

Analysis of Advantages, Limitations, and Barriers of Genetic Counseling Service Delivery Models

Stephanie A. Cohen¹ · Rachele C. Huziak² · Shanna Gustafson³ · Robin E. Grubs⁴

Received: 1 October 2015 / Accepted: 7 January 2016 / Published online: 14 January 2016
© National Society of Genetic Counselors, Inc. 2016

Abstract Previous studies on genetic counseling service delivery models (SDMs) have shown that genetic counselors (GCs) are incorporating alternate models to address growing service demand and improve access to genetic services. This study sought to identify barriers, limitations and advantages to previously identified genetic counseling SDMs. A qualitative research design was employed, in which 20 practicing GCs who utilize a variety of SDMs were interviewed using an email interview format. Interview transcripts were analyzed using a thematic analysis to identify themes related to implementation and utilization of SDMs. Factors that led GCs to implement SDMs other than in-person genetic counseling included: 1) travel distance, 2) wait time and 3) convenience. Logistical issues such as billing and reimbursement, equipment set up, making arrangements for genetic testing and the inability to see the patient are major limitations to alternative genetic counseling SDMs in clinical practice. However, GCs interviewed stated that the convenience to the patient and genetic counselor of alternative SDMs outweighed these

limitations. More research is needed to assess the outcomes of SDMs in practice to demonstrate an impact on the identified barriers of travel distance, wait time and convenience.

Keywords Service delivery models · Genetic counseling · Access

Introduction

The field of genetics continues to rapidly advance, creating a need to adjust the provision of genetic counseling services to meet the increase in demand. As genetic/genomic testing becomes increasingly available and requested more frequently by patients, physicians have reported they feel inadequately prepared to address these requests (Cox et al. 2012). While genetic counselors are well-suited to fill this gap in knowledge, there has been widespread concern that there are not enough genetic counselors to meet this need. Recent studies have documented that genetic counselors have been making changes in their practices to improve access and efficiency of genetic counseling services (Cohen et al. 2013). Interestingly, this study demonstrated the wait time to see a genetic counselor was less than 2 weeks for most genetic counseling specialties, and less than 1 week for prenatal genetics, which suggests genetic counselors are able to meet current demand for services, yet the barriers and limitations to adopting new strategies of delivery are not well described.

The National Society of Genetic Counselors (NSGC) created and tasked the Service Delivery Model Task Force (SDMTF) to identify service delivery models in practice. In reviewing the literature, it became clear that there was no consistency in the way that service delivery models were represented. The group proposed common language to describe genetic counseling service delivery models according to their

Electronic supplementary material The online version of this article (doi:10.1007/s10897-016-9932-2) contains supplementary material, which is available to authorized users.

✉ Stephanie A. Cohen
sacohen@stvincent.org

¹ Cancer Genetics Risk Assessment Program, St. Vincent Health, 8301 Harcourt Rd. #100, Indianapolis, IN 46260, USA

² Cancer Genetics Program, University of Pittsburgh Medical Center, Pittsburgh, PA, USA

³ InformedDNA, Saint Petersburg, FL, USA

⁴ Department of Human Genetics, University of Pittsburgh, Pittsburgh, PA, USA

approach or method of delivery, the mode of entry into the service and components that determine how the service is provided (Cohen et al. 2012).

To further identify service delivery models (SDMs) in practice, the SDMTF went on to survey the membership about current use of models and the associated wait times, billing practices and design of the service delivery. The initial belief was that there would be a “best practice” model of genetic counseling. However, it soon became clear that there were several variations of a best practice model, and that there were many variables that determine which model would work best (Cohen et al. 2013). Almost half of genetic counselors reported that they use more than one SDM in their practice. Little has been published about the specific barriers to traditional genetic counseling that led to the implementation of a particular service delivery model, such as telephone counseling. In addition, information about the limitations of each service delivery model as well as the components of a delivery model that make it more or less efficacious within the U.S. healthcare service delivery systems have not been explored.

At the time of initiation of this project, most literature on service delivery in genetics came from Great Britain and Wales, which does not accurately represent the limitations and barriers experienced within the United States (Elwyn et al. 2005; Iredale et al. 2007; Tempest et al. 2005). More recently, studies have been conducted within the United States, largely related to experiences with telemedicine and telephone for cancer genetic counseling (Meropol et al. 2011; Schwartz et al. 2014). The goal of the current study was to provide information regarding different service delivery models used in the practice of genetic counseling in the United States and to identify advantages and limitations of these models, as well as barriers to implementation. This will provide genetic counselors with information that will facilitate the process of selecting the best practice model that will address barriers to access and efficiency in their own practice.

Methods

Participant Recruitment

Study participants were recruited in four different ways;

1. Participants who previously participated in the internet survey administered by the NSGC SDMTF (Cohen et al. 2013) were given the option to allow future contact from task force members. Individuals who gave their consent for future contact were potential participants for this study. Among these individuals, potential participants were selected so that there would be representation of genetic counselors from the most common genetic counseling specialties (e.g., prenatal, pediatric, cancer

and general genetics) and that each type of service delivery model was represented (in-person, telephone, telemedicine, group).

