

**AN EXPLORATION OF SERVICE DELIVERY MODELS IN GENETIC
COUNSELING: A THEMATIC ANALYSIS**

by

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BS, Pennsylvania State University, 2010

Submitted to the Graduate Faculty of
the Graduate School of Public Health in partial fulfillment
of the requirements for the degree of
Master of Science

University of Pittsburgh

2012

UNIVERSITY OF PITTSBURGH

Graduate School of Public Health

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Because genetic counseling is a relatively young field, there is little research on how genetic counseling services are delivered. The majority of the literature on genetic counseling models comes from Great Britain and Wales, so does not accurately represent the limitations and barriers experienced within the United States. Thus, this study sought to provide information regarding service delivery models used in the practice of genetic counseling, identifying limitations and barriers to these models, as well as potential advantages. A qualitative research design was employed, in which 20 practicing genetic counselors that utilize unique service delivery models were interviewed using an email interview format. Interview transcripts were analyzed using a thematic analysis, and themes relating to the research question were identified and presented. Two major themes were identified: 1.) Alternative service