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Closing the Gap: Using the ECHO Model to Improve Access to Hereditary Colorectal Cancer Risk Assessment and Genetic Counseling in the Rural Setting

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Discover Health Systems

Brief Communication

Closing the gap: using the ECHO model to improve access to hereditary colorectal cancer risk assessment and genetic counseling in the rural setting

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Abstract

Background There is underutilization of colorectal (CRC)-related cancer genetic counseling services nationally, especially in underserved regions. Novel models of cancer genetic care in rural states like Maine are needed to narrow the practice gap, reflected in an improvement in the percentage of individuals meeting genetic testing guidelines referred for cancer genetic counseling.

Goal To lower the CRC cancer genetic counseling practice gap within a Maine-based integrated health system by building clinician capacity to identify hereditary CRC risk and facilitate provision of genetic counseling and testing services via the Project ECHO® hub-and-spoke telementoring model.

Intervention MaineHealth (MH) and The Jackson Laboratory (JAX) partnered to generate tools and systems to: (1) identify baseline MH practice gaps via a gastroenterology clinician needs assessment survey; (2) promote genetic assessment of CRC patients through a standardized risk assessment tool; and (3) implement and assess Cancer Genetic ECHO (CG-ECHO) to build clinician knowledge and confidence.

Outcomes Clinicians had variable baseline comfort levels with aspects of cancer genetic care. Most (68%) were comfortable performing an initial risk assessment; comfort levels were lower for providing pretest counseling (28%), selecting genetic tests (23%), and managing patients with variants of uncertain significance (41%). There was interest in education about choosing tests (67%), genetic testing indications (62%), and interpreting results (62%). Spoke site engagement and participation was low; participants included healthcare providers, trainees, and support personnel.

Conclusions Despite institutional support, staff effort and technology demands were barriers to developing and implementing CG-ECHO. Low participant recruitment and engagement posed significant challenges to CG-ECHO, likely reflecting competing demands, to include COVID-related burdens, on clinicians and institutions. These barriers and challenges are critical to the development and sustainability of future cancer genetic ECHO programs.

1 Background

A pivotal step in access to cancer genetic counseling and testing involves assessment of personal and family risk based on established criteria [1], and referral of those meeting criteria. However, there is a significant national practice gap, reflected in an underutilization of cancer genetic counseling and testing services in the US, particularly among underserved populations. The smaller, more economically-disadvantaged and isolated the community, the

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more difficult it is to access high-quality healthcare services. This is particularly the case with specialty care services, including cancer genetic counseling and testing [2–4].

The most rural state in the nation, 62% of Maine's ~ 1.3 million population live in geographically-remote communities [5–7]. Cancer is the state's leading cause of death; age-adjusted cancer incidence and mortality rates are higher than the rest of the nation [8]. Maine has focused on reducing colorectal cancer (CRC) incidence, in particular due to the potential for early detection and prevention through screening [9]. While the state's CRC incidence (20.6 per 100,000) is slightly lower than the national average (21.7 per 100,000), rates vary significantly, with the highest rates reaching 25.1 and 28.5 per 100,000 in Knox and Hancock counties, respectively [10, 11]. There are 629 new cases of CRC in Maine annually [11]. MaineHealth (MH) is the largest health system in the state, composed of 10 acute care hospitals, including a tertiary center, Maine Medical Center (MMC). Collectively, MH provides direct cancer care to 72% of cancer cases diagnosed annually statewide (unpublished data).

Based on familial clustering studies, an estimated 20–30% of colon cancers have a potentially identifiable genetic cause [12, 13]. Consistent with our own unpublished data, previous studies revealed a > 50% practice gap between CRC patients deemed eligible for genetic services versus those referred; with additional drop-off in those presenting for care, and further for those undergoing genetic testing [14]. Known sociodemographic barriers to care are negative predictors of a recommendation for genetic evaluation and testing [1]. Novel resources and models of care are needed to address this gap.

The Project ECHO model® (Extension for Community Health Outcomes) was initially conceptualized and developed at the University of New Mexico to improve access to liver specialists for patients with hepatitis C [15]. Regularly scheduled telehealth clinics bring together specialists, typically at an academic center (hub), and community-based providers (spokes). Learning is bidirectional, blending didactics and de-identified case presentations. Through shared problem-solving, this collaboration results in improved knowledge, skills, and self-efficacy among participating providers, thus increasing local capacity [16].

