## Improving Patient Adherence-Behavioral Theories and Risk Communication Skills

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## Readings

- Ransohoff DF and Sandler RS. <u>Screening for colorectal cancer</u>. New England Journal of Medicine. 2002, 346(1): 40-44.
- Beck RS, Daughtridge R, Sloane PD. <u>Physician-patient communication in the primary care office: A Systematic Review.</u> Journal of the American Board of Family Practice. 2002,15: 25–38.

#### Improving Patient Adherence-Behavioral Theories and Risk Communication Skills

#### Educational Objectives

Upon completion of this program, participants will be able to:

- Identify key components of four widely accepted behavioral theories, which can be used to describe patient motivation for preventive care.
- Apply behavioral theories in the clinical setting to motivate patient adherence to preventive care.
- Provide an appropriate level of health education through assessing patients' readiness for change.
- Demonstrate effective physician-patient communication skills to optimize constructive information exchange with patients.
- Apply the Shared Decision Making model during medical encounters to facilitate a more participatory style for making health care decisions.
- Explain the difference between relative, attributable, absolute and lifetime risk.
- Understand the relative importance of risk factors for colorectal cancer.
- Elicit patients' perceptions about colorectal cancer risk and screening.
- Clarify misconceptions about colorectal cancer risk and screening.
- Assist patients in making an informed decision about colorectal cancer screening of the basis of personal risk factors.
- Explain the benefit of early detection of disease on decreasing mortality from colorectal cancer.

#### **Behavioral Theories**

#### Introduction

Although screening has been proven to reduce the mortality rate of colorectal cancer (CRC), national surveys indicate that utilization rates are less than 50%. (1)

This module will address two important questions:

- Why are some people motivated to obtain CRC screening while others choose not to be screened?
- How can clinicians improve the adherence of their patients to prescribed regimens?

There is no single model to explain all behaviors. However, theories of health behavior can give insight and suggest strategies that can enhance patient adherence.

This module includes information about four theoretical frameworks:

- The Health Belief Model
- Social Cognitive Theory
- The Transtheoretical Model (also called Stages of Change)
- The Precaution Adoption Model

#### **Health Belief Model**

The Health Belief Model (HBM) is a psychosocial approach to explaining health-related behavior. Introduced in the 1950's by psychologists Rosenstock, Hochbaum, Leventhal and Kegeles, it has been one of the most widely used conceptual frameworks over the past 3 decades.

The model incorporates 4 variables:

- Perceived susceptibility
- Perceived seriousness
- Perceived benefits
- Perceived barriers

#### **Perceived Susceptibility**

Individuals will seek preventive care if they believe they are personally at risk. The *perceived susceptibility* of a disease refers to the subjective probability that an individual could, in fact, get the disease.

#### **Perceived Seriousness**

The *perceived seriousness* of a disease may or may not be related to the actual severity of the disease. People tend to be more motivated to prevent serious diseases than less serious ones. Susceptibility and seriousness combine to form an overall perceived threat of a disease.

#### **Perceived Benefits**

The *perceived benefits* of a behavior refer to how effective a person thinks the behavior will be. Taking aspirin for a headache is likely to be perceived as very effective, since it has a rapid and noticeable result. Obtaining regular fecal occult blood tests to enhance early detection of colorectal cancer, however, usually has no short-term benefit. It may therefore be perceived as less effective.

#### **Perceived Barriers**

Perceived barriers also influence action. A patient may feel that a treatment or screening takes too much time, requires too much effort, or is too difficult to obtain.

The highest likelihood of action occurs when the perceived threat of a disease is high and the perceived benefits outweigh the barriers.

#### **Other Principles**

Additional principles of the Health Belief Model include a **cue to action** such as a health education message or recommendation by a physician. **Self-efficacy**, a concept introduced by Bandura (2) and added to the HBM by Rosenstock, et al. (3), refers to confidence in one's ability to take action. (See <u>Table 1</u>.)

The HBM also recognizes **predisposing**, **enabling**, and **reinforcing** factors that influence behavior. Predisposing factors include values, beliefs, attitudes and perceptions of disease. Enabling factors include availability and accessibility of health resources. Reinforcing factors include peer support, feedback, and reassurance from the clinician.

#### Applying the HBM to CRC Screening

Physician recommendation strongly influences whether a patient is screened for colorectal cancer. (4) The HBM can help you increase the power of that recommendation. If a patient is not going for regular screening, you can work with that patient to identify the reasons. You can then tailor strategies (educational materials, counseling, etc.) to eliminate the identified barrier(s) using the framework of the HBM.

Figure 1 illustrates the way in which the HBM may apply to CRC screening.

#### Addressing Disparities with the HBM

The Health Belief Model provides an appropriate framework for addressing CRC screening in diverse populations. In particular, it can be helpful with patients of low socioeconomic status. It can also help to overcome racial disparities in screening.

Low socioeconomic status creates multiple barriers to screening, including poor access to care, lack of resources to cover the cost of screening examinations, and lack of awareness of the risks for colorectal cancer and the modalities used for screening. (41, 42) In fact, socioeconomic factors such as low educational attainment, lack of health insurance, or lack of access to a usual source of care are associated with underutilization of CRC screening. (1) Socioeconomic status can also contribute to racial disparities in health care: 24% of African Americans and 23% of Hispanics live below the poverty level compared to 11% of whites, while 18% of African Americans and 35% of Hispanics are medically uninsured compared to 12% of whites. (1)

Cultural affiliations (including medical mistrust and cancer fatalism), religious and spiritual ideologies, and personal perceptions and beliefs affect one's desire to participate in screening. (41, 42) Individuals may encounter racial discrimination when seeking health care services. There may be language barriers that prevent discussion and contribute to higher rates of cancer discovered at later stages. Lack of confidence and skills to navigate the health care system, negative attitudes toward the tests themselves, fear of the consequences of screening, and inadequate social support have also been suggested as potential barriers. (41, 42)

Most, if not all, of these barriers are modifiable and can be addressed through the use of tailored interventions. Exploring a patient's beliefs, fears, expectations, and resources can provide essential information. With that information, the clinician can work with the patient to overcome barriers that would prevent CRC screening.

# Figure 1: The Health Belief Model Applied to Patient Scenarios About Having Regular CRC Screening

#### **Predisposing Factors**

(Attitudes, beliefs, and values of patient)

#### **Positive**

## "I want a high quality of life and to live a long, healthy life."

"FOBT, flexible sigmoidoscopy and colonoscopy have been proven to be effective methods to detect polyps and CRC."

