cancers such as breast cancer, specific minority populations, and cancer prevention. These materials are updated regularly and can be downloaded from the ACS website (http://www.cancer.org).

Another source of commonly cited data is the Surveillance, Epidemiology, and End Results Program (SEER), which is available in many formats (http://seer.cancer.gov/data/). Currently, SEER data include incidence, mortality, and survival rates from 1973 through 2011. Data from the nine SEER geographic areas are collected and represent an estimated 9.5% of the U.S. population. Currently, the database contains information on 8.2 million cases diagnosed since 1973. Approximately 125,000 new cases are added yearly. This information can be obtained easily at the NCI website (http://www.seer.ims.nci.nih.gov/). The SEER database allows the user to view the data in many different forms, in both table and graph formats, and is extremely helpful when looking for trends in cancer (**Figure 5-2**).

FUTURE RESEARCH

Future research should evaluate the process of risk notification and its effects on knowledge, attitudes, emotions, practices, and outcomes related to health and disease status. Most of the studies of perceived risk have been cross-sectional in nature, which makes it difficult to determine whether the perceived risk is a cause or an effect in relation to cancer screening.[49] This relationship could be better understood if longitudinal studies were conducted to measure perceived risk in defined populations with different cancer screening histories, with the studies also including follow-up for screening and repeated measures of risk perception. Such investigations should include controlled clinical trials to evaluate different counseling protocols. This type of research will provide information on the impact and effectiveness of cancer risk assessment and counseling. The Oncology Nursing Society has identified increasing screening in minorities and those individuals at risk for a poor outcome as a research priority.[75]

Clearly, more information is needed on the roles played by cognition, affective state of the individual, developmental differences, and personal values, along with the way in which these individual qualities influence cancer risk communication.[24] More research is also needed to determine the best persons (including an interdisciplinary approach)



Number of New Cases and Deaths per 100,000: The number of new cases of colon and rectum cancer was 41.0 per 100,000 men and women per year. The number of deaths was 15.1 per 100,000 men and women per year. These rates are age-adjusted and based on 2009–2013 cases and deaths.

Lifetime Risk of Developing Cancer: Approximately 4.5 percent of men and women will be diagnosed with colon and rectum cancer at some point during their lifetime, based on 2010–2012 data.

Prevalance of This Cancer: In 2013, there were an estimated 1,177,556 people living with colon and rectum cancer in the United States.

FIGURE 5-2

SEER Stat Fact: Colon and Rectum Cancer.

Source: National Cancer Institute, Surveillance, Epidemiology, and End Results Program (SEER), seer.cancer.gov.

to communicate cancer and genetic risks.[11,71] Likewise, information is needed on how to facilitate decision making regarding the management of cancer risks.

Prospective studies are needed to determine the psychological and behavioral implications of risk information. To date, little research has been done on the long-term implications of cancer screening activities.[50] Assessments should optimally be conducted at multiple time points and include outcome variables. More research is needed to understand why two individuals react differently to similar information regarding cancer risk.

Moreover, little research has focused on how people cope with information related to their risk of disease. Models of coping with disease may not encompass the concept of coping with increased risk for developing a disease such as cancer. Coping may be influenced by the extent to which an individual believes he or she can control the outcome through screening.[24] People who apply problem-focused forms of coping may be more likely to engage in screening, but this is an area that requires much more research to elucidate the relationships. Overall, the effect of cancer risk assessment on cancer screening behaviors merits more attention.

In addition, technical issues in cancer screening require more research. Little is known about the effectiveness of screening protocols. Clearly, nurses could provide comprehensive screening services and education if clear guidelines or screening protocols were available to them.[6,52,67] Rising healthcare costs dictate a need for more research on the cost-effectiveness of cancer risk assessment.[4,62]

Currently, formal education for nurses and healthcare professionals about communicating risk and genetic concepts is lacking. Future studies need to address effectiveness of this education.[64,76–78]

CONCLUSION

Oncology nurses need to view risk factor assessment as a wonderful opportunity for patient education on not only cancer risk factors, but also cancer prevention and early detection activities. Cancer risk assessment can be a technical process requiring expertise. Oncology nurses have an ethical responsibility to communicate risk information in understandable terms and as accurately as possible. Indeed, risk assessment entails more than just collecting assessment data from the patient—a critical component of the process is communicating the risk-related information to patients in a meaningful way.

