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ORIGINAL ARTICLE

IMPACT webinars: Improving Patient Access to genetic Counselling and Testing using webinars—the Alberta experience with hypertrophic cardiomyopathy

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Abstract

Growing demand for genetic counselling and testing has created a need for innovative service delivery models to provide quality care in an efficient manner. The goal of this study was to develop and evaluate a patient-facing webinar providing pre-test genetic counselling to individuals with hypertrophic cardiomyopathy. A patient-facing webinar was developed and implemented between April 2019 and January 2021. It was evaluated using the Alberta Quality Matrix for Health framework, which considers the patient experience across the domains of effectiveness, appropriateness, acceptability, accessibility, and efficiency. The webinar group showed comparable scores to controls with regard to self-perceived knowledge and decisional conflict. The majority of patients reported that the webinar met their expectations and was an acceptable replacement for a 1:1 genetic counselling appointment. Finally, the webinar reduced genetic counsellor time to an average of 24 min per patient. Providing pre-test genetic counselling to index hypertrophic cardiomyopathy patients via a group webinar has achieved a high quality of care, and optimized use of provider and space resources.

Keywords Hypertrophic cardiomyopathy · Service delivery models · Genetic counselling · Webinar

Introduction

The growing demand for genetic counselling and testing has created a need for innovative service delivery models (SDMs) to provide quality care in an efficient manner (Cohen et al. 2012, 2013; Khan et al. 2020). Various alternative SDMs for genetic counselling have been evaluated, including telephone, telemedicine, and in-person group appointments. Fournier et al. (2018) reviewed SDM performance for breast and ovarian cancer and found that telephone counselling was non-inferior to in-person group appointments. The NSGC Task Force for SDMs reviewed data supporting telegenetics as comparable to 1:1 appointments for patient satisfaction and knowledge, while highlighting the need for new SDMs that are efficient and cost-effective while maintaining high-quality care (Cohen et al. 2012). Otten et al. (2015) evaluated the delivery of in-person group genetic counselling in the context of cardiomyopathy patients. Perceived personal control was improved while anxiety decreased following service provision. Similarly, Cloutier et al. (2017) found that group genetic counselling following a positive prenatal screening result significantly decreased patient anxiety, increased perceived personal control, decreased decisional conflict, and increased knowledge.

With increasing utility for cardiac genetic testing and genetic counselling, a novel approach to manage the high demand is needed, particularly for common inherited cardiac conditions such as hypertrophic cardiomyopathy

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(HCM). Although in-person group genetic counselling can accommodate seeing more patients efficiently and reduce wait times, indication-specific group sessions can only be offered with a limited frequency based on the number of patients eligible to attend for a particular indication. This may mean that patients are only offered a very limited number of scheduling options. In addition, scalability of group genetic counselling to smaller clinical services and for less common referral indications is not possible. The goal of this study was to develop and evaluate a live, patient-facing, interactive, provincial webinar for pre-test genetic counselling for patents with a clear or suspected clinical diagnosis of HCM. If successful, the goal of this pilot was to expand the use of patient-facing webinars to other patient populations.

Method

Webinar development

Clinical and Metabolic Genetics Services, within Alberta Health Services (AHS), serves a population of 4.2 million Albertans across a large geography through two tertiary and three outreach sites. An AHS provincial HCM webinar steering committee was created, consisting of cardiac GCs from three clinical sites, a patient-care manager, and the IT provincial lead for evaluation of Unified Communications Services. The committee engaged with various AHS system partners to develop a patient-facing webinar process that reflected consensus practices and preferences of relevant clinicians, fulfilled necessary privacy and patient-care requirements, and offered patients and providers a streamlined IT solution. Zoom was chosen for its end-to-end secure encryption, compliance with relevant personal health information privacy legislation, and the potential to interface with the province's clinical information system. The steering committee piloted a number of small-scale webinars and found the webinar platform satisfactory.

All patients were registered for the webinar and their attendance was recorded. Patients could privately submit questions through the Zoom Q&A feature. Webinars were conducted by a "host" GC who presented information on (1) the pathophysiology, symptoms, and typical management of HCM, (2) the genetics and inheritance, (3) clinical screening recommendations for at-risk relatives, and (4) the option of genetic testing including the benefits, limitations, and potential results. A "moderator" GC was also present and managed patient questions. Participants received a short phone call from a cardiac GC after the webinar to answer questions and determine if the patient was interested in proceeding with genetic testing. A post-webinar email was sent to participants that included a recorded version of the webinar and links to patient resources. For those patients who proceeded with genetic testing, a 1:1 genetic counselling appointment was coordinated once results were available.

