Knowledge, perceptions, attitudes, and barriers pertaining to genetic literacy among surgeons: a scoping review

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Background: The rapid evolution of genetic technologies and utilization of genetic information for clinical decision-making has necessitated increased surgeon participation in genetic counselling, testing, and appropriate referral of patients for genetic services, without formal training in genetics. We performed a scoping review to describe surgeons' knowledge, perceptions, attitudes, and barriers pertaining to genetic literacy in the management of patients who had confirmed cancer or who were potentially genetically at risk.

Methods: We conducted a scoping review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews checklist. We performed a comprehensive literature search, and 2 reviewers independently screened studies for inclusion. These studies included surgeons involved in the care of patients with confirmed gastrointestinal, breast, and endocrine and neuroendocrine cancers, or patients who were potentially genetically at risk for these cancers.

Results: We analyzed 17 studies, all of which used survey or interview-based formats. Many surgeons engaged in genetic counselling, testing, and referral, but reported low confidence and comfort in doing so. Knowledge assessments showed lower confidence in identifying genetic inheritance patterns and hereditary cancer syndromes, but awareness was higher among surgeons with greater clinical volume or subspecialty training in oncology. Surgeons felt responsible for facilitating these services and explicitly requested educational support in genetics. Barriers to genetic literacy were identified and catalogued at patient, surgeon, and system levels.

Conclusion: Surgeons frequently engage in genetics-related tasks despite a lack of formal genetics training, and often report low knowledge, comfort, and confidence in providing such services. We have identified several barriers to genetic literacy that can be used to develop interventions to enhance genetic literacy among surgeons.

Contexte : L'évolution rapide des technologies génétiques et l'utilisation d'information génétique pour la prise de décisions cliniques ont mené à une augmentation inévitable de la participation des chirurgiens aux conseils et aux tests génétiques ainsi qu'à l'aiguillage approprié des patients vers des services génétiques, sans pour autant avoir reçu la formation nécessaire dans le domaine. Nous avons effectué une synthèse exploratoire visant à décrire l'état des connaissances des chirurgiens, leurs perceptions et leurs attitudes à l'égard de la littératie génétique, et les obstacles auxquels ils se butent dans la prise en charge de patients ayant un diagnostic de cancer confirmé ou qui pourraient être génétiquement à risque.

Méthodes : Pour notre synthèse exploratoire, nous avons suivi la liste de vérification Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews. Nous avons effectué une revue exhaustive de la littérature, et 2 relecteurs ont évalué indépendamment les études à inclure. Les études retenues devaient porter sur des chirurgiens ayant participé aux soins de patients ayant un diagnostic confirmé de cancer du sein ou de tumeur gastro-intestinale, endocrine ou neuroendocrine, ou encore de patients présentant un risque génétique potentiel pour ces types de cancers.

Résultats : Nous avons analysé 17 études examinant les résultats de sondages ou d'entrevues. Beaucoup de chirurgiens donnent des conseils en génétique, prescrivent des tests et font des aiguillages, mais disent avoir peu confiance en leurs capacités et être peu à l'aise de le faire. Les évaluations des connaissances ont montré des niveaux de confiance inférieurs concernant la mise en évidence de configurations génétiques indiquant une transmission héréditaire et de syndromes héréditaires prédisposant au cancer, mais le niveau de connaissances était plus élevé chez les chirurgiens ayant un fort volume clinique ou une surspécialisation en oncologie. Les chirurgiens se

sentaient responsables de faciliter l'accès à ces services et ont explicitement demandé une formation complémentaire en génétique. Les entraves à la littératie génétique ont été recensées et classées à l'échelle des patients, des chirurgiens, et du système.

Conclusion : Les chirurgiens accomplissent régulièrement des tâches relevant de la génétique, bien qu'ils n'aient suivi aucune formation dans le domaine, et disent fréquemment avoir peu de connaissances sur le sujet et être peu à l'aise ou confiants lorsqu'ils doivent prodiguer de tels services. Nous avons mis en évidence plusieurs obstacles à la littératie génétique qui pourraient être abolis par l'élaboration d'interventions visant l'amélioration de cette littératie chez les chirurgiens.