"When colorectal polyps or cancer are found early, I have an excellent chance of living a long life."

#### **Negative**

"What I don't know won't hurt me."

"No one in my family had colorectal cancer, so why should I worry?"

"These tests are embarrassing."

"I don't even have time to take care of more important issues."

#### **Enabling Factors**

(Conditions of the environment, transportation, availability and accessibility of health resources, community/government laws)

#### **Positive**

## "I can perform FOBT in the privacy and convenience of my own home."

"Insurance companies pay a portion of the cost of the CRC screening, as does Medicare."

#### **Negative**

"Having flexible sigmoidoscopy/colonoscopy on an ongoing basis is costly."

"No transportation is available to assist me in getting to a flexible sigmoidoscopy/ colonoscopy facility."

#### **Reinforcing Factors**

(Social support, family peer influence, advice and feedback by health care providers)

#### **Positive**

"I respect my physician's judgment."

"My physician and I have a good relationship. I follow my physician's recommendations for colorectal cancer screening."

"Major health authorities recommend regular colorectal cancer screening."

#### **Negative**

"My family members and friends consider colorectal cancer screening unnecessary."

"My relative said her flexible sigmoidoscopy/colonoscopy was painful."

"My friend had colorectal cancer screening but (s)he ended up with colorectal cancer anyway."

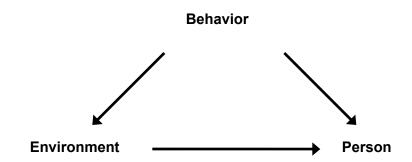
**Table 1: Summary of the Health Belief Model** 

Concept	Definition	Application
Perceived Susceptibility	One's opinion of chances of developing a condition.	Define population(s) at risk, risk levels.  Personalize risk based on a person's features or behavior.  Heighten perceived susceptibility if too low.
Perceived Severity	One's opinion of how serious a condition and its sequelae are.	Specify consequences of the risk and the condition.
Perceived Benefits	One's opinion of the efficacy of the advised action to reduce risk or seriousness of impact.	Define action to take: how, where, when; clarify the positive effects to be expected.
Perceived Barriers	One's opinion of the tangible and psychological costs of the advised action.	Identify and reduce barriers through reassurance, incentives, assistance.
Cues to Action	Strategies to activate "readiness".	Provide how-to information, promote awareness, reminders.
Self-Efficacy	Confidence in one's ability to take action.	Provide training, guidance in performing action.

Glanz, K., and Rimer, B. (1995). <u>Theory at a Glance: A Guide for Health Promotion Practice</u> (p 19). U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health.

#### **Social Cognitive Theory**

Introduced by psychologist Albert Bandura, Social Cognitive Theory, previously known as social learning theory, explains human behavior in terms of a dynamic, reciprocal, and continuous interaction between the individual and the environment. (5) Bandura calls this **reciprocal determinism**.



Adapted from: Kaplan, R., et al. (1993). Health and Human Behavior (pp 50-51). McGraw-Hill.

According to the theory's concept of **behavioral capability**, before a person will act in a given situation, he or she needs to know what to do and how to do it. The person also needs the knowledge and skills to perform the specific behavior. Two cognitive processes particularly influence behavior: **outcome expectations** and **self-efficacy expectations**.

#### **Outcome expectations**

An outcome expectation is the belief that a behavior will produce a specified outcome or effect. Outcomes can be either positive or negative. A person will choose an action that he or she believes will maximize a positive result or outcome and/or minimize a negative result or outcome.

#### **Self-efficacy**

As in the HBM, self-efficacy refers to the belief in one's ability to take control of behavior, as well as the confidence that one can successfully perform a specific task.

Self-efficacy influences how an individual thinks, feels, acts, and is motivated. Self-efficacy also affects a person's choice of the setting, the amount of effort expended on a task, and emotional reactions.

# Person Behavior Outcome Efficacy Outcome Expectations Expectations

The Theoretical Framework

Strecher, V., et al. (1986). The role of self-efficacy in achieving health behavior change. <u>Health Education Quarterly</u>, 13(1), 73-91.

#### Other Influences

**Observational learning** or **modeling** describes how one acquires information and skills through the actions of others. By observing others, as children do when they learn from their parents' actions, one can develop an understanding of and be prepared for the consequences (good or bad) of particular actions.

A final key concept is **reinforcement**. The response to a person's behavior can influence whether or not that behavior will be repeated. Reinforcements or rewards can be positive, making it more likely that the behavior will be repeated; or they can be negative. Both punishment and lack of response tend to make repetition of the behavior less likely.

#### **Applying Social Cognitive Theory to Colorectal Cancer Screening**

A clinician can use social cognitive theory to promote CRC screening in several ways.

To help encourage positive **outcome expectations**, you can:

- Explain the purpose of screening in plain language. Emphasize the fact that screening and follow-up can prevent colon cancer or reduce mortality if cancer is found.
- Give information about what to expect before, during, and after a screening procedure.
- Encourage questions.

To help promote a patient's feelings of **self-efficacy**, you can:

- Make sure the patient knows when to obtain screening.
- Provide information on how to make a screening appointment or schedule the appointment directly from your office.
- Educate the patient about how to do a home test (e.g., a fecal occult blood test) or how to prepare for an in-office screening (e.g., colonoscopy).
- Discuss obstacles such as transportation and insurance coverage, and provide options to help minimize these obstacles when possible.

To take advantage of **observational learning** and modeling, you can:

- Let your patient know that screening is a standard part of your practice and a common procedure.
- Offer informational materials which relate others' experiences. The American Cancer Society (<a href="www.cancer.org">www.cancer.org</a>) has <a href="comments on colonoscopy">comments on colonoscopy</a> from patients who have experienced it. Many people are also encouraged by celebrity Katie Couric's story. After her husband died from colon cancer, she broadcast her own colonoscopy experience on national television and continues to advocate for screening.

Finally, to provide **reinforcement**, you can:

- Review the screening results with your patient, making it clear that you value the information obtained.
- Offer praise for making and keeping a screening appointment. This both provides reinforcement and makes it clear that you consider CRC screening to be an important part of preventive care.

