Familial Risk and Colorectal Cancer Screening

December 8th, 2016
1:00pm ET
Purpose of Today’s Webinar

• Understand what we know and don’t know about CRC screening for those with a familial risk of CRC
• Review the recent article: *Understanding the contribution of family history to colorectal cancer risk and its clinical implications: A state-of-the-science review*
• Consider results, implications and recommendations for next steps
• Q&A
Presenters:

Paul Schroy III, MD, MPH (Moderator)
Clinical Director
Boston Medical Center
NCCRT Family History and Early Onset CRC Task Group Co-chair

Dennis J. Ahnen, MD
Gastroenterology of the Rockies
Professor Emeritus, University of Colorado School of Medicine
NCCRT Steering Committee Member and Family History and Early Onset CRC Task Group Co-chair

Jan Lowery, PhD, MPH
Analytics Data Scientist
Catholic Health Initiatives Institute for Research and Innovation
Why Focus on FH?

• Basis of Hereditary CRC Syndromes
• Risk Factor for “Sporadic” CRC
  • FH changes screening recommendations but….
    • Guidelines vary
    • Screening rates are low
CRC Risk Factors

Demographic
- Country of origin
- Age
- Sex
- Race/Ethnicity
- SES
- Family History

Lifestyle
- Obesity
- Low Physical Activity
- Smoking
- Alcohol

Diet
- High Red/Processed Meat
- Low Fiber
- Low Fruits and Vegetables

Failure to get screened
Familial and Hereditary CRC

- Sporadic (≈ 70%)
- Familial (≈ 25%)
- Lynch Syndrome (2-3%) (HNPCC)
- Familial Adenomatous Polyposis (<1%)
- Rare CRC Syndromes
CRC Risk Factors- Age and FH

Family History of CRC Increases Risk

[Graph showing screening intensity levels]

Lifetime Risk 5%

Having an FDR with an advanced adenoma is associated with similar increases in risk of CRC
Colonoscopy Rates Are Improving In FDRs

Colonoscopy within 10 years

Percent

80

60

40

20

0

FDRs ≥50

Non-FDRs ≥50

Tsai et al. Prev Chronic Dis 2015;12:140533
Colonoscopy Rates Improving But…

Colonoscopy within 10 years

Tsai et al. Prev Chronic Dis 2015;12:140533
Why Focus on FH?

• FH of CRC or Advanced Adenoma is.....
  • Common
  • Important risk factor that alters screening recommendations but screening rates are low
  • Review current state of knowledge and identify gaps and opportunities
Purpose and Goal

• To understand the state-of-the-science around Family History and Colorectal Cancer relative to:
  ▪ CRC risk
  ▪ Screening rates, barriers and facilitators
  ▪ Interventions
  ▪ Tools used to collect family history

• Information gleaned will inform:
  ▪ Research gaps and needs
  ▪ How/where to prioritize efforts to improve screening
  ▪ Need for collaborations between current NCCRT members and new partners
Methods

• Conducted comprehensive literature review of articles published within past 10 years around 6 questions:

Q1: What are the risks for CRC associated with a FH of CRC or adenomas?

Q2: What are the existing screening recs for persons with a FH of CRC or adenomas?

Q3: What are the rates of adherence to screening recs among persons with a FH of CRC or adenomas?

Q4: What are the predictors and barriers to CRC screening in high-risk populations?

Q5: What interventions have proven effective for improving screening rates in high risk populations?

Q6: What types of tools are available for assessing FH to inform CRC screening?
Methods

• Standardized protocol for search, inclusion criteria, abstraction and synthesis

• Identified and reviewed 5,280 articles; 76 met criteria and included

• Results presented in terms of ‘what is known’ and ‘what is not known’

• Findings reviewed by expert panel convened by NCCRT

• Provide 8 recommendations for next steps
Q1: What are the risks for CRC associated with a FH of CRC?

*If SDR with CRC, range = 1.22-2.49 fold higher risk
Q1: What are the risks for CRC associated with a FH of adenomas?

Risk of CRC associated with FH of adenoma (n=4 studies)

**What is not Known? To what degree are hereditary cancers included?; role of environmental factors; few studies on adenomas (by type, size, location)**
Q2: What are the existing screening recommendations for persons with a FH of CRC or adenomas?

What is known?