Cancer risk communication is a continuous process, and risk assessment is a large component of this process. It demands effective communication with patients so that they are informed about the best possible choices regarding cancer prevention and early detection activities. Like other components of the cancer screening process, a cancer risk assessment is most effective if it is updated and reviewed annually.

Once risk is communicated, education about cancer screening options must be provided. This effort should include accurate information about the accuracy, benefits, and risks associated with the test(s). Each individual must decide which types of testing her or she is willing to accept.

Once testing is complete, the results must be interpreted to the patient. Individuals with normal screening results should understand when the next round of screening is indicated. Patients with abnormal screens need to be directed through appropriate follow-up.

Nurses need to consider epidemiological terms and calculations when conducting risk assessments. They also need to teach patients and their families about the strengths and weaknesses of various screening or surveillance strategies. This education includes a discussion of the sensitivity and specificity of various screening tests, as well as a discussion of why screening is available for some cancers and not for others. Individuals at higher risk for developing cancer because of genetic susceptibility need to recognize that the screening recommendations for people of average risk, which are issued by groups such as the ACS, may be inadequate for persons with higher risk.

REFERENCES

1. Weitzel JN, Blazer KR, MacDonald DJ, Culver JO, Offit K. Genetics, genomics, and cancer risk assessment. *CA Cancer J Clin.* 2011;61(5):327-359.
2. Brawley O, Byers T, Chen A, et al. New American Cancer Society process for creating trustworthy cancer screening guidelines. *JAMA.*2011; 306(22):2495-2499.
3. American Cancer Society. *Cancer Prevention and Early Detection Facts & Figures 2013.* Atlanta, GA: American Cancer Society; 2013.
4. Smith RA, Manassaram-Baptiste D, Brooks D, et al. Cancer screening in the United States, 2014: a review of current American Cancer Society guidelines and current issues in cancer screening. *CA Cancer J Clin.* 2014;64(1):30-51.
5. Croswell JM, Ransohoff DF, Kramer BS. Principles of cancer screening: lessons from history and study design issues. *Semin Oncol.* 2010; 37(3):202-215.
6. Craft M. Cancer Screening in the older adult: issues and concerns. *Nurs Clin North Am.* 2014;49(2):251-261.
7. Hampel H. NCCN increases the emphasis on genetic/familial high-risk assessment in colorectal cancer. *J Natl Compr Canc Ntwk.* 2014;12(5S): 829-831.
8. American Cancer Society. *Cancer Facts & Figures—2016.* Atlanta, GA: American Cancer Society; 2016.
9. American Cancer Society. *Breast Cancer Facts & Figures 2013-2014.* Atlanta, GA: American Cancer Society; 2013.
10. Brierley KL, Blouch E, Cogswell W, et al. Adverse events in cancer genetic testing: medical, ethical, legal, and financial implications. *Cancer J.* 2012;18(4):303-309.
11. Mahon S. Managing families with a hereditary cancer syndrome. *Oncol Nurs Forum.* 2011;38(6):641-644.
12. O'Neill S, Peshkin B, Luta G, Abraham A, Walker L, Tercyak K. Primary care providers' willingness to recommend *BRCA1/2* testing to adolescents. *Fam Cancer.* 2010;9(1):43-50.
13. Fears TR, Guerry D, Pfeiffer RM, et al. Identifying individuals at high risk of melanoma: a practical predictor of absolute risk. *J Clin Oncol.*2006; 24(22):3590-3596.
14. Freedman AN, Slattery ML, Ballard-Barbash R, et al. Colorectal cancer risk prediction tool for white men and women without known susceptibility. *J Clin Oncol.* 2009;27(5):686-693.
