The Important Role of Primary Care Providers at the Beginning of the Cancer Journey

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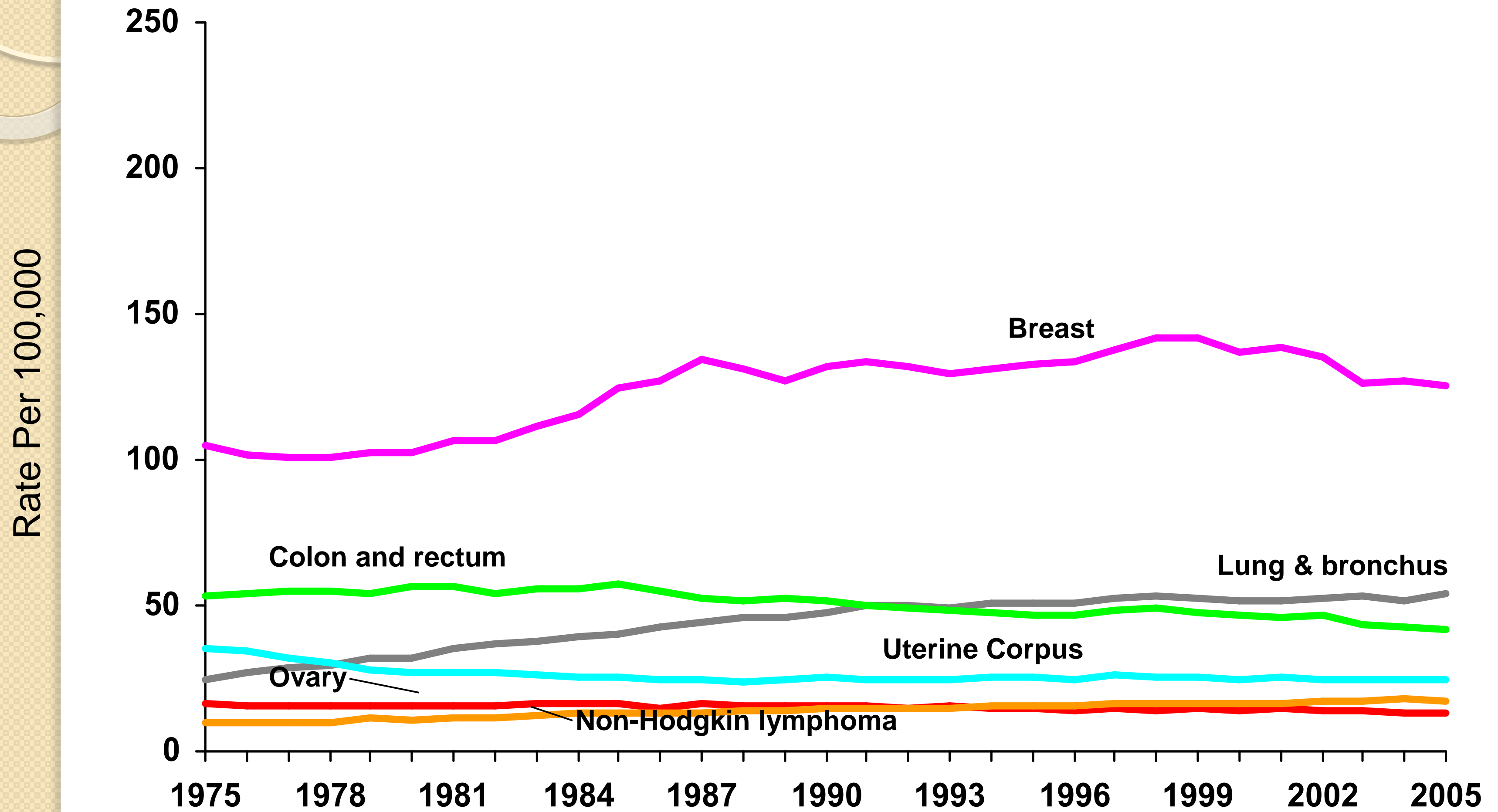
The five "C's" of Primary Care