The rapid evolution of genetic testing technology over recent decades has allowed genetic information to guide clinical care. Approximately 5%–10% of cancers are hereditary, and once an underlying germline mutation is identified, this information has implications for affected patients and their health care professionals when weighing management options, as well as for unaffected relatives who may benefit from screening, risk-reducing surgeries, or both.[1] Results from genetic testing are increasingly used in therapeutic decision-making pertaining to surgery and systemic therapy, such as the use of poly–adenosine diphosphate ribose polymerase (PARP) inhibitors in patients with genetic alterations causing ovarian, prostate, and breast cancer.[2,3] As such, there is a gap between the number of health care professionals with specialized training in genetics and the patients who may benefit from such services. Consequently, health care professionals with minimal or no formal training in genetics are increasingly required to provide basic services related to ordering tests, providing pretest counselling, and initiating clinical management.[4,5] However, there is growing evidence that these health care professionals may be ill-prepared to provide such services.[6–8]

Surgeons are frequently involved in the care of patients who require genetic services, including referral of patients identified to be at increased risk for further genetic risk assessment and counselling, appropriate counselling regarding screening and surgical management, and subsequent surveillance of those with confirmed cancer. However, little is known about surgeons' practices within those domains. Thus, we sought to perform a scoping review to summarize the current literature pertaining to knowledge of, perceptions about, attitudes toward, and barriers to referrals and genetic literacy among practising surgeons involved in the care of patients who had confirmed cancer or who were potentially genetically at risk.

Methods

We performed a scoping review of the literature to identify and summarize studies of referrals for genetic risk assessment and counselling, and knowledge, perceptions, attitudes, and barriers pertaining to genetic literacy among surgeons. This study was designed and conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR),[9] as well as the methodological framework developed by Arksey and O'Malley.[10]

Data sources and search strategy

We employed a comprehensive search approach to locate published studies and conference materials. A preliminary search was conducted in Ovid Embase, followed by an analysis of relevant citations, to identify applicable text words and subject headings. We developed a comprehensive search approach in Ovid Embase and then adapted it for Ovid MEDLINE and Web of Science Core Collection. All databases were searched from 2000 to August 2021 and limited to English language. The complete search strategies for all databases are provided in the supplementary data (Appendix 1, available at www.canjsurg.ca/lookup/doi/10.1503/cjs.001523/tab-related-content). All search results were imported into Covidence systematic review software for deduplication and screening. The reference lists of all eligible studies were screened to identify any additional studies.

Inclusion and exclusion criteria

Studies were included for analysis if they reported on knowledge, perceptions, attitudes, and barriers with respect to genetic literacy and referrals for genetic risk assessment and counselling among surgeons (i.e., general, colorectal, breast, and endocrine surgeons, and surgical oncologists) who manage the following cancer types: breast, colon, rectum, stomach, pancreas, thyroid, parathyroid, adrenal, and neuroendocrine or carcinoid. Studies were excluded if they assessed other cancer types or if they reported on surgeons within other surgical subspecialties (i.e., urology or urologic oncology, and gynecology or gynecologic oncology). Additional reasons for exclusion were studies involving pediatric populations and cancers, duplicate studies, abstracts with insufficient details for data abstraction and analysis, studies with inadequate surgeon-level data, or studies that summarized only clinical practice patterns.

Screening

Screening of studies for inclusion and analysis was conducted by 2 reviewers (Z.M.M. and L.Y.N.F.) independently. Any