Pilot participants

Patients with a clear or suspected clinical diagnosis of HCM, without a known familial pathogenic variant or previous genetic testing, were considered for enrollment. Patients referred to any of the five AHS sites offering Clinical & Metabolic Genetic Services (Alberta Children's Hospital in Calgary, University of Alberta Hospital in Edmonton, Chinook Regional Hospital in Lethbridge, and the Public Health Units in Red Deer and Medicine Hat) were asked if they would be interested in attending a live webinar reviewing information about genetic testing for HCM or whether they preferred to remain on the waitlist for a 1–1 genetic counselling appointment or an in-person group session. Eligibility criteria for the study included having an email address to access a link to online surveys, no significant learning difficulties or sensory impairments, and age greater than 17 years. Participants were also asked if they felt comfortable receiving care in English or would prefer to have an interpreter present. If they indicated that they were not comfortable receiving care in English, they were excluded from the study. Patients meeting the above criteria who expressed interest in the webinar were invited to take part in the evaluation study. Controls included patients seen prior to the roll out of the webinar, and those who declined the webinar option. Controls received pre-test genetic counselling by an in-person group session, or a 1:1 genetic counselling appointment. Prior to the March 2020 COVID-19 pandemic, non-webinar genetic counselling appointments were conducted in person. Subsequently, 1:1 genetic counselling appointments occurred virtually, either by phone or over Zoom.

Data collection

Participants were invited to complete an online survey before and after attending their pre-test genetic counselling appointment (webinar, in-person group, or 1:1 appointment) (Supplemental Material). The pre-survey for both cases and controls included 33 questions. The post-survey included 27 questions for cases, and 19 questions for controls. The additional eight questions for cases were specific to the webinar experience. Surveys were created and managed using the REDCap electronic data capture tool hosted at the University of Alberta (Harris et al. 2009) and each took approximately 10 min to complete.

Quality was evaluated considering the domains of acceptability, accessibility, effectiveness, appropriateness, and efficiency, adapted from the Alberta Quality Matrix for Health framework (hqca.ca). The goal was to evaluate outcomes of patients with HCM before and after receiving pre-test

genetic counselling via a webinar compared to current practice (1:1 genetic counselling appointment or in-person group information session). Acceptability evaluated the extent to which patients had a positive healthcare experience by asking about needs, preferences, and expectations. Accessibility considered how easy it was for patients to obtain healthcare services by attending an in-person appointment. Effectiveness measured if the genetic counselling intervention facilitated the desired outcome for patients by assessing self-perceived knowledge. Appropriateness judged if the webinar supported patient needs and preferences by comparing pre/post genetic counselling decisional conflict about genetic testing, including an understanding of the associated benefits and limitations. Finally, efficiency was evaluated by considering use of health system resources by calculating the average GC time per patient.

Demographic information was also collected as well as an open-ended question for additional comments at the end of the post-surveys. In addition, data was collected on attendance rate, and the length of the post-webinar phone call.

Data analysis

Self-perceived knowledge was scored on a 5-point Likert scale (0 = no knowledge and 4 = a lot of knowledge) with regard to the diagnosis of HCM, inheritance of HCM, genetic testing for HCM, and overall HCM knowledge (average score of the 3 concepts). Decisional conflict is defined as the confidence one has in choosing between competing options and was scored out of 5. An overall decisional conflict score out of 100 was calculated as well as five subscale scores also out of 100. Continuous variables are presented as means with standard deviations. Categorical variables are presented as counts with percentages. Paired *t*-test analysis was used to evaluate the difference between pre and post knowledge and decisional conflict scores. Stata Statistical Software: Release 13 (College Station, TX: StataCorp LP) was used for statistical analysis. Comparison between webinar and control groups was descriptive in nature due to the limited power of the study.