- First Contact
- Continuous
- Comprehensive
- Coordinating
- Care

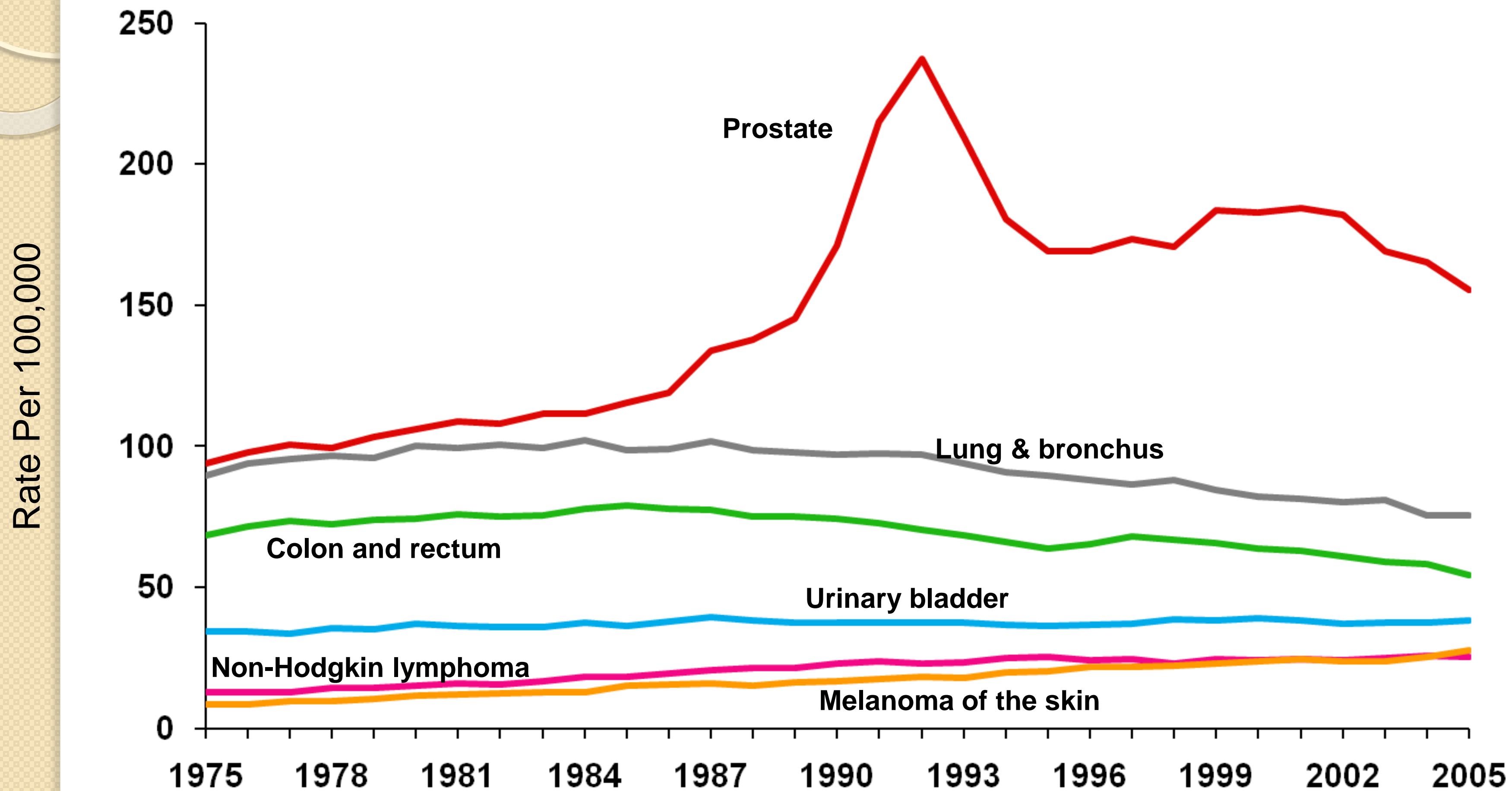
Cancer Rates in America

Cancer **incidence** rates for women



*Age-adjusted to the 2000 US standard population and adjusted for delays in reporting.
Source: Surveillance, Epidemiology, and End Results Program, Delay-adjusted Incidence database: SEER Incidence Delay-adjusted Rates, 9 Registries, 1975-2005, National Cancer Institute, 2008.

Cancer **incidence** rates for men



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Primary Care Role in
“Cancer Care”

Cancer Care Continuum

Prevention
- Diet/Exercise
- Sun Exposure