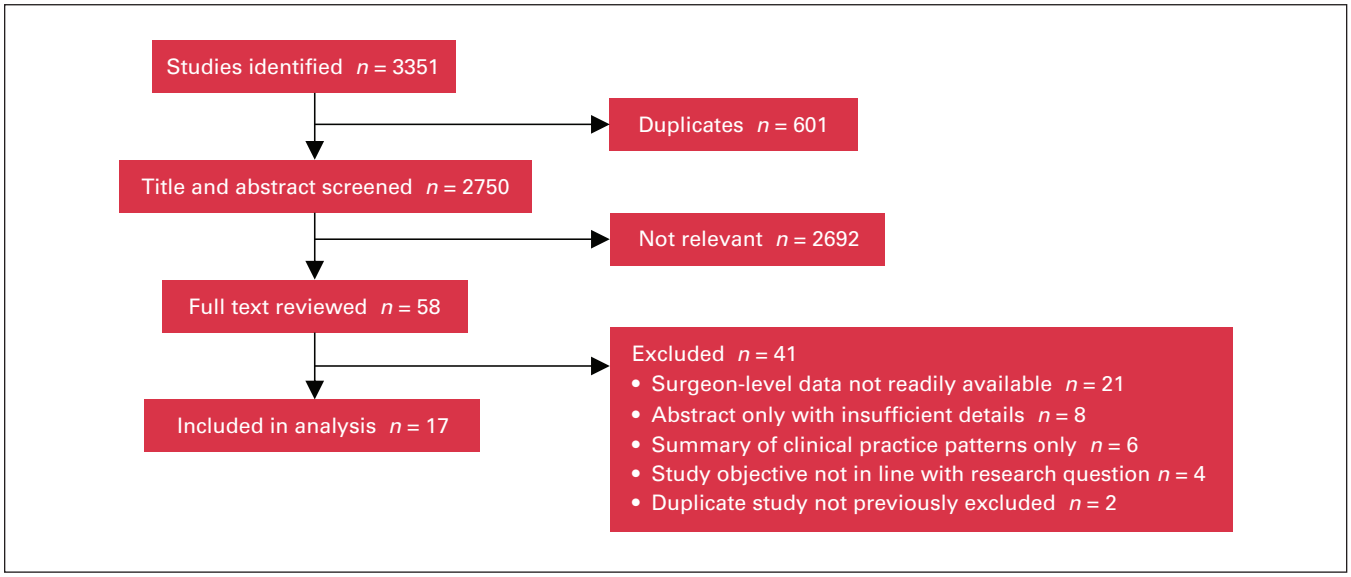

Fig. 1. Flow diagram of study screening and selection for final analysis.

differences were resolved through group discussion with an additional reviewer (S.J.M.).

Data abstraction and analysis

Two reviewers (Z.M.M. and L.Y.N.F.) abstracted the data from the included full-text articles independently and then cross-checked for discrepancies. A data abstraction table was developed a priori for this process, which included study details (i.e., year of publication, study period, analytic method, and study design), surgeons' knowledge, self-reported perceptions and attitudes, and barriers to referrals and genetic literacy. Thematic analysis was conducted to categorize barriers by patient-, surgeon-, and system-level factors.[11]

Results

Using the search strategy outlined, we identified 3351 studies, of which 601 were identified as duplicates and removed (Figure 1). After title and abstract screening, 58 studies remained for full-text review, and 17 were included in the final analysis.[12–28] The most common reason for exclusion of full-text articles was a lack of surgeon-level data (n = 21). The relevant details of each included study are provided in Table 1.

Among the 17 studies evaluated, the earliest was published in 2005. All studies used either survey (n = 14) or interview (n = 3) formats for data collection. Eight studies were from the United States, 6 were from Europe, 2 were from Australia or New Zealand, and 1 was from Canada. Analytic approaches included quantitative (n = 8), qualitative (n = 3), and mixed methods (n = 6). Five studies assessed surgeons' genetic knowledge, 17 studies characterized their perceptions and attitudes, 7 studies described barriers to genetic literacy, and 1 study evaluated an intervention to improve genetic literacy among surgeons.

Knowledge assessment

Five studies performed knowledge assessments of surgeons' genetic literacy (Table 2). These examined surgeons' awareness of the availability of genetic testing, understanding of genetic inheritance patterns, and familiarity with indications for genetic screening and surveillance, and referral for genetic risk assessment and counselling. Subspecialty-trained surgical oncologists reported higher awareness of genetic testing options and knowledge of the referral process for genetic risk assessment and counselling than those without subspecialty training (Table 2). Commonly, surgeons had some difficulty with questions testing genetic inheritance patterns and criteria to identify hereditary cancer syndromes.

Perceptions and attitudes

Most of the included studies provided surgeons' self-reported perceptions about and attitudes toward genetic literacy (Table 3). Across 4 studies, surgeons felt they should take on a leading role in referring patients for genetic testing or counselling.[12,16,25,27] Surgeon confidence and comfort with counselling patients regarding genetic testing or its results varied across 6 studies.[13,15,16,18–20] Repeatedly, surgeons acknowledged the need for improved genetic literacy and its value in their clinical practice.[12,13,15,21]

Barriers

We compiled all of the surgeon-reported barriers to genetic literacy, testing, referral, and counselling within

