Literature Resources on Telegenetics

Compiled by Michael Edwards, PhD, Consultant for Northeast Telehealth Resource Center, Oct 2017
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ABSTRACTS


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Abstract

Demand for cancer genetic counseling has grown rapidly in recent years as germline genomic information has become increasingly incorporated into cancer care, and the field has entered the public consciousness through high-profile celebrity publications. Increased demand and existing variability in the availability of trained cancer genetics clinicians place a priority on developing and evaluating alternate service delivery models for genetic counseling. This mini-review summarizes the state of science regarding service delivery models, such as telephone counseling, telegenetics, and group counseling. Research on comparative effectiveness of these models in traditional individual, in-person genetic counseling has been promising for improving access to care in a manner acceptable to patients. Yet, it has not fully evaluated the short- and long-term patient- and system-level outcomes that will help answer the question of whether these models achieve the same beneficial psychosocial and behavioral outcomes as traditional cancer genetic counseling. We propose a research agenda focused on comparative effectiveness of available
service delivery models and how to match models to patients and practice settings. Only through this rigorous research can clinicians and systems find the optimal balance of clinical quality, ready and secure access to care, and financial sustainability. Such research will be integral to achieving the promise of genomic medicine in oncology.

**Examination of the Patient-Focused Impact of Cancer Telegenetics Among a Rural Population: Comparison with Traditional In-Person Services.**


**Abstract**

**BACKGROUND:**
Telecommunication models promise to improve access to cancer genetic counseling. Little is known about their impact among the geographically underserved. This work examined knowledge and emotional outcomes and attitudes/beliefs regarding cancer telegenetic services (via live-interactive videoconferencing) in Maine.

**MATERIALS AND METHODS:**
Cancer telegenetic patients seen at two remote sites and control (in-person) patients responded to pre-/postsurveys assessing care impact on hereditary breast and ovarian cancer (HBOC) knowledge and emotional health, ease of access to services, and telegenetics satisfaction/acceptability.

**RESULTS:**
158/174 (90%) participants returned pre- and immediate postcounseling surveys (90 remote and 68 in-person). Fewer returned 1-month postsurveys. Remote patients were older with lower education levels, more likely to live in rural counties and to have cancer histories. The two groups were matched relative to gender, race, and health insurance status. HBOC knowledge improved equally in both groups pre- versus immediately postcounseling and was maintained at 1 month in both groups. Decreased anxiety was evident postcounseling with no significant difference between groups. Depression improved significantly in remote patients immediately postcounseling; 1-month depression measures were lower in both groups. The availability of telegenetics eased transportation needs/work absences, and patients reported satisfaction with telecommunication quality. Despite overall acceptance of telegenetics, 32% of remote patients noted preference for in-person care.

**CONCLUSIONS:**
There were few differences in HBOC knowledge and emotional outcomes comparing traditional in-person cancer genetic services with telegenetics, and satisfaction with/acceptance of this
model was high. These data relate to scalability of cancer telegenetics in rural regions regionally and nationally.

Reaching high-risk underserved individuals for cancer genetic counseling by video-teleconferencing.
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Abstract
BACKGROUND:
Breast and colorectal cancers are common cancers for which genetic risk assessment and counseling are available. However, these services are often limited to metropolitan areas and are not readily accessible to underserved populations. Moreover, ethnic and racial disparities present additional obstacles to identifying and screening high-risk individuals and have a bearing on treatment outcomes.

OBJECTIVE:
To provide cancer genetic risk assessment and counseling through telemedicine to the remote, underserved primarily Hispanic population of the Texas-Mexico border region.

METHODS:
Program participants were mailed a questionnaire to assess their satisfaction with the program so that we could determine the acceptability of video-teleconferencing for cancer risk assessment.

RESULTS:
The overall level of satisfaction with the program was very high, demonstrating the acceptability of a cancer genetic risk assessment program that relied on telemedicine to reach and underserved minority community.

LIMITATIONS:
Delivery model requires the availability of and access to communication technologies; trained staff are needed at remote sites for sample collection and patient handling.

CONCLUSION:
Video-teleconferencing is an acceptable method of providing cancer risk assessment in a remote, underserved population.

Similar articles


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Abstract

BACKGROUND:
Videoconferencing has been used to expand medical services to low-access populations and could increase access to genetic services at community sites where in-person visits with genetic providers are not available.

OBJECTIVE:
To evaluate the feasibility of, patient feedback of, and cognitive and affective responses to remote two-way videoconferencing (RVC) telegenetic services at multiple sociodemographically diverse community practices without access to genetic providers.

