2021

Improving the Collection of the Family Health History: One Office's Experience

Danielle Marie Andrusko
CUNY College of Staten Island, Danielle.Andrusko@csi.cuny.edu

IMPROVING THE COLLECTION OF THE FAMILY HEALTH HISTORY: ONE OFFICE'S EXPERIENCE

Danielle Andrusko, DNP, ANP-C

WHAT IS THE FAMILY HEALTH HISTORY?

- Health record of a patient and his/ her relatives
- Includes the information of three generation of relatives including: children, brothers/ sisters, parents, aunts/ uncles, nieces/ nephews, grandparents and cousins
- Helps the healthcare provider assess a patient's risk for hereditary cancers and diseases

"AN ACCURATE FAMILY HISTORY IS A WELL-ESTABLISHED METHOD TO RECOGNIZE GENETIC DISORDERS AND SUSCEPTIBILITIES THAT MAY POSE RISKS FOR FUTURE HEALTH PROBLEMS. IT REMAINS ONE OF THE MOST POWERFUL "GENETIC TESTS" TO IDENTIFY INDIVIDUALS AT RISK FOR INHERITABLE DISORDERS"

American Medical Association, 2004[1]

WHY COLLECT THE FHH?

- Empower the patient and the healthcare provider

- Identify a patient at risk then:
  - patient can be proactive in managing their health
  - healthcare provider has guidance and evidence on recommendations for further testing/ screening

THE PROBLEM IN COLLECTION OF THE FHH: UNDERUTILIZATION

- Provider
  - Lack of time
  - Lack of knowledge
  - Lack of a standardized format

- Patient
  - Lack of family history knowledge
  - Lack of knowledge of importance of the FHH

NEED FOR PROJECT

- Need for improvement recognized by the CDC, NIH and the Surgeon General
- One survey showed that 96 percent of Americans believe that knowing their family history is important, but only one-third of Americans have tried to obtain a FHH.[2]
- Another study found that despite the launch of the Surgeon General's campaign, 93% still need "encouragement" to obtain their FHH. [3]

STATISTICS

- 5-10% of cancers, a hereditary genetic mutation is the cause. [4]
- Colorectal cancer is the third leading cause of death in the United States, fourth leading cause of death worldwide. [5]
- The American Cancer Society estimates the number of colorectal cancer cases in the United States for 2021 are: 104,270 new cases of colon cancer and 45,230 new cases of rectal cancer.[6]
- Evidence reveals that as many as 1 in 3 people who develop colorectal cancer have other family members who have had it and approximately 5% of people who develop colorectal cancer have inherited gene mutations that have caused the cancer.[7] These patients may have benefited from early FHH analysis which could have indicated earlier screening or a referral for genetic counselling

