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: Semi-structured 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. Interviews were audiotaped, transcribed, and thematically analyzed. 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.

Key words: telemedicine, satisfaction, genetic counseling, hereditary breast cancer

Introduction

Telemedicine through videoconferencing is well established throughout many parts of Australia, with over 209 videoconferencing sites in New South Wales (NSW) alone.1 Services using telemedicine include psychiatry, pain management, pediatric services,2 and more recently, genetic counseling for hereditary breast/ovarian cancer, other types of familial cancers, and general genetics.3–8 Hereditary breast/ovarian cancer is particularly suited to telemedicine because the focus of the consultation is on information exchange, education, and psychosocial care. Often a diagnosis has already been made and a clinical examination is not necessary. Telegenetics, or the use of videoconferencing for
clinical genetics services, is becoming an increasingly utilized method of service delivery.

There are several models for providing genetic services to rural and remote areas in Australia. Historically, clinical geneticists and genetic counselors traveled from the metropolitan hospitals to rural outreach clinics for face-to-face consultations. However, even with the introduction of telegenetics, some states, such as Western Australia, South Australia, and Victoria, have continued to send their genetic clinicians out to rural outreach clinics and have adopted telegenetics infrequently. In other states, for example, NSW, Queensland, and the Australian Capital Territory (ACT), genetic counselors are situated on-site in rural and outreach locations. In these states, videoconferencing can be utilized by having the genetic counselor present with the patient, and clinical genetics services, such as those for familial cancer, can be offered remotely, with the genetic clinician remaining at a metropolitan hospital and the genetic counselor on-site in an outreach location.

Typically, in this process, patients receive an intake appointment, generally face-to-face, with their local genetic counselor, followed by a variable number of additional preclinic contacts. During these face-to-face encounters, the genetic counselor collects medical records, provides genetic education, and offers psychosocial support. The patient is seen by the genetic clinician, such as a clinical geneticist or oncologist with specialist training in familial cancer, only via a real-time videoconferencing system at the telegenetics appointment. The genetic counselor is present with the patient during this appointment and will follow-up after the consultation as necessary (Fig. 1).

In NSW, telegenetics is conducted using a variety of systems with a range of connection speeds and image quality. All use an integrated services digital network connection with a real-time videoconferencing speed of 384 kilobits per second (kbps) at a total cost of A$115 per hour. At this stage there is no government subsidy through the national health system (in Australia, this is called Medicare) for the consultations.

Several studies have evaluated practitioners’ experiences of telemedicine in various settings, including clinical genetics, and found a high level of satisfaction. Coelho et al. compared telegenetics for familial cancer genetics against traditional face-to-face genetic counseling and concluded that there was no significant difference in genetic counseling outcomes. Gray evaluated patient and practitioner satisfaction in Wales and found practitioners to be generally satisfied with the technology. Genetic nurses recorded the lowest satisfaction, feeling that telemedicine changed the dynamics of the consultation and that they felt superfluous to the interaction between the doctor and the patient. This was also reflected in a further study by Iredale et al. Evaluations of telegenetics, however, have been limited predominantly to quantitative studies with small sample sizes. This article reports on initial findings from a qualitative study that explored practitioners’ perspectives and experiences with telegenetics services for hereditary cancer risk. This was undertaken as part of a larger study assessing patient and practitioner perspectives and prospectively evaluating telegenetics outcomes, which will be reported separately.

**Methods**

Studies to date have focused on patient satisfaction and have used quantitative designs. An important disadvantage of quantitative methodologies is that the researcher assumes dimensions of participant beliefs beforehand, and when dimensions are predetermined by the researcher, the ensuing results are more likely to reflect professional rather than participants’ standards, leading to decreased internal validity. Therefore, in this study we employed a qualitative methodology to identify the range of attitudes and experiences in the use of telegenetics services.

**FIG. 1.** The telehealth process. Face-to-face contact with the genetic counselor is marked by a circle. Videoconferencing with the genetic clinician is marked by a box.
SAMPLE

All familial cancer centers in Australia were contacted and surveyed to ascertain whether they had ever participated in telegeneics. Seventeen practitioners were identified. Fifteen practitioners were based in NSW and the ACT; hence, a decision was made to limit the study to NSW and the ACT practitioners. All genetic clinicians and genetic counselors from these areas who had access to videoconferencing services (n = 15) were invited by mail to participate in an interview-based study. Practitioners who had participated in at least one telegeneics consultation were eligible for the study. The response rate was 100% (15/15). Approval for the study was provided by the relevant ethical review boards covering the researchers’ institutions as well as seven Area Health Services in which a potential participant resided. Informed consent was obtained from each participant.