Worldwide, examples of ECHO implementation in oncology include cancer screening and prevention, management, survivorship, and palliative care, as well as disease-specific cancer ECHOs [17–19]. Large medical centers and organizations such as the American Cancer Society (https://echo.cancer.org) and the Association of Community Cancer Centers (ACCC) run multiple oncology-focused ECHO programs (https://www.accc-cancer.org).

Acknowledging ECHO as an evidence-based model to increase capacity to provide complex chronic care in medically-underserved communities, and capitalizing on institutional resources supporting growth of ECHO programs within the MH system, here we describe our experience developing and implementing Cancer Genetic ECHO at a health system level. The overall goal of this work was to reduce the MH CRC cancer genetic practice gap.

2 Methods

2.1 Setting and design

Per ethical standards, the MaineHealth IRB determined that this work was exempt from review as it was an assessment of an educational program, with a focus on institutional quality improvement. As an educational initiative, participant informed consent was not required. Based at Maine Medical Center, cancer genetic risk assessment and counseling services are offered via referral to the MH Cancer Risk and Prevention Program (CRPP), staffed at the time of this work by two physicians and five cancer genetic counselors. CRPP has historically served and continues to serve cancer-affected individuals as well as at-risk cancer-unaffected individuals. Referrals are made from primary and specialty care clinicians both within the MH system as well as outside the health system. Services are offered as traditional in-person visits at MMC or via telehealth, in partnership with two MH sites serving central and coastal regions of the state; with a shift toward fully remote, i.e., largely in-home, telehealth during the COVID-19 pandemic.

Mirroring national statistics, unpublished data on CRC referral rates collected prior to the pandemic revealed a > 50% practice gap in referral to cancer genetic services among new MH CRC patients. Recognizing ECHO's impact on increasing access to complex chronic medical care among medically underserved communities, we partnered with members of the Clinical Education Program at The Jackson Laboratory (JAX) to develop and implement the regional MH Cancer Genetic ECHO (CG-ECHO) to improve access to cancer genetic services among those at risk

for hereditary CRC. JAX is a non-profit genomic biomedical research organization; the Clinical Education Program empowers clinicians to integrate genomics into clinical practice.

The primary objectives of CG-ECHO were to: increase capacity of MH gastroenterology and oncology care team members to assess risk for hereditary CRC-associated syndromes; facilitate provision of genetic counseling and testing through either point-of-care services by local gastroenterology or oncology providers or referral to CRPP; support the short- and long-term management of test-positive probands; and promote cascade testing of at-risk relatives.

At the time of CG-ECHO development, MaineHealth had a Project ECHO program that was supporting the implementation of a range of ECHOs throughout the health system in non-cancer disciplines. This well-established program provided essential infrastructure to our team, to include access to a masters-trained ECHO program manager who supported all CG-ECHO development and implementation efforts, as well as state of the art telecommunication technology with links to all MH institutions. Our hub team was comprised of clinical staff from the MH CRPP, i.e., a medical oncologist and genetic counselor, members of JAX's Clinical Education team, and the MH Project ECHO program manager. To promote interest, meetings were held with stakeholders throughout the health system, including gastroenterologists, medical oncologists, nurse navigators, and oncology administrators. Discussions presented the ECHO aims and addressed cancer genetic service needs relative to the MH gap in provision of genetic services to those at risk for hereditary CRC. Identified site champions, representing the MH system, supported CG-ECHO implementation. Tools and systems were generated to drive this program. These included: a standardized hereditary CRC risk assessment and referral tool designed based on known hereditary CRC risk factors, to include suggestive features of the individual's personal or family history, or pathological evidence of tumor mismatch repair deficiency [20]; an inventory of CG ECHO learning objectives; communication systems to provide updates of CG-ECHO schedules, topics and cases; survey instruments to assess CG-ECHO attendee knowledge, attitudes and beliefs; and a dashboard to track numbers, backgrounds and locations of attendees longitudinally and by session.

Based on feedback from site champions, each hour-long, monthly CG-ECHO videoconference began at noon to minimize clinic disruption. Participants were recruited from initial stakeholder meetings with clinicians and navigator workgroups, as well as through the MH Cancer Care Network (MHCCN) newsletter, the MH ECHO website, word of mouth, and regional genetic counseling graduate programs. A list of CG-ECHO participants, to include email addresses, was generated and added to, based on attendance at each session. This list was used to distribute invitations in advance of each session. Hub team members began with a 15–30 min didactic presentation. De-identified cases were elicited from and presented by spoke sites with support from CRPP staff. Sessions without spoke site case presentations were supplemented with CRPP cases. Questions and discussions related to aspects of cancer genetic counseling and care did not need to align with the month's didactic topic. Review of cases was moderated by the hub team and intermittent guest faculty, offering feedback and promoting key messages to attendees.