SITE

DLDC/ GI Medical Services

GI Practice

North Shore of Staten Island, NY

Consists: One MD, One NP and 6 office staff members

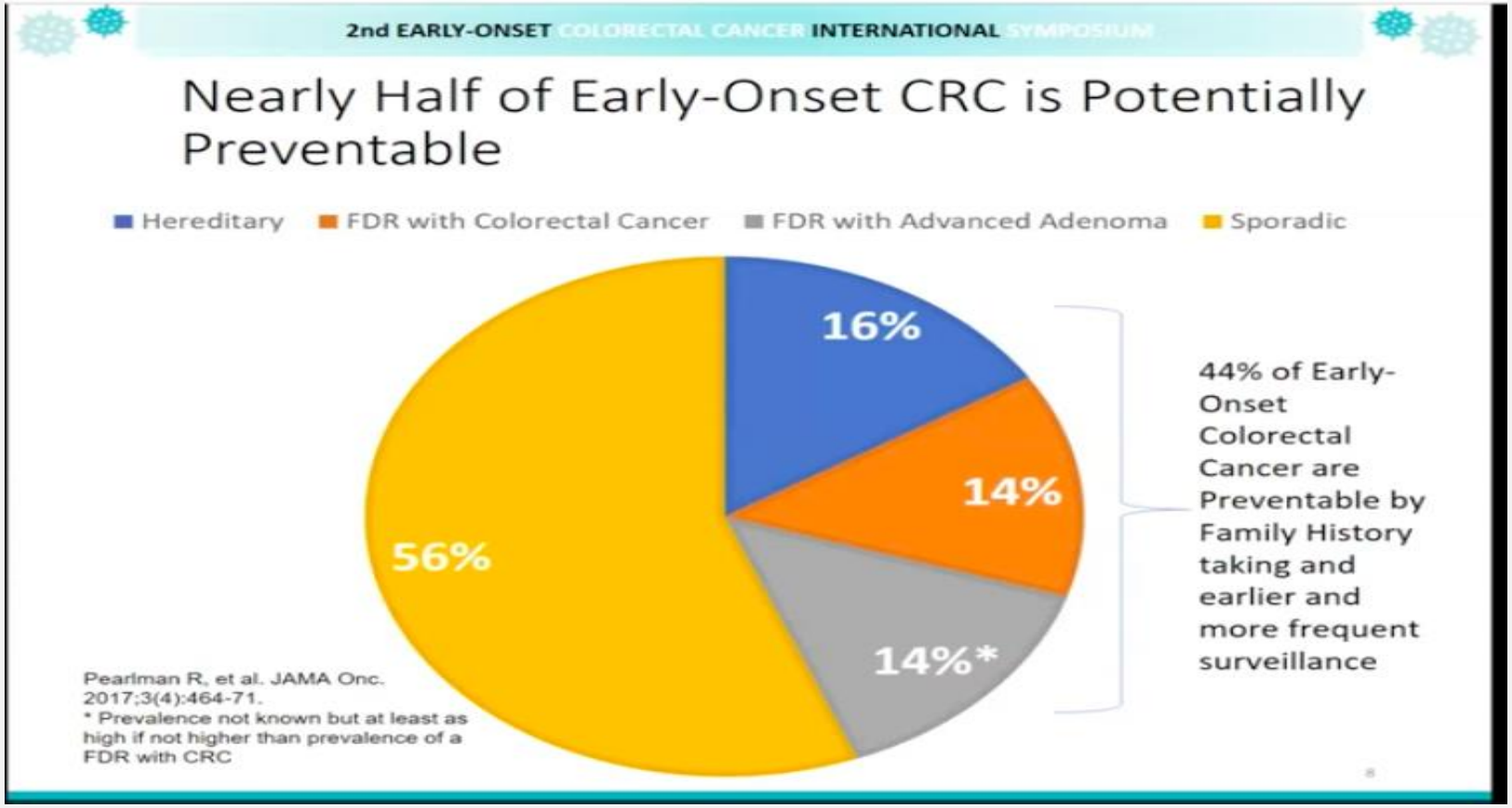
Patient screening for family history of cancer/ diseases- needs improvement

SITE RELATED STATISTICS

- In NYC, more than 1,200 adults die each year from colon cancer. Second leading cause of cancer death in NYC. In New York State the rate of developing colon cancer is 39.1 per 100,000 people. [8,9]

- There is a population affected by a cancer with potential genetic predispositions, which may benefit from early screening at project site.

GI CANCERS


2nd EARLY-ONSET COLORECTAL CANCER INTERNATIONAL SYMPOSIUM
Nearly Half of Early-Onset CRC is Potentially Preventable
Hereditary
FDR with Colorectal Cancer
FDR with Advanced Adenoma
Sporadic
16%
14%
14%*
56%
44% of Early-Onset Colorectal Cancer are Preventable by Family History taking and earlier and more frequent surveillance
Pearlman R, et al. JAMA Onc. 2017;3(4):464-71.
* Prevalence not known but at least as high if not higher than prevalence of a FDR with CRC

AIM

The aim of the project was to improve the collection of the FHH. The influence of patient education and use of an electronic app was used to determine if these two factors would improve the collection of the FHH, possibly resulting in heightened patient preventative strategies/ actions, such as genetic counseling or earlier/ increased screening practices.

OBJECTIVES

- To expand the patient's knowledge on the importance of the FHH
- Investigate if an app was a feasible and accurate tool to collect the FHH
- Determine if the app would offer the health care provider patient specific screening recommendations.

BENEFITS OF PROJECT

SHORT TERM BENEFITS

- Decrease patient anxiety of the unknown
- Encourage the patient to start health related behaviors
- Decrease potential hospitalizations and procedures
- Delay disease onset

LONG TERM BENEFITS

- Prevent avoidable death
- Improve the patient's quality of life
- Reduce prevalence of complications from genetic diseases and cancers

KURT LEWIN'S MODEL OF CHANGE

Unfreezing

- Convincing patients that the FHH is important and should be collected. This was done through patient education.