- Alcohol
- Tobacco Control
- Chemo-prevention

Early Detection
- Cancer screening
  - ✓Pap test
  - ✓Mammogram
  - ✓PSA/DRE
  - ✓Fecal occult blood test
  - ✓Colonoscopy
- Awareness of cancer risk, signs, symptoms

Diagnosis
- Oncology/ surgery consultation
- Tumor staging
- Patient counseling & decision making
- Clinical trials
- Informed Decision Making

Treatment
- Chemotherapy
- Surgery
- Radiation
- Symptom management
- Psychosocial
- Maintenance therapy

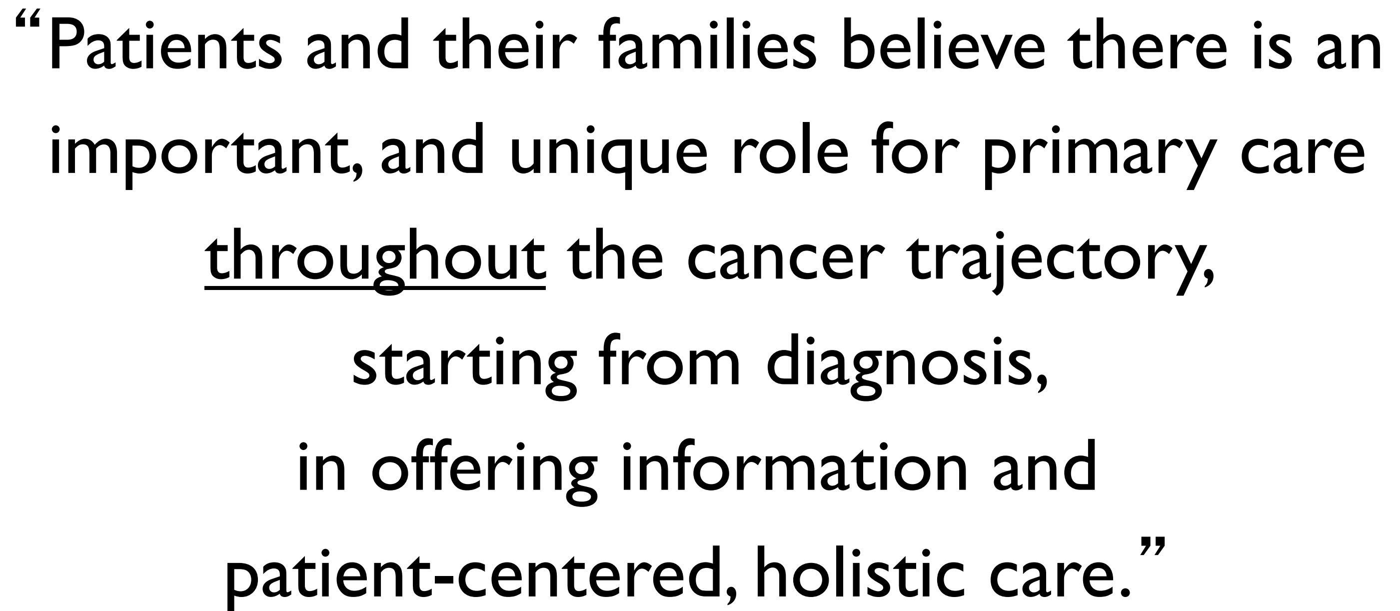
Survivorship
- Long-term follow-up/ surveillance
- Manage late-effects
- Rehabilitation
- Coping
- Health promotion
- Prevention
- Palliative Care