2.2 Data collection

In advance of CG-ECHO implementation, a needs assessment survey was created to determine current needs relative to provision of cancer genetic care at a health system level, as well as relevant didactic topics of interest among gastroenterology providers. The survey was sent to Maine gastroenterologists and advanced practice providers through the Maine GI Society Listserv. Following ECHO implementation, a CME evaluation survey was distributed to participants after each ECHO session assessing demographic data, suggestions for future sessions, and educational outcomes, to include self-perceived gains in knowledge and confidence. Response to both surveys was voluntary and collected without personal identifiers.

3 Outcomes

Twenty-two out of 60 gastroenterology providers (36.7%) participated in the needs assessment survey. While 68% were comfortable performing cancer genetic risk assessment; confidence was lower for other aspects of cancer genetic care, including comfort choosing among genetic tests (23%), providing pretest counseling (28%), and managing patients with variants of uncertain significance (41%). Educational topics identified most frequently included choosing among genetic tests (67%), interpreting genetic test results (62%), and indications for cancer genetic testing (62%).

Table 1 CG-ECHO didactic topics

Educational topic
Family history collection: strategies and challenges
Risk assessment for CRC
Risk assessment for polyposis syndromes
Identification of hereditary risks through genomic tumor testing
Risk models for hereditary cancer syndromes
Genetic testing of minors
Pretest genetic counseling
Communicating with patients about genetics in plain language
Addressing financial barriers to genetic counseling and testing
Tumor-based testing for Lynch syndrome
Management of Lynch syndrome
Impact of tumor MSI status on management decisions
Pancreatic cancer screening: controversies and approaches

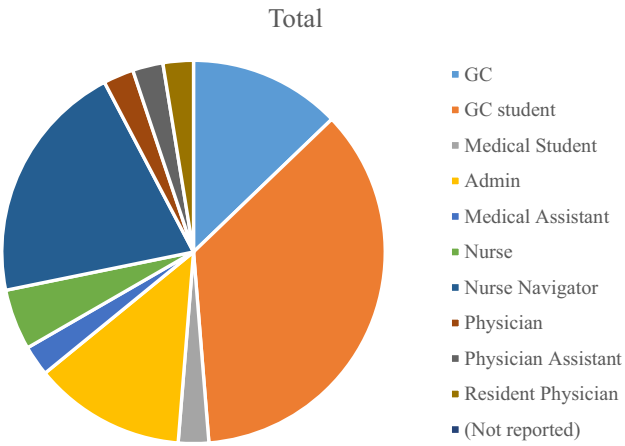

Fig. 1 CG-ECHO attendees by discipline. GC, genetic counselor; Admin, administration

From January 2021 to June 2022, 16 ECHO sessions were offered. Didactic topics, selected largely based on needs assessment results and CME survey feedback, are listed in Table 1. Several of these topics were presented more than once over the course of this program. Despite efforts to solicit cases from sites, a total of 7 cases were submitted and presented by spoke site representatives, all other cases discussed were hub site generated.

A total of 41 individuals attended one or more CG-ECHO sessions, in addition to seven faculty members tasked with providing didactic content. Summarized in Fig. 1, this included 19 from the intended target audience (physicians, nurses, nurse navigators, physician assistants, practice administrators), 17 trainees (residents, genetic counseling students, medical students) and 5 specialists (genetic counselors). Fifty-nine percent of attendees were from Maine; 41% were out-of-state genetic counseling trainees. Of those in Maine, 21% and 79% practiced in a rural versus non-rural setting, respectively. ECHO sessions had an average of 6.6 attendees (range 3–11) and each attended an average of 2.4 ECHO sessions (range 1–8). Forty-six CE credits were granted.

Across all CME evaluations, self-reported knowledge and confidence increased among attendees. Average knowledge increased from 2.67 out of 5 to 3.23 ($p < 0.0001$). Average confidence increased from 2.42 to 3.04 ($p < 0.0001$). For individual sessions with 5 or more completed evaluations, knowledge and confidence changes were assessed and shown to improve.