Results

Between April 2019 and January 2021, 101 patients with a clear or suspected diagnosis of HCM were booked into 13 webinars. A total of 82 patients attended the webinar (attendance rate of 81%). Of the patients who attended the webinars, 77 were invited to be part of the study (5 missed being invited) and 43 completed both the pre- and post-survey (participation rate of 56%). The mean length of time for the individual phone calls following the webinar was 10 min (range of 1 to over 60 min), with a median of 8.5 min. The webinar itself was approximately 45 min in length.

Twenty-six patients agreed to be part of the control group of whom 20 (77%) completed both the pre- and post-survey. Seven control participants attended an in-person group session, and 13 attended a 1:1 appointment (9 in-person, 3 virtual, and 1 telephone). Demographic data were similar across webinar and control groups (Table 1).

Acceptability

In the pre-survey, 44% ($n = 19$) of cases did not have a preference for a 1:1 versus online webinar, 30% ($n = 13$) indicated that they would prefer to attend an online webinar, and 25% ($n = 11$) preferred a 1:1 appointment. In comparison, 20% ($n = 4$) of controls did not have a preference for a 1:1 versus online webinar, 25% ($n = 5$) indicated that they would prefer to attend an online webinar, and 55% ($n = 11$) preferred a 1:1 appointment. Thirty-seven percent ($n = 16$) of cases and 50% ($n = 10$) of controls had previously attended a webinar. Finally, 98% ($n = 42$) of cases and 90% ($n = 19$) of controls were either somewhat or very comfortable with technology. Data describing how webinar and control group participants report that they best learn medical information is described in Fig. 1. Overall, both groups describe learning best from a 1:1 genetic counselling appointment.

Following the webinar, participants were asked to score their experience on a scale of 1 to 5 according to 7 positive statements (1 = strongly disagreed and 5 = strongly agreed). All aspects were reported on average at or above 4.4/5 (Fig. 2). Forty-nine percent ($n = 21$) felt comfortable asking questions during the webinar while 51% ($n = 22$) indicated that they did not have any questions. Eighty-eight percent ($n = 38$) indicated that the webinar was an acceptable replacement for a 1:1 appointment, and 93% ($n = 40$) indicated that they would be willing to attend similar webinars in the future (3 patients responded "maybe"). Additional comments are shown in Table 2.

Accessibility

Forty percent ($n = 17$) of cases and 60% ($n = 13$) of controls indicated that it was either somewhat or very difficult to attend an in-person appointment.

Effectiveness

Self-perceived knowledge was scored out of 4, with a higher score indicating better self-perceived knowledge. Overall, scores increased by an average of 2.1 for the webinar group and 1.2 for both control groups (in-person group and 1:1 appointment) ($p < 0.0001$ and $p = 0.0002/p = 0.02$, respectively). Scores for knowledge about HCM (diff = 1.7,

Table 1 Webinar and control group demographics

Characteristics		Webinar group *n* (%)	Control group: 1:1 appointment	Control group: In-person group
Gender	Male	29 (67%)	8 (67%)	4 (57%)
	Female	14 (33%)	4 (22%)	3 (43%)
	Transgender/non-binary/third gender	0 (0%)	0 (0%)	0 (0%)
	I prefer not to say	0 (0%)	0 (0%)	0 (0%)
Age	18–25	0 (0%)	0 (0%)	0 (0%)
	26–35	1 (2%)	1 (8%)	1 (15%)
	36–45	8 (19%)	3 (25%)	3 (43%)
	46–55	15 (35%)	4 (33%)	2 (29)
	56–65	14 (33%)	2 (17%)	1 (15%)
	> 65	5 (12%)	2 (17%)	0 (0%)
Education	High school	7 (16%)	0 (0%)	0 (0%)
	College	18 (42%)	5 (42%)	1 (14%)
	Undergraduate	12 (28%)	5 (42%)	1 (14%)
	Graduate	4 (9%)	0 (0%)	4 (57%)
	Other	2 (5%)	2 (17%)	1 (15%)
Residence	Rural	4 (9%)	1 (8%)	1 (15%)
	Urban	39 (91%)	11 (92%)	6 (85%)
Primary language	English	39 (91%)	12 (100%)	7 (100%)
	Other	4 (9%)	0	0