Table 2: Summary of Social Cognitive Theory

Concept	Definition	Application
Reciprocal Determinism	Behavior changes result from interaction between person and environment; change is bi-directional.	Involve the individual and relevant others; work to change the environment, if warranted.
Behavioral Capability	Knowledge and skills to influence behavior.	Provide information and training about action.
Expectations	Beliefs about likely results about in adv	
Self-Efficacy	Confidence in ability to take action and persist in action.	Point out strengths; use persuasion and encouragement; approach behavior change in small steps.
Observational Learning	Beliefs based on observing others like self and/or visible physical results.	Point out others' experience, physical changes; identify role models to emulate.
Reinforcement	Responses to a person's behavior that increase or decrease the chances of recurrence.	Provide incentives, rewards, and praise; encourage self-reward; decrease possibility of negative responses that deter positive changes.

Glanz, K., and Rimer, B. (1995). <u>Theory at a Glance: A Guide for Health Promotion Practice</u> (p 23). U.S. Department of Health and Human Services, Public Health Service, National Institute of Health.

#### **Transtheoretical Model (Stages of Change)**

The Transtheoretical Model (TTM), also known as the Stages of Change model, was developed by psychologists Prochaska and DiClemente. It suggests that an individual changes behavior by moving through a series of motivational stages: precontemplation, contemplation, decision/determination, action, maintenance and relapse. (6) (See Figure 2.)

#### **Precontemplation**

In the precontemplation stage, the individual has not thought about or considered a change in behavior and, therefore, has no intention of adopting the behavior.

#### Contemplation

During contemplation, the individual is seriously contemplating the behavior but has not yet taken action.

#### **Decision/Determintation**

In the decision/determination phase the person is making a plan to change.

#### **Action**

In the action phase, the person makes an initial behavioral change. The action phase covers the first six months of changed behavior.

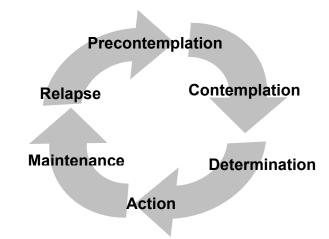
#### **Maintenance**

After the first six months the person enters the maintenance stage, in which the change is maintained and sustained over time.

#### Relapse

Relapse is classified as a secondary stage of change. It describes reversion back to an earlier stage after having tried but failed to maintain a behavior. It may happen at any time after action is taken.

Figure 2. Stages of Change Cycle



ACP-ASIM 2000-Counseling for Behavior Change

#### Applying the Transtheoretical/Stages of Change Model to CRC Screening

Identifying a patient's stage of change can help you decide how to approach the discussion of CRC screening. At every stage, there is an opportunity to help guide your patient closer to a behavior change: in this case, to making the decision to have regular CRC screening.

The first step is to assess the stage your patient is in. <u>Figure 3</u> offers a general description of thoughts and behaviors at each stage. <u>Figure 3a</u> applies the model specifically to CRC screening.

Next, tailor your counseling to the patient's stage. <u>Table 3</u> gives general descriptions of appropriate counseling at each stage. For example, if the patient's stage is:

**Precontemplation.** Offer information about benefits of CRC screening. If possible, personalize the information with specific risks (family history, age, etc.).

**Contemplation.** Reinforce benefits of screening. Review <u>screening modalities</u> and encourage the patient to select one.

**Decision.** If needed, review screening modalities and decide on one together. Assist the patient in making an appointment for screening or provide FOBT cards. Provide complete instructions and answer all questions.

**Action.** Once screening is completed, review results with the patient. Make sure the patient is aware of the next step, whether follow-up or future screening.

**Maintenance.** Send reminders for future screenings. Track any follow-up and continue to make sure the patient is aware of any needed tests or treatments.

Figure 3: Stages of Change

Major Focus of Primary Care Counseling					
Precontemplation	Contemplatio n	Determination/ Preparation	Action	Maintenance	Relapse
No!	Should I or shouldn't I?	Yes!	Go!	Cruising	Ugh!
Patient not yet or not currently considering the possibility of change.	Period characterized by ambivalence: patient both considers change and rejects it. Has reasons for concern and justification for lack of concern.	The patient's statements reflect a good deal of what might be judged to be "motivation".  This stage represents preparation as much as it does further developing determination.	Patient engages in particular actions intended to bring about a change.	Patient attempts to sustain the change accomplished by previous action, and to prevent relapse.	Full scale return to previous behavior, with no pretense of continuing the change. Patient surrenders.  Returns to earlier stage of change, often precontemplation

Developed by Steve Taylor, DHSc., Mercy Family Medicine Residency, Denver, CO. Built around work of Prochaska, DiClemente and Norcross (see <u>American Psychologist</u>, 47, 1102-14, 1992) Some wording adopted from Miller and Rollnick's <u>Motivational Interviewing: Preparing people to Change Addictive Behavior</u>, Ch. 2 and 13, Guilford Press, 1991.

Figure 3a: Stages of Change as Applied to Colorectal Cancer Screening

	PRECONTEMPLATION
	No intention of having CRC screening in near future.  Not thinking about/considering CRC screening.  Never had a CRC screening test.
	CONTEMPLATION/PREPARATION
	Considering having CRC screening.  May intend to have one in the near future.  May have never had a CRC screening test in the past.
-\(\sigma^* \dagger\)	DECISION/DETERMINATION
	Has made a decision to have a CRC screening test. Is motivated and prepared to have a CRC screening test. Might have an appointment to have a CRC screening test.
	ACTION
12	Has had at least one CRC screening test within the recommended interval.  Intends to continue to have CRC screening at recommended interval.
* *	MAINTENANCE
	Has had at least 2 CRC screening tests at recommended intervals.  Intends to continue to have CRC screening at recommended intervals.
A	RELAPSE RISK
	On schedule with recommended intervals.  Not planning on having another CRC screening test.
	RELAPSE
	Has had at least one prior CRC screening, but now off schedule.  No repeat CRC screening within recommended interval.  Not planning to have another CRC screening test.

Adapted from: Steve Taylor, DHSc., Mercy Family Medicine Residency, Denver, CO. Built around the work of Prochaska, DiClemente and Norcross (see <a href="American Psychologist">American Psychologist</a>, 47: 1102-14,1992.)