INTERVIEWS

Semistructured interviews were conducted by E.Z., averaging 40 min (range: 20–60 min) either face-to-face or by telephone, depending on the preference of the participant. The interview schedule, based on an extensive literature review and expert consultation, was designed to guide the interview, while leaving wording and sequencing of questions open. Interviews explored perceived aims of the service, satisfaction, experiences of telegeneics in general as well as hereditary cancer specifically, and advantages and disadvantages of the technology. Interviews were audiotaped and transcribed verbatim.

ANALYSIS

The conceptual framework of Miles and Huberman was chosen to guide the analysis. One of the strengths of this framework lies in its emphasis on the explicitness of different strategies a researcher might use to guard against researcher bias and increase the validity of findings. The qualitative data analysis software QSR N6 was used to categorize the data and to facilitate comparisons by professional group (genetic clinician vs. genetic counselors) and other participant characteristics. Transcript text was analyzed to identify and index themes and categories within them. Agreement across the coding scheme was ensured by selecting two early and two mid-way interviews to be coded by E.Z., B.M., and E.L.; E.Z. coded the remainder. Coding was compared and discrepancies were discussed until a consensus was achieved. Data analysis was iterative and E.Z., B.M., and E.L. participated in this process to identify and agree upon emergent themes (Table 1).

RESULTS

All 15 practitioners agreed to participate in the study (response rate: 100%; genetic clinicians = 6 and genetic counselors = 9). Three practitioners were men and the remaining 12 were women. There was a range of years of experience in genetic clinicians of 2–7 years, with a mean of 2.4 years. Genetic counselors reported a range of experience with telegeneics of less than 1–2 years (mean = 1.6 years). Seven genetic counselors and all geneticists surveyed were conducting at least monthly telegeneics clinics. Five practitioners (two genetic clinicians and three genetic counselors) used videoconferencing for cancer telegeneics only. One genetic clinician and two genetic counselors also used videoconferencing for general clinical genetics clinics and seven practitioners (three genetic clinicians and four genetic counselors) used it for cancer genetic counseling, general genetics clinics, supervision, and education.

SATISFACTION

All practitioners expressed a high level of personal satisfaction with telegeneics services, primarily because of the convenience and efficiency it offered.

I think that I like it because I see quite a range of people in a short time. I feel as if I’m quite useful and effective in a short period. (Genetic Clinician 004)

Participants were generally satisfied with the reliability of the videoconferencing equipment and the adequate picture resolution. Although they felt it was intimidating at first, they quickly found it to be easy to use. Those centers that already had the infrastructure reported it to be a convenient alternative to traditional outreach clinics.

ADVANTAGES

Participants found the main advantages to be increased efficiency and convenience for clinicians by reducing travel and associated costs. Sixty percent of the participants (n = 9) perceived telegeneics as offering equitable specialist services to rural and outreach areas in an efficient and timely manner and saw it as a way to increase access to areas that the genetic clinician would otherwise not attend. Appointments could be easily facilitated for urgent and impromptu cases and could be held at centers that may not otherwise be serviced by regular outreach clinics. Additionally, if an existing clinic was cancelled, the clinician’s appointments could easily be offered to an alternative outreach clinic.

DISADVANTAGES

Eight participants felt that the technology inhibited rapport building between the genetic clinician and the patient and increased the difficulty in detecting nonverbal cues.
### Table 1. Example Comments for Emergent Themes and the Frequency of Occurrence Within Genetic Clinician and Genetic Counselor Transcripts