End of Life
- Support *patient & family*
- Hospice
- Informed decision making

Phase

Important priorities for cancer services affected by primary care

- Cancer risk reduction
- Early detection of cancer or late complications of cancer treatments
- Timely access to specialist treatment
- Support of patient throughout cancer care



Kendall, M et al. Family Practice (2006) 23(6).

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Phase

Cancer care before treatment

Primary Care Responsibilities & Cancer Care

- Before diagnosis
- During diagnosis
- After diagnosis and before treatment

- Cancer risk assessment
- Cancer prevention
- Cancer screening

Cancer Risk Assessment

- Some patients have a higher than average risk for particular cancers
  - Age and gender specific
  - Lifestyle risk factors
  - Family history / genetic predisposition
    - BRCA mutation carriers (breast, ovary)
    - Lynch syndrome (uterine, colorectal, stomach)

Cancer Prevention

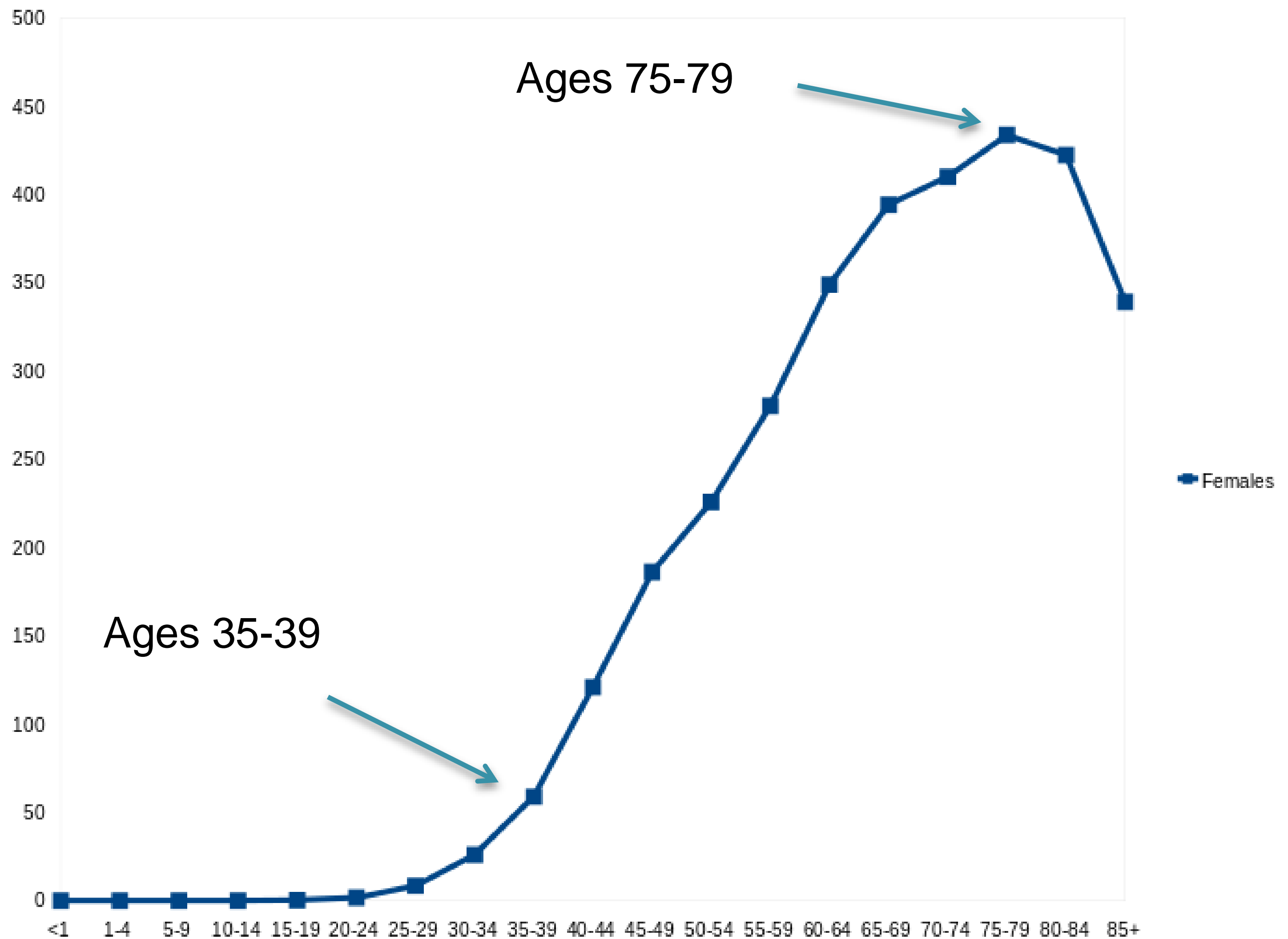
- Patient interventions: Lifestyle changes
  - 40% of cancers are due to factors that are within our control ("modifiable risks")
    - Smoking, obesity, sedentary lifestyle, excessive sun exposure, poor nutrition, no immunizations. unsafe sex
- Medical interventions for high risk pts
  - Breast cancer: Raloxifene, tamoxifen
  - Ovarian cancer: OCs, BSO