Table 3: Summary of Stages of Change

Concept	Definition	Application
Precontemplation	Unaware of problem. Hasn't thought about change.	Increase awareness of need for change, personalize information on risks and benefits.
Contemplation	Thinking about change in near future.	Motivate, encourage making specific plans.
Decision/Determination	Making a plan to change.	Assist in developing concrete action plans, setting gradual goals.
Action	Implementation of specific action plans.	Assist with feedback, problem-solving, social support, reinforcement.
Maintenance	Continuation of desirable actions or repeating periodic recommended step(s).	Assist in coping, reminders, avoiding slips/relapses.

Glanz, K., and Rimer, B. (1995). <u>Theory at a Glance: A Guide for Health Promotion Practice</u> (p 18). U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health.

#### **Decisional Balance**

Movement through the <u>stages</u> is influenced by a person's view of the potential advantages and disadvantages of changing a behavior. Weighing of the pros and cons is referred to as **decisional balance**. (7) On a sheet of paper, the clinician and the patient create a chart organizing the reasons for changing and the reasons for remaining the same.

	No Change	Change	
Old	Like about?	Worried	
Behavior	LIKE about:	about?	
New	Worried	Like about?	
Behavior	about?	Like about?	

Some recommend beginning the conversation by asking, "What do you like about the current habit?" After listing these things, the clinician can next ask what concerns the patient has about the habit.

Then the new behavior is considered. Concerns and worries about the new behavior should be listed first, then the potential benefits.

A completed decision balance chart can help clarify the patient's stage and inform what steps to take. In precontemplation, the cons exceed the pros, either in number or in magnitude. The chart also reveals the specific reasons why the individual does not want to make a change in behavior. In the action and maintenance stages, there is positive decisional balance; that is, pros outweigh the cons.

#### **Decisional Balance and Colorectal Cancer Screening**

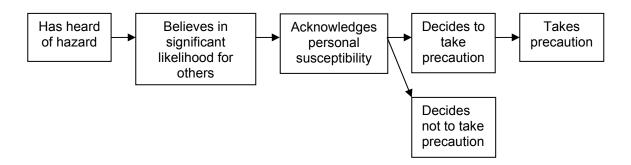
Figure 4 is a sample decisional balance chart for CRC Screening. Note that not all patients will think of all the items on this chart. Some will have concerns or expectations that are not included here. Decisional balance exercises can be particularly useful for patients who are hesitant to undergo screening.

Figure 4: The Benefits and Drawbacks of Having Regular Colorectal Cancer Screening

Benefits of Having Regular Screening	Drawbacks of Having Regular Screening
Every person is at risk of developing CRC.  It detects colorectal cancer early, before symptoms are noted.  When colorectal polyps or cancer are detected early there is a greater chance of cure.  Treatment is easier and can begin promptly when cancer is detected early.  Insurance companies pay a portion of the cost of CRC screening, as does Medicare.  Risk of complications is extremely low.  Can reduce the colorectal cancer death rate by 33%.	Takes time. Costs money. May be uncomfortable-test or preparation. Not foolproof - some polyps or cancers may be missed. If something is found, treatment will be necessary which may cause discomfort Rather not think about it or know if I have cancer. I may not get colorectal cancer and therefore it's not necessary. May get biopsy unnecessarily.
Endorsed by major health organizations.  Benefits of Not Having Regular Screening	Drawbacks of Not Having Regular Screening
No discomfort from the procedure or preparation.  Can save money.  "What I don't know won't hurt me."  Don't have to travel and wait for procedure to be completed.  Time saved.  Don't have to consider the chance of error.  Don't have to find a qualified gastroenterologist.  Don't have to follow through if something is found.	Always wondering and worrying that "something" might be growing.  Poor role model for other family members.  Not assuming responsibility for own health maintenance.  Treatment options may not be as good.  Cancer can show up at any time - one FOBT, flexible sigmoidoscopy or colonoscopy is not sufficient.  Lose opportunity to find disease before there are symptoms.  Greater chance of death due to late stage of detection.

#### **Precaution Adoption Model**

The Precaution Adoption Model (PAM) is a theoretical paradigm of preventive behavior. It defines an orderly sequence of cognitive steps that individuals must complete in order to modify behavior. (8)



Like the Transtheoretical Model (TTM), PAM is a theory comprising multiple stages. It assumes two important points:

- People at specific points of the PAM behave differently than those in other parts of the model.
- The types of interventions that move people closer to action vary by stage.

The PAM has seven stages. The first three stages address an individual's belief about his or her susceptibility to harm. A person in the first stage is **unaware** of the hazard. In the second stage, the person **has heard of the hazard**, but does not necessarily apply it to himself. This stage may include *optimistic bias*, the incorrect belief that one's own risk is less than that of others. Given vague information, obtained from mass media or acquaintances, people may fail to personalize their own risk. In the third stage, additional hazard messages have convinced the person that the risk is **personally significant**. Personal experience, education about specific risk factors, and witnessing of precautions taken by peers can all help move a person to this stage.

According to the PAM, once a person perceives a significant personal threat, he or she will examine the severity of the hazard, look at the effectiveness of precautions, and calculate the cost involved before deciding whether to act. (Cost is defined in terms of time and effort, monetary expense, undesirable side effects, and loss of pleasure secondary to behavior change.) This process leads to the next three stages of the PAM: the **decision to act** or **not to act** and the **action** itself.

Finally, if the person takes action and then chooses to continue the behavior he has started, he may reach a seventh stage: **maintenance** of the behavior.

#### **Factors Influencing the Decision to Act**

A number of factors influence the progression from intention to action.

- Certain versus probabilistic outcomes. The cost of adopting a new behavior is obvious and "certain": it takes time, it costs money, it involves inconvenience. The benefits, in contrast, may be hypothetical: with screening, there is only a possibility that the hazard (e.g, colorectal cancer) will ever appear.
- Salience. The way in which a hazard is "framed" impacts the attention that an individual gives to it. For example, discussing a procedure in terms of survival, as opposed to mortality, results in different choices.
- Time dependency of costs and benefits. Time dependency refers to how quickly a cost or a benefit will manifest. Research reveals that short-term consequences may weigh more heavily than long-term effects in making decisions.
- Direct influence on the decision to act. When the subject matter is
  particularly complicated, information is difficult to obtain, the experience
  with the hazard is limited, and/or the cost of acting is relatively small,
  decisions may be made based on the opinions and behavior of others.
- The role of emotions. Emotions such as fear and worry are powerful in their ability to focus attention on a given hazard and to personalize the risk of that hazard. Emotions can affect behavior modifications positively or negatively.