2. A description of the study was posted on the NSGC discussion board, requesting that potential participants contact the lead author.
3. A flyer was posted at the 30th NSGC Annual Education Conference requesting that potential participants contact the lead author.
4. Participants who were interviewed were given the opportunity to provide names of genetic counselors who they thought would be potential participants for the study.

All participants gave informed consent prior to being interviewed. The study had IRB approval from the University of Pittsburgh (PRO11020128).

Participant Interviews

Interviews with participants were conducted by the lead author using email. Email interviews have been described as an appropriate alternative to in-person or telephone interviews, and allow for interviewees to be reflective and thoughtful about their answers (Hamilton and Bowers 2006). The target population of genetic counselors are highly educated, motivated, and are connected to email. These factors were considered when choosing email interviews as the data collection technique. Guided questions for the interview were developed with reference to the previous survey of genetic counselor service delivery models and aimed to further explore the benefits and limitations of each model in practice (Cohen et al. 2013). See Appendix A for an outline of example interview questions. The email interview process was conducted by sending participants three to five questions at a time for six to seven cycles of questions. Participant email responses were reviewed and probes based on their answers to questions as well as additional questions were sent to participants within 24 to 48 h. The email transcripts were copied and pasted into Microsoft Word for analysis. Responses were collected verbatim; no revisions were applied to the transcripts in order to retain the integrity of the email interview.

Thematic Analysis

For this study, an inductive thematic analysis approach was utilized because few studies have analyzed service delivery models in genetic counseling, especially seeking to identify the limitations and barriers, as well as the advantages of these models. Thematic analysis allowed for the identification of themes within the interviews related to the overall research question. Thematic analysis in this study included analytic coding, memo writing, and characterization of themes. Methods were adapted from Braun and Clarke (2006)

including coding for as many potential themes/patterns as possible, maintaining the surrounding data when coding so the context is not lost and coding individual pieces of data into as many codes as relevant. Line-by-line coding was used and gives at least one code to each phrase, line, or sentence in the data set. Coding was done in Microsoft Word and the process was facilitated by taking notes in the text, and identifying segments of data using color coding (Braun and Clarke 2006).

Memo writing was performed utilizing strategies to break groups of codes into their components which spurs researchers to begin digging into implicit, unstated, and condensed meanings (Charmaz 2004). This phase occurred throughout the course of thematic analysis, with memos being written at the beginning of the process, when first conducting interviews, while re-reading the interview transcripts, and in the final steps of identifying and describing the themes. The investigator (RH) conducted all coding for the thematic analysis. Throughout the data analysis, she reviewed the coding with another member of the research team (REG) to check the “fit” of her conceptualization with the interview data. When there appeared to be ambiguity or confusion pertaining to a developing theme, RH sought additional codes and/or interview data that further explicated or clarified the theme.

Identification and characterization of themes occurred throughout the interview process. Potential themes were noted when first reading through the transcripts and evolved throughout the entire coding process to produce the final report. Codes were applied to the interview transcripts, and were sometimes included under more than one theme. Thematic categories were identified, and codes were arranged to illustrate the themes. Upon completion of coding and classification of themes, memos were written that described each theme and their connection to each other.

Results

Study Sample

Twenty seven individuals agreed to participate in the study but 3 did not respond to the first set of questions and 4 did not complete all cycles of the interview questions. The remaining 20 participants who completed each cycle of interview questions were included in the analysis. All 20 participants were female and practiced in the United States (Table 1). One-third of the participants specialized in cancer genetics (35 %) and had between 10 and 15 years of experience (35 %). Of the 20 participants, 75 % used some degree of in-person genetic counseling, with 30 % using in-person exclusively and 25 % of participants using telephone counseling only. The remaining participants used a combination of different models.

Thematic Analysis

The thematic analysis identified two major themes relating to the use and limitations of service delivery models in genetic counseling. The first theme identified was that the major reason an alternate service delivery model was implemented was due to the increased convenience to the patient and genetic counselor. The second theme related to the limitations of implemented service delivery models, which were largely logistical.

Theme #1: Convenience of Service Delivery

Service delivery models, whether in the form of telephone counseling, group counseling, telemedicine, or a variation of the traditional in-person genetic counseling model, were commonly adopted by genetic counselors in their practices to add convenience, either to their patients or to themselves. Specifically, these include a reduction in the travel distance for both counselor and counselee, a reduction in wait times, and enhancing access.

Reduced Travel Distance A major convenience that telephone and telemedicine counseling offers is reduced travel. Participant GC09 adopted telephone counseling into her practice after realizing that only offering in-person counseling was not serving her population of patients given the geography of her surroundings. GC09 uses telephone counseling 10–20 % of the time, stating that she works in a “large state with a small population and travel is prohibitive for many patients.” She went on to say that the majority of the patients she counsels over the telephone live 70 miles or more from her center. However, the reduced travel distance was not just a benefit for the patients; the interviewees often cited it as a benefit for the genetic counselor themselves.