METHODS:
Patients at 3 community sites in 2 US states outside the host center completed RVC pretest (visit 1, V1) and post-test (visit 2, V2) genetic counseling for cancer susceptibility. Surveys evaluated patient experiences, knowledge, satisfaction with telegenetic and cancer genetics services, anxiety, depression, and cancer worry.

RESULTS:
A total of 82 out of 100 (82.0%) approached patients consented to RVC services. A total of 61 out of 82 patients (74%) completed pretest counseling and 41 out of 61 (67%) proceeded with testing and post-test counseling. A total of 4 out of 41 (10%) mutation carriers were identified: BRCA2, MSH2, and PMS2. Patients reported many advantages (eg, lower travel burden and convenience) and few disadvantages to RVC telegenetic services. Most patients reported feeling comfortable with the video camera--post-V1: 52/57 (91%); post-V2: 39/41 (95%)--and that their privacy was respected--post-V1: 56/57 (98%); post-V2: 40/41 (98%); however, some reported concerns that RVC might increase the risk of a confidentiality breach of their health information--post-V1: 14/57 (25%); post-V2: 12/41 (29%). While the majority of patients reported having no trouble seeing or hearing the genetic counselor--post-V1: 56/57 (82%); post-V2: 39/41 (95%)--51 out of 98 (52%) patients reported technical difficulties. Nonetheless, all patients reported being satisfied with genetic services. Compared to baseline, knowledge increased significantly after pretest counseling (+1.11 mean score, P=.005); satisfaction with telegenetic (+1.74 mean score, P=.02) and genetic services (+2.22 mean score, P=.001) increased after post-test counseling. General anxiety and depression decreased after pretest (-0.97 mean anxiety score, P=.003; -0.37 mean depression score, P=.046) and post-test counseling (-1.13 mean anxiety score, P=.003; -0.75 mean depression score, P=.01); state anxiety and cancer-specific worry did not significantly increase.

CONCLUSIONS:
Remote videoconferencing telegenetic services are feasible, identify genetic carriers in community practices, and are associated with high patient satisfaction and favorable cognitive and affective outcomes, suggesting an innovative delivery model for further study to improve
access to genetic providers and services. Potential barriers to dissemination include technology costs, unclear billing and reimbursement, and state requirements for provider licensure.

**Online genetic counseling from the providers' perspective: counselors' evaluations and a time and cost analysis.**

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**Abstract**

Telemedicine applications are increasingly being introduced in patient care in various disciplines, including clinical genetics, mainly to increase access to care and to reduce time and costs for patients and professionals. Most telegenetics reports describe applications in large geographical areas, showing positive patients' and professionals' satisfaction. One economic analysis published thus far reported lower costs than in-person care. We hypothesized that telegenetics can also be beneficial from the professional's view in relatively small geographical areas. We performed a pilot study in the Northern Netherlands of 51 home-based online counseling sessions for cardiogenetic and oncogenetic cascade screening, and urgent prenatal counseling. Previously, we showed patient satisfaction, anxiety, and perceived control of online counseling to be comparable to in-person counseling. This study focuses on expectations, satisfaction, and practical evaluations of the involved counselors, and the impact in terms of time and costs. Most counselors expected disadvantages of online counseling for themselves and their patients, mainly concerning insufficient non-verbal communication; few expected advantages for themselves. Afterwards, counselors additionally raised the disadvantage of insufficient verbal communication, and reported frequent technical problems. Their overall mean telemedicine satisfaction item score was 3.38 before, and 2.95 afterwards, being afterwards slightly below the minimum level we set for a satisfactory result. We estimated reduced time and costs by online counseling with about 8% and 10-12%, respectively. We showed online genetic counseling to be effective, feasible and cost-efficient, but technical improvements are needed to increase counselors' satisfaction.

**Telegenetics use in presymptomatic genetic counselling: patient evaluations on satisfaction and quality of care.**

Otten E\(^1\), Birnie E\(^1\), Rancho AV\(^2\), van Langen IM\(^1\).

**Abstract**

In recent years, online counselling has been introduced in clinical genetics to increase patients' access to care and to reduce time and cost for both patients and professionals. Most telegenetics reports so far evaluated online oncogenetic counselling at remote health centres in regions with large travelling distances, generally showing positive patient outcomes. We think online counselling--including the use of supportive tools that are also available during in-person counseling--of presymptomatic patients in their homes can also be feasible and valuable for
patients in relatively small regions. We performed a single-centre pilot study of online genetic counselling for 57 patients who were presymptomatic cardiogenetic (n=17), presymptomatic oncogenetic (n=34) and prenatal (3 couples). One-third of presymptomatic patients we approached consented to online counselling. Patient evaluations of practical aspects, satisfaction and psychological outcomes were assessed and compared with a matched control group. Patients managed to fulfill the preparations, were significantly more satisfied with their counsellor and counselling session than controls and were satisfied with the online counselling more than they expected to be beforehand. Psychological outcomes (decreased anxiety and increased control) did not differ with control patients. Technical problems occurred in almost half of online sessions. Nonetheless, online counselling in patients' homes proved to be feasible and was appreciated by a substantial part of presymptomatic patients at our genetics centre in the Netherlands. Based on these outcomes, we conclude online counselling can be a valuable addition to existing counselling options in regular patient care.


