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METHODOLOGY

Telemedicine vs in-person cancer genetic counseling: measuring satisfaction and conducting economic analysis

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Abstract: Cancer genetic counseling (CGC) provides benefits and is the standard of care for individuals at increased risk of having a hereditary cancer syndrome. CGC services are typically centered in urban medical centers, leading to limited access to counseling in rural communities. Telemedicine has the potential to improve access to CGC, increase efficient use of genetic counselors, and improve patient care in rural communities. For telemedicine CGC to gain wide acceptance and implementation it needs to be shown that individuals who receive telemedicine CGC have high satisfaction levels and that CGC is cost-effective; however little research has been conducted to measure the impact of telemedicine CGC. This paper describes the design and methodology of a randomized controlled trial comparing telemedicine with in-person CGC. Measurement of patient satisfaction and effectiveness outcomes are described, as is measurement of costs that are included in an economic analysis. Study design and methodologies used are presented as a contribution to future comparative effectiveness investigations in the telemedicine genetic counseling field.

Keywords: cancer genetics, genetic counseling, rural health services, telemedicine, satisfaction, cost

Introduction

Because of its many documented benefits, CGC has become the standard of care for individuals at increased risk of having a hereditary cancer syndrome. CGC effectively delivers complex information that facilitates informed decision making for prevention, early detection, and treatment.[1–3] CGC has been associated with facilitating surgical decision-making for women recently diagnosed with breast cancer;[4,5] improved adherence to recommended risk management behaviors;[6,7] decreased cancer worry and anxiety;[8,9] and enhanced communication of cancer risk-related issues among family members.[10] With at least 15% of women with breast and ovarian cancer and similar percentages of those with other cancers being appropriate candidates for CGC,[11] a large group of cancer patients and their family members stand to benefit from CGC. Accordingly, the US Preventive Services Task Force[12] and many professional organizations[13–15] have recognized the benefits of CGC.

In spite of these recognized benefits, access to CGC is suboptimal for several groups. Historically, rural and minority populations have been less likely than other groups to have access to CGC.[16,17] To address this problem, since 2005 the Duke Comprehensive Cancer Center has been performing monthly in-person outreach to improve access to CGC in several rural North Carolina oncology clinics. This service is well accepted[18] but has limitations. First, traveling to the outlying oncology clinics

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limits the number of patients seen in one day and hinders the efficient use of genetic counselors. Second, and perhaps more importantly, visiting each clinic only once per month creates delays for many recently diagnosed women who want to incorporate genetic testing results into their breast cancer treatment decisions. As genetic testing results are increasingly incorporated into decision making,[1,2,19] the travel and time limitations of providing in-person counseling at rural clinics can deprive some individuals of optimal care.

Telemedicine, defined by the Institute of Medicine as "the use of electronic information and communications technologies to provide and support health care, when distance separates the participants",[20] has the potential to improve access to CGC in underserved and rural areas. Through telemedicine underserved communities can gain access to scarce medical expertise by using technology to link rural health centers to specialists at tertiary health centers. Telemedicine has shown such promise in numerous specialties including dermatology,[21] psychiatry,[22] and oncology.[23,24] Data from studies of telemedicine in these specialties show that telemedicine improves access to medical care in underserved communities and patients are as satisfied with receiving medical care via telemedicine as with the same specialty consultations performed in person.[21–24] Of note, equal satisfaction holds for groups that might not be expected to be comfortable with telemedicine technology, such as the elderly.[24] Finally, others have shown telemedicine specialty consultations can lead to improvements in clinical outcomes.[25]

While limited, the research conducted specifically for telemedicine in genetics is encouraging. A few studies have examined the comparative effectiveness of telemedicine in clinical genetics,[26–28] prenatal genetic counseling,[29] sickle cell anemia counseling,[30] and CGC,[31] finding equivalent patient satisfaction in telemedicine vs in-person consultations.

Although previous telemedicine studies show promise, most have limitations that may hamper their real-world application. Few telemedicine studies have used a randomized controlled trial study design,[32,33] preventing an unbiased comparison of telemedicine consultations with in-person consultations. In measuring effectiveness, few telemedicine studies relied on validated patient satisfaction measures,[32,33] leaving doubt that studies are measuring what they intend to measure. And as often is the case with comparative effectiveness studies, few studies have measured the economic impact of telemedicine,[32] an important consideration given that many telemedicine studies have used videoconferencing technology that costs tens of thousands of dollars to purchase and maintain – costs difficult to absorb in real-world settings.