GC04: “For telephone counseling, distance is the issue on our end. For example, we serve a maternal/fetal medicine practice but do not have a physical office there (and all of us [genetic counselors] are 2.5 h from [there]). We run in-person clinics once or twice a month in this location, but clearly in a maternal/fetal medicine setting there are needs weekly and thus we do those cases via phone if we are not having an in-person clinic that week.”

GC15: “It [telephone counseling] allows the genetic counselors to work from home and we can spread all over the country...counseling over the telephone is efficient because the genetic counselor and the patient do not have to travel to the clinic. This allows for more flexible appointment times (e.g. we have some evening appointments available).”

Table 1 Participant demographics

Participant	Specialty	Years of experience	Place of employment ^a	Primary model	Secondary model
GC01	Cancer	10	Hospital/Medical Center	In-person	
GC02	Cancer	5	Hospital/Medical Center	In-person	
GC03	Prenatal	15	Hospital/Medical Center	In-person	
GC04	No specialty declared	7	Non-profit organization	In-person	
GC05	Cardiac	7	Private practice	In-person	
GC06	Pediatrics	2	Hospital/Medical Center	In-person	Telephone
GC07	Cancer	10	Private practice	In-person	Telephone
GC08	Cancer/Prenatal	6	Private company	Telephone	Telemedicine
GC09	Cancer	10	Hospital/Medical Center	In-person	Telephone
GC10	Pediatrics	2	Private company	Telephone	
GC11	No specialty declared	27	Private company	Telephone	
GC12	Cardiac	5	University Medical Center	Telephone	
GC13	No specialty declared	3	Private company	Telephone	
GC14	Pediatrics	1	Private company	Telephone	Telemedicine
GC15	Prenatal	1	Laboratory	Telephone	
GC16	Cancer	6	Hospital/Medical Center	In-person	Telemedicine
GC17	Cancer	12	Hospital/Medical Center	In-person	Group
GC18	Cancer	>15	University Medical Center	In-person	Group
GC19	Cardiac	10	University Medical Center	In-person	
GC20	Cancer/Prenatal	13	Hospital/Medical Center	In-person	Telephone

^a All participants were employed by different institutions/companies

Reduced Wait Times The genetic counselors interviewed often cited that the adoption of new SDMs was a result of the long wait times they were experiencing in their centers.

GC16: “The hospital that I work at services a very large service area, and I see patients from as far away as 90–100 miles...I have been seeing patients at an outreach clinic (contracted with another hospital) that is 230 miles away. Those clinics were scheduled every 6 weeks previously. Now, I am trying to see as many of those patients by telemedicine as possible, allowing for less travel time for me, and shorter referral times for the patients.”

GC17: “What has evolved during my tenure here is that several years ago, simply due to high volume, we stopped bringing in negative results. Eventually, our wait time for new visits reached 7 months, clearly NOT acceptable, which led to the use of triage and creation of group counseling route, to put through larger number of patients more quickly, which did successfully take care of the wait time.”

Another participant, GC08, addressed that wait time can be reduced with implementation of telephone counseling, because her patients are not required to take time off from work, and thus are able to have their genetic counseling discussion via the telephone. This increases convenience for the patient, while decreasing the time they must wait to speak to a genetic counselor.

GC08: “Many of our patients take their appointments while they’re on break at work during the weekday, so they may step out of their office and go to a private place on their cell phone.”

Enhancing Access to Services When asked why services were provided as they are, and if changes had been made in their practice, a common response among participants was that their service delivery model was implemented to increase access for their patients. This was often related to geographic distance, but financial access was also cited.

GC08: “Our company was founded as an organization that provides telephone genetic counseling in order to increase access to genetic counselors and minimize a variety of barriers.”

GC12: “They [the patients] are from across the country. We are set up so that we are a national genetic counseling service providing over the phone genetic counseling, and take patients from anywhere in the country. They typically come from areas that do not have a cardiac genetic counselor in their area.”

GC18: “I developed the group education session on genetic testing for HBOC [hereditary breast and ovarian cancer] to reduce the financial barrier experienced by patients in getting accurate information for a qualified professional. The group sessions are free to the public. If, afterwards, a patient decides she wants to pursue the

testing, I only have to charge for a more brief, face-to-face appointment where we review the specifics of their family history and fill out the paperwork before drawing the blood sample.”

Theme #2: Barriers and Limitations in SDM Implementation are Largely Logistical

Several barriers were identified in the implementation process of new genetic counseling service delivery models. Most of these barriers were related to logistical issues, such as equipment set-up and arranging for genetic testing, but other issues such as billing and reimbursement and the inability to actually see the patient for feedback cues were also noted. Overall, participants stated that the benefit of convenience outweighed the limitations.

Equipment Set-Up Availability and set up of necessary equipment was also reported as a major barrier to implementing telemedicine services, causing an increase in wait time in some instances.