<table>
<thead>
<tr>
<th>THEME</th>
<th>CLINGEN</th>
<th>GCOUNS</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aim</td>
<td>6</td>
<td>9</td>
<td>To provide a prompt, accessible service. Where once upon a time we'd have a clinic every 4 or 5 months, we now have one every 1–2 months. So it's to provide a prompt, accessible service, that's easy to access as well—GCouns027</td>
</tr>
<tr>
<td>Equitable care</td>
<td>3</td>
<td>5</td>
<td>To provide a prompt, accessible service. Where once upon a time we'd have a clinic every 4 or 5 months, we now have one every 1–2 months. So it's to provide a prompt, accessible service, that's easy to access as well—GCouns027</td>
</tr>
<tr>
<td>Access to specialist</td>
<td>2</td>
<td>6</td>
<td>I feel that the aims of telehealth are an opportunity for people to see a subspecialist consultant for up-to-date information about whatever their needs are that they may not have had an opportunity to meet with because of distance or availability—GCouns005</td>
</tr>
<tr>
<td>Reduced cost</td>
<td>1</td>
<td>4</td>
<td>It's a cost benefit for me, as well as a cost benefit for the patient—ClinGen004</td>
</tr>
<tr>
<td>Reduced travel</td>
<td>5</td>
<td>7</td>
<td>So it's the same as doing a clinic except that we can see them without having to travel to them or for them not having to travel to us—ClinGen007</td>
</tr>
<tr>
<td>Efficiency and urgent cases</td>
<td>5</td>
<td>1</td>
<td>And so that's tremendous for the little impromptu ones. So for instance on Friday I'll be seeing several members of a family in Broken Hill and it was out of the question before. You’d have to put them off for six months until the next available clinic in Broken Hill. And now you can just take an hour out of your day to see them and then go back to whatever you were doing—ClinGen002</td>
</tr>
<tr>
<td>Satisfaction with telegenetics</td>
<td>6</td>
<td>9</td>
<td>It’s been entirely positive—ClinGen002</td>
</tr>
<tr>
<td>ClinGen as visiting specialist</td>
<td>3</td>
<td>4</td>
<td>You tend to cut to the chase a bit faster with telemedicine and the counselor has already gone through a lot of the niceties of everyday conversation initially outside, before they bring the patient in and you know you get straight down to tin tacks and talk about why they're there and deliver the information—ClinGen002</td>
</tr>
<tr>
<td>GCouns acting as extension of ClinGen</td>
<td>4</td>
<td>5</td>
<td>I find my role is very much in setting the scene and observing for body language issues when that discussion's going on and being a facilitator or advocate for making sure that the geneticist is aware of any changes in body language or anything that she may have more difficulty in sensing because she's not face-to-face—GCouns005</td>
</tr>
<tr>
<td>Difficulty in detecting nonverbal cues</td>
<td>4</td>
<td>5</td>
<td>I think there’s a bit more going on the other end and I guess there’s one example I guess I bring to mind a lady I think it was a cancer patient, a lady who was crying and I kept wittering on probably for about a half minute or so before I realized that things weren’t going as well as they should—ClinGen001</td>
</tr>
<tr>
<td>Rapport building inhibited</td>
<td>3</td>
<td>5</td>
<td>I think that they do run a lot quicker than a face to face appointment just because there’s less of that kind of general banter that can sometimes go on as the geneticist gets a feel for the client, because generally that’s the only time they see them—with the telehealth, so there’s not a lot of time for just developing any sort of rapport of any sort—GCouns025</td>
</tr>
<tr>
<td>Reduced emotional exploration in telegenetics</td>
<td>3</td>
<td>5</td>
<td>It’s just not the forum for that much discussion—GCouns027Maybe some times the structure can be an issue because if you’ve got an agenda that we need keep and we need to keep to time things that may curtail some of the issues that can be dealt with particularly on this day—GCouns005</td>
</tr>
<tr>
<td>Degree to which emotional needs are met is dependent on GCouns experience</td>
<td>1</td>
<td>3</td>
<td>I guess more of the experienced counselors who’ve been around for a while will potentially intervene at appropriate moments you know and if they perceive that the client’s not necessarily understanding what’s going on, jump in and you know make that clear. I guess they’re there on the spot, so I’m relying on them particularly to be aware of how the client’s coping emotionally—ClinGen001</td>
</tr>
</tbody>
</table>

ClinGen, genetic clinician; GCouns, genetic counselor.
It's not the same as a normal consultation where you can read people more, you are looking at them eye to eye, you get a feeling for how they are, you don’t get that with [telegenetics]. You can see a person might be crying but you can’t pick up on all the other subtleties and I feel like you just don’t get that rapport with the patient that you usually do. (Genetic Counselor 009)

Over half the participants \((n = 8)\) saw videoconferencing as a more structured interaction than occurs in the traditional face-to-face setting, with less time for discussion and emotional exploration.