Source: Mayo Clinic

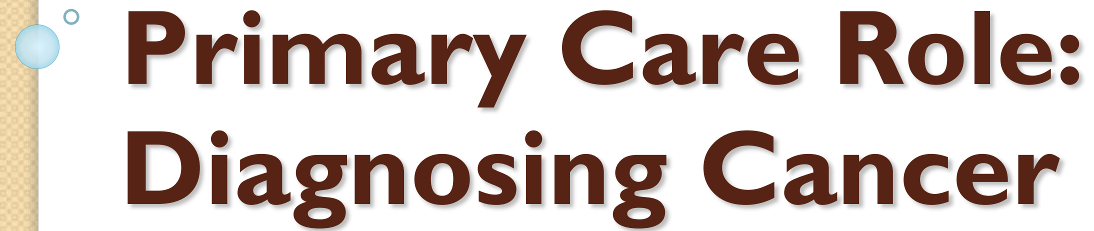
Cancer Screening

- Mammograms, PSA, pap test, colonoscopy
- Which tests for which risk groups?
  - Example: Breast cancer screening
    - Mammogram every 1 or 2 years?
- Screening intervals based on risk
  - Colonoscopy
    - Every 2, 5 or 10 years?
  - Pap smears
    - Every 1 or 2 years? Or never?

Age-Specific Breast Cancer Rate



Age-Specific SEER Incidence Rates, 2003-2007


Primary Care Role:
Diagnosing Cancer

Primary Care Responsibilities: Diagnosing Cancer

- Making the cancer diagnosis
  - Screening asymptomatic patients
  - Appropriate and timely work up of symptomatic patients
- Informing the patient/family of the diagnosis

Asymptomatic patients

- Primary care has almost exclusive role in ensuring that asymptomatic patients get appropriate and timely cancer screening
- Continuous debate about value in reducing mortality in certain populations of patients

Symptomatic patients

- 80% of symptomatic patients with common cancers first present with symptoms to their PCP.
- Work-up falls on PCP