15. Park Y, Freedman AN, Gail MH, et al. Validation of a colorectal cancer risk prediction model among white patients age 50 years and older. *J Clin Oncol.* 2009;27(5):694-698.
16. Rockhill B, Spiegelman D, Byrne C, Hunter DJ, Colditz GA. Validation of the Gail et al. model of breast cancer risk prediction and implications for chemoprevention. *J Natl Cancer Inst Monogr.* 2001;93(5):358-366.
17. Hinton RB. The family history: reemergence of an established tool. *Crit Care Nurs Clin North Am.* 2008;20(2):149-158.
18. Tyler CV Jr, Snyder CW. Cancer risk assessment: examining the family physician's role. *J Am Board Fam Med.* 2006;19(5):468-477.
19. Hoskins KF, Zwaagstra A, Ranz M. Validation of a tool for identifying women at high risk for hereditary breast cancer in population-based screening. *Cancer.* 2006;107(8):1769-1776.
20. Twomey J. Ethical, legal, psychosocial, and cultural implications of genomics for oncology nurses. *Semin Oncol Nurs.* 2011;27(1):54-63.
21. Warren GW, Marshall JR, Cummings KM, et al. Automated tobacco assessment and cessation support for cancer patients. *Cancer.* 2014; 120(4):562-569.
22. Drohan B, Roche C, Cusack J Jr, Hughes K. Hereditary breast and ovarian cancer and other hereditary syndromes: using technology to identify carriers. *Ann Surg Oncol.* 2012;19(6):1732-1737.
23. Rauscher GH, Johnson TP, Cho YI, Walk JA. Accuracy of self-reported cancer-screening histories: a meta-analysis. *Cancer Epidemiol Biomarkers Prev.* 2008;17(4):748-757.
24. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev.* 2013;2:CD001865.
25. Villani J, Mortensen K. Patient–provider communication and timely receipt of preventive services. *Prev Med.* 2013;57(5):658-663.
26. Rothman AJ, Kiviniemi MT. Treating people with information: an analysis and review of approaches to communicating health risk information. *J Natl Cancer Inst Monogr.* 1999;25:44-51.
27. Green VL. Breast cancer risk assessment, prevention, and the future. *Obst Gynecol Clin North Am.*2013;40(3):525-549.
28. Amir E, Freedman OC, Seruga B, Evans DG. Assessing women at high risk of breast cancer: a review of risk assessment models. *J Natl Cancer Inst Monogr.* 2010;102(10):680-691.
29. Gail MH, Mai PL. Comparing breast cancer risk assessment models. *J Natl Cancer Inst Monogr.* 2010;102(10):665-668.
30. Claus EB, Risch N, Thompson WD. Autosomal dominant inheritance of early-onset breast cancer: implications for risk prediction. *Cancer.* 1994;73(3):643-651.
31. Claus EB, Schildkraut JM, Thompson WD, Risch NJ. The genetic attributable risk of breast and ovarian cancer. *Cancer.* 1996;77(11):2318-2324.
32. Couch FJ, DeShano ML, Blackwood MA, et al. *BRCA1* mutations in women attending clinics that evaluate the risk of breast cancer. *N Engl J Med.* 1997;336(20):1409-1415.
33. Shattuck-Eidens D, Oliphant A, McClure M, et al. *BRCA1* sequence analysis in women at high risk for susceptibility mutations: risk factor analysis and implications for genetic testing. *JAMA.* 1997;278(15): 1242-1250.
34. Berry DA, Iversen ES Jr, Gudbjartsson DF, et al. BRCAPRO validation, sensitivity of genetic testing of *BRCA1/BRCA2*, and prevalence of other breast cancer susceptibility genes. *J Clin Oncol.* 2002;20(11):2701-2712.
35. Frank TS, Deffenbaugh AM, Reid JE, et al. Clinical characteristics of individuals with germline mutations in *BRCA1* and *BRCA2*: analysis of 10,000 individuals. *J Clin Oncol.* 2002;20(6):1480-1490.
36. Gilpin CA, Carson N, Hunter AG. A preliminary validation of a family history assessment form to select women at risk for breast or ovarian cancer for referral to a genetics center. *Clin Genet.* 2000;58(4):299-308.
37. Lindor NM, Johnson KJ, Harvey H, et al. Predicting *BRCA1* and *BRCA2* gene mutation carriers: comparison of PENN II model to previous study. *Fam Cancer.* 2010;9(4):495-502.