Table 1. Summary of studies included in review

Study number	Authors	Year of publication	Location	Analytic method	Study design	No. of institutions	Study year(s)	No. of surgeons	Surgical subspecialty or disease site	Element(s) assessed
1	Burcher et al.[12]	2013	Australia New Zealand	Quantitative	Survey	4	2012	40	Breast plus others	Perceptions and attitudes
2	Beitsch and Whitworth[13]	2014	United States	Mixed methods	Survey	Database	2013	907	Breast	Perceptions, attitudes, and barriers
3	Carroll et al.[14]	2008	Canada	Mixed methods	Survey	Database	2002–2003	202	Breast, ovarian, and colorectal	Knowledge, perceptions, attitudes, and barriers
4	Douma et al.[15]	2016	Netherlands	Mixed methods	Interview	1	2015	4	Colorectal	Perceptions, attitudes, barriers, and intervention
5	Spellman et al.[16]	2013	United States	Qualitative	Survey	3+	2010–2011	10	Breast	Perceptions, attitudes, and barriers
6	Harper et al.[17]	2010	New Zealand	Quantitative	Survey	1	NA	77	General surgery	Knowledge, perceptions, and attitudes
7	Kurian et al.[18]	2017	United States	Quantitative	Survey	2	2014–2015	377	Breast	Perceptions and attitudes
8	Frey et al.[19]	2014	United States	Quantitative	Survey	1	2011–2012	62	General surgery	Knowledge, perceptions, and attitudes
9	Hallowell et al.[20]	2019	United Kingdom	Qualitative	Interview	1	2017–2018	7	Breast	Perceptions, attitudes, and barriers
10	Wevers et al.[21]	2017	Netherlands	Mixed methods	Survey	12	2008–2010	16	Breast	Perceptions and attitudes
11	Nippert et al.[22]	2014	France Germany Netherlands United Kingdom	Mixed methods	Survey	Unknown	2009–2010	1223	Breast	Perceptions and attitudes
12	Agnese et al.[23]	2006	United States	Quantitative	Survey	Unknown	Unknown	364	Surgical oncology	Perceptions and attitudes
13	Graves et al.[24]	2011	United States	Qualitative	Interview	Unknown	2008	5	Breast	Perceptions and attitudes
14	Katz et al.[25]	2018	United States	Quantitative	Survey	1	2013–2015	377	Breast	Perceptions, attitudes, and barriers
15	Wideroff et al.[26]	2005	United States	Quantitative	Survey	1	1999–2000	431	General surgery plus others	Knowledge, perceptions, and attitudes
16	Monahan et al.[27]	2014	United Kingdom	Quantitative	Survey	3	2012	144	Colorectal	Perceptions, attitudes, and barriers
17	Van Riel et al.[28]	2010	Netherlands	Mixed methods	Survey	28	NA	38	NA	Knowledge, perceptions, and attitudes

NA = not available.

the included studies (Table 4). After thematic analysis, similar barriers were grouped and classified as surgeon-, patient-, or system-level challenges (Table 5). Nine unique barriers were identified in this manner, with most (n = 5) being at the system level. These included a lack of clarity regarding the health care provider responsible for initiating genetic testing and managing high-risk patients, ease of patient referral to genetic risk assessment and counselling, timeliness of appointments following referral, availability of genetics clinics, and difficulties posed by private insurance coverage for genetic testing and counselling. Uncertainty surrounding provider responsibility was the most commonly cited challenge by surgeons within the included studies. Surgeon-level barriers (n = 3) included scarcity of time to provide counselling, difficulty surrounding interdisciplinary communication, and surgeon attitude toward genetic testing and counselling. The only patient-level barrier reported was compliance with attending appointments.

Table 2. Knowledge assessment of genetic literacy among surgeons within the included studies

Study number	Elements of knowledge assessment and their results
3	Aware genetic testing for breast and ovarian cancer is available in Ontario: 90% of surgeons and 100% of surgical oncologists
	Aware genetic testing for colorectal cancer is available in Ontario: 83% of surgeons and 89% of surgical oncologists
	Know where to refer patients and their families for cancer genetic counselling: 74% of surgeons and 89% of surgical oncologists
6	32%–96% correct response rate to knowledge questions of Bethesda criteria and features of Lynch syndrome
	88% of surgeons knew of immunohistochemistry testing for colorectal cancer
	93% of surgeons would refer to regional genetic service after positive immunohistochemistry
	83% of surgeons discuss screening and surveillance with patient after positive immunohistochemistry result
8	Knowledge-based questions about malignancy in patients diagnosed with Lynch syndrome:
	a) Average age for developing colon cancer (86% answered correctly)
	b) Lifetime risk for developing colon cancer (32% answered correctly)
	c) Risk for endometrial cancer (29% answered correctly)
	d) Respondents were least knowledgeable about the risk for developing both colon and endometrial cancer
15	Assessed surgeon knowledge of the following:
	a) *BRCA1* or *BRCA2* paternal inheritance (45% correct, 38.8% unsure)
	b) Percentage of breast cancer patients with *BRCA1* or *BRCA2* mutations (57.8% correct, 20.9% unsure)
	c) Penetrance of hereditary nonpolyposis colorectal cancer mutations (38.0% correct, 50.1% unsure)
	d) Availability of tests for *BRCA1* and *BRCA2* (5% thought not available, 17.7% not sure)
	e) Availability of tests for *MLH1* and *MSH2* (7.2% thought not available, 55.4% not sure)
	f) Availability of tests for *APC* (6.3% thought not available, 59.0% not sure)
17	Average knowledge score of breast cancer heredity (range 0–7) among surgeons was 6.4 (95% confidence interval 6.14–6.66)