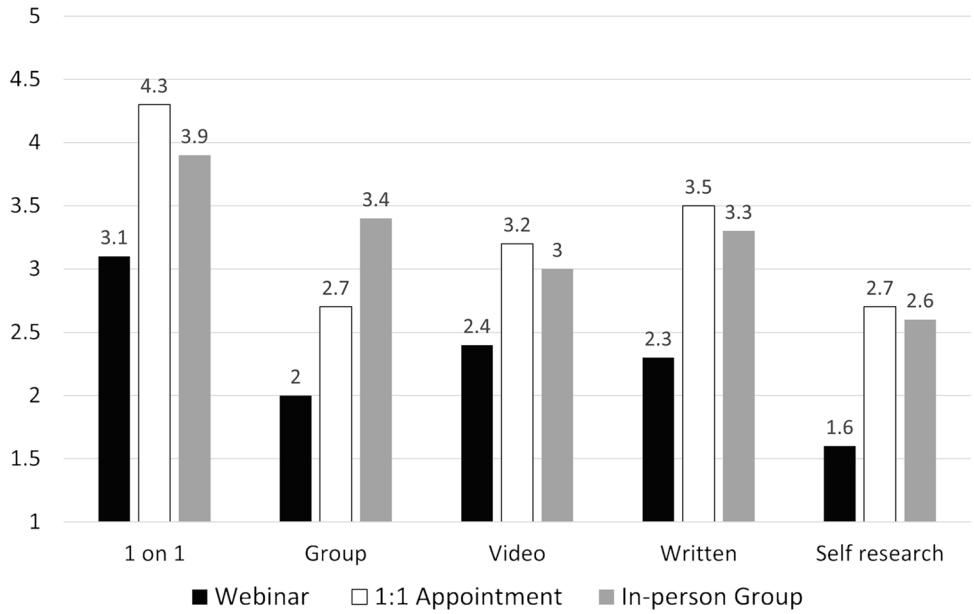

Fig. 1 Description of how participants report they best learn medical information. 1 = I can't learn this way and 5 = I learn best this way

$p < 0.0001$), inheritance of HCM (diff = 2.4, $p < 0.0001$), and genetic testing for HCM (diff = 2.9, $p < 0.0001$) all increased significantly in the webinar group (Fig. 3). Scores also increased significantly with regard to knowledge of HCM for participants attending a 1:1 appointment (diff = 0.6, $p = 0.0009$). With regard to knowledge about HCM inheritance and HCM genetic testing, both control groups reported significant gains in knowledge (1:1 appointment- diff = 1.1, $p = 0.002$ and diff = 1.8, $p = 0.0001$, respectively and in-person group- diff = 1.3, $p = 0.01$ and diff = 2, $p = 0.01$, respectively). There was a trend towards higher overall self-perceived knowledge scores in the webinar group, although the sample size lacked the power for comparisons between groups.

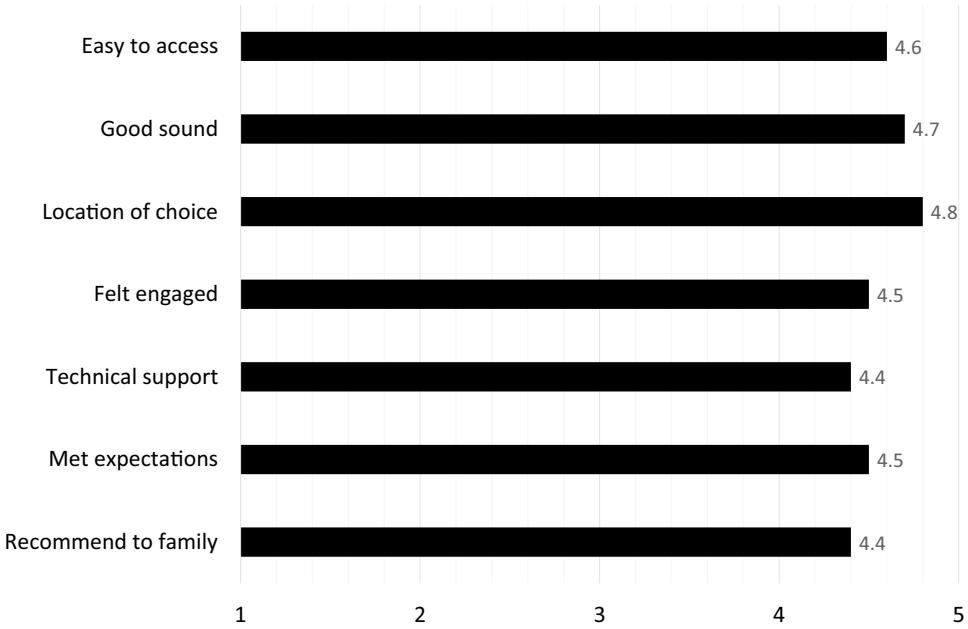

Fig. 2 Participants experience with the HCM virtual webinar. 1 = Strongly disagree and 5 = Strongly agree