The structure can be an issue because if you’ve got an agenda that we need to keep and we need to keep to time, that may curtail some of the issues that can be dealt with, particularly on this day. (Genetic Counselor 005)

This is an interesting finding as, from an external perspective, there are few differences in the clinic bookings between telegenetics and face-to-face consultations. In either context it is important to keep to time. With additional probing the genetic counselors were unable to identify which aspect of telegenetics imposed this additional pressure. As this was reported by the majority of genetic counselors \((n = 5)\), it is, however, important to acknowledge the perceived time pressures the technology was felt to impose.

Technical disadvantages reported included microphones not being capable of accommodating two people talking simultaneously, leading to slightly delayed speech, and some instances that led to a more formal and sterile consultation.

Several genetic counselors questioned whether telegenetics was effective for less-literate patients as information was delivered more quickly, with less visual aides, and there was less time for clarification.

It really is quite good for most people who are literate and educated and maybe done high school in the last 10–15 years and they’ve done a little bit of genetics. It’s really good but I do get a lot of people who fall outside of that and sometimes they don’t quite catch it. (Genetic Counselor 026)

One genetic counselor found that videoconferencing did not provide an environment for breaking bad news, such as a mutation positive test result so she structured her clinic to avoid this situation.

I use a model where I [break bad news beforehand face-to-face] and that’s my only priority for the session, that I answer any questions they’ve got but there’s a lot of silence there and a lot of support. You can’t do that on [telegenetics]. You can’t sit there staring at each other over a screen allowing silence. It doesn’t work. It feels very artificial. (Genetic Counselor 027)

**BALANCING THE ADVANTAGES AND DISADVANTAGES**

The efficiency of videoconferencing for three genetic counselors was reported as coming at the cost of postclinic case discussions, where the genetic clinician would disconnect the call at the end of the last patient, rather than, as in face-to-face clinics, having postclinic discussions with the genetic counselor.

A few participants reported that consultation times were shortened because of preclinic intake, education, and preparation by the genetic counselor, thus allowing information to be delivered quickly and efficiently during the tele genetics consultation. However, two participants reported that because of the preclinic preparation and communication between genetic clinician and counselor, it was difficult for another clinician to stand in if there was illness.

It isn’t easy for somebody else to do your clinics. [Telegenetics] is more difficult because it does depend a lot on the fact that I’ve already talked to the counselor about the patient, so it’s very hard for somebody else to come in and to do it in the same amount of time and because you’ve cut everything to the bare bones it’s very difficult for anybody else to do that. (Genetic Clinician 004)

Financially, the disadvantages of not being able to fund the consultation through Medicare\(^a\) and uncertainty over ongoing funding for the service was balanced by gains in genetic clinician efficiency and reduced travel costs.

**TELEGENETICS WORKS WELL IF . . .**

Although there was a high level of satisfaction expressed, it was not without reservations. The majority of participants \((n = 14)\) reported that telegenetics worked well when the health professional with the patient was a genetic counselor. The skills and training of the genetic counselor allowed the genetic clinician to delegate tasks such as education about familial cancer and appropriate family history taking. Most genetic clinicians \((n = 5)\) and three genetic counselors felt that the telegenetics experience was largely dependent on the organizational ability and experience of the genetic counselor.

Actually it does [work]. I was really surprised, but in reality, as long as your genetic counselor is with you, as long as they’re the extension of your being able to comfort, and as long as they’re happy to settle the distress then that works fine. (Genetic Clinician 004)

Several genetic counselors \((n = 5)\) expressed the view that the success of the telegenetics consultation was largely dependent on preclinic contact with the patient.

Disadvantages arise I think when you haven’t some sort of relationship with that person to begin with. So I know that there’s a time when we had to see a patient in [telegenetics] that [sic] neither the [genetic clinician] or I had anything to do with before and that was
probably the most difficult consult that we had to do because we didn’t have that insight into the personalities that they were or the issues of support that they may personally need. (Genetic Counselor 005)

All participants felt that equipment needed to be of an adequate visual resolution to detect facial expressions and other nonverbal cues. It needed to be reliable for the session to run smoothly as line dropouts and delays in transmission were disconcerting for patients and practitioners and delayed the remaining clinic.

Discussion

This study revealed a high level of satisfaction by both clinical geneticists and genetic counselors with telegenetics, which is in keeping with other studies.\(^3,5,7,10,13–16,18\) Although more efficient, however, this technology-driven setting may deprive the genetic clinician of some of the more rewarding aspects of their role in genetic counseling such as personal proximity\(^4\) and that of giving negative results in the context of testing for an identified family-specific mutation, where this was often left to the genetic counselor.