GC16: “We have had a really successful telemedicine network in place for a while, but I had to wait until the other hospital I contract with for my outreach clinic was up to speed with the technology before it could move forward...For my telemedicine consults, since there are support staff members involved and equipment in addition to my time, I am generally seeing about a 2 week scheduling timeframe from referral.”

Low patient uptake of telemedicine services was a barrier identified by another participant.

GC08: “We do have the capability to use web conferencing as well, but don’t use this often as there is little patient demand for this model...I think patients would like this option, but for most of them, it’s just easier logistically to do things over the phone. They don’t need to worry about having a good internet connection and/or computer with a camera.”

Arranging for Genetic Testing Another reported issue that complicates implementing new SDMs is the logistics of arranging for genetic testing. When individuals are counseled via telephone counseling or telemedicine services and decide to pursue genetic testing, the genetic counselor must have a process in place for how and

where the individual(s) can have their sample collected. The genetic counselor must also arrange for the correct paperwork to be completed and signed by the patient, as well as the ordering provider.

GC16: “When I use telemedicine, I need to make sure that there is staff on the other end that can coordinate my blood draws when needed and fill out the paperwork appropriately. As well, I have had to work out the printing of educational materials that I would otherwise hand out during my consults.”

Billing and Reimbursement Inability to bill for services was a major limitation with implementation of all types of service delivery models, and having the ability to bill would increase satisfaction with the model utilized. When asked why billing was not possible, responses typically reflected a lack of information about how to bill for genetic counseling services. Respondents indicated they were told by administration that establishing a billing process was too time consuming, or not possible due to lack of state licensure. Although this study is small, it appears from these interviews that even when genetic counselors using two SDMs do bill for in-person encounters, they do not necessarily bill for services using alternate SDMs.

The participants who do bill for genetic counseling services were often unsure of the billing logistics, apparently due to this being handled by administrative personnel. Additionally, when asked, these participants did not usually know the level of reimbursement for their services. Some genetic counselors who billed for their services reported billing incident to a physician, and this was recognized as a barrier.

GC17: “We are required by the hospital’s compliance policy (billing compliance) to have an MD present in every session-MDs join us at the end of the session, generally; if we end up seeing someone without an MD, we do not bill. Our institution does not at this time recognize billing using GC [genetic counseling] codes, despite our past attempts. There is also no licensure in our state, although not sure it would change the institutional policy.”

Inability to See the Patient An issue raised by participants who use telephone counseling was a lack of visual cues as to what the patient is thinking or feeling, making it more difficult to ascertain client emotions/understanding. Additionally, not being able to see a patient affects the genetic counselor’s ability with regard to clinical decision making. This was

particularly noted by one pediatric genetic counselor that uses telephone genetic counseling:

GC10: “Of course, another limitation is that we are not using clinical features..... as a way to guide the most appropriate test.”

Many genetic counselors use visual aids to help increase the understanding of complex genetic/medical information for their patients. Performing a session via the telephone introduces a barrier to the traditional use of visual aids. GC14 provided a description of the way her center seeks to overcome this barrier.

GC14: “The GC [genetic counseling] team also writes the Results Binder that the families receive. This 3-ring binder is similar to a patient letter but is much longer and more in depth: it has a glossary, pictures, table of contents, the actual test results, a “flipbook” (containing pictures that are very similar to what a counselor typically uses in the clinic). We also provide abstracts (and URL to the abstract on PubMed) to published articles that are relevant to the specific finding and CMA and Fragile X testing.”

Other genetic counselors utilize similar practices, publishing visual aids on a website that the patient(s) can access to aid in the discussion.

Barriers vs. Benefits

There was an overall feeling that despite any barriers that were experienced with implementing alternative service delivery models, the benefits different SDMs offered outweighed any of these potential barriers.

GC15: “Overall, I am very satisfied with the model we are using for genetic counseling services. I think the benefits of increased access and convenience far outweigh any limitations associated with phone counseling.”

This attitude was expressed throughout the interviews. When asked what the overall satisfaction with the models used in their genetic counseling practice, it was often said to be quite high. This was despite any limitations and barriers that were disclosed.

GC14: “Other limitations would include the basic limitations of telephone counseling (no body language clues, poor cell service, etc.) although there are also many benefits to telephone counseling..... Overall, I am very satisfied with the service delivery model that my company provides. I think that we are fulfilling a need in the autism/DD/ID community and I love being able to talk to families of such a diverse patient population (geographically and diagnostically).”

Discussion

This study utilized email interviewing and thematic analysis to explore the benefits and limitations of implementing new genetic counseling service delivery models. The major emerging theme for adoption of service delivery models was convenience for both the genetic counseling provider and clients, particularly in reducing travel and wait times for appointments. Logistical barriers such as technical set up and sample coordination, along with billing and reimbursement were the prominent limitations to initiating these models (Fig. 1).