Table 2 Additional comments provided by webinar participants

Gender	Age	Comment
Male	46–55 years	Excellent job. I appreciate the opportunity to try this "new" method and strongly encourage that it be used more pervasively in the future!
Male	56–65 years	Good information without having to travel
Male	36–45 years	Great webinar information was well explained and learned a lot about the genetics of HCM
Female	46–55 years	I do not have a computer at home so using my phone or tablet works but is very small
Male	56–65 years	I felt the webinar was very beneficial. I like that there was a follow up phone call as well as a review email of the presentation. Often times you forget questions in a face to face meeting. Very comprehensive and very knowledgeable presenters. Thank you very much all!
Male	> 65 years	I think it went well considering it was new to me and did provide a lot of information
Male	26–35 years	Information was no better than what I was able to find with a simple google search. Felt like it was directed to an older demographic. The follow up phone call was the only beneficial part
Male	56–65 years	It was far better than I expected and would do it again anytime, saved a lot of driving for me
Female	> 65 years	No comments, I am quite satisfied with the format
Male	46–55 years	Overall good and I am very impressed with the presenters and team
Male	56–65 years	[The genetic counsellor] was an excellent host. Understood her material and was very respectful of the patients. Very much an over-performing and it was appreciated due to the seriousness of the topic
Male	> 65 years	[The genetic counsellor] did a good presentation
Female	56–65 years	The webinar was very well presented and the follow-up one on one phone call was very quickly received which was very much appreciated. All in all, very professionally executed! Thank you!
Female	46–55 years	Throughout my career I have used several different webinar platforms. I found this platform to be solid and trustworthy. The platform did not interfere with the presentation of the information

Appropriateness

Prior to attending the webinar, 60% ($n = 26$) of participants indicated that they planned to proceed with genetic testing for HCM and 40% ($n = 17$) indicated that they were unsure. Following attending the webinar, 90% ($n = 39$) of participants indicated that they planned to proceed with genetic testing, 2% ($n = 1$) decided not to have genetic testing, and 7% ($n = 3$) were still unsure. In the control groups, prior to counselling, 55% ($n = 11$) planned to have genetic testing and 45% ($n = 9$) were unsure, whereas after counselling, 95% ($n = 19$) planned to have genetic testing and 5% ($n = 1$) were unsure.