Telemedicine uptake among Genetics Professionals in Europe: room for expansion.

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Abstract

Today's economic challenges and the changing landscape of clinical genetics are forcing us to consider alternative ways of providing genetic services, to comply with budget limitations and at the same time meeting the demands of increasing patient numbers and patient-centered care delivery. Telegenetics could be an effective and efficient way of counseling, but its use in Europe is not widely reported, nor is there evidence of international collaboration. We conducted an online survey among 929 genetics professionals, to explore the current availability and use of different telegenetics modalities in Europe. Our questionnaire was completed by 104 clinically active European genetics professionals. Telephone genetic counseling was used by 17% of respondents. Videoconferencing facilities were available to 24%, but only 9% of them used these for patient counseling. Various barriers to availability and use were cited, ranging from practical constraints, lack of professional support/knowledge, to lack of perceived suitability and need. The results show that telegenetics modalities are not currently in widespread use by our respondents, in part due to perceived barriers. To meet the changing economic, genetic, and societal circumstances, we recommend consideration of greater integration of telegenetics into regular clinical genetic care, to supplement existing care modalities. Professional cooperation, sharing knowledge, and establishing guidelines on a national and international level could contribute to successful and more widespread implementation of telegenetics. However, the perceived practical and regulatory barriers have to be overcome.

Similar articles

Randomized Trial of Telegenetics vs. In-Person Cancer Genetic Counseling: Cost, Patient Satisfaction and Attendance.

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Abstract
Telegenetics-genetic counseling via live videoconferencing-can improve access to cancer genetic counseling (CGC) in underserved areas, but studies on cancer telegenetics have not applied randomized methodology or assessed cost. We report cost, patient satisfaction and CGC attendance from a randomized trial comparing telegenetics with in-person CGC among individuals referred to CGC in four rural oncology clinics. Participants (n = 162) were randomized to receive CGC at their local oncology clinic in-person or via telegenetics. Cost analyses included telegenetics system; mileage; and personnel costs for genetic counselor, IT specialist, and clinic personnel. CGC attendance was tracked via study database. Patient satisfaction was assessed 1 week post-CGC via telephone survey using validated scales. Total costs were $106 per telegenetics patient and $244 per in-person patient. Patient satisfaction did not differ by group on either satisfaction scale. In-person patients were significantly more likely to attend CGC than telegenetics patients (89 vs. 79 %, p = 0.03), with bivariate analyses showing an association between lesser computer comfort and lower attendance rate (Chi-square = 5.49, p = 0.02). Our randomized trial of telegenetics vs. in-person counseling found that telegenetics cost less than in-person counseling, with high satisfaction among those who attended. This study provides support for future randomized trials comparing multiple service delivery models on longer-term psychosocial and behavioral outcomes.


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Abstract

PURPOSE:
The rate of adherence to regular colonoscopy screening in individuals at increased familial risk of colorectal cancer (CRC) is suboptimal, especially among rural and other geographically underserved populations. Remote interventions may overcome geographic and system-level barriers. We compared the efficacy of a telehealth-based personalized risk assessment and communication intervention with a mailed educational brochure for improving colonoscopy screening among at-risk relatives of patients with CRC.

METHODS:
Eligible individuals age 30 to 74 years who were not up-to-date with risk-appropriate screening and were not candidates for genetic testing were recruited after contacting patients with CRC or their next of kin in five states. Enrollees were randomly assigned as family units to either an active, personalized intervention that incorporated evidence-based risk communication and behavior change techniques, or a mailed educational brochure. The primary outcome was medically verified colonoscopy within 9 months of the intervention.

RESULTS:
Of the 481 eligible and randomly assigned at-risk relatives, 79.8% completed the outcome assessments within 9 months; 35.4% of those in the personalized intervention group and 15.7% of those in the comparison group obtained a colonoscopy. In an intent-to-treat analysis, the telehealth group was almost three times as likely to get screened as the low-intensity comparison group (odds ratio, 2.83; 95% CI, 1.87 to 4.28; P < .001). Persons residing in rural areas and those with lower incomes benefitted at the same level as did urban residents.

CONCLUSION:
Remote personalized interventions that consider family history and incorporate evidence-based risk communication and behavior change strategies may promote risk-appropriate screening in close relatives of patients with CRC.