Reasons for pursuing alternate service delivery models such as telephone and telemedicine described in this study support previous studies, particularly reflecting the need to increase access to genetic counseling services. The majority of genetic services are located in urban areas, producing a challenge for clients living in rural areas. Most interestingly, previous studies have focused on a service delivery model’s ability to reduce barriers for clients to reach genetic counselors, with reduced travel distance cited as a benefit to offering telemedicine and telephone services (Abrams and Geier 2006; Coelho et al. 2005; Koil et al. 2003; Lea et al. 2005; Ormond et al. 2000; Peshkin et al. 2008; Platten et al. 2012). No previous study has described the difficulty that traveling can pose for the genetic counselors. Travel distance was directly related to the decision to provide genetic counseling with a telephone or telemedicine service delivery model. Adopting telephone and telemedicine models reduced travel for both the clients as well as the providers. These SDMs were reported by multiple genetic counselors that covered populations with large geographic catchment areas, including provision of services nationally.

Alternative service delivery models have also been adopted in response to long wait times for a genetic counseling appointment (Ridge et al. 2009; Wang 2000). Participant responses in this

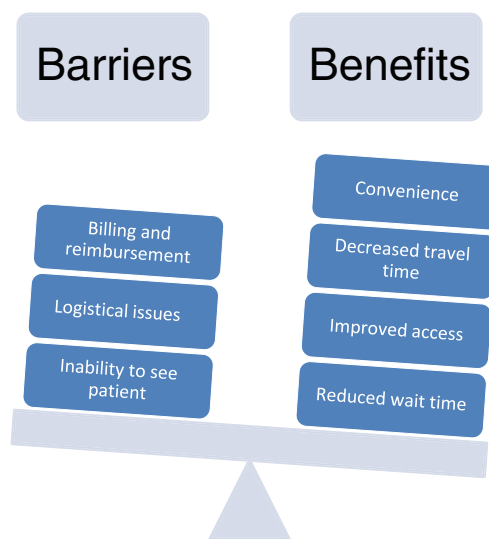


Fig. 1 Weighing the barriers to implementation and benefits of alternative genetic counseling SDMs

study support this benefit, with a reduction in wait times reported after implementation of group genetic counseling and telephone service delivery models. This reduction in wait times with alternate service delivery models is supported in the literature, with 77 % of telephone genetic counseling models able to provide service in less than a week, compared to 35 % of in-person genetic counseling (Cohen et al. 2013). Additionally, telephone genetic counseling increased the reach of participant's services to urban areas not typically covered by genetic counselors. This was also identified in the aforementioned study, where almost half of telegenetic and a third of telephone genetic counseling reached patients who lived more than 4 hours away, compared to in-person genetic counselors who provided services to patients who lived within 30 minutes half of the time (Cohen et al. 2013).

Barriers to implementing alternative service delivery models were reported in all of the SDMs described (Fig. 1). Billing and reimbursement was a major challenge noted here and has previously been reported in traditional in-person models (Gustafson et al. 2011; Harrison et al. 2010). This issue, therefore, is not unique to alternate service delivery models. The prior study on SDMs identified that 31 % of genetic counselors providing in-person genetic counseling do not bill for their service and according the most recent NSGC Professional Status Survey, as many as 38 % of genetic counselors either did not bill or did not know if any billing was occurring (2014 NSGC Professional Status Survey Executive Summary 2014; Cohen et al. 2013). Failing to bill occurs less often for in-person genetic counseling, however, than in other service delivery models, as 68, 48 and 41 % of telephone, telegenetic and group service delivery models respectively reported no billing for services (Cohen et al. 2013). In this study, for participants who were using more than one SDM, there was a higher likelihood of billing for the in-person genetic counseling than the secondary model. Some genetic testing companies offer genetic counseling by telephone as part of the genetic testing service; it is not often billed as a separate service. An internet-based company of private practice genetic counselors does bill for telephone genetic counseling either as a contractual agreement with insurance companies or institutions (Sutphen et al. 2010b). The issue of reimbursement will likely not be solved solely by adopting new SDMs and instead will result from continued education of administrators on how to establish billing practices, insurance companies on the value of genetic counseling and obtaining recognition on a federal level from the Centers for Medicare and Medicaid Services (CMS).

Logistical issues related to telemedicine and telephone genetic counseling were additional barriers identified. Telemedicine was complicated by technical equipment set-up and availability. Some participants reported having the ability at their center to offer telemedicine services, however logistics and lack of equipment on the client side limited implementation. Some prior studies support this, reporting technological difficulties as a significant

limitation, which can result in the inability to complete a genetic counseling appointment (Gray et al. 2000; Lea et al. 2005; Zilliacus et al. 2010). Web-based technology allowing patients to access genetic counseling from home would have fewer technology requirements and lower costs to the provider (Meropol et al. 2011). However, this may be a barrier for patients without personal computer access, which is more common among low-income, elderly, disabled and rural patients (Fox 2011; McIlhenny et al. 2011).