Ferguson RJ, et al. Thorax 1996
Bain NSC, et al. Fam Pract 2000

Work up of Suspicious Sx/Signs

- Symptoms are usually non-specific and poorly predictive for cancer
- Patients consider this most important part of their "cancer journey"
  - Stage at diagnosis is most important determinant of survival

Jones R, et al. Br Med J 2001
Summerton N. Br J Gen Pract 2002
Auvinen A, et al. IARC Sci Publ 1997

The Clock Starts Now

- The patient's "Cancer Experience" begins at the moment cancer is suspected (i.e., palpable breast mass, abnormal screening mammogram).
- Patients need:
  - Timely and accurate communication
    - coordination of care
    - timely response to phone calls
- A bad experience at the onset will resonate through the duration of the cancer experience
  - Fumbled coordination can make some patients feel like they have to be hyper-vigilant for the remainder of their care.
    - "I didn't trust them to take care of me".

Kendall, et al. FP 2006;23:644-650
RRMG Patient Focus Group, 2011

Primary Care Role:
Informing the Patient

Informing the patient & family of cancer diagnosis

- PCP responsibility
- Patients prefer to hear result from PCP
- How information is convey is VERY important

Kendall, et al. FP 2006;23:644-650

Delivering bad news

Definition of bad news:

"Information that negatively alters the patient's view of the future."

"If we do it badly, the patients or family members may never forgive us;
if we do it well, they may never forget us."

Buckman R, 1992

"Bad News" and Cancer

- At time of initial diagnosis
  - *"You have cancer"*
- At time of recurrence
  - *"The cancer is back"*
- At the end of failed cancer treatment
  - *"The treatment is no longer working…"*
  - End of life discussion/hospice

S.P.I.K.E.S. mnemonic

- **S**etting the environment
- **P**erception
- **I**nvitation
- **K**nowledge
- **E**motions
- **S**trategy and **S**ummary

Baile WF, et al. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–311

S.P.I.K.E.S.

Setting the environment

- Privacy
- Introductions
- Appropriate people present
- Provide comfortable space
- Ensure no interruptions

Baile WF, et al. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–311

S.P.I.K.E.S.

- **P**erception
  - Prepare before speaking
  - Ask about patient's perception of what is going on

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S.P.I.K.E.S.

Invitation

- Ask questions to invite the patient into conversation
- Ask how much information the patient wants to hear

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S.P.I.K.E.S.

Knowledge

- Deliver the message
  - Use plain language
  - Be mindful of body language
  - Get to the point
  - Give information in small chunks…pause…
  - Wait for reaction
- Use "teach back" to verify that message was received

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S.P.I.K.E.S.

Emotions

- Be prepared for the patient's and family's emotional response
- Anticipate fear, anger, sadness, denial, guilt
- Be mindful of your own responses
  - You don't have to agree with a patient's emotional response in order to validate it
- Comfort the patient
  - Appropriate to culture, age and gender

Baile WF, et al. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302–311

S.P.I.K.E.S.

Strategy and **S**ummary

- Assess patient's readiness for planning
  - Negotiate next steps
  - Verify support structure
  - Acknowledge and answer question
    - Even if the answer is "I don't know yet"
- Summarize plan
  - Use "teach back" technique
  - Follow up plan

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Primary Care Role:
After Diagnosis and Before Onset of Treatment

Primary Care Responsibilities: Before Treatment*

- Coordination of care
  - Can be delegated to support staff
- Shared decision making regarding options
- Advocacy
  - Can be delegated to support staff
- Management of co-morbidities
- Psychosocial support

* and during treatment.