Efficacy of a Telehealth Intervention on Colonoscopy Uptake When Cost Is a Barrier: The Family CARE Cluster Randomized Controlled Trial.
Abstract

BACKGROUND:
We tested the efficacy of a remote tailored intervention Tele-Cancer Risk Assessment and Evaluation (TeleCARE) compared with a mailed educational brochure for improving colonoscopy uptake among at-risk relatives of colorectal cancer patients and examined subgroup differences based on participant reported cost barriers.

METHODS:
Family members of colorectal cancer patients who were not up-to-date with colonoscopy were randomly assigned as family units to TeleCARE (N = 232) or an educational brochure (N = 249). At the 9-month follow-up, a cost resource letter listing resources for free or reduced-cost colonoscopy was mailed to participants who had reported cost barriers and remained nonadherent. Rates of medically verified colonoscopy at the 15-month follow-up were compared on the basis of group assignment and within group stratification by cost barriers.

RESULTS:
In intent-to-treat analysis, 42.7% of participants in TeleCARE and 24.1% of participants in the educational brochure group had a medically verified colonoscopy [OR, 2.37; 95% confidence interval (CI) 1.59-3.52]. Cost was identified as a barrier in both groups (TeleCARE = 62.5%; educational brochure = 57.0%). When cost was not a barrier, the TeleCARE group was almost four times as likely as the comparison to have a colonoscopy (OR, 3.66; 95% CI 1.85-7.24). The intervention was efficacious among those who reported cost barriers; the TeleCARE group was nearly twice as likely to have a colonoscopy (OR, 1.99; 95% CI, 1.12-3.52).

CONCLUSIONS:
TeleCARE increased colonoscopy regardless of cost barriers.

IMPACT:
Remote interventions may bolster screening colonoscopy regardless of cost barriers and be more efficacious when cost barriers are absent.

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Genetic counseling for women referred for advanced maternal age: a telegenetic approach.
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Acceptability of telemedicine and other cancer genetic counseling models of service delivery in geographically remote settings.
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Abstract
This work examined acceptability of cancer genetic counseling models of service delivery among Maine residents at risk for hereditary cancer susceptibility disorders. Pre-counseling, participants ranked characteristics reflecting models of care from most to least important including: mode-of-communication (in-person versus telegenetics), provider level of training (genetic specialty versus some training/experience), delivery format (one-on-one versus group counseling), and location (local versus tertiary service requiring travel). Associations between models of care characteristic rankings and patient characteristics, including rural residence, perceived cancer risk, and perceived risk for a hereditary cancer risk susceptibility disorder were examined. A total of 149/300 (49.7% response rate) individuals from 11/16 Maine counties responded; 30.8% were from rural counties; 92.2% indicated that an important/the most important model of care characteristic is provider professional qualifications. Among other characteristics, 65.1% ranked one-on-one counseling as important/the most important. In-person and local counseling were ranked the two least important characteristics (51.8% and 52.1% important/the most important, respectively). Responses did not vary by patient characteristics with the exception of greater acceptance of group counseling among those at perceived high personal cancer risk. Cancer telegenetic services hold promise for access to expert providers in a one-on-one format for rurally remote clients.

Extending Comprehensive Cancer Center Expertise in Clinical Cancer Genetics and Genomics to Diverse Communities: The power of partnership
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Abstract
Rapidly evolving genetic and genomic technologies for genetic cancer risk assessment (GCRA) are revolutionizing our approach to targeted therapy and cancer screening and prevention, heralding the era of personalized medicine. Although many academic medical centers provide GCRA services, most people receive their medical care in the community setting. Yet, few community clinicians have the knowledge or time needed to adequately select, apply and interpret genetic/genomic tests. This article describes alternative approaches to the delivery of GCRA services, profiling the City of Hope Cancer Screening & Prevention Program Network (CSPPN) academic and community-based health center partnership as a model for the delivery of the highest quality evidence-based GCRA services while promoting research participation in the community setting.

Growth of the CSPPN was enabled by information technology, with videoconferencing for telemedicine and web conferencing for remote participation in interdisciplinary genetics tumor boards. Grant support facilitated the establishment of an underserved minority outreach clinic in the regional County hospital. Innovative clinician education, technology and collaboration are powerful tools to extend GCRA expertise from a NCI-designated Comprehensive Cancer Center, enabling diffusion of evidenced-base genetic/genomic information and best practice into the community setting.

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Abstract

OBJECTIVE:
Evaluate whether telemedicine can be used to perform dysmorphology and neurologic examinations in the neonatal intensive care unit (NICU) by determining the examination accuracy, limitations and optimized procedures.