The benefits of a telephone model of genetic counseling are that it offers additional scheduling flexibility, reduces geographic barriers to access, and may be more convenient for the patient than an in-person visit. It parallels the in-person model of genetic counseling because it uses a highly trained professional in a one-on-one session. There may be less overhead cost for this type of model, although data are currently lacking in this regard. Patients seem to accept this model of delivery as well as an in-person model (Baumanis et al. 2009; Doughty Rice et al. 2010; Schwartz et al. 2014; Sutphen et al. 2010a), although some of the studies to date have focused on results delivery rather than initial consultation. Additionally, telephone counseling has been documented to increase access and decrease cost (Schwartz et al. 2014).

Telephone genetic counseling has been considered detrimental in some scenarios due to the inability to see the patient and assess physical cues or utilize visual educational tools (Ormond et al. 2000; Platten et al. 2012; Sangha et al. 2003; Wang 2000). Participants confirmed this challenge in utilizing telephone genetic counseling. Additionally, building provider-client rapport can be a challenge by telephone, and concern has been raised that the potential to impede the emotional connection could result in higher anxiety (Sangha et al. 2003). In the current culture of technology with many interactions occurring anonymously through social media, one could theorize that comfort with telephone or web-based experiences are becoming less likely to cause distress, although this requires future study. Despite these complications, telephone genetic counseling was reported by participants in this study to be convenient for the client and the provider. Genetic counselors are trained in visual and nonvisual methods to assess client understanding and readiness for genetic information, and use of nonvisual cues would be increased in telephone genetic counseling. As this SDM becomes more commonly used, additional training available through GC degree programs may be considered.

Genetic counselors who provide telegenetic and telephone genetic counseling both reported that coordinating genetic testing sample collection when appropriate was a challenge. This has been previously reported (Lea et al. 2005; Peshkin et al. 2008). This may change as more genetic testing is available with saliva collection sample kits but will need to be addressed as utilization of this model expands.

Using a group genetic counseling model, Ridge et al. (2009), calculated that as many as four patients could be seen in the same time required for an individual appointment, theoretically increasing available appointment times. This experience was supported by one study participant, who used this model to reduce a 7-month wait time for new appointments. It is important to note, however, that limited experience with group genetic counseling was described in this study, with only two participants reporting use of group counseling as a secondary model. Larger analysis on the benefits and limitations of group genetic counseling is warranted.

Ultimately, genetic counselors need to weigh the barriers and benefits of a service delivery model to assess how it may fit into their practice (Fig. 1). Unique circumstances, such as geography, population and resources will determine which model is a best fit for an individual genetic counselor's practice. Findings of this study support the idea that there is no one "best practice" model, but that there are several models that work well in different situations. For some genetic counselors, an alternate service model gets implemented because the benefits outweigh the barriers. However, it is important to recognize that, in some cases, even when multiple benefits exist, an alternate service delivery model may not be adopted because the presence of a barrier may be insurmountable. Future research is needed to identify circumstances and settings that would lend themselves to alternative service delivery models for genetic counselors to recognize when it would be most beneficial to incorporate new models into their practice (Vig and Wang 2012).

Limitations

This study aimed to elucidate themes in adopting alternative service delivery models, and with its small size it cannot be considered a fully representative sample. Designed to be an exploratory qualitative study, the purpose was not to produce generalizable findings that would apply to all genetic counselors who are utilizing alternative service delivery models. Information identified here, such as decreasing wait times and reducing travel distance, was based on the experience of the individual genetic counselor interviewed, not on empiric data. Additional research may identify other themes, depending on the specific circumstances and setting in which genetic counseling is provided.

Email interviews were chosen for the convenience provided. Generally, email interviews are shorter than in-person or telephone interviews and less costly because data from the interview emails are generated in electronic format, requiring no transcription before analysis (Meho 2006). While performing interviews by email have been shown to allow for detailed and thoughtful responses in an efficient manner, a limitation of email interviews is that the interviewer loses spontaneity and visual cues throughout the process. Although participants can express themselves by use of capital letters,

italics, etc., non-verbal cues, such as tone of voice and pauses in speech, are lost (Hamilton and Bowers 2006). It is possible that in-person or telephone interviews would have generated a different type of response from participants. Seven individuals agreed to participate in the study but did not complete the email interviews. It is possible that the format of email interviews contributed to the loss of these participants and an in-person or telephone interview would have been perceived more favorably by them.

Conclusion

Identifying the benefits and barriers to implementing new service delivery models in genetic counseling is beneficial for genetic professionals who are considering or beginning the process of adding alternate service delivery models. This study highlights many of the conveniences, such as reduced travel or wait times (for both patients and providers), which can be achieved using these alternate models. With the growing demand for genetic expertise in health care, and the increasing knowledge regarding the genetic basis of disease, genetic counseling providers will need to adapt to meet this need. Early awareness of the barriers that can occur is important so that more providers can develop the tools to address them. Additional study focused on the specific details of the barriers to implementing a service delivery model is recommended. The participants interviewed were generally satisfied with the decision to pursue service delivery models outside the traditional in-person model. Challenges to implementing service delivery models were reported by many of the participants, regardless of model used. However, the benefits of increasing access to genetic counseling and increased convenience to both the patient and the provider outweighed these barriers.