#### **Taking Action**

Major obstacles such as lack of access to medical care or financial cost may deter an individual from deciding to act. However, minor barriers like locating necessary information and lack of time management skills may be enough to prevent a person from taking action. In many cases, time constraints are the rate-limiting factor. Reaching the action stage depends also on the complexity of the precaution, on the availability of information, and on reminders to take action.

#### The PAM and Colorectal Cancer Screening

The PAM is most applicable to complex, non-habitual behaviors with an emphasis on cognitive issues. This paradigm is particularly relevant to cancer screening.

According to the PAM, before a patient will agree to screening he or she must

#### Stage 1

Have heard of colorectal cancer.

#### Stage 2

Understand that CRC is a deadly disease that affects many people.

#### Stage 3

• Recognize his or her personal susceptibility to colorectal cancer.

#### Stage 4 and 5

- Decide that being screened for CRC would be beneficial.
- Decide that the benefits outweigh the costs (e.g., fear of screening, distaste for the screening method, the need to take time from work for a screening appointment).

#### Stage 6

Carry through with screening.

#### Stage 7

Continue on the recommended screening schedule.

## **Physician-Patient Communication**

An effective physician-patient encounter includes constructive information exchange and optimal decision-making. Research reveals that a favorable patient-physician dynamic positively affects short, intermediate and long-term patient outcomes. (9)

Physician empathy, courtesy, and encouragement of questions have been associated with patient satisfaction, compliance and comprehension. Reflective listening, communicating at a patient's level of understanding, and addressing a patient's daily living situation have been shown to enhance information exchange. In addition, research suggests that patients who are integrally involved in their own medical decisions have better health outcomes. (9)

#### **Shared Decision Making**

Several decision-making models exist. One option is the traditional **informed choice model**, in which information regarding the available options and their statistical success rates is presented objectively. This exchange, also termed the **independent choice model**, has been criticized because it removes the physician's influence and guidance in the name of patient autonomy. On the opposite end of the continuum is the **paternalistic approach** to medical decision-making. This "doctor knows best" approach may spare patients the anxiety of making difficult choices, but the lack of patient autonomy is felt to outweigh any such benefit.

In between these two options is **shared decision making**, which combines informed consent with physician guidance. In this model, the physician uses his or her knowledge and experience to help the patient choose the option that best matches that person's goals, values, and beliefs. Some experts have suggested that every conversation addressing medical decisions should follow this model and include the six tasks listed below. (10)

Table 4: Elements of a Decision Making Conversation

Discuss the clinical issue and type of decision to be made.

Review all the alternatives.

Discuss the risks and benefits of all alternatives.

Explain the uncertainties involved and the consequences of refusing specific alternatives.

Assess the patient's understanding.

Provide an opportunity for the patient to express a preference.

Braddock CH III, Finn SD, Levinson W, et al. How doctors and patients discuss routine clinical decisions: Informed decision making in the outpatient setting. *J Gen Intern Med.* 1997; 12: 339-345.

Research has revealed that patients of physicians who use participatory decisionmaking are more satisfied with their care and have better health outcomes. So do patients who actively seek out medical information, ask questions and express their opinions. (10)

The "tools" needed for shared decision-making include knowing the patient, providing complete information, individualizing one's style, handling disagreement, and guiding patients to more information. (9) Familiarity with a patient's values and goals, as well as his/her fears, can help the physician to guide a patient toward the appropriate medical decision. At the same time, providing complete information and fully informing a patient about a disease is imperative. Even people who do not want to participate in making medical decisions often appreciate any information relevant to their medical condition.

In addition to providing information, the physician must be flexible in his or her approach to imparting information. Different patients will have different levels of medical understanding, of interest, and of ability to participate in decision-making. The desire for information tends to be lower among elderly patients, those younger than 30, and those with less education. (10)

Directing patients to appropriate sources of information, such as a credible website on the Internet (e.g., the <u>American Cancer Society</u>), can be helpful and reassuring. (10) This is best accomplished after the physician has determined the patient's values, goals and fears, as well as the patient's <u>health literacy</u>.

A potential barrier to shared medical decision making is disagreement between physician and patient. Determining the source of the disagreement can help direct the course of action. A patient may refuse a treatment because he or she thinks it would be useless; on the other hand, the patient may simply be afraid of side effects and need reassurance that a treatment is safe. Sometimes, arranging for a second opinion can facilitate resolution of disagreements.

In some cases, cultural differences impede doctor-patient communication. Shared decision making requires exploring this possibility and tailoring the conversation to address cultural values as well as physical, psychological, and informational needs. "Culture" can include religious, ethnic, and even regional heritage. There may be great diversity within these groupings. Interpretations of values may differ from person to person even if their cultural heritage is shared.

If a patient's capacity to make a decision is impaired, further evaluation of the patient's competence may be warranted, especially in potentially life-threatening situations.

### **Shared Decision Making and Colorectal Cancer Screening**

An important part of shared decision making is informing the patient about possible advantages, disadvantages, risks and benefits of a given test or treatment. The checklist in Table 5 may help you and your patients differentiate the CRC screening modalities and select the most appropriate one.