Discussion

In recent years, the shortage of genetic counsellors, lengthy wait times of genetics clinics, and increased availability and awareness of genetic information have resulted in a greater need for health care professionals with minimal or no formal training in genetics to provide genetics-related services. In this study, we have shown that surgeons participate in many such genetics-related tasks despite low confidence in knowledge, and the considerable challenges posed by barriers at system, surgeon, and patient levels.

Most surgeons order genetic testing and provide genetic counselling to patients.[13,14,16–18,21,23] This is despite variable knowledge pertaining to genetic inheritance patterns for breast and colorectal cancer, availability of testing, and criteria for at-risk patient identification.[14,17,19] Inadequate curricular exposure to genetics and other cancer-related specialties during surgical residency may contribute to those findings.[29,30] To that end, there is variable description of genetics and hereditary cancer topics within the curricula of several surgical accreditation bodies.[31–33] With the increasing complexity of genetic information, testing may lead to results requiring more nuanced interpretation and counselling.[34,35] Poor genetic literacy among surgeons can lead to negative consequences for patient care. For example, ordering of incorrect genetic tests can lead to pathogenic variants being missed in relevant genes or increased detection of variants of uncertain importance that may be confusing for patients and health care professionals to interpret. Misinterpretation of test results, along with insufficient, incorrect, or missed opportunities for genetic counselling are also possible and may result in underuse or inappropriate utilization of screening and prophylactic surgery both for affected individuals and their at-risk unaffected relatives.[36–38] These findings underscore an important need for knowledge-based interventions to improve genetic literacy among surgeons.

Provision of genetics-related services by health care professionals with minimal or no formal training in genetics is met with mixed opinions.[37,38] Surgeons often report low comfort with the provision of genetics-related services. In one study, the proportion of surgeons comfortable with counselling their patients regarding hereditary colorectal cancer ranged from 21% to 63%.[19] While we noted similar results among surgeons managing hereditary breast cancer, our findings also indicate that confidence with and utilization of genetic services increases with clinical volume and subspecialty training.[13,14,18] Interestingly, several surgeons explicitly requested educational support for genetic knowledge, testing, and counselling.[13,15] This suggests that low comfort may be related to gaps in genetic literacy, a notion that is bolstered by surgeons' desire to participate in genetics-related services for their patients.[12,16] Many surgeons feel that their participation in ordering genetic testing, for example, can expedite care and minimize delays.[16]

"Mainstreaming" of genetic testing has been proposed as an approach to address some of the concerns outlined above and is currently implemented across several jurisdictions in Canada.[20,39,40] Mainstreaming interventions provide health professionals with minimal or no knowledge in genetics with education, as well as a systematized approach for genetic testing and obtaining results.[41] Within the province of Ontario, for example, physician-led mainstreaming initiatives have been recommended and initiated to provide standardized organization and delivery of genetic services.[40] Once the initial testing has been

performed, patients who require further access to specialized genetic health professionals may then be selectively referred. To that end, surgeons within our analysis held favourable views toward the mainstreaming of genetic testing.[12,21] While mainstreaming appears to be a promising approach, a robust characterization of the attitudes of interested parties and patient outcomes across cancer sites is likely necessary. Furthermore, mainstreaming in itself

Table 3 (part 1 of 2). Key findings of perceptions and attitudes pertaining to genetic literacy among surgeons within included studies