Acknowledgments Thanks to the NSGC Service Delivery Model Task Force for input on the design of this study and to thesis committee members Elizabeth A. Gettig, MS, CGC and Jessica Burke, PhD, MHS.

Compliance with ethical standards

Conflict of Interest Authors Stephanie A. Cohen, Rachele C. Huziak and Robin E. Grubs declare they have no conflict of interest.

Author Shanna Gustafson declares she is employed by a private company which uses telephone genetic counseling and owns shares in the company.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all participants for being included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

References

- 2014 NSGC Professional Status Survey Executive Summary. (2014). Retrieved April 28, 2014, from www.nsgc.org.
- Abrams, D. J., & Geier, M. R. (2006). A comparison of patient satisfaction with telehealth and on-site consultations: a pilot study for pre-natal genetic counseling. *Journal of Genetic Counseling*, *15*(3), 199–205. doi:10.1007/s10897-006-9020-0.
- Baumanis, L., Evans, J., Callanan, N., & Susswein, L. (2009). Telephoned BRCA1/2 genetic test results: prevalence, practice, and patient satisfaction. *Journal of Genetic Counseling*, *18*(5), 447–463. doi:10.1007/s10897-009-9238-8.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. doi:10.1191/1478088706qp0630a.
- Charmaz, K. (2004). Premises, principles, and practices in qualitative research: revisiting the foundations. *Qualitative Health Research*, *14*(7), 976–993. doi:10.1177/1049732304266795.
- Coelho, J. J., Arnold, A., Nayler, J., Tischkowitz, M., & MacKay, J. (2005). An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations. *European Journal of Cancer*, *41*(15), 2257–2261. doi:10.1016/j.ejca.2005.06.020.
- Cohen, S., Gustafson, S., Marvin, M., Riley, B., Uhlmann, W., Liebers, S., & Rousseau, J. (2012). Report from the National Society of Genetic Counselors Service Delivery Model Task Force: a proposal to define models, components, and modes of referral. *Journal of Genetic Counseling*, *21*(5), 645–651. doi:10.1007/s10897-012-9505-y.
- Cohen, S. A., Marvin, M. L., Riley, B. D., Vig, H. S., Rousseau, J. A., & Gustafson, S. L. (2013). Identification of genetic counseling service delivery models in practice: a report from the NSGC Service Delivery Model Task Force. *Journal of Genetic Counseling*, *22*(4), 411–421. doi:10.1007/s10897-013-9588-0.
- Cox, S. L., Zlot, A. I., Silvey, K., Elliott, D., Horn, T., Johnson, A., & Leman, R. F. (2012). Patterns of cancer genetic testing: a randomized survey of oregon clinicians. *Journal of Cancer Epidemiology*, *2012*, 11. doi:10.1155/2012/294730.
- Doughty Rice, C., Ruschman, J. G., Martin, L. J., Manders, J. B., & Miller, E. (2010). Retrospective comparison of patient outcomes after in-person and telephone results disclosure counseling for BRCA1/2 genetic testing. *Familial Cancer*, *9*(2), 203–212. doi:10.1007/s10689-009-9303-3.
- Elwyn, G., Edwards, A., Iredale, R., Davies, P., & Gray, J. (2005). Identifying future models for delivering genetic services: a nominal group study in primary care. *BMC Family Practice*, *6*(1), 14. doi:10.1186/1471-2296-6-14.
- Fox, S. (2011). Health, digital divide. *Pew Internet*. from www.pewinternet.org/reports/2011/healthtopics.
- Gray, J., Brain, K., Iredale, R., Alderman, J., France, E., & Hughes, H. (2000). A pilot study of telegenetics. *Journal of Telemedicine and Telecare*, *6*(4), 245–247.
- Gustafson, S. L., Pfeiffer, G., & Eng, C. (2011). A large health system's approach to utilization of the genetic counselor CPT[reg] 96040 code. *Genetics in Medicine*, *13*(12), 1011–1014.
- Hamilton, R. J., & Bowers, B. J. (2006). Internet recruitment and e-mail interviews in qualitative studies. *Qualitative Health Research*, *16*(6), 821–835. doi:10.1177/1049732306287599.
- Harrison, T. A., Doyle, D. L., McGowan, C., Cohen, L., Repass, E., Pfau, R. B., & Brown, T. (2010). Billing for medical genetics and genetic counseling services: a national survey. *Journal of Genetic Counseling*, *19*(1), 38–43. doi:10.1007/s10897-009-9249-5.
- Iredale, R., Elwyn, G., Edwards, A., & Gray, J. (2007). Attitudes of genetic clinicians in Wales to the future development of cancer genetics services. *Journal of Evaluation in Clinical Practice*, *13*(1), 86–89. doi:10.1111/j.1365-2753.2006.00657.x.