We are conducting a randomized controlled trial that provides CGC either via videoconferencing (the intervention arm) or in person (the usual care control arm) in 4 rural North Carolina oncology clinics. Our focus in this study is to determine whether we can use telemedicine technology to provide CGC that is at least as satisfactory to patients as in-person counseling while reducing wait times for receiving counseling and genetic testing results and do so in a manner that is more cost efficient than in-person counseling. In this paper we describe our study's design, the telemedicine technology we implemented for CGC, the satisfaction surveys and outcome measures we are using, and the economic analysis methodology we will employ. We hope that this information will be useful to other researchers and oncology treatment centers planning to conduct comparative effectiveness research or implement telemedicine CGC.

Methods

Study design

Study population

Four cancer treatment centers are participating in the study: Maria Parham Oncology Center (Henderson, Vance County, NC), Johnston Hematology-Oncology (Smithfield, Johnston County, NC), Gibson Cancer Center (Lumberton, Robeson County, NC), and Scotland Cancer Treatment Center (Laurinburg, Scotland County, NC). The counties in which these clinics are located have significant African American, Native American, and Hispanic populations, groups which have been historically underserved by CGC.[16,34,35] Each of these clinics is a member of the Duke Oncology Network, which supports clinical and research activities and, since 2005, monthly CGC. Prior to the introduction of the current in-person outreach program, individuals traveling from these areas to Duke Clinic in Durham, NC had an average round-trip driving time of 3.5 hours.

The sample population for this study is individuals who are referred or self-refer for CGC and would rather have their appointment in one of the four project clinics than travel to Duke University Medical Center. The majority of individuals receiving CGC have breast or ovarian cancer. Nevertheless, all individuals appropriate for CGC are eligible to participate in the study, including those with no personal but significant family history of cancer and those at risk for hereditary cancers other than hereditary breast and ovarian cancer (HBOC) syndrome (such as Lynch syndrome).

Randomization

We are using a randomized, 2-group design (see Figure 1) to compare telemedicine CGC vs in-person counseling. Medical oncologists or primary care physicians at the four participating clinics refer patients for CGC according to generally recognized criteria for genetic counseling referral (eg, early age at cancer diagnosis, multiple relatives with cancer). Individuals are also allowed to self-refer for CGC. Once candidates are referred from the clinics for CGC, study personnel contact them by phone, explain the study, and ask them to participate. If they are interested, they are consented over the phone and demographic information is obtained. They are then randomly assigned to either the telemedicine or in-person treatment arm and given an appointment for their CGC. The Duke University Institutional Review Board approved this study.

Genetic counseling process

Patients in both groups receive standard-of-care CGC.[14,36] Prior to the genetic counseling session, the counselor calls patients to take a detailed personal and family cancer history. These data are used to calculate risks for cancer and for having a hereditary cancer syndrome. Patients who choose to have genetic testing are able to do so at the end of the CGC session. For the telemedicine group, a staff member at each clinic obtains a blood sample and completes a genetic testing requisition form. Fees for phlebotomy (usually about $20, if not waived) and for genetic testing (as much as $4,040) are charged to patients or their insurance company as in usual care. For patients who do not have insurance coverage or cannot afford testing, the genetic counselor applies to the genetic testing laboratory's "financial hardship" program for waiver of payment. For patients in each group, plans are made to follow up as appropriate, including discussion of genetic testing results, if applicable.

Telemedicine implementation for CGC

To closely approximate in-person counseling, we sought to develop telemedicine technology that would enable the same type of verbal and visual interactions as in-person CGC. We wanted patients and counselors to connect personally as if they were sitting in the same room, with nonverbal cues made available to both participants, and to share and update informational documents such as pedigrees and educational materials. We developed an innovative hybrid videoconference system to meet these requirements (Figure 2). In this system, traditional videoconference is enhanced by a collaborative form of document sharing that enables patient and counselor to view and revise documents in ways that closely resemble in-person sessions. For example, should a patient mention a new relative diagnosed with cancer, the genetic counselor can immediately add this relative to the pedigree both parties are simultaneously viewing by drawing on a pad linked to a document screen. The technology allows us to approximate sitting down in a physical space with patients and interacting with them in all the visual, verbal, nonverbal, and collaborative modes required for successful face-to-face consultation.