STUDY DESIGN:
Prospective evaluation of NICU patients referred for subspecialty consultation for dysmorphic features (n=10) or encephalopathy (n=10). A physician at bedside (bedside clinician) performed an in-person examination that was viewed in real time by a remote physician (remote consultant). Standardized examinations were recorded and compared. Subsequently, a qualitative approach established technique adjustments and optimization procedures necessary to improve visualization.

RESULT:
Telemedicine examinations identified 81 of 87 (93%) dysmorphology examination abnormalities and 37 of 39 (92%) neurologic examination abnormalities. Optimization of remote consultant visualization required an active bedside clinician assisting in camera and patient adjustments.

CONCLUSION:
Telemedicine can be used to perform accurately many components of the dysmorphology or neurologic examinations in NICU patients, but physicians must be mindful of specific limitations.

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Providing predictive testing for Huntington disease via telehealth: results of a pilot study in British Columbia, Canada.

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Abstract

Predictive testing (PT) for Huntington disease (HD) usually requires several in-person appointments which acts as a barrier to testing for those from remote regions. This pilot study reports the use of telehealth PT to examine whether such telehealth testing improves access to HD PT while maintaining quality of care and support. Individuals underwent PT via the telehealth protocol or standard in-person protocol and were asked to complete surveys regarding their experience. Results reveal no significant differences between the in-person-tested and telehealth-tested groups with respect to quality of care, information, counselling and support. The majority of participants in both groups stated that pre-test counselling had provided them with sufficient knowledge about the advantages and disadvantages of undergoing testing, the
opportunity to ask questions, and the ability to make an informed decision. The majority of participants in both groups were satisfied by the manner in which results were delivered and stated they had received sufficient information regarding the implications of these results. This study reveals that telehealth PT improves access while maintaining quality of care and support.

Telegenetic medicine: improved access to services in an underserved area.
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Abstract
We used telemedicine to improve genetics services to patients in the rural northwestern region of Florida. Patients were first seen via videoconference by a genetic counsellor, who obtained family and medical history. A local paediatrician then performed the physical examination, and a plan for evaluation was established. The videoconferencing equipment was connected at a bandwidth of 384 kbit/s, using three ISDN lines. During the first three telemedicine clinics, seven patients were evaluated and then returned to the centre for a face-to-face consultation with the clinical geneticist. No new diagnoses were made face-to-face that had not been identified by telemedicine. No diagnoses made by telemedicine were judged to be wrong when the child was evaluated face-to-face. During a two-year study of patient satisfaction with 12 telegenetics clinics, the 50 families evaluated via videoconferencing were asked to complete surveys; 40 surveys were returned (a response rate of 80%). All individuals either strongly agreed or agreed that the evaluation of their child was appropriate, sufficient and sufficiently protective of their child's privacy. The waiting time for a new patient consultation with the clinical genetics team was 16.9 months (SD 1.9) at the start and 3.0 months (SD 1.0) at the end of the trial period. The difference was significant (t-test, P < 0.0001). Telegenetics allows more rapid assurance that a genetic syndrome has not been identified, or a quicker initial evaluation and diagnosis for children who do have an identifiable genetic syndrome.

Telegenetics: a systematic review of telemedicine in genetics services.
Hilgart JS1, Hayward JA, Coles B, Iredale R.
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Abstract
PURPOSE:
Telemedicine is being increasingly used in many areas of health care, particularly to reduce the barriers that rural populations face in accessing health-care services. Telemedicine may also be effectively utilized in clinical genetics services—an application that has been termed "telegenetics."

METHODS:
A systematic review of the literature was conducted to identify studies of genetic consultations carried out through videoconferencing so as to determine whether conclusions can be drawn
about the value of telegenetics. A total of 14 articles reporting data from 12 separate studies met the inclusion criteria.

**RESULTS:**
In a majority of these studies, patients received their telegenetics consultation at a local clinic or outreach center, from where they communicated via a synchronous video link with a genetics practitioner. All the studies reported high levels of patient satisfaction with telegenetics, and patients were generally more receptive to telegenetics than the genetics practitioners were. The studies had limitations of small sample sizes and lack of statistical analyses.

**CONCLUSIONS:**
This review suggests that telegenetics may be a useful tool for providing routine counseling and has the potential to evaluate pediatric patients with suspected genetic conditions. Prospective, fully powered studies of telegenetics that explore the accuracy of diagnoses and patient outcomes are needed to allow informed decisions to be made about the appropriate use of telemedicine in genetics service delivery.

E-genetics: exploring the acceptability and feasibility of using technology in cancer genetics services.
Hilgart J¹, Hayward JA, Iredale R.
¹Institute of Medical Genetics, Cardiff University, Cardiff, UK.