**Table 5: Considerations for CRC Screening Options** 

Test	Advantages	Disadvantages
Stool testing	<ul><li>□ No bowel preparation</li><li>□ Done at home</li><li>□ No risk of bowel tears or infections</li></ul>	<ul> <li>□ Requires handling stool</li> <li>□ Will miss most polyps and some cancers</li> <li>□ High false-positive rate</li> <li>□ Colonoscopy necessary if abnormalities are detected.</li> </ul>
Guaiac-based fecal occult blood test	□ Supported by randomized controlled trials	□ Dietary restriction needed prior to test □ Must be performed annually
Fecal immunochemical testing	<ul><li>□ No need for dietary restriction</li><li>□ Minimal handling of stool</li></ul>	□ Must be performed annually
Stool DNA test	□ No need for dietary restriction	<ul> <li>□ Appropriate screening interval uncertain</li> <li>□ A relatively new technology, not as well studied as some of the other options</li> <li>□ Tests common DNA mutations, will miss cancers that do not have these mutations</li> <li>□ Strict requirements for submitting sample (must send with ice pack, can only send on certain days)</li> </ul>
Flexible sigmoidoscopy	<ul> <li>□ Brief procedure</li> <li>□ Done in office</li> <li>□ No need for sedation</li> <li>□ May allow biopsy/removal of some polyps</li> <li>□ Needed only once every five years</li> </ul>	<ul> <li>□ Requires bowel preparation</li> <li>□ Does not check upper half of colon</li> <li>□ May involve some discomfort</li> <li>□ Very small risk of bowel tear</li> <li>□ Colonoscopy necessary if abnormalities are detected</li> </ul>
Double-contrast barium enema	<ul> <li>□ Views entire colon</li> <li>□ Needed only once every five years</li> <li>□ No need for sedation</li> </ul>	<ul> <li>□ Will not reveal very small polyps or cancers</li> <li>□ Requires full bowel preparation</li> <li>□ Some discomfort during test</li> <li>□ Very small risk of bowel tear</li> <li>□ Colonoscopy required if abnormalities are detected</li> </ul>
Colonscopy	<ul> <li>□ Views entire colon</li> <li>□ Allows biopsy and removal of polyps</li> <li>□ Need only once every ten years</li> <li>□ Can diagnose other disease</li> </ul>	<ul> <li>□ Requires full bowel preparation</li> <li>□ Sedation usually needed</li> <li>□ Usually requires missing a workday</li> <li>□ Risk of bowel tears is low, but higher than other options</li> <li>□ Can miss small polyps</li> </ul>
CT Colonography	<ul><li>□ Non-invasive</li><li>□ Brief procedure</li><li>□ No need for sedation</li></ul>	<ul> <li>□ Requires full bowel preparation</li> <li>□ Some radiation exposure</li> <li>□ May be more likely than colonoscopy to miss flat tumors</li> <li>□ Requires colonoscopy if abnormalities are found</li> <li>□ A relatively new technology, research on its effectiveness still in progress</li> </ul>

Adapted in part from: Foxhall, LE. Colorectal cancer screening: A renewed prescriptive. AAFP CME Bulletin 2003: Vol. 2(2).

## Risk Communication: Information for the Clinician about Colorectal Cancer Risk

Colorectal cancer is the third most common cancer in both men and women and the second leading cause of cancer mortality. Only prostate and lung cancer in men, and breast and lung cancer in women, are more common. The <a href="American Cancer Society">American Cancer Society</a> estimates that there will be 148,810 new cases of colorecal cancer and 49,960 deaths from CRC in 2008 in the United States. (45)

CRC has received widespread public attention in recent years. A number of celebrities have shared their diagnoses or discussed screening with the public. Awareness of CRC is important for three major reasons.

- Colorectal cancer is detectable by several screening modalities.
- Detection at an early stage has a substantial <u>impact on survival</u>.
- Risk can be modified by attention to medical history and lifestyle choices.

#### **Describing Risk**

Risk of colorectal cancer can be expressed in four ways: **relative risk**, **attributable risk**, **absolute risk** and **lifetime risk**. Each of these measures is useful for specific purposes, but their use in the popular media, where they are often taken out of context, can lead to confusion. Misinterpretation of statistics has caused a great deal of unnecessary fear in the general public. At the same time, misunderstandings can obscure the important message about the demonstrated benefits of early detection of colorectal cancer.

- Relative risk is a measure of the relationship between a given risk factor
  and a disease. It compares the incidence or mortality among individuals
  with a specific risk factor to those without that risk factor. The larger the
  relative risk associated with a given factor, the more likely it is to be an
  important factor for a disease. Relative risk is used mainly in describing the
  causes of a disease. For example, smokers have roughly a 10-fold
  increased risk of lung cancer compared to those who have never smoked,
  or a relative risk of 10:1. (14)
- Attributable risk addresses the question: How many cases of a disease could be eliminated if a specific factor were removed? It is the difference in incidence between those with a trait or exposure and those without that trait or exposure. Attributable risk is useful in gauging the importance of a risk factor from the point of view of public health. A factor can have a small relative risk and yet have a large attributable risk if it has a high prevalence in the population. This is true of the role of smoking in causing heart disease. The relative risk for heart disease among smokers compared to never smokers is much smaller than for lung cancer. However, even with a smaller relative risk, the number of cases of heart disease caused by smoking is larger than the number of lung cancer cases caused by smoking. Thus, the attributable risk due to smoking is greater for heart disease than for lung cancer.
- **Absolute risk** is the incidence of disease in a given population. It can indicate the magnitude of disease in a given population with a certain exposure. However it does not take into consideration the risk of disease in the unexposed population. (15)
- Lifetime risk is the probability that an individual in his or her lifetime will be diagnosed with, or die from, a certain disease. Both men and women in the United States have a lifetime risk of about 5-6% for colorectal cancer, or 1 in 19. (44) However, the risk only reaches this level if a person lives to be 85. (1) Rather than thinking about lifetime risk, it is more informative and less alarming to think about the probability of developing colorectal cancer within certain age intervals, as shown below:

AGES	PROBABILITY		
	<u>Males</u>	<u>Females</u>	
Birth to 39	1 in 1,329	1 in 1,394	
40 to 59	1 in 109	1 in 138	
60 to 69	1 in 63	1 in 89	
70 and older	1 in 21	1 in 23	
Birth to death	1 in 18	1 in 19	

Cancer Facts and Figures 2008. American Cancer Society.

### **Risk Factors for Colorectal Cancer**

#### Non-modifiable Risk Factors

**Age.** Incidence of colorectal cancer rises rapidly with age. 90% of cases of CRC are diagnosed in individuals older than 50. (45) The incidence in those 65 and over is almost 20 times that of those under 65. This makes age a much stronger risk factor than any of the personal health or lifestyle factors identified to date and discussed below.

Because of the strong relationship of age to colorectal cancer, early detection is most effective in older men and women. However, it is crucial to convey that early detection of colorectal cancer can increase the chance of survival at any age; screening should begin at age 50 in average risk patients, even though the risk is less at age 50 than at age 70. Routine fecal occult blood test (FOBT) can reduce the risk of dying from colorectal cancer by approximately 30% (16).