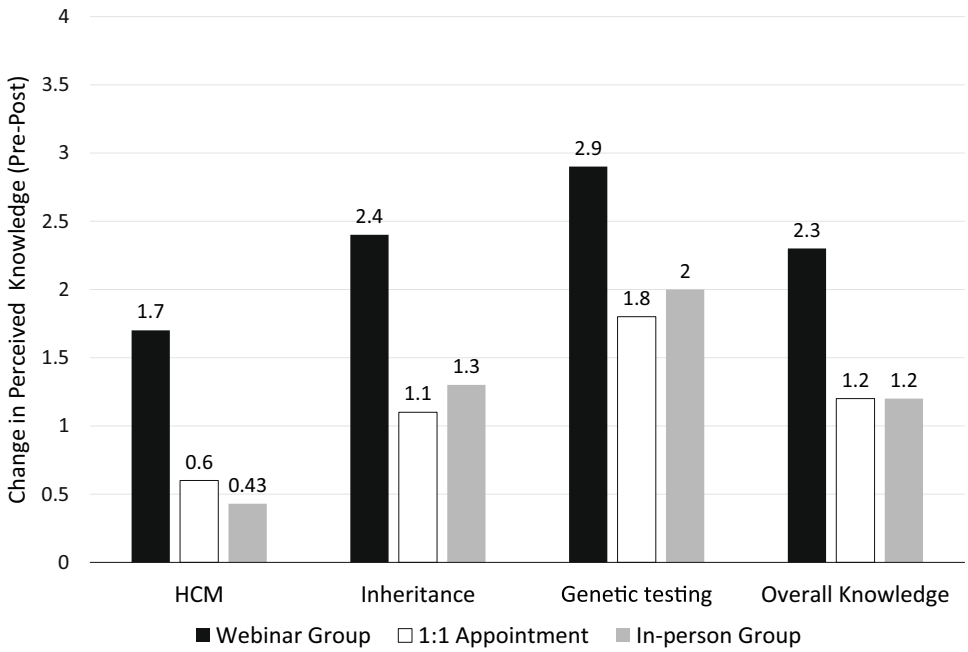

Fig. 3 Difference in self-perceived knowledge for the webinar group and control groups. 1 = I know nothing and 4 = I know a lot

Scores significantly improved between the pre- and post-survey with regard to overall decisional conflict and for each subscale, for both the webinar and control groups (Table 3). Decisional conflict scores were higher (less decisional conflict) in the control groups but no statistical comparison was performed due to the limited power of the study.

Efficiency

An average of 6.3 patients attended each webinar, with two GCs present for the webinar and 10 min required on average for each post-webinar phone call. As a result, an average of 153 GC minutes was provided per webinar for an average of 24 min per patient. This compares with ~ 60 min per patient for a traditional 1:1 genetic counselling appointment.

Translation to other areas of service

Given the success of the HCM webinar pilot and the unique challenges of providing care during a pandemic, patient webinars were developed and implemented for a variety of referral indications including hereditary cancer, hemochromatosis, cystic fibrosis, and sensorineural loss. From June 2020 to October 2021 (inclusive), 595 patients were seen using webinar as the SDM.

Discussion

The development of a provincial patient-facing webinar providing pre-test genetic counselling to index HCM patients was complex and required significant

Table 3 Change in decisional conflict scores for the webinar and control groups

Subscales	Webinar group ($n=43$)	Control group: 1:1 appointment ($n=13$)	Control group: In-person group ($n=7$)
Informed	37.6 ($p<0.0001$)	57.1 ($p<0.0001$)	60.7 ($p=0.0001$)
Values	32.4 ($p<0.0001$)	60.6 ($p<0.0001$)	51.8 ($p=0.0005$)
Support	34.3 ($p<0.0001$)	54.8 ($p<0.0001$)	50 ($p=0.001$)
Uncertainty	30.2 ($p<0.0001$)	42.3 ($p=0.001$)	48.2 ($p=0.003$)
Effective decision	26.6 ($p<0.0001$)	50 ($p=0.0001$)	47.3 ($p=0.003$)
Overall decisional conflict	31.4 ($p<0.0001$)	52.8 ($p<0.0001$)	51.6 ($p=0.0004$)

preparation and coordination. However, high-quality care was observed across all dimensions evaluated. Notable improvements included standardizing care provincially, and decreasing provider time and space resources.

Maintain high-quality care

Our results demonstrate that the HCM pre-test genetic counselling patient webinar is a viable alternative to traditional 1:1 and in-person group genetic counselling, maintaining measures of healthcare quality. Significant improvements were observed with regard to self-perceived knowledge and decisional conflict. Of note, a trend was observed with webinar participants reporting greater gains in knowledge and less improvement in decision conflict compared to our control groups. This may be related to the webinar placing a greater emphasis on education with less emphasis on the decision-making process. Regardless, the vast majority of webinar participants reported this as an acceptable replacement for 1:1 genetic counselling, despite an initial preference for learning via a 1:1 appointment.

Standardized care

A standardized genetic testing and genetic counselling approach for HCM index patients across the province was achieved through this pilot project. This provincial initiative is in keeping with a national roadmap for Genetic Services resumption in a pandemic (Chad et al. 2020). Consistent care across AHS for HCM families is also anticipated to increase patient confidence with the healthcare system as discrepancies in care (i.e., wait times, variability in panel selection, resources provided to patients) have been resolved.