Movement

- Patients agree that the FHH is important and useful and collect the history through the app. FamGenix

Refreezing

- Patients continue to place importance on the FHH and educate others on it
- Patients share their FHH with other health care providers and their family members
- Patients expand upon/ add to the FHH when indicated

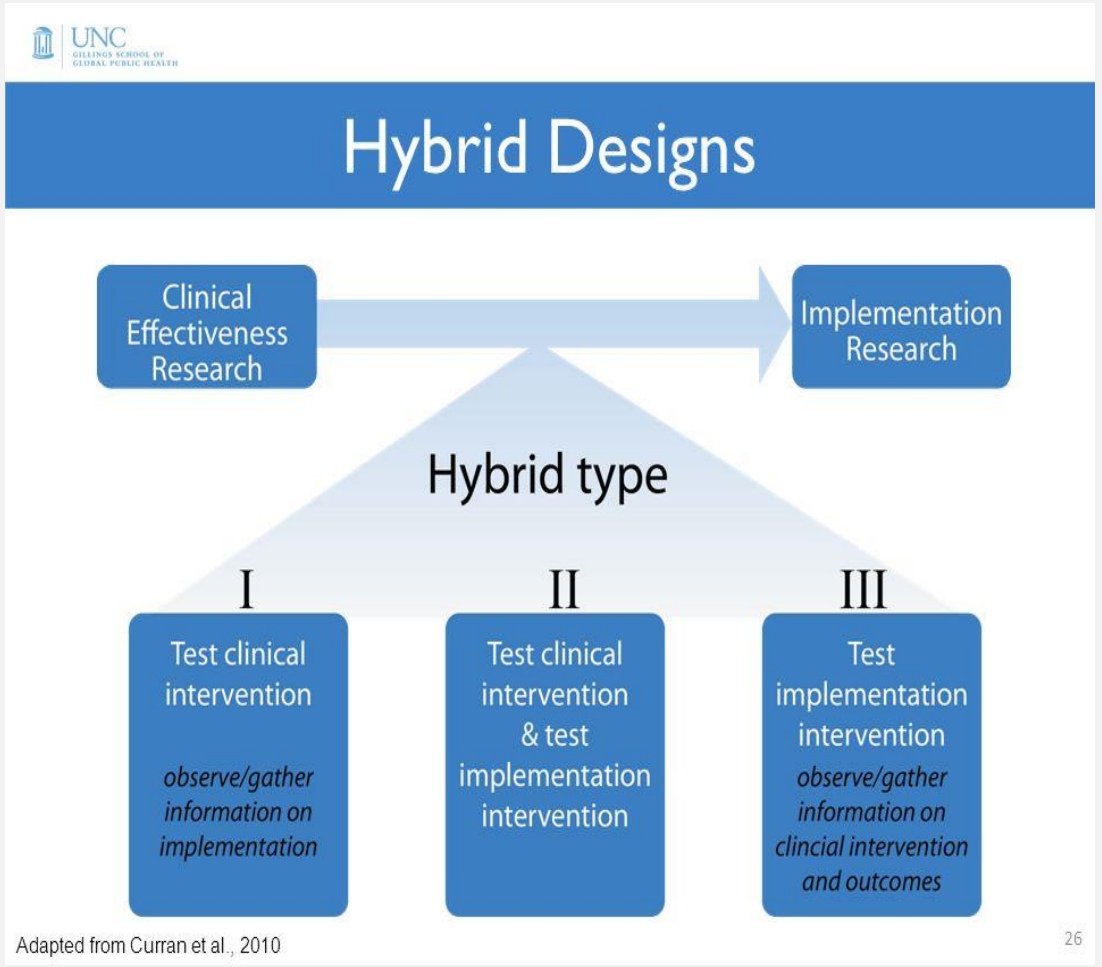
TIMELINE FOR PROJECT

- September 2020: Mailing out of information and request for patients to participate in the research
- October- November 2020: Collection of data
- December 2020: Analyzation and summarization of data

DESIGN

Hybrid Implementation Effectiveness Trial

Hybrid Type 3 = testing an implementation intervention (patient education and FamGenix app) while gathering information on the clinical intervention and related outcomes.



FUNDING

The project was financed through a grant in the amount of $3000.00 provided by the PSC/CUNY Professional Development Funds in the Adjunct and Continuing Education Teacher Series.

METHODOLOGY

Staff Education and Stakeholder Meetings

Meetings 2 weeks prior to start of project

Staff Education

Recruitment

Convenience Sample 200 + patients were invited to participate

Strict Inclusion Criteria

Recruitment through: Flyer and Personal Invitation

Enrollment

Aim = 20 patients

Express interest and then be provided materials for project

METHODOLOGY

Participant Instructions

1. Sign informed consent
2. Complete pre-intervention survey
3. Read the FHH pamphlet
4. Collect the FHH data from their family
5. Download the FamGenix app
6. Enter the FHH information and the appropriate clinician code into the FamGenix app

Pre-intervention Survey

Returned in office at time of sign up

Participant Education

Read pamphlet:*A Guide to Family Health History*

SURVEY

	Completely Disagree	Mostly Disagree	Somewhat Disagree	Somewhat Agree	Mostly Agree	Completely Agree
I can easily recall the health history for most of my relatives.						
Collecting family health history is helpful for understanding my own disease risk.						
Collecting family health history is helpful for understanding my family's disease risk.						
Family health history collection can help me reduce risks for heritable diseases (diseases that run in my family).						
Reporting family health history could aid in the early detection of chronic diseases including cancer.						
Family health history does not have the power to predict my personal health outcomes.						