**Abstract**
The use of information and communication technologies (ICTs) in the delivery of cancer genetics services could improve equality of access in rural areas and help meet the increasing demand for specialist genetics services. An online patient survey and focus groups with patients and staff from the Cancer Genetics Service for Wales (CGSW) were used to explore the acceptability and feasibility of utilizing ICTs within genetics services, which we have termed e-genetics. A total of 225 patients completed the online survey. Many aspects of e-genetics proposed in the survey were highly acceptable to patients, including an electronic version of the family history questionnaire, an email facility for cancer genetic queries, and a computerized decision-aid. Participants in the focus groups emphasized the importance of patient choice when developing new models of service delivery. For example, the use of genetic counselling via telemedicine was not considered to be preferable to face-to-face clinic appointments but could benefit those unable to travel. This article highlights the fact that e-genetics initiatives may not be appropriate for all cancer genetics service users. However, user-friendly developments that can be easily implemented and attend to individual needs could improve efficiency and cost-effectiveness, whilst providing high-quality services to remote areas.

Trends in telehealth versus on-site clinical genetics appointments in Manitoba: a comparative study.
Elliott AM¹, Mhanni AA, Marles SL, Greenberg CR, Chudley AE, Nyhof GC, Chodirker BN.
Abstract
Telehealth involves the use of information and communications technology to deliver health services to patients over distance. Canada is well suited to benefit from telehealth since many individuals live in remote, rural and isolated locations. Manitoba is the easternmost prairie province and MBTelehealth is an active Canadian program that currently has 105 sites in 73 communities. Although studies of patient satisfaction comparing telehealth to on-site clinical visits have been conducted, a comparative study of the types of genetics patients seen via these two modalities has not been performed previously. In this study we: (1) examined the uptake of telehealth in Genetics in Manitoba; (2) contrasted telehealth usage in Genetics with other clinical programs; and (3) performed a comparative study of the types of Genetics referrals seen in 2008 on-site versus via telehealth. Results indicate the uptake of telehealth is increasing and has made genetics outreach clinics unnecessary. The Program of Genetics and Metabolism is consistently one of the top ten utilizers of telehealth within the province. With respect to discipline, chi square analysis revealed the trends were not significantly different for on-site and telehealth encounters, with prenatal referrals being the most common and Hereditary Breast and Ovarian Cancer referrals being the least common. Referrals within each discipline varied depending on the need for fetal assessment and physical examination. Telehealth was utilized regularly for test results sessions across all disciplines.

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Abstract
Telegenetics is a new development in the service delivery of Genetic Services in Australia. This project was designed to establish if it was an acceptable alternative to a face-to-face consultation in the genetic assessment of intellectual disability, including morphological assessment, of the patient. Ten children from two outreach clinics in rural NSW who were referred by their pediatrician were assessed by a single geneticist via telehealth and then seen again face-to-face as a ‘gold standard’. Satisfaction surveys were then sent to both the parents and the referring pediatricians. After the face-to-face appointment, the clinical geneticist reviewed the recordings of both the transmitted footage and the high definition footage that was sent separately. There were very few morphological findings missed by the telegenetic assessments. The discrepancies that were noted could decrease in frequency as staff become more familiar with the methods. The parents of the patients reported no problem with the cameras and telehealth. They would have preferred face-to-face appointment but would be happy to have the telehealth appointment if it meant being seen earlier. This pilot study suggests that clinical genetic diagnostic assessment could be performed by telemedicine.
Extending comprehensive cancer center expertise in clinical cancer genetics and genomics to diverse communities: the power of partnership.

MacDonald DJ, Blazer KR, Weitzel JN.

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Abstract

Rapidly evolving genetic and genomic technologies for genetic cancer risk assessment (GCRA) are revolutionizing the approach to targeted therapy and cancer screening and prevention, heralding the era of personalized medicine. Although many academic medical centers provide GCRA services, most people receive their medical care in the community setting. However, few community clinicians have the knowledge or time needed to adequately select, apply, and interpret genetic/genomic tests. This article describes alternative approaches to the delivery of GCRA services, profiling the City of Hope Cancer Screening & Prevention Program Network (CSPPN) academic and community-based health center partnership as a model for the delivery of the highest-quality evidence-based GCRA services while promoting research participation in the community setting. Growth of the CSPPN was enabled by information technology, with videoconferencing for telemedicine and Web conferencing for remote participation in interdisciplinary genetics tumor boards. Grant support facilitated the establishment of an underserved minority outreach clinic in the regional County hospital. Innovative clinician education, technology, and collaboration are powerful tools to extend GCRA expertise from a National Cancer Institute-designated Comprehensive Cancer Center, enabling diffusion of evidenced-based genetic/genomic information and best practice into the community setting.