38. Umar A, Boland CR, Terdiman JP, et al. Revised Bethesda guidelines for hereditary nonpolyposis colorectal cancer (Lynch syndrome) and microsatellite instability. *J Natl Cancer Inst Monogr.* 2004;96(4):261-268.
39. Monteiro Santos E, Valentin M, Carneiro F, et al. Predictive models for mutations in mismatch repair genes: implication for genetic counseling in developing countries. *BMC Cancer.* 2012;12(1):64.
40. Gale J. "PREMM 1,2,6 Model" as a new gene specific prediction model for Lynch syndrome: retrospective review of mutation positive cases. *Hered Cancer Clin Pract.* 2012;10(suppl 2):A67.
41. Niendorf KB, Goggins W, Yang G, et al. MELPREDICT: a logistic regression model to estimate *CDKN2A* carrier probability. *J Med Genet.* 2006;43(6):501-506.
42. Goldstein AM, Chan M, Harland M, et al. Features associated with germline *CDKN2A* mutations: a GenoMEL study of melanoma-prone families from three continents. *J Med Genet.*2007;44(2):99-106.
43. Matsuno RK, Costantino JP, Ziegler RG, et al. Projecting individualized absolute invasive breast cancer risk in Asian and Pacific Islander American women. *J Natl Cancer Inst Monogr.* 2011;103(12):951-961.
44. Ready K, Arun B. Clinical assessment of breast cancer risk based on family history. *J Natl Compr Canc Ntwk.* 2010;8(10):1148-1155.
45. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. *J Natl Cancer Inst Monogr.* 2011;103(19):1436-1443.
46. Nelson HD, Zakher B, Cantor A, et al. Risk factors for breast cancer for women aged 40 to 49 years: a systematic review and meta-analysis. *Ann Intern Med.* 2012;156(9):635-648.
47. National Comprehensive Cancer Network. Breast cancer screening and diagnosis version 1.2016. 2016. http://www.nccn.org/professionals/physician_gls/pdf/breast.pdf Accessed August 13, 2016.
48. Coldman A, Phillips N, Wilson C, Sam J. Information for physicians discussing breast cancer screening with patients. *BCMJ.* 2013;55(9):420-428.
49. Klein WMP, Stefanek ME. Cancer risk elicitation and communication: lessons from the psychology of risk perception. *CA Cancer J Clin.* 2007;57(3):147-167.
50. Mahon SM. *Breast Cancer.* Pittsburgh, PA: Oncology Nursing Society; 2011.
51. Zapka JM, Klabunde CN, Arora NK, Yuan G, Smith JL, Kobrin SC. Physicians' colorectal cancer screening discussion and recommendation patterns. *Cancer Epidemiol Biomarkers Prev.* 2011;20(3):509-521.
52. Jimbo M, Rana GK, Hawley S, et al. What is lacking in current decision aids on cancer screening? *CA Cancer J Clin.* 2013;63(3):193-214.
53. Kaphingst KA, Persky S, McCall C, Lachance C, Beall AC, Blascovich J. Testing communication strategies to convey genomic concepts using virtual reality technology. *J Health Commun.* 2009;14(4):384-399.
54. Garcia-Retamero R, Okan Y, Cokely ET. Using visual aids to improve communication of risks about health: a review. *Sci World J.* 2012;2012:10.
55. Flight IH, Wilson CJ, Zajac IT, Hart E, McGillivray JA. Decision support and the effectiveness of web-based delivery and information tailoring for bowel cancer screening: an exploratory study. *JMIR Res Protoc.* 2012;1(2):e12.
56. Cameron LD, Muller C. Psychosocial aspects of genetic testing. *Curr Opin Psychiatry.* 2009;22(2):218-223.
57. Hassan C, Pickhardt PJ, Rex DK. Performance improvements of imaging-based screening tests. *Best Pract Res Clin Gastroenterolo.*2010;24(4):493-507.