Personal history of adenomatous polyps. A personal history of adenomatous polyps increases an individual's risk of developing colorectal cancer. Histology of the polyps is critical: tubulovillous and villous adenomatous polyps have the greatest malignant potential. Individuals with tubulovillous or villous adenomatous polyps and those with adenomas greater than 1 cm are three times more likely to progress to CRC than those without such polyps. The National Polyp Study (NPS) revealed that removal of adenomatous polyps leads to a 76-90% decrease in the risk of developing CRC. (17) People found to have polyps on screening require more frequent follow-up; the NPS suggests that about a third of people with adenomatous polyps removed during colonoscopy will be found to have additional polyps at three years. (43)

**Family history of adenomatous polyps.** Individuals with a family history of adenomatous polyps in a first-degree relative (parent or sibling) have a 1.9 fold increased risk of developing CRC. (18)

Personal or family history of CRC. Persons with a personal history of CRC are at an increased risk of recurrence and development of new colorectal malignancies. In addition, according to a meta-analysis of studies of familial risk, a family history of colorectal cancer in one first-degree relative (parent, sibling, child) increases a person's risk by 2-3 fold. Those with two affected first-degree relatives have a risk approximately 4 times greater than the average risk population. In general, personal risk declines as the age of the affected family member increases, so that a diagnosis in a relative under 45 increases personal risk 3.8 times, while a diagnosis in a relative over age 59 increases personal risk only about 1.8 times. Colon cancer in a second-degree relative appears to increase risk by a lesser extent, about 1.5 times the average-risk population. (18)

Inflammatory Bowel Disease. Individuals with inflammatory bowel disease (IBD) are at increased risk of colorectal cancer, and the risk increases with the duration of IBD. The precise relative risk is not known. Studies differ in terms of duration of disease, advances in treatment may make earlier statistics inapplicable, and certain patients may have higher risk than others. (19) For ulcerative colitis, a 2002 meta-analysis offered cumulative cancer incidence rates of 1.6% after 10 years of disease, 8.3% after 20 years, and 18.4% after 30 years. More recent studies suggest lower cumulative incidence. The apparent decline may be due to treatment and increased vigilance, including medical therapy, surgery, and colonscopic surveillance. (35)

Studies of cancer in Crohn's disease also show increased risk, but the magnitude varies widely and many of these studies predate current treatments. Duration of disease, extent of disease, involvement of the colon, and presence of colonic strictures all appear to increase risk. (36)

**Genetic Syndromes.** Certain genetic syndromes predispose individuals to the development of colorectal cancer. **Familial adenomatous polyposis** (FAP) is an inherited or acquired germline defect in the adenomatous polyposis coli (APC) gene. Mutations in this gene result in the presence of thousands of adenomas blanketing the colon, with a nearly 100% risk of developing CRC. **Hereditary non-polyposis colorectal cancer** (HNPCC) is an autosomal dominant defect known to result from a germline mutation. The Finnish Cancer Registry revealed that 82% of people who carried this genetic defect developed CRC by age 70. (18) CRC typically arises in the right colon in individuals with HNPCC and appears at a younger age (<50 years). HNPCC is also associated with the appearance of multiple cancers in family members. The following extracolonic tumors may be found: endometrial, gastric, ovarian, hepatobiliary, urinary tract and small bowel. While diagnosis of HNPCC may be less obvious than that of FAP since it may resemble sporadic cancer, the presence of cancer in multiple first-degree relatives is a valuable clue.

#### **Modifiable Risk Factors**

A number of lifestyle factors are associated with colorectal cancer, either as risk factors or protective factors. It is important to understand that this information derives from observational studies, which have well-known limitations. For example, there may be something different about people who choose to adopt an intervention versus those who are randomly assigned to it. Nevertheless, studies strongly suggest that lifestyle factors play an important role in modifying the risk of colorectal cancer.

Many of these behaviors tend to cluster in the same individual. For example, physical activity appears to be protective for CRC, whereas obesity appears to be a risk factor. But since those who are physically active tend to be leaner, these two associations may point to a single underlying causal factor. Similarly, people who consume more fruits and vegetables and less meat (two dietary factors which may reduce CRC risk) are also likely to be less obese.

**Physical Activity**. Both leisure-time physical activity and job-related physical activity are associated with reduced risk for CRC. Several studies show a 40-50 percent reduction in risk for people who engage in regular exercise, with the largest reduction for people who are the most active. (20) Evidence for this benefit is stronger for men than for women.

The American Cancer Society recommends engaging in moderate physical activity (e.g., brisk walking, bicycling, vacuuming, gardening) for 30 minutes or more at least 5 times per week. Forty-five minutes or more of moderate to vigorous activity (e.g., running, aerobics, heavy yard work) is believed to augment the risk reduction. (37, 38)

Physical activity is particularly relevant with regard to Hispanics and African Americans. In 2005, 33.2% of Hispanic adults and 32.2% of African American adults reported no leisure time physical activity, compared to 22.2% of whites. (38)

**Red Meat**. Several prospective studies and meta-analyses have reported an increased risk for CRC with increasing consumption of red meat, but other studies have failed to demonstrate a connection. Two recent cohort studies, appearing in the Journal of the American Medical Association and the Journal of the National Cancer Institute, do support an increased risk in people with a high vs. low intake of red meat. (20, 21, 22) The American Cancer Society continues to recommend reducing red meat consumption.

**Multivitamin use.** Two large cohort studies have found a possible connection between decreased CRC risk and long-term intake of folate supplements or multivitamins with folate. Vitamin B6 may also help reduce risk. (23, 24) On the other hand, a 2004 meta-analysis of antioxidant vitamin use (beta-carotene and vitamins A, C, and E) found no decreased risk. (28) Recent studies suggest that magnesium may have a protective effect.

Calcium and Vitamin D. Epidemiologic studies suggest that calcium may have a protective effect against CRC. A Cochrane Review article in 2005 found some evidence in populations already at increased risk due to previous adenomas. However, the evidence was not deemed strong enough to recommend the general use of calcium as a preventive measure. (29) More recently, Women's Health Initiative centers carried out a large, double-blind, placebo controlled study of calcium plus vitamin D intake and CRC risk in postmenopausal women. This study failed to find a reduction in risk, but the study period was only 7 years; the researchers note that the long latency of CRC could have contributed to the apparent null effect. (30)

**Obesity.** Obesity is associated with increased risk of CRC. In one study, obesity in premenopausal women was associated with a 50% increase in risk. (20) Obese men have been found to be at 40% higher risk. (32) Other studies have shown similar connections.