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The virtual consultation: practitioners’ experiences of genetic counseling by videoconferencing in Australia.

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Abstract

OBJECTIVE:
Videoconferencing for clinical genetics services, or telegenetics, is becoming an increasingly utilized method of delivering genetic counseling to rural areas; however, there has been little qualitative exploration of the practitioner's experience, particularly for hereditary breast/ovarian cancer counseling.

METHODS:
Semistructured interviews were conducted with genetic practitioners (n=15) delivering telegenetics services in New South Wales, Australia. Interviews explored experiences, perceived aims of the service, satisfaction, and the advantages and disadvantages of the technology.

RESULTS:
All practitioners were highly satisfied with telegenetics. They perceived the advantages of videoconferencing as primarily increased efficiency and convenience for genetic clinicians, minimized travel for the patient, reduced costs, and increased access to rural areas. Disadvantages included the inhibition of rapport building between genetic clinician and patient and the difficulty in detecting nonverbal cues. Telegenetics was seen as a structured interaction that allowed less time for emotional exploration than a traditional face-to-face consultation. Technical disadvantages involved visual resolution, connection speed, and interruptions to voice transmission.

**CONCLUSION:**
Practitioners were satisfied with telegenetics and perceived the advantages as outweighing the disadvantages.
described undertaking multiple roles during the telehealth process. Two models of interaction were observed. The medical model reduced the interaction to a dyadic consultation by having the genetic counselor off-screen and included minimal clinician meetings and supervision. The triadic co-facilitation model incorporated a high level of information exchange, counselor autonomy and included the counselor onscreen. The co-facilitation model offers a useful framework for telehealth genetic counselling, offering complementary roles between practitioners and efficient service delivery.

**Breast.** 2006 Dec;15 Suppl 2:S65-70.
Moving genetics into clinical cancer care: examples from BRCA gene testing and telemedicine.
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**Abstract**
The translation of genetic knowledge from the research laboratory into the clinical arena is a complex and challenging process. The skills and expertise required are different from those required by a successful laboratory scientist. Recognising the scale of the challenge, University College London has established the Institute of Human Genetics and Health; a unique, multidisciplinary initiative examining the impact of genetic knowledge on human health and disease. The testing of the BRCA1 and 2 genes in the North East Thames region is an interesting example of the translation of genetic testing into clinical care, and the corresponding complexities relating to informed consent that can arise. The development of a remote cancer genetics service within North East Thames Regional Genetics Service, which uses live, real time teleconferencing technology, is a powerful example of the fact that the National Health Service (NHS) can adapt, and integrate new technology into its working practice.

A comparison of patient satisfaction with telehealth and on-site consultations: a pilot study for prenatal genetic counseling.
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**Abstract**
Many different fields of medicine are now utilizing video conferencing as a means to offer consultations to individuals in rural communities. However, there is a lack of published literature regarding the use of telehealth in clinical genetics and, specifically, in genetic counseling. Those experiences that have been reported mostly centered on cancer genetic counseling, sickle cell anemia consultation and care, or pediatric/adult genetic assessment. In these studies, the patients reported an overall satisfaction with telehealth, signifying that this type of communication may play an important role in the future of medicine. This pilot study compared patient satisfaction with prenatal genetic counseling performed via video conferencing versus that performed on-site. The results show that there was a high level of patient satisfaction when video conferencing was
used to conduct prenatal genetic counseling consultations, suggesting that telehealth can be utilized as a means to offer this service to underserved populations.

An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations.

Coelho JJ, Arnold A, Nayler J, Tischkowitz M, MacKay J.
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**Abstract**
There are few published studies regarding the use of telemedicine in counselling families with a history of cancer. In this study, cancer genetic counselling was evaluated when conducted via telemedicine and compared to face-to-face consultations. Participants were placed into a telemedicine group or a face-to-face group depending on their geographical location. Telemedicine consultations took place using real-time videoconferencing technology ISDN6 digital telephone lines. Sixteen participants were evaluated in the telemedicine compared to 21 in the face-to-face group and all participants were asked to complete both a precounselling and postcounselling questionnaire, which assessed their understanding of cancer genetics, anxiety levels, satisfaction levels, and allowed for personal comments. In both the telemedicine and face-to-face groups, a significant reduction in cancer related anxiety levels and high satisfaction levels were reported. There was a trend towards increased cancer genetic knowledge post genetic counselling in both groups. The results show that telemedicine is a useful alternative by which to provide cancer genetic services when geographical distance is an issue.