Coordination of Care
The Cancer Care Team

- Primary Care Physician
- Surgeon
- Medical Oncologist
- Radiation Oncologist
- Reconstructive Plastic Surgeon
- Radiologist
- Pathologist
- Anesthesiologist
- Lymphedema physical therapist
- Case manager/Navigator
- Psychologist
- Radiation Therapist
- Oncology Nurse
- Social Worker
- Occupational Therapist
- Prosthesis specialist

Shared Decision Making

- Regarding treatment choices
- An essential PCP function
  - Do not delegate to non-physician staff
- PCP can be "sounding board" for the patient and the family
- Appropriate for level of education
- Culturally sensitive
- Respectful of personal values

Decision making challenges

- Limited comprehension
  - Biology, human anatomy, science, statistics
- Cultural barriers
- Family dynamics
- Misinformation
  - from friends and family
  - Internet

Rutten LF, et al. NCI 2007; La Porta M, et al. J cancer educ 2007

Misinformation and the Web

- Cancer patients are among the most active users of the Internet.
- Up to 60% of cancer patients and their companions routinely use the Internet to search for information about their disease and treatment options.

Rutten LF, et al. NCI 2007; La Porta M, et al. J cancer educ 2007

NCCN GUIDELINES FOR TREATMENT OF CANCER BY SITE (www.NCCN.org)

- Acute Lymphoblastic Leukemia
- NCCN Guidelines
- Acute Myeloid Leukemia
- Anal Carcinoma
- Bladder Cancer
- Bone Cancer
- Breast Cancer
- Cancer of Unknown Primary (See Occult Primary)
- Central Nervous System Cancers
- Cervical Cancer
- Chronic Myelogenous Leukemia
- Colon/Rectal Cancer
- Lymphoma
- Myelodysplastic Syndromes
- Neuroendocrine Tumors
- Non-Hodgkin's Lymphomas
- Non-Melanoma Skin Cancers
- Basal and Squamous Cell Skin Cancers
- Dermatofibrosarcoma Protuberans
- Merkel Cell Carcinoma
- Non-Small Cell Lung Cancer
- Occult Primary
- Ovarian Cancer
- Pancreatic Adenocarcinoma
- Penile Cancer
- Prostate Cancer
- Small Cell Lung Cancer
- Soft Tissue Sarcoma
- Testicular Cancer
- Thymomas and Thymic Carcinomas
- Thyroid Carcinoma
- Uterine Neoplasms
- Cutaneous Melanoma (See Melanoma)
- Endometrial Cancer (See Uterine Neoplasms)
- Esophageal and Esophagogastric Junction Cancers
- Fallopian Tube Cancer (See Ovarian Cancer)
- Gastric Cancer
- Head and Neck Cancers
- Hepatobiliary Cancers
- Hodgkin Lymphoma
- Kidney Cancer
- Malignant Pleural Mesothelioma
- Melanoma
- Multiple Myeloma/Other Plasma Cell Neoplasms
- Multiple Myeloma

Psychosocial Support

- Cancer dx brings mix of reactions
  - Disappointment, fear, hopelessness
  - Guilt
    - Reexamination in relation to past life experiences, stressful events and bad habits
- Exacerbation of pre-existing mental illness
  - Post-Traumatic Stress Disorder
  - Depression, anxiety disorder, etc.

Psychological aspects of the cancer patients' education: thoughts, feelings, behavior and body reactions of patients faced with diagnosis of cancer. Klikovac, T and Djurdjevic, A. 2010, Journal of the Balcan Union of Oncology, pp. 15(1):153-6

“Good Medical Care”

IOM DEFINITION:

"The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. “

Institute of Medicine

“Good Medical Care”

PATIENT DEFINITION:

“Care that is individualized and provided by competent, non-judgmental, compassionate doctors and their staff who listen, communicate clearly, and follow-up when they say they will.”

RRMG Patient Focus Group, 2011

Best model for Primary Care to provide optimal cancer care?

- No clear winner
- Patient-centered medical home holds great promise
- Whatever the model of care, the patient's PCP will still need to remain closely involved or else optimal cancer care will not be realized.

Stay involved

Stay in touch

Email questions

AShaw@RRMG.com