- Guidelines for high risk exist from 7 organizations
  - ACS, NCCN, MSTF, ACG, ASGE, American College of Physicians (ACP), Institute for Clinical Systems Improvement (ICSI)

- Guidelines consistent if 1 FDR with CRC <60; differ if FDR >=60

- 2 of 7 specify ‘advanced adenoma’; 5 only ‘adenoma’

- Only 3 of 7 contain recs if affected is SDR
### FH Risk Group

<table>
<thead>
<tr>
<th>FH Risk Group</th>
<th>Recommended Screening Exam</th>
<th>Starting Age Interval</th>
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<tbody>
<tr>
<td>1 FDR with CRC or Adenoma/Adv Ad &lt; age 60 or &gt; 1 FDR with CRC</td>
<td>Colonoscopy</td>
<td>40 or 5-10 years younger than earliest CRC in family q 5 yrs</td>
</tr>
<tr>
<td>1 FDR with CRC or Adenoma/Adv Ad &gt; age 60</td>
<td>Any (ACS,MSTF) or Colonoscopy (NCCN,ACG,ASGE) or No rec (ACP,ICSI)</td>
<td>40 or 50 q 5-10 yrs</td>
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**Q2: What are the existing screening recs for persons with a FH of CRC or adenomas?**
Q2: What are the existing screening recommendations for persons with a FH of CRC or adenomas?

What is not known?

- Provider adherence; who is using what? What are patients being told and do they understand the guidelines?

- Limited evidence to support recommended intervals
Q3: What are the rates of adherence to screening recs among persons with a FH of CRC or adenomas?

What is known?

• Rates are low: EVER had colonoscopy <50% (26-54%)
• Lower adherence to risk-appropriate screening: ~30%
• Even lower adherence over time: ~6%
• Population-based estimates suggest that screening rates are improving, though NOT for persons 40-49

What is not known?

• Adherence over time? Few studies examine this
• Adherence in general population – current surveillance systems cannot adequately measure risk-appropriate screening
**Q4: What are the predictors and barriers to CRC screening in high-risk populations? PATIENTS**

<table>
<thead>
<tr>
<th>Facilitators/Predictors</th>
<th>Barriers</th>
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<tbody>
<tr>
<td>• Physician recommendation</td>
<td>• No symptoms</td>
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<tr>
<td>• Multiple affected relatives</td>
<td>• Fear of test; anticipated pain</td>
</tr>
<tr>
<td>• Relationship with affected family member (closeness)</td>
<td>• No doctor recommendation</td>
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<tr>
<td>• Social influence of family and friends</td>
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</table>
Q4: What are the predictors and barriers to CRC screening in high-risk populations? PROVIDERS

Facilitators/Predictors

• Access to simple messages about risk with practical rules for applying recommendations
• Communication with patients about risk based on FH
• Targeted educational messages

Barriers

• Lack of educational resources for managing high risk patients
• Poor systems for capturing family history
• Challenges in talking with family members

What is not known?

- How much of non-adherence is due to patients not knowing the guidelines?
- How to communicate risk? Will this improve screening?
- Need effective interventions to test methods of communication within families
- Will systematically collecting FH change outcomes?
Q5: What interventions have proven effective for improving screening rates in high risk populations?

What is known?

- 8 studies (RCTs); various approaches and strategies (mail, phone web-based, in person); behavioral theory; study populations; definitions of FH and follow-up time
- Targeted, behavioral interventions moderately increase screening adherence in FDRs (*11-30% increase*)
- More **intensive** interventions = bigger impact

What is not known?

- Will these have long lasting effects?
- Can these interventions be implemented into clinical or population-based settings and will they be effective?
- Lack systems for identifying persons at increased risk who would be eligible for targeted interventions
Q6: What types of tools are available for assessing FH to inform CRC screening?

What is known?

• Several freestanding tools exist; vary broadly in their intended use, inputs and endpoints
  — focus on FH collection, risk assessment or both
• Can provide guidance on screening, CRC risk
• Publically-available and private/commercial

What is not known?

• Few tools evaluated for reach, utility, acceptability
• How to link tools with EHRs?
• Does collecting FH change clinical practice?
Recommendations

#1: Establish a clinical consensus regarding the essential elements of a high quality FH section of the EHR that can be entered into EHR or integrated from FH tools

#2: Advocate including FH collection and updates as a quality metric in primary care

#3: Catalyze an effort to come to a consensus on screening guidelines for individuals with a single FDR with CRC > age 60

#4: Conduct additional studies to assess risk of CRC associated with a FH of adenomas and efficacy of interval screening in persons at increased risk

#5: Educate primary care providers on appropriate use of guidelines for high risk

#6: Develop standard reporting metrics for disclosing endoscopy findings (specifically information about polyps) and screening recs for at-risk relatives to patients

#7: Enlist efforts from patient advocate groups and state cancer registries to promote CRC screening for family members of persons affected by CRC