Provider resources

Improvements were noted with regard to the number of patients seen per hour of clinical care as a result of the HCM patient webinar. Compared to a traditional 60-min 1:1 genetic counselling appointment, the webinar required 24 min of GC time per patient. Given the early restrictions on webinar enrollment, GC time per patient is anticipated to further decrease as the number of webinar participants increases. It has been noted that the traditional 1:1 genetic counselling SDM is time intensive and not practical to reach a large population, and that the need for improvements in efficiency and access is critical to ensuring that the growing number of patients seeking genetic services receive appropriate care (Cohen et al. 2013).

The virtual nature of the webinar also results in additional resource savings related to space. For every patient booked into the webinar, approximately 60 min of clinical space becomes available for other patients to receive healthcare services. With a move to more virtual 1:1 genetic counselling during the COVID-19 pandemic, the need for clinical space may be less relevant for genetic counselling but may become a useful resource for specialities that require an in-person evaluation. This is particularly relevant when cardiac genetic services are physically embedded within a larger clinical genetics program, where the demand for in-person evaluation of patients with undiagnosed rare diseases continues to grow.

Given that increases in the number of patients seen are accompanied by increased need for the post-clinic tasks, it is important for any clinic adopting this model to maximize the efficiency of these tasks. Khan et al. (2020) offer a number of suggestions to use existing infrastructure to facilitate the implementation of innovative SDMs while maximizing available resources, including delegating some tasks to non-genetic staff.

Patient preference

The utilization of a virtual platform has the added opportunity for patients to attend their healthcare appointment from a preferred location. During the COVID-19 pandemic, this reduced the number of patients entering a clinical facility and potentially contracting or transmitting the virus. In addition, as has previously been reported in relation to telegenetics, a webinar is often more convenient for families and can lead to cost savings related to travel (Voils et al. 2018; Vrečar et al. 2017). Several participants in our study commented specifically on the benefit of not having to travel to the appointment, which has also been noted in other studies (Cohen et al. 2013). Chad et al. (2020) also highlight the need for accommodation of patient preferences for location and timing of care for genetics patients in resuming care during the pandemic.

Practice implications

To date, 595 patients have been seen using webinar as the SDM in our province. Our experience offering healthcare services via patient-facing webinars has not only made a significant impact on our overall clinic wait times, but also offered patients a safer option for care during the COVID-19 pandemic. Increased comfort with virtual care during this unique period in time will likely increase the uptake of webinar as a SDM as we move forward. To date, our webinars have focused on proband or carrier testing; however, other areas of genetic counselling should be considered. Cascade genetic testing for family members at-risk of an inherited heart condition is an area of high demand. The introduction of a webinar to this populations could potentially allow for more focused psychosocial counselling during the follow-up phone call.

Evaluation of GCs' experience with telegenetics has highlighted concerns around technical problems, inability to develop rapport with patients, and lack of ability to assess nonverbal cues (Vrečar et al. 2017; Zierhut et al. 2018). In contrast, others have reported high satisfaction related to the increased efficiency and convenience for the clinician (Zilliacus et al. 2009). The Canadian College of Medical Genetics pandemic roadmap highlights that not all clinicians are comfortable with virtual care, which may influence perspective on providing care in this manner (Chad et al. 2020). Similarly, Khan et al. (2020) highlighted that GCs may benefit from additional training in technology that often accompanies the implementation of new SDMs. This is of particular importance considering the potential for a privacy breach if technology is not established and implemented in accordance with relevant health information privacy considerations.

Study limitations

Not all participants attending the webinar, an in-person group information session, or 1:1 genetic counselling appointment completed the evaluation limiting the generalizability of our findings. Although demographics collected for the webinar and control group were similar, the majority of participants in all groups had post-secondary education potentially biasing the finding from the study. In addition, there is the potential for selection bias given some control participants specifically requested an in-person genetic counselling appointment and patients who were not comfortable receiving care in English were excluded from the study. Due to the changing environment during the study with the arrival of COVID-19, the control group is heterogeneous including patients seen through an in-person group, and 1:1 in-person and virtual genetic counselling appointment. The sample was also limited in size. Finally, self-perceived knowledge was evaluated, which may or may not reflect true gains in knowledge.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s12687-021-00564-x.

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Author contribution Susan Christian confirms that she had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Julia Tagoe and Raechel Ferrier were involved in development of the webinar, data acquisition, analysis, interpretation, revising, and final manuscript approval. Ruth Kohut, Lenore Delday, and Francois Bernier were involved in development of the webinar, revising, and final manuscript approval.