FAMGENIX

METHODOLOGY

FamGenix	Confirmation of Participant Enrollment	Review
Download FamGenix App Enter Clinician Code Enter FHH	Two weeks prior Day Prior	Prior to follow- up visit healthcare provider will log in and review data

METHODOLOGY

Post-Intervention Survey

Occurred after patient has entered the data into the FamGenix App. This was given a paper copy of this at follow-up visit.

Discussion and Follow-up

Discussion of results and recommendation had with pt. at follow-up visit.

Referrals made at this time.

One month after referrals are made then the health care provider will follow up with pt. to ensure that pt. followed through with recommendations.

Patient Compensation

Delivered to participant at their point of completion.

ANALYSIS

Patient Knowledge	No statistical significance between the means of the pre and post intervention surveys indicates that patients are already aware of the importance of the FHH.
Patient Ability	Patient's accurate and complete data entry using the app demonstrates that an app/ electronic data entry may be an effective and time efficient way to gather patient FHH.
Accuracy of the FHH	In regard to improving accurate collection of the FHH, 4 participant's data (20%) that were entered into the app improved. This reveals that even with the awareness of the importance of FHH there is room for improvement in the collection of the FHH.
Identification of high-risk patients	Ten percent of the sample being newly identified as high risk for genetic cancer, demonstrates that electronic use of FHH apps/ programs may increase identification of patients that may potentially be affected by genetic cancers/ diseases.

LIMITATIONS

- Small sample size
- One practice
- Homogenous Sample
- Bias
- Patients had to be able to download and use the app

CONCLUSIONS

- Improving the collection of the family health history can increase the identification of patients at high risk for genetic diseases and cancers of adult patients in a gastrointestinal practice through the incorporation of a family health history tool and patient education.
- Collecting an accurate FHH does have the potential to result in earlier detection of genetically inherited cancers and diseases.
- Health care providers need to be aware of barriers of collecting an accurate FHH and also take the time to screen patients, but they then also need to know how to apply the data collected. Providers need to be aware of current screening guidelines and practices.
- Patients need to make a concentrated effort to collect an accurate family health history and in turn be prepared to share this information with their health care provider.

RECOMMENDATIONS

- Vary the Demographic
- Non-specialized medical practice
- Different Collection Tools

REFERENCES

1. American Medical Association (AMA). (2004). Family Medical History in Disease Prevention. file:///C:/Users/danie/Downloads/family_history02.pdf
2. Office of the Surgeon General, Office of the Assistant Secretary for Health (OASH). (2009). About the surgeon general's family health history initiative. Retrieved from https://www.hhs.gov/programs/prevention-and-wellness/family-health-history/about-family-health-history/index.html
3. Sweeney SM, Hastrup JL, Hyland A, Rivard C. A Follow-Up Community Survey of Knowledge and Beliefs About Cancer and Genetics. *J Cancer Educ*. 2016;31(2):253-260. doi:10.1007/s13187-015-0856-6
4. NIH National Cancer Institute. (2017). *Genetics.* Retrieved from https://www.cancer.gov/about-_cancer/causes-prevention/genetics
5. Centers for Disease Control and Prevention (CDC). (2017). *Colorectal cancer statistics.* Retrieved from: https://www.cdc.gov/cancer/colorectal/statistics/index.htm
6. Colorectal Cancer Statistics. Cancer.org. Accessed October 1, 2021. https://www.cancer.org/cancer/colon-rectal-cancer/about/key-statistics.html
7. Colorectal Cancer Risk Factors. Cancer.org. Accessed October 1, 2021. https://www.cancer.org/cancer/colon-rectal-cancer/causes-risks-prevention/risk-factors.html
8. New York State Cancer Registry. *Cancer Incidence and Mortality in New York State, 1976-2014.* Retrieved from: http://www.health.ny.gov/statistics/cancer/registry/.
9. NYC Health. (2018). *Colon Cancer.* Retrieved from: http://www1.nyc.gov/site/doh/health/health-topics/colon-cancer.page
10. Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. *Med Care*. 2012;50(3):217-226. doi:10.1097/MLR.0b013e3182408812