Study number	Perceptions about and attitudes toward genetic referral, testing, and counselling
1	Assessed the perceived value and usefulness of treatment-focused genetic testing for treatment and management of breast cancer, the perceived impact of treatment-focused genetic testing on treatment decision-making, and preference for best professional to make initial offer of treatment-focused genetic testing
	a) 25.1% of surgeons agreed treatment-focused genetic testing is useful for patient care, treatment, and management
	b) 11.0% of surgeons strongly agreed or agreed genetic knowledge has impact on treatment decision-making
	c) The best professional to make initial treatment-focused genetic testing offer should be surgeon (66.7%), genetic counsellor (25%), oncologist (8.3%), and breast care nurse (0%)
2	Assessed breast cancer surgeon skill and practice in *BRCA* test counselling and desire for education
	a) 54.0% of surgeons ordered their own *BRCA* testing
	b) 51.6% provided pre- and post-*BRCA* test counselling as standard practice, 36.6% of surgeons reported another provider usually does counselling, 11.8% of surgeons not confident in counselling
	c) 63.3% obtain ≥ 3-generation pedigree family history from patients as standard practice
	d) 39% had ordered expanded genetic mutation panels
	e) 85% strongly agree or agree they would like educational support in genetic testing
3	Assessed use of cancer genetics service and satisfaction with cancer genetics program (timeliness of testing results, availability of clinics, quality of referral letters)
	a) 70% of surgeons and 94% of surgical oncologists have referred to hereditary cancer genetic services in the past or had previous contact with them
	b) 63% of surgeons and 94% of surgical oncologists have referred to genetic counselling in the past year
	c) During the past year, surgeons referred 5 ± 6 people, and surgical oncologists referred 11 ± 9 for genetic counselling regarding hereditary cancer
	d) 23%–25% of surgeons and 11% of surgical oncologists satisfied with notification of availability of genetic testing for hereditary breast, ovarian, and colorectal cancer by Ontario Ministry of Health and Long-Term Care
4	Gaps identified included extent of discussion of family history and genetic counselling with patients, sufficient history for optimal referral for genetic testing, and lack of knowledge in genetics
5	Assessed perception of clinical utility of Oncotype DX, perception about impact of patient preference, and communication of test results (risk) to patients
	a) All surgeons believed surgeons ordering tests facilitated care and minimized delays: "arranging for the testing to happen as soon as possible, ideally ordered around the time of surgery in order to expedite receipt of the results has been our practice pattern"
	b) Perception of impact: 95% of oncologists reported patients' preferences for chemotherapy affected both the decision to order testing and how the results would be used
	c) Risk communication: "My other concern is that the intermediate score is very difficult to explain to a patient"
6	Examined provider awareness of Bethesda criteria and features of Lynch syndrome and counselling and referral practices
	a) 93% of surgeons would refer to regional genetic service after positive immunohistochemistry
	b) 83% of surgeons discuss screening and surveillance with patient after positive immunohistochemistry result
7	Studied timing, ordering, and discussion of genetic testing, and surgeon confidence in discussing testing
	a) Surgeon orders genetic testing without referring to counsellor: 26% (1–20 patients/yr), 35% (21–50 patients/yr), 37% (> 50 patients/yr)
	b) Surgeon does not delay surgery for test results: 38% (1–20 patients/yr), 27% (21–50 patients/yr), 17% (> 50 patients/yr)
	c) Will offer breast-conserving surgery in patient with *BRCA1* or *BRCA2* mutation: 36% (1–20 patients/yr), 25% (21–50 patients/yr), 43% (> 50 patients/yr)
	d) Would manage a patient with variant of uncertain significance same as *BRCA1* or *BRCA2* mutation carrier: 50% (1–20 patients/yr), 42% (21–50 patients/yr), 24% (> 50 patients/yr)
	e) Confidence in discussing testing: 73% in surgeons with higher volume (> 51 breast cancer patients/yr) and 35% with lower volume (1–20 patients/yr) of breast cancer
8	Described surgeon comfort in counselling patients regarding genetic inheritance pattern of Lynch syndrome, available genetic tests, criteria for genetic testing, and current consensus recommendation for colorectal cancer and endometrial cancer screening in patients with Lynch mutation
	a) 52% comfortable in counselling on Lynch syndrome genetic inheritance pattern
	b) 21% comfortable in counselling on Lynch syndrome available genetic testing
	c) 63% comfortable in counselling on Lynch syndrome criteria for genetic testing
	d) 21% comfortable in counselling on Lynch syndrome endometrial cancer screening
	e) 63% comfortable in counselling on Lynch syndrome colon cancer screening
9	Described surgical team's perceptions of mainstreaming:
	a) Perception of role responsibility in treating cancer: "We don't have the time or skills to counsel people about gene testing"
	b) Redesigning the care pathway: mainstreaming treatment-focused genetic testing will increase workload beyond capacity
	c) Relevance for practice: treatment-focused genetic testing less relevant for surgical practice

Table 3 (part 2 of 2). Key findings of perceptions and attitudes pertaining to genetic literacy among surgeons within included studies