#8: Collaborate with national/local organizations that promote and/or monitor CRC screening (ex. CRCCP, NCCRT, BRFSS, NHIS) to include high risk groups
Recommendations

#1: Establish a standardized, core set of data items for collecting cancer family history directly into EHRs, or integrating these into EHRs from family history tools

#2: Require collection and updates of family history as a quality metric in primary care

#3: Catalyze an effort to come to consensus on screening guidelines for individuals with a single FDR with CRC > age 60

#4: Conduct additional studies to assess risk of CRC associated with a family history of adenomas (specified according to size, histology of polyp), and efficacy of interval screening in persons at increased risk

#5: Educate primary care providers on appropriate application of guidelines for high risk patients

#6: Develop standard reporting metrics for disclosing endoscopy findings (specifically information about polyps) and screening recommendations for at-risk relatives to patients

#7: Enlist efforts from survivor groups and state cancer registries to promote CRC screening in family members of persons affected by CRC

#8: Collaborate with national/local organizations that promote and/or monitor CRC screening (ex. CRCCP, NCCRT, BRFSS, NHIS) to include high risk groups
What:
• Participants took a 18-question online Delphi survey

Participants:
• 30 experts- PCPs, GCs, GI/CRC Surg

Purpose:
• To try to develop consensus around the minimal essential content that should be expected in the family history section of any high-quality electronic health record (EHR).

Domains:
1. Goals
2. Essential elements- sites, relatives, polyps?
3. Maintained- by whom and how often
4. Capacities
5. Incentives
Goals of FH Section of EHR

- Identifying patients who meet clinical criteria for genetic counseling/testing for Lynch syndrome and Hereditary Breast and Ovarian Cancer syndrome
- Identifying patients who meet clinical criteria for genetic counseling/testing for any hereditary cancer syndrome
- Identifying patients who should be referred for genetic counseling
- Identifying patients who should have a more detailed family history obtained
- Identifying patients who are at higher than average risk for colon, breast, endometrial, or ovarian cancer and who, as a result, should have more intense screening
- Identifying patients who are at higher than average risk for any cancer due to family history and, as a result, should have more intensive screening and/or cancer
- Gathering sufficient data to allow for clinical decision support when changes in cancer screening, recommendations occur
Consensus

- Goals of FH Section-ID pts who....
  - Should be referred for GC
  - Are at higher risk of any cancer due to their FH and need more intensive screening
  - Meet criteria for hereditary cancer syndrome

- Elements essential in PMH
  - PH of all cancers and colon polyps with age at diagnosis

- Elements essential in FH
  - All affected FDRs and SDRs with ages (option for range)
  - All cancer types that would change screening recommendations
Consensus

• Data Elements should be
  – Entered as discrete options in searchable fields
  – Importable from FH tool or patient portal
  – Updated when new information becomes available but no discrete time
• FH section should have capacity to provide
  – Alert for elevated cancer risk due to FH/hereditary cancer or need for different screening
  – Links to current FH-based screening guidelines
• Linkage of FH to decision making should be....
  – Incorporated by vendors
  – Guided by national standards

No consensus that FH collection/updates should be a quality metric
#1: Establish a standardized, core set of data items for collecting cancer family history directly into EHRs, or integrating these into EHRs from family history tools

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## Guidelines - Increased Risk Group

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<td>1 FDR ≥ 60 or ≥2 SDRs CRC/Adenoma</td>
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<td>NCCN</td>
<td>1 FDR ≥ 60 CRC</td>
<td>Colonoscopy</td>
</tr>
<tr>
<td></td>
<td>1 SDR with CRC &lt; 50</td>
<td>Colonoscopy</td>
</tr>
<tr>
<td></td>
<td>FDR with Adv Aden</td>
<td>Colonoscopy</td>
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Discuss CRC Screening with Primary Care Professional by age 40
CRC Screening By Age Group

CRC Screening Rate (%)

- 50-54
- 55-59
- 60-64
- 65+

(National Colorectal Cancer Roundtable)
Recommendations

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New brief for GIs on identifying high risk patients and families

Available at nccrt.org/80by2018
1. Take a focused family history annually for every patient in your practice.

2. Keep abreast of the colorectal cancer screening guidelines for patients with a family history of colorectal cancer or colonic adenomas.

3. Establish a process for referral or care for patients who meet high-risk family history criteria.

4. Identify intermediate/high risk families through the endoscopy suite.

5. Use or develop tools to provide screening recommendations to first degree relatives of patients identified to be at intermediate or high colorectal cancer risk.
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Join us for the following upcoming webinar:

Tuesday, January 10th, 2:00pm ET – How to Pay for Screening Navigation Toolkit
Save the date! Registration available soon at www.nccrt.org.

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