58. American Cancer Society. *Colorectal Cancer Facts & Figures 2011-2013.* Atlanta, GA: American Cancer Society; 2011.
59. Burt RW, Cannon JA, David DS, et al. Colorectal cancer screening. *J Natl Compr Canc Ntwk.* 2013;11(12):1538-1575.
60. Lin KW, Sharangpani R. Screening for colorectal cancer. *Am Fam Physician.* 2010;81(8):1017-1018.
61. Sarfaty M, Wender R, Smith R. Promoting cancer screening within the patient centered medical home. *CA Cancer J Clin.* 2011;61(6):397-408.
62. Bensink ME, Ramsey SD, Battaglia T, et al. Costs and outcomes evaluation of patient navigation after abnormal cancer screening: evidence from the Patient Navigation Research Program. *Cancer.* 2014;120(4):570-578.
63. Plescia M, Richardson LC, Joseph D. New roles for public health in cancer screening. *CA Cancer J Clin.* 2012;62(4):217-219.
64. Mahon SM, Crecelius ME. Practice considerations in providing cancer risk assessment and genetic testing in women's health. *J Obstet Gynecol Neonat Nurs.* 2013:42(3);274-286.
65. Greco K, Mahon S. Genomic health care has arrived, but are nurses competent to deliver it? *Am Nurse Today.* 2012;7(11):37-38.
66. Greco KE, Mahon SM. The state of genomic health care and cancer: are we going two steps forward and one step backward? *Ann Rev Nurs Res.* 2011;29(1):73-97.
67. Escoffery C, Rodgers K, Kegler M, Ayala M, Pinsker E, Haardorfer R. A grey literature review of special events for promoting cancer screenings. *BMC Cancer.* 2014;14(1):454.
68. Plutynski A. Ethical issues in cancer screening and prevention. *J Med Philos.* 2012;37(3):310-323.
69. Tkatch R, Hudson J, Katz A, et al. Barriers to cancer screening among orthodox Jewish women. *J Community Health.* 2014;39(6):1200-1208.
70. Liss DT, Baker DW. Understanding current racial/ethnic disparities in colorectal cancer screening in the United States: The contribution of socioeconomic status and access to care. *Am J Prev Med.* 2014;46(3):228-236.
71. Mahon SM. Time studies of the tasks associated with comprehensive cancer genetics counseling. *J Natl Compr Canc Ntwk.* 2014;12(3):303.
72. Ekwueme DU, Uzunangelov VJ, Hoerger TJ, et al. Impact of the national breast and cervical cancer early detection program on cervical cancer mortality among uninsured low-income women in the U.S., 1991–2007. *Am J Prev Med.* 2014;47(3):300-308.
73. Elstad E, Sheridan S, Lee JL, Rini C, Earp J, Brewer N. Have screening harms become newsworthy? News coverage of prostate and colorectal cancer screening since the 2008 USPSTF recommendation changes. *J Behav Med.* 2014;37(6):1242-1251.
74. American Cancer Society. *Global Cancer Facts & Figures.* 2nd ed. Atlanta, GA: American Cancer Society; 2011.
75. LoBiondo-Wood G, Brown C, Knobf M, et al. Priorities for oncology nursing research: the 2013 national survey. *Oncol Nurs Forum.* 2014;41(1):67-76.
76. Berliner J, Fay A. Risk assessment and genetic counseling for hereditary breast and ovarian cancer: recommendations of the National Society of Genetic Counselors. *J Genet Couns.* 2007;16(3):241-260.
77. Pal T, Lee JH, Besharat A, et al. Modes of delivery of genetic testing services and the uptake of cancer risk management strategies in *BRCA1* and *BRCA2* carriers. *Clin Genet.* 2013; 85(1): 49-53.
78. Mahon SM. Complexities of genetic care: implications for advanced practice nurses. *J Nurse Practitioners.* 2012;8(8):e23-e27.