Study number	Perceptions about and attitudes toward genetic referral, testing, and counselling
10	Outlined surgeon attitudes regarding referral of patients to RGCT
	a) Surgeon attitudes regarding referral of patients RGCT (I consider the possibility of referral for RGCT as important) 81.3% at start v. 93.8% at end of study
	b) Surgeon attitudes regarding referral of patients RGCT (I consider RGCT as burdensome for the patient) 31.3% v. 43.8%
	c) Surgeon attitudes regarding referral of patients RGCT (The advantages of RGCT outweigh the disadvantages for the professional) 68.8% v. 75%
	d) Surgeon attitudes regarding referral of patients RGCT (The advantages of RGCT outweigh the disadvantages for the patient) 81.3% v. 60%
11	Described breast surgeons' attitude toward practice responsibilities:
	a) Surgeons from Netherlands felt they should explain inheritance pattern of familial breast cancer to patients, whereas most surgeons from France, Germany, and United Kingdom felt a genetic specialist should do this
	b) Surgeons from UK felt that a genetic specialist should provide support after breast cancer genetic testing, whereas most surgeons from France, Germany, and Netherlands felt support should be provided by the surgeon
	c) Most surgeons in all 4 countries felt a genetic specialist should be responsible for disclosing breast cancer genetic test results to patients and informing about management options based on genetic testing
12	Most surgeons discussed hereditary cancer syndromes and genetic testing with their patients (94.4% frequently or occasionally) and more than half (60.4%) had personally ordered genetic testing, although it is unknown whether any counselling, either by the surgical oncologist or a genetics counsellor, was provided before testing
13	Assessed surgeons' perception of barriers and facilitators to genetic testing among African American women with moderate to high risk; themes identified were as follows:
	a) patient–provider communication (4/5 surgeons)
	b) patient motivators for genetic counselling and testing (5/5 surgeons)
	c) effects of testing (5/5 surgeons)
	d) cultural beliefs and practices of patients (3/5 surgeons)
	e) patient refusal (5/5 surgeons)
	f) access factors (2/5 surgeons)
	g) provider referral (5/5 surgeons)
14	Tendency to order genetic testing, surgeon's confidence in discussing genetic testing with patients, surgeon's annual patient volume, and patient factors (race and ethnicity, insurance status)
	a) The odds of a patient receiving genetic testing would increase more than twofold (odds ratio 2.48, 95% CI 1.85–3.31) if she saw a surgeon with a genetic test ordering rate that was 1 SD above that of a surgeon with the mean test rate (independent of the patient's pretest risk of mutation carriage)
	b) The odds of testing being ordered increased by 1.88 (95% CI 1.49–2.38) for each 1-SD increase in the scale score for surgeon volume
	c) Patients with no or public insurance or Black ethnicity were less likely to get tested
16	Surgeons were the only specialty with most answering that they had responsibility for managing patients with colorectal cancer with elevated inherited risk

CI = confidence interval; RGCT = rapid genetic counselling and testing; SD = standard deviation.

does not preclude the need for high-quality interventions targeting genetic literacy among surgeons.

We identified and catalogued various barriers to genetic literacy, referral, testing, and counselling. The most common surgeon-level barrier reported was a lack of time to devote toward genetics-related activities.[15] We noted that system-level barriers were related to the process of referrals made to certified genetic counsellors. To that end, we identified only 1 study within this evidence synthesis that employed a checklist-based intervention to simplify the identification of patients as potential candidates for genetic counselling referrals.[15] Unfortunately, this intervention did not lead to significant differences in patient referral. A more recent study not described in our analysis yielded similar results, in which health literacy interventions for surgical oncologists and nurses did not improve referrals to genetic counselling.[42] These findings suggest that further work is needed to better understand existing barriers, and to design and implement effective interventions to improve the genetic literacy and capacity of surgeons.

Optimal strategies to address the barriers to genetic literacy that our work has identified remain undefined. Nonetheless, we hypothesize that several surgeon- and system-level barriers may be addressed by relatively straightforward measures. These may include, for example, identifying the most responsible practitioner within a cancer disease site team to triage and make referrals for further genetic work-up, provision of a framework to simplify the referral process (e.g., electronic referrals), and mandating a time frame within which all new referrals must be seen. The addition of a patient navigator role and genetic specialists to cancer disease site teams or multidisciplinary tumour conferences may lead to improved patient attendance at genetics appointments and better interdisciplinary contact for surgeons. In the province of Ontario, Cancer Care Ontario has published a series of recommendations with the intention of enhancing delivery of clinical cancer genetic services.[40] These recommendations were developed by a working group and are aimed at the interdisciplinary team, the patient's episode of care, and the province as a whole.