Telemedicine and clinical genetics: establishing a successful service.
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**Abstract**
There is a surprising lack of published experience on the use of videoconferencing in clinical genetics. Patients were randomly allocated to either a telegenetic (cases) or face-to-face (control) conventional clinic. The telegenetic consultation was done by videoconferencing, using ISDN lines at 384 kbit/s. Evaluation by the doctor and counsellor took place immediately after each appointment. The patient was asked to evaluate the appointment by telephone questionnaire about four weeks after the event. Forty-two patients were invited to participate and 33 (79%) returned their consent forms. Four patients declined to participate and were seen in ordinary face-to-face clinics. Preliminary results showed that the assessment of the telegenetics consultations by doctors, counsellors and patients was very favourable, and they responded positively when asked if they would be happy to use telemedicine in the future. For use in selected consultations, videoconferencing does appear to fulfil a useful role in clinical genetics.

**Similar articles**
Who is using telegenetics in the United States: A national survey
Conference Paper · November 2014
Conference: 142nd APHA Annual Meeting and Exposition 2014
Mann S, Keehn A, Andersson HC.

Abstract
Background: A priority for the Health Resources and Services Administration (HRSA) funded National Coordinating Center for the Regional Genetics Collaboratives (NCC) is to develop activities to increase access to genetic and newborn screening services to underserved populations. One strategy that has been proposed to expand access is to use telehealth applications. In order to determine who is currently using telegenetics and how they are using it, the NCC Telegenetics Work Group developed and implemented a national survey of genetic service providers. Methodology: A survey was developed by the NCC Telegenetics Work Group. The survey was tested within each Regional Genetics Collaborative and revised until a final survey was approved by the work group. The final survey was administered on-line using Survey Monkey. The survey was advertised through listservs of clinical geneticists, genetic counselors and metabolic geneticists. Results: There were 233 respondents to the survey with 35.3% (82) reporting that they use telegenetics in their practice. The majority of telegenetics users are genetic counselors. Most respondents use dedicated videoconferencing equipment for video consultations. Not surprisingly, the most common type of visits are for out-patient evaluation and management and prenatal patients. Discussion: Information about telegenetics providers and their practices across the United States will be presented. Next steps to expand telegenetics also will be discussed.

Telemedicine in Genetic Counseling
Chapter · 2017
In: Career Paths in Telemental Health, pp.213-222
Landgren S.

Abstract:
Genetic counselors help patients understand and adjust to the psychological, biological, and familial implications of hereditary conditions. Genetic counselors have graduate training in the biology and biochemistry of genetics and the psychology of counseling. There are 32 accredited graduate programs training genetic counselors in 22 states in the United States and 3 provinces in Canada. In North America, genetic counselors are certified by the American Board of Genetic Counselors, Inc. As of the end of 2013, there were 3260 certified genetic counselors in the United States and 235 in Canada. In 2012, full-time certified genetic counselors earned between $30,000 and $120,000 per year. Some employers also provide budgets to the genetic counselors for purchase of books, travel to professional meetings, continuing medical education studies, and occasionally sabbaticals. However, the most meaningful benefits for the counselor are the reactions from the patients they counsel. These reactions are important as they help to balance the burden the counselor faces of dealing with many patients whose own prognoses are poor. Genetic counseling is unusual in that family members often accompany the patient in the counseling session. Because of the limited number of genetic counselors, many patients live far from the nearest one. Recently technology has made it possible to offer counseling by telemedicine. These sessions are similar to face-to-face counseling sessions. They begin with introductions and discussions about the nature of heredity. The counselor then reviews the patient’s family medical history. The counselor assesses the risk for a hereditary condition and
presents options for genetic testing. Finally, the session focuses on medical management and familial issues.

Current Genetic Medicine Reports
June 2017, Volume 5, Issue 2, pp 84–90
Benefits and Challenges of Telemedicine: the JScreen Program Experience
MW Hardy, KA Grinzaid - Current Genetic Medicine Reports, 2017 - Springer

Abstract:

Purpose of Review
The purposes of the present study are to evaluate telemedicine via analysis of the JScreen program and describe the benefits and challenges of telemedicine for genetic services.

Recent Findings
There are a number of considerations in establishing and using telemedicine services. These may include technology and the need for future upgrades, overcoming difficulties in connecting with patients, state regulations on genetic testing and provision of services, and data security and confidentiality. Also, providers must adjust and expand their skills to overcome the unique challenges that may arise during patient consultation. Despite the challenges, telemedicine is a valuable tool that increases patient access to genetic services and makes provision of these services more convenient for both patients and providers.

Summary
Benefits of telemedicine far outweigh the challenges, making it a favorable alternative service delivery model. JScreen provides a model for optimizing benefits and overcoming challenges in the successful provision of genetic services via telemedicine to patients across the country.