Key elements that will increase feasibility of telemedicine CGC adoption include technology that is easy for clinic staff and patients to use; protection of patient confidentiality with a robust security protocol; and low-cost implementation and limited maintenance. To meet these challenges we developed our own videoconferencing system using off-the-shelf personal computers, monitors,

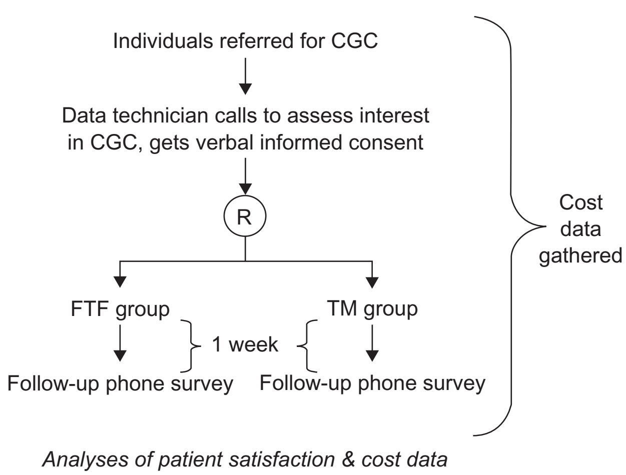

Figure 1 Study design.
Abbreviations: CGC, cancer genetic counseling; FTF, face to face; TM, telemedicine.

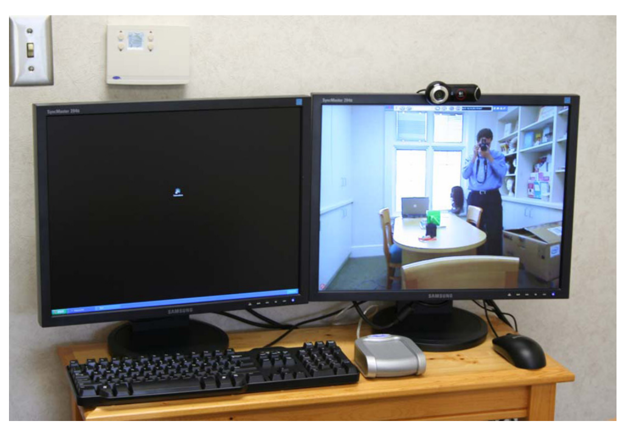

Figure 2 Videoconference set-up.

webcam, and networking equipment. Each clinic designated a staff member to initiate telemedicine sessions. These staff members participated in a 1-hour training session led by the study's IT expert and genetic counselor and received an illustrated notebook reviewing training topics. To ensure a secure system, we protect the system with firewalls and timely monitoring and updating of security patches and virus protection. To prevent compromised data, we do not store Protected Health Information on the remote-clinic system, and sessions are encrypted via 128-bit AES industry-standard encryption.

Data collection

One week after genetic counseling participants are called to complete the follow-up survey, which takes approximately 20 minutes to administer. The survey is captured electronically using a Microsoft Access® database, allowing study personnel to read the questions from their computer screen and input the data simultaneously. Participants receive by mail a study packet that includes a color-coded guide to ease responses during the follow-up survey.

Outcome measures

Patient satisfaction

The study uses 2 validated scales to measure patient satisfaction. The Visit-Specific Satisfaction Questionnaire (VSQ),[37,38] modified to be specific to CGC, uses 5-point Likert-type responses (poor, fair, good, very good, excellent) and has 4 dimensions: interpersonal care, office waiting time, technical care and general satisfaction. The VSQ has shown high validity and strong reliability (internal consistency) for all four dimensions and for the total scale.[37,38] External validity has been shown by VSQ scores strongly predicting patient intention to comply with behaviors recommended by their physician[37] and by an increased likelihood among less satisfied patients to seek another physician within 6 months.[39]

The Genetic Counselor Satisfaction Survey, a 6-item scale validated in prenatal and cancer genetics settings, uses a 5-point Likert-type scale (strongly disagree, disagree somewhat, neutral, agree somewhat, strongly agree) to measure patients' stress, decision-making knowledge, feelings about health, time needed for counseling, perception of counselor's concern for patient's well-being, and perceived value of counseling.[40,41]

The aggregate scores of the VSQ and the Genetic Counselor Satisfaction Survey may be used as effectiveness measures in comparative effectiveness analyses.