Fruits and Vegetables. A diet rich in fruits and vegetables may decrease the risk of CRC. In one large Swedish study, people consuming less than 1.5 servings of fruits and vegetables per day had a relative risk of CRC of 1.65, compared to people who ate more than 2.5 servings. However, an analysis of data from two large prospective studies, the Nurses' Health Study and the Health Professionals Follow-up Study, did not show a connection. (20) Neither did a 2006 Women's Health Initiative report of a randomized controlled trial which included increased fruit and vegetable intake as part of a low-fat diet, with 8 years of follow-up. (33) Further study will be needed to clarify any association. Meanwhile, the American Cancer Society recommends a diet rich in fruits and vegetables as a general preventive measure.

**Fiber.** Evidence for fiber as a protective factor is mixed. One meta-analysis of case-control studies showed a decrease in risk with consumption of fiber-rich foods. Other studies have supported this finding. However, the large, prospective Nurses' Health Study failed to show a decrease in risk, at least for women. (20)

**Alcohol.** Alcohol, particularly beer, is associated with increased risk of CRC. Both meta-analyses and later case-control studies support this finding. (20)

**Tobacco.** A connection between cigarette smoking and CRC is supported by multiple case studies as well as large cohort studies. Based on data from the Cancer Prevention II cohort study, 12% of colorectal cancers in the U.S. may be attributable to smoking. (20)

According to the Behavior Risk Factor Surveillance System data from 2005, 20.6% of all American adults, 20.4% of White adults, 20.7% of African American adults, and 19.5% of Hispanic adults currently smoke. (40)

**Aspirin.** Aspirin use is associated with decreased risk of CRC. For example, in the Health Professionals Follow-up Study of 47,000 men, those who took aspirin at least twice a week had a 30% reduction in risk compared to those who never took aspirin. The Nurses' Health Study showed a similar trend, although risk reduction did not become significant until after 10 years of use. There appears to be a doseresponse trend, so that higher intake is associated with lower risk. However, this must be balanced against the risk of gastrointestinal bleeding. (20) The U.S. Preventive Services Task Force does **not** recommend aspirin for CRC chemoprevention, at least until benefits and harms are evaluated further. (34)

**Exogenous hormones**. Postmenopausal hormone therapy reduces the risk of colon cancer, but it is not recommended for prevention. A risk reduction of 20% was shown in a meta-analysis among women who had ever taken hormone replacement, compared to those who had never taken hormones. The largest reduction, 44%, was seen among current users. (26) It is not clear whether a longer duration of use confers greater protection. There was also a reduction in colorectal cancer reported among women taking combined estrogen and progestin in the Women's Health Initiative's randomized double-blinded clinical trial (hazard ratio 0.63). (27) Data from this study did show that cancers in the women taking HRT were more advanced at the time of discovery, however. (20) Because hormone therapy carries increased risk of other morbidities, such as heart disease, stroke, and thromboembolism, it is not recommended for the prevention of colorectal cancer.

## **Conclusions**

All average-risk patients age 50 or over should be screened for colorectal cancer. Screening can prevent cancer through removal of pre-cancerous polyps and can reduce morbidity and mortality by allowing prompt treatment if cancer is present. Patients at higher risk need earlier and/or more frequent screening, depending on the medical history.

Doctor-patient interactions provide multiple opportunities to steer patients toward screening and enhance compliance rates. Behavioral science offers useful frameworks for increasing colorectal cancer screening.

- Health Belief Model. Patient decisions are based on perceived seriousness of disease, ideas about personal susceptibility, perceived barriers vs. benefits, and personal confidence in ability to take action.
- Social Cognitive Theory. Decisions are influenced by reciprocal interaction with the environment, including sense of personal control, observation of others' behaviors, and expectations about outcomes.
- Stages of Change. Decision-making proceeds along a continuum from pre-contemplation to action. To be most effective, counseling should be tailored to the patient's current stage.
- Precaution Adoption Model. Taking precautions against a disease requires knowledge of the disease, impressions of general risk, and a conception of personal risk.
- Shared Decision-Making. Interactive communication helps prevent clinicians from prescribing screening modalities with which individual patients are unlikely to comply.

Both <u>primary</u> and <u>secondary prevention</u> of colorectal cancer are crucial to reduce colorectal cancer mortality. By promoting screening, clinicians can have an enormously beneficial effect on their patients. Discussing an individual's perception of his or her own colorectal cancer risk, thoughts about screening, and perceived benefits and barriers can favorably influence his or her decision to obtain regular colorectal cancer screening.

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## **DEFINITIONS AND LINKS**

### **Outcome expectations**

The belief that a behavior will produce a specified outcome or effect.

## **Self-efficacy**

The belief in one's ability to take control of behavior, as well as the confidence that one can successfully perform a specific task.

## **Observational learning**

Acquiring information and skills through the actions of others.

#### Reinforcement

A response to behavior which can influence whether or not that behavior will be repeated. Positive reinforcements or rewards make it more likely that the behavior will be repeated. Negative reinforcements, either punishment or lack of response, tend to make repetition of the behavior less likely.

## **Stages of Change**

- Precontemplation
- Contemplation
- Decision/Determination
- Action
- Maintenance

## **Health Literacy**

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

### **Screening Modalities**

From the 2008 guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology:

Testing Options for the Early Detection of Colorectal Cancer and Adenomatous Polyps for Asymptomatic Adults Aged 50 Years and Older

## Tests that Detect Adenomatous Polyps and Cancer

Flexible sigmoidoscopy every 5 years, or

Colonoscopy every 10 years, or

Double-contrast barium enema every 5 years, or

Computer tomographic colonography every 5 years

### **Tests that Primarily Detect Cancer**

Annual guiac-based fecal occult blood test with high test sensitivity for cancer, or

Annual fecal immunochemical test with high test sensitivity for cancer, or

Stool DNA test with high sensitivity for cancer, interval uncertain

Adapted from: Levin B, et al. Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. CA Cancer J Clin. March 5, 2008; e-pub ahead of print.

#### Five Year Survival Rate for CRC

Stage of Disease	5-Year Survival Rate
<b>Localized:</b> cancer is confined to the organ of origin.	90%
<b>Regional:</b> cancer has affected adjacent organs or lymph nodes or both.	65%
Distant: cancer has metastasized.	9%

## **Primary Prevention**

Measures intended to prevent the onset of a targeted disease.

## **Secondary Prevention**

Measures intended to interrupt, minimize, or prevent the progress of a disease in its early stages.