- Koils, C. E., Everett, J. N., Hoehstetter, L., Ricer, R. E., & Huelsman, K. M. (2003). Differences in physician referral practices and attitudes regarding hereditary breast cancer by clinical practice location. *Genetics in Medicine*, *5*(5), 364–369.
- Lea, D. H., Johnson, J. L., Ellingwood, S., Allan, W., Patel, A., & Smith, R. (2005). Telegenetics in Maine: successful clinical and educational service delivery model developed from a 3-year pilot project. *Genetics in Medicine*, *7*(1), 21–27.
- McHenry, C. V., Guzik, B. L., Knee, D. R., Wendekier, C. M., Demuth, B. R., & Roberts, J. B. (2011). Using technology to deliver healthcare education to rural patients. *Rural and Remote Health*, *11*, 1798.
- Meho, L. I. (2006). E-mail interviewing in qualitative research: a methodological discussion. *Journal of the American Society for Information Science and Technology*, *57*(10), 1284–1295. doi:10.1002/asi.20416.
- Meropol, N. J., Daly, M. B., Vig, H. S., Manion, F. J., Manne, S. L., Mazar, C., . . . Zubarev, V. (2011). Delivery of Internet-based cancer genetic counselling services to patients' homes: a feasibility study. *Journal of Telemedicine and Telecare*, *17*(1), 36–40. doi:10.1258/jtt.2010.100116.
- Ormond, K., Haun, J., Cook, L., Duquette, D., Ludowese, C., & Matthews, A. (2000). Recommendations for telephone counseling. *Journal of Genetic Counseling*, *9*(1), 63–71. doi:10.1023/A:1009433224504.
- Peshkin, B. N., Demarco, T. A., Graves, K. D., Brown, K., Nusbaum, R. H., Moglia, D., . . . Schwartz, M. D. (2008). Telephone genetic counseling for high-risk women undergoing BRCA1 and BRCA2 testing: rationale and development of a randomized controlled trial. *Genet Test*, *12*(1), 37–52. doi:10.1089/gte.2006.0525.
- Platten, U., Rantala, J., Lindblom, A., Brandberg, Y., Lindgren, G., & Arver, B. (2012). The use of telephone in genetic counseling versus in-person counseling: a randomized study on counselees' outcome. *Familial Cancer*, *11*(3), 371–379. doi:10.1007/s10689-012-9522-x.
- Ridge, Y., Panabaker, K., McCullum, M., Portigal-Todd, C., Scott, J., & McGillivray, B. (2009). Evaluation of group genetic counseling for hereditary breast and ovarian cancer. *Journal of Genetic Counseling*, *18*(1), 87–100. doi:10.1007/s10897-008-9189-5.
- Sangha, K., Dircks, A., & Langlois, S. (2003). Assessment of the effectiveness of genetic counseling by telephone compared to a clinic visit. *Journal of Genetic Counseling*, *12*(2), 171–184. doi:10.1023/A:1022663324006.
- Schwartz, M. D., Valdimarsdottir, H. B., Peshkin, B. N., Mandelblatt, J., Nusbaum, R., Huang, A. T., . . . King, L. (2014). Randomized Noninferiority Trial of Telephone Versus In-Person Genetic Counseling for Hereditary Breast and Ovarian Cancer. *J Clin Oncol*. doi:10.1200/jco.2013.51.3226.
- Sutphen, R., Davila, B., Shappell, H., Holtje, T., Vadaparampil, S., Friedman, S., . . . Armstrong, J. (2010a). Real world experience with cancer genetic counseling via telephone. *Familial Cancer*, *9*(4), 681–689. doi:10.1007/s10689-010-9369-y.
- Sutphen, R., Steenblock, K., Carmany, E., Trivedi, A., & Lewis, K. (2010b). Identification and Referral of Appropriate Patients for Genetic Services in the Community Setting: An Innovative Approach. *San Antonio Breast Cancer Symposium* (P2-10-06).
- Tempest, V., Iredale, R., Gray, J., France, L., Anstey, S., & Steward, J. (2005). Pedigree construction and disease confirmation: a pilot study in Wales exploring the role of nonclinical personnel. *European Journal of Human Genetics*, *13*(9), 1063–1070. doi:10.1038/sj.ejhg.5201454.
- Vig, H. S., & Wang, C. (2012). The evolution of personalized cancer genetic counseling in the era of personalized medicine. *Familial Cancer*, *11*(3), 539–544. doi:10.1007/s10689-012-9524-8.
- Wang, V. (2000). Commentary: what is and is not telephone counseling? *Journal of Genetic Counseling*, *9*(1), 73–82. doi:10.1023/A:1009437308575.
- Zilliaccus, E., Meiser, B., Lobb, E., Dudding, T. E., Barlow-Stewart, K., & Tucker, K. (2010). The virtual consultation: practitioners' experiences of genetic counseling by videoconferencing in Australia. *Telemedicine and e-Health*, *16*(3), 350–357. doi:10.1089/tmj.2009.0108.