Time to intervention

We are collecting data on the length of time from referral for CGC to appointment (in days) (ie, wait time) and the number of "no show" visits that occurred for each intervention group. To document wait times from referral to initial appointment, we use the Duke Hereditary Cancer Clinic database to count from date referred (a database field) to the date the appointment is completed (another database field).

Other measures

In addition to the main outcomes measures, we are assessing certain variables to determine whether randomization is successful in selecting groups with similar characteristics. These include demographic variables (assessed during baseline interview) and several variables that will be drawn from the Duke Hereditary Cancer Clinic database, in which they are entered as a part of usual care. These variables include cancer status, insurance status, genetic testing uptake, and, when appropriate, risk of having a hereditary cancer syndrome (eg, HBOC or Lynch syndrome risk, as calculated by BRCAPRO[42] or MMRPRO[43] model). We will also test the equivalence of the two groups on knowledge and optimism. Patients who discussed HBOC syndrome, which we anticipate will be the large majority of participants, will be asked the Breast Cancer Genetics Knowledge scale,[44] a 27-item scale validated to assess post-counseling knowledge of content discussed in a typical breast cancer genetic counseling session. Because optimism has been associated with cancer genetic testing uptake[45] we will compare the groups on optimism via the Life Orientation Test.[46]

Economic analysis

Fully informed implementation decisions require not only information about outcomes and effectiveness but also information about the costs of the interventions being considered, their impact on the health care system's budget, changes in health care utilization that result from their use, and the economic burden that they pose to patients. Therefore, a comprehensive comparative effectiveness analysis should include an economic analysis component. We will conduct the economic analysis from the societal perspective, taking into consideration costs incurred by both the genetic counseling provider and the patient. CGC costs have 2 main components: labor cost and equipment cost.

Labor cost

The main labor cost component is the genetic counselor's time. For both telemedicine and in-person CGC, the genetic counselor uses a spreadsheet to account for case preparation, the counseling time itself, and post-appointment follow-up (eg, dictations, summary letters). For in-person counseling, the counselor also accounts for the travel time to the four cancer facilities. In-person counseling requires substantial time for the counselor to travel to the various clinics. This travel time has a societal opportunity cost in terms of foregone opportunity to counsel other patients had the counselor not had to travel. An additional personnel cost that differs by group is the time and cost for the genetic counselor to set up a telemedicine appointment, which typically involves mailing a genetic testing kit to the clinic and making necessary charts available on the document screen; therefore, we also accounted for this time.

The second labor cost component is the time needed by the staff member at each clinic to set up the telemedicine equipment for a genetic counseling session and to explain to the patient how the telemedicine counseling system works. This staff member records the amount of time spent performing these functions for each patient.

The amount of training time needed for the counselor and staff members to learn to use the telemedicine technology has been recorded and will be included in the cost calculations.

To calculate labor costs, we will collect salary and fringe benefit data for the genetic counselor and clinic staff members and derive cost-per-minute wage rates. These rates will be multiplied by the total number of minutes the counselor engages in the counseling process and in travel and the minutes staff members help the telemedicine patients to derive total labor cost for each treatment arm. Study-driven labor cost (eg, conducting the follow-up survey) will not be included in the economic analysis. However, equipment failure that extends a telemedicine genetic counseling session or requires a session to be rescheduled will be included in the analysis. Costs incurred will be calculated not only for those who have counseling or follow-up visits but also for "no-show" visits. To estimate mileage costs for each group, the genetic counselor will use a spreadsheet to track the number of miles driven to and from each clinic and for what purpose (ie, for in-person counseling or telemedicine set-up and training) and multiply by our institution's mileage reimbursement rate.

Equipment cost

Equipment costs for each clinic and the genetic counselor include a desktop computer, 2 computer monitors, video conferencing software, web camera, microphone, and digital pen tablet. We accounted for the equipment required in each treatment arm and, because telemedicine equipment prices change rapidly (generally decreasing), we will apply respective market price for each item at the conclusion of the study. We chose not to account for space and overhead costs because these costs will be incurred regardless of whether CGC is implemented via telemedicine or in person.

Patient costs

We account for 2 types of patient costs: time lost from work to attend the CGC session and travel cost. At the 1-week follow-up survey, we ask the participant if she or anyone who came with her to the CGC session missed work in order to attend the session, and if so, we ask how many hours of work were missed. Because the economic analysis is being conducted from a societal perspective, we will derive mean hourly wage rate from the US Bureau of Labor Statistics.[47] This mean wage rate will be multiplied by the hours of work missed to derive productivity loss cost. To estimate travel cost we will multiply the number of miles each participant traveled for her CGC session by the mileage reimbursement rate allowed by the Internal Revenue Service.