4 Discussion

The ECHO model is optimal for conditions that are common; require complex management for improved outcomes; have critical impact on public health and cost to society, particularly if untreated; and where best treatment practices are rapidly evolving [21]. Cancer genetics is an area in oncology care meeting these criteria. Despite this alignment, literature on the application of ECHO to improve access to hereditary cancer assessment and care is limited. In an earlier study of the ECHO model, one group -focused on improving access to genetic education and testing for patients with breast cancer-demonstrated provider interest, and increase in provider knowledge, as well as improved patient access to genetic education and testing from a five-session hereditary cancer ECHO. This program involved 76 participants, primarily serving rural patients across Kansas and Western Missouri [22].

The work described herein aimed to engage Maine providers in CG-ECHO through comprehensive cancer genetic education; coupled with case management, and risk assessment and referral support resources, collectively focused on reducing the hereditary CRC genetic counseling referral gap. We showed that CG-ECHO improved knowledge and confidence among attendees. However, despite frequent communication and requests for cases, competing demands on the target audience, to include the COVID-19 pandemic, resulted in low attendance and limited numbers of spoke site case presentations, the latter of which is a key tenant of the Project ECHO® model.

As MH had an established process and infrastructure for developing new ECHOs, administrative, technology and start-up cost were not barriers to CG-ECHO implementation. Critically, lack of institutional ECHO infrastructure and resources would be expected to pose a challenge for others considering development of cancer genetic ECHOs. Faculty time was partially grant supported; however, substantial hub-site program development and implementation effort impacted long-term CG-ECHO sustainability and expansion. Low participant engagement greatly impacted our ability to reach key stakeholders focused on reducing the hereditary CRC practice gap at the health system level. Specifically, there were few physician attendees, likely reflecting clinical demands.

Our experience with low CG-ECHO engagement and participation mirrors that of ECHOs in other disciplines. For example, an ECHO focused on medication-assisted treatment for opioid addiction in the primary care setting experienced challenges in recruiting and retaining participants, despite positive feedback on the program from attendees. System-level barriers, including insufficient support from leadership, and scheduling challenges likely impacted participation in this program [23]. Other published experiences revealed that ECHO implementation can be effort-intensive, and that participant recruitment and engagement can pose significant challenges due to competing demands [24, 25]. In their qualitative analysis of 5 distinct ECHO programs offered by the ECHO Center at the School of Public Health at Indiana University-Purdue University, justifying time spent in ECHO sessions and scheduling constraints were identified as top barriers to participation. However, once engaged, ECHOs provided value by promoting provider continuing education, networking, and access to expert opinion, as well as opportunity to address difficult cases [24].

The difficulty experienced by our team in engaging spoke site clinicians is relevant to the technically complex and evolving field of cancer genetics, and the well-recognized genetic practice gap among CRC patients. This is particularly relevant to those clinicians serving patients with healthcare disparities, to include geographic isolation, where access to cancer genetic services is often more problematic. Although we attribute some of the difficulties experienced in engaging clinicians to the added burden of the COVID pandemic, it is not likely that this was the full explanation for the low CG-ECHO participation rate among physicians. Attention to system-level barriers to CG-ECHO engagement should include support from leadership, and recognition of the need to make scheduling changes that allowclinicians to attend ECHO sessions. Efforts should also be taken to improve clinicians' awareness of existing cancer genetic practice gaps, and the impact that these gaps have on long term outcome of cancer survivors and their at-risk family members.

5 Conclusion

Our work highlights facilitators and barriers to developing and implementing a hereditary CRC-focused ECHO within a major health system, serving a substantial rural patient population. Hub site barriers included time demands, and significant administrative and technical support needs. Spoke site participant engagement proved to be a major limitation to CG-ECHO implementation, particularly among physicians. Competing demands on spoke site clinicians will likely continue to impact the development and sustainability of future cancer genetic ECHO programs nationally.

Author contributions Susan Miesfeldt, Stephanie Sharp, Linda Steinmark, Emily Edelman, Kate Reed and Kelly Barnes made substantial contributions to the conception or design of the work, or the acquisition, analysis, or interpretation of data; drafted the work or revised it critically for important intellectual content; approved the version to be published; and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Data availability The datasets generated and analyzed are not available publicly as they were collected as a component of our institutional educational initiative. These are available from the corresponding author upon reasonable request.

Declarations

This work was partially funded through the Maine Cancer Foundation. The authors declare no competing interests.

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