Interestingly, Gray\(^3\) and later Iredale et al.\(^3\) found that genetic nurses were dissatisfied with their role in telegenetics, feeling that videoconferencing disrupted their supportive role and inhibited interaction by all participants. Although some genetic counselors in our study expressed similar views, the majority saw their role in the telegenetics consultation as one component in a larger process, with involvement outside of the videoconferencing consultation, and hence expressed a much higher level of satisfaction. This attitude may be representative of a more systemic view of the value of genetic counseling such as personal proximity\(^4\) and that of giving nonverbal cues. It is interesting to note that all practitioners interviewed were operating with a connection speed of 384 kbps. In telepsychiatry, 124 kbps has been found to be adequate for mental health applications,\(^3,5\) so it is unclear whether the practitioners’ concerns were a product of the resolution available, or reflective of a lack of confidence with the technology. Other strategies such as camera angle and zoom may need to be employed and may highlight a need for further training for practitioners involved in telegenetics.

Although telegenetics has not been found to affect patient outcomes such as knowledge, anxiety, depression, and satisfaction,\(^3,5,13\) the impact of reduced rapport building and emotional exploration reported by participants on the patient’s subjective experience of telegenetics is yet largely unknown and is an area of current investigation. Patients who are actively involved in a patient-centered consultation experience better clinical outcomes.\(^24–26\) Iredale et al.\(^3\) found that practitioner satisfaction was influenced by the degree of rapport established and the level to which they felt the patient was relaxed. Patient-centered telegenetics may give scope through the complementary roles of the genetic clinician and genetic counselor, for the genetic counselor to engage the client, attend to psychosocial aspects, and establish sufficient rapport outside of the videoconferencing appointment itself. Whether the genetic counselor can, or does, provide an adequate environment of patient-centeredness and rapport to maintain the increased adherence and satisfaction that this approach offers will be an area of further research.

Concerns were also raised by genetic counselors about the efficacy of videoconferencing for less-literate patients. Videoconferencing has been shown to be effective in areas similar to genetic counseling, such as diabetes education,\(^27\) with less-literate groups such as asthma education for inner-city immigrants,\(^28\) and for home-based geriatric health education.\(^29\) d’Agincourt-Canning et al.\(^8\) also found in a study of telegenetics in British Columbia that genetic counselors were more critical of videoconferencing than patients and the genetic counselors in this study have also identified concerns. Lobb et al.,\(^30\) however, found that during face-to-face consultations, clinical geneticists used more facilitative behaviors such as summarizing, inviting questions, and using diagrams with patients from a nonprofessional background. There is no evidence to suggest that the telegenetics patient population has lower literacy than its metropolitan counterparts. However, in this study, participants reported having less time for exploration of emotional issues, summarizing and clarification, which are techniques known to improve under-
standing. Given that such behaviors were described by participants as being less likely to be employed in telegenetics, the effects of providing genetic counseling via videoconferencing on patient knowledge and genetic counseling outcomes will require close scrutiny in future research. Videoconferencing has been found to be effective for diabetes education. This may be an instance where continuity of care through the genetic counselor provides the educational reinforcement that a remote connection takes away.

Limitations
This study is limited by a small sample size of only 15 practitioners and included practitioners from only two of the seven health services in Australia (NSW and ACT). It does, however, reflect the views of all practitioners who had or were currently delivering telegenetics services. As such, it reports on the experiences of practitioners already using telegenetics and does not explore barriers to uptake by practitioners not yet utilizing the technology. The experience of practitioners is also situated within the context of their health service and so the findings from this study could not be extrapolated across to other health services in Australia, internationally, or to models of delivering cancer genetic counseling using videoconferencing. For example, all practitioners in this study adopted a model utilizing local outreach or rural genetic counselors on-site with the patient during telegenetics. The study does not explore alternative models, such as having an alternative health professional present with the patient.

To better inform clinical practice, we are currently supplementing the existing research in videoconferencing for cancer genetic counseling with a similar ongoing qualitative study of the perspectives of women at high inherited risk for breast and ovarian cancers. A larger quantitative comparison of genetic counseling outcomes between telegenetics and face-to-face consultations currently being undertaken will also inform the results presented in this article.

Conclusion
All genetics practitioners viewed telegenetics’ advantages as outweighing its limitations. For outreach areas it allowed a cost-effective, efficient service to be delivered, but it was acknowledged that the technology inhibited rapport and communication between the genetic clinician and the patient.

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