Analysis plan

Patient satisfaction

We will summarize responses to the 8 items of the VSQ by tabulating them within each group. As others have done,[39] we will examine each item on the 5-point scale by assigning values of 1–5 (corresponding poor–excellent) to each response and also by dichotomizing them into "excellent" vs "not excellent". We will also calculate an overall VSQ score for each participant by summing the scores for the eight questions. We will analyze the Genetic Counselor Satisfaction Survey in a similar manner, assigning values ranging from 1 for "strongly disagree" to 5 for "strongly agree". Main between-group comparisons will be through tabulations and summary statistics of the variables within each group. To quantify the probability of a difference between groups, we will calculate and examine P-values using chi-square tests for dichotomous variables and the Wilcoxon-rank sum test for discrete ordinal and continuous variables.

Economic analysis

All associated costs, including genetic counselor labor, productivity loss costs and travel, clinic staff member labor, equipment, and participant travel and productivity costs will be aggregated in each treatment arm and divided by the number of participants in each arm to derive mean total cost incurred. The type of economic analysis we perform will depend on the patient satisfaction results, as well as the mean cost results. If satisfaction scores for telemedicine and in-person CGC are equivalent, the economic analysis can be limited to a cost minimization analysis, where the alternative with the lower mean cost is considered the better means of implementing CGC. If either form of CGC yields significantly higher satisfaction score and has lower mean cost, it will be considered the dominant strategy for implementing CGC. If, however, telemedicine or in-person CGC has significantly higher satisfaction but also has higher cost, we will calculate a cost-effectiveness ratio that assesses the incremental cost incurred for the incremental gain in satisfaction. If telemedicine CGC is the alternative with the higher mean cost, we will also calculate cost-effectiveness ratios assessing the incremental cost per day saved from referral to CGC appointment. Although these cost-effectiveness measures may not be as conventional as dollars per quality-adjusted life years saved as recommended by the US Panel on Cost Effectiveness,[48] we believe that this information will nonetheless be useful for decision- and policy-making purposes.

Discussion

Incorporation of one's genetic information into a personalized plan for managing cancer risk is just one way in which genetic information is being used in medicine. It is predicted that the use of genetic and genomic information in assessing risks and developing management plans for other common, complex diseases will become routine and will greatly improve health outcomes.[49,50] Yet, these gains in health outcomes will not be comprehensively and equitably distributed if access to genomic services is limited. Using telemedicine technology to reach underserved communities is one way to improve the likelihood that these communities will not be left out of the "genomic revolution". But before this technology can be implemented broadly comparative effectiveness studies are needed to maximize its potential and efficiency.

The study we have described will provide guidance on whether telemedicine CGC is as satisfactory as, and more efficient than, in-person CGC in outreach clinics. But, our findings will need to be replicated in other populations and with other telemedicine technology. Further, showing that patients are as satisfied with telemedicine CGC as they are with in-person CGC is only the first step in determining the clinical utility of telemedicine technology. Such findings would help this technology pass the "first, do no harm" test. But, it is unclear whether patients who have CGC via telemedicine would experience the same benefits documented for those who have had CGC in person.[1–10] For example, would such patients experience the same reduction in anxiety or improved adherence to cancer risk management behaviors as their in-person counterparts? This question merits rigorous examination as telemedicine CGC is being implemented.

Finally, there is the practical matter of who will pay for the implementation of telemedicine CGC. Recent research has shown wide variability in methods and extent of reimbursement for genetic services.[51] For many centers providing genetic counseling, reimbursement is minimal. Downstream revenue from imaging and prophylactic surgery can offset the costs of providing CGC,[52] but institutions providing CGC to community clinics will not necessarily reap such downstream revenue. Thus, it remains to be seen whether telemedicine CGC will be economically viable.

In summary, we hope that our experience in conducting a comparative effectiveness study for telemedicine CGC and attempting to address the limitations in previous telemedicine CGC research will be of help to others as they plan their telemedicine studies or implementation projects. Further, we hope that our study findings will be a catalyst for further research that will better determine the clinical utility of telemedicine CGC.

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Disclosure

The authors declare no conflicts of interest.

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