Table 4. Catalogue of barriers to genetic literacy, referral, and counselling, as identified by surgeons within included studies

Study number	Barriers	Type of barrier
2	Ease of insurance approval, ease of referral to a genetic counsellor, and patient compliance	System, patient
	a) Ease of insurance approval "is burdensome, but we get it done," according to 58% of surgeons; 26% felt it was "easy and straightforward" to obtain insurance approval of genetic testing for their patients, 9% considered insurance "too burdensome for us to deal with in our setting," and 7% said approval was "often denied"	
	b) Ease of referral to a genetic counsellor: 51% reported easy local access, 17% provided own clinic counselling, 3% consulted genetic counsellor by telephone, 16% felt it was a "burdensome" process, 14% felt local access was "inadequate"	
	c) Patient compliance with genetic counsellor appointment: 61% reported patients attend appointment > 50% of time, and 22% reported their patients fail to keep appointments > 50% of time	
3	Survey respondents suggest changes to Ontario cancer genetics program: increased provider education and awareness, and public awareness; broadened criteria for access; increased provider autonomy (i.e., order genetic tests themselves); and increased access, availability, and resources (rural, timeliness, more clinics)	System
	a) 40% of surgeons and 56% of surgical oncologists are satisfied with availability of cancer genetics clinics in area	
	b) 39% of surgeons and 18% of surgical oncologists are satisfied with timeliness of referral appointments with cancer genetics clinics	
	c) 23% of surgeons and 6% of surgical oncologists are satisfied with timeliness of genetic testing results	
	d) 68% of surgeons and 69% of surgical oncologists are satisfied with quality of the referral letters from genetic counsellors	
4	Lack of time during busy clinics	Surgeon
5	Decision of which provider should order genetic testing for incorporating testing in multidisciplinary care	Surgeon
9	Little contact between interprofessional teams impede communication about mainstreaming (i.e., surgeons and clinical genetics teams rarely met and did not know each other well)	Surgeon, system
	Lack of comprehensive guidelines detailing how patients should be managed	
14	Variation in surgeon attitude about genetic testing and counselling associated with receipt of genetic testing after breast cancer diagnosis	Surgeon
16	Poor understanding of the current guidelines among clinicians and variable clinical pathways for patients; also, a perception that another unspecified clinician is undertaking this work	Surgeon, system

Table 5. Thematic list of barriers to genetic literacy, ordered by frequency within included studies

Group	Barrier	Study number
System	Uncertainty of provider responsible for ordering genetic testing or managing patients with elevated inherited genetic risk	5, 9, 16
	Ease of approval and availability of insurance	2
	Ease of referral to genetic counsellor	2
	Availability of genetic clinics	3
	Timeliness of referral appointments	3
Surgeon	Lack of time for counselling during busy clinic	4, 9
	Little interdisciplinary contact	9
	Surgeon attitude regarding genetic testing and counselling	14
Patient	Patient compliance and attendance at genetic appointment	2

Within the broader Canadian context, future research may aim to determine the effectiveness of such strategies and if they should be adopted in other provinces and territories.

Our work provides a comprehensive and context-specific synthesis of the literature relating to surgeons' referral patterns, and knowledge, perceptions, attitudes, and barriers pertaining to genetic literacy. In doing so, we have catalogued reported barriers based on their role at the surgeon, patient, and system levels. These findings may now guide future studies of targeted interventions to improve surgeons' genetic literacy, allowing them to more effectively incorporate genetic services within routine clinical practice. The strengths of our evidence synthesis include a comprehensive search strategy and rigorous screening process, based on PRISMA guidelines for scoping reviews.

Limitations

Our findings and list of barriers are context-specific to the surgeons and cancer disease sites included in this study and may not be generalizable to other health care professionals and disease sites, which is an important limitation. We analyzed data from studies conducted in Europe, Canada, Australia and New Zealand, and the US, but were unable to find relevant studies from other geographic locations where issues related to referral and genetic literacy may be different. Finally, the results from the included studies are heavily dependent on surgeon self-reporting, which is subject to reporting bias.[43]

Conclusion

We found that surgeons managing gastrointestinal, breast, and endocrine and neuroendocrine cancers are frequently engaged in genetics-related services. Surgeon knowledge, comfort, and confidence in providing these services is often low but is increased with clinical volume and subspecialty training. There is both a need and desire for knowledge-related and non-knowledge-related interventions targeting surgeons' genetic literacy.

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