Data availability Data available within the article or upon request.

Declarations

Conflict of interest The authors declare no competing interests.

Human studies and informed consent Approval to conduct this human subject research was obtained by the Research Ethics Board at the University of Alberta and the University of Calgary. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Implied informed consent was obtained for individuals who voluntarily completed the online survey and submitted their responses.

Animal studies Not applicable.

References

Boothe E, Greenberg S, Delaney CL, Cohen SA (2020). Genetic counseling service delivery models: a study of genetic counselors' interests, needs, and barriers to implementation. Journal of Genetic Counseling. https://doi.org/10.1002/jgc4.1319

Chad L, Dawson AJ, Goh ES-Y (2020). Canadian College of Medical Geneticists (CCMG) points to consider: resuming genetic services in a pandemic-a summary. Journal of Medical Genetics. https://doi.org/10.1136/jmedgenet-2020-107394

Cloutier M, Gallagher L, Goldsmith C, Akiki S, Barrowman N, Morrison S (2017) Group genetic counseling: an alternate service delivery model in a high risk prenatal screening population. Prenat Diagn 37(11):1112–1119. https://doi.org/10.1002/pd.5149

Cohen SA, Gustafson SL, Marvin ML, Riley BD, Uhlmann WR, Liebers SB, Rousseau JA (2012) Report from the National Society of Genetic Counselors service delivery model task force: a proposal to define models, components, and modes of referral. J Genet Couns 21(5):645–651. https://doi.org/10.1007/s10897-012-9505-y

Cohen SA, Marvin ML, Riley BD, Vig HS, Rousseau JA, Gustafson SL (2013) Identification of genetic counseling service delivery models in practice: a report from the NSGC Service Delivery Model Task Force. J Genet Couns 22(4):411–421. https://doi.org/10.1007/s10897-013-9588-0

Fournier DM, Bazzell AF, Dains JE (2018) Comparing outcomes of genetic counseling options in breast and ovarian cancer: an integrative review. Oncol Nurs Forum 45(1):96–105. https://doi.org/10.1188/18.ONF.96-105

Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG (2009). Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377–81.

Khan A, Cohen S, Weir C, Greenberg S (2020). Implementing innovative service delivery models in genetic counseling: a qualitative analysis of facilitators and barriers. J Genet Counsel, Early view. https://doi.org/10.1002/jgc4.1325

O'Connor AM (1995) Validation of a decisional conflict scale. Medical Decision Making : an International Journal of the Society for

Medical Decision Making 15(1):25–30. https://doi.org/10.1177/0272989X9501500105

Otten E, Birnie E, Ranchor AV, van Tintelen JP, van Langen IM (2015) A group approach to genetic counselling of cardiomyopathy patients: satisfaction and psychological outcomes sufficient for further implementation. European Journal of Human Genetics : EJHG 23(11):1462–1467. https://doi.org/10.1038/ejhg.2015.10

Shaw T, Metras J, Ting ZAL, Courtney E, Li S-T, Ngeow J (2018) Impact of appointment waiting time on attendance rates at a clinical cancer genetics service. J Genet Couns 27(6):1473–1481. https://doi.org/10.1007/s10897-018-0259-z

Voils CI, Venne VL, Weidenbacher H, Sperber N, Datta S (2018) Comparison of telephone and televideo modes for delivery of genetic counseling: a randomized trial. J Genet Couns 27(2):339–348. https://doi.org/10.1007/s10897-017-0189-1

Vrečar I, Hristovski D, Peterlin B (2017) Telegenetics: an update on availability and use of telemedicine in clinical genetics service. J Med Syst 41(2):21. https://doi.org/10.1007/s10916-016-0666-3

Zierhut HA, MacFarlane IM, Ahmed Z, Davies J (2018) Genetic counselors' experiences and interest in telegenetics and remote counseling. J Genet Couns 27(2):329–338. https://doi.org/10.1007/s10897-017-0200-x

Zilliacus E, Meiser B, Lobb E, Barlow-Stewart K, Tucker K (2009) A balancing act–telehealth cancer genetics and practitioners' experiences of a triadic consultation. J Genet Couns 18(6):598–605. https://doi.org/10.1007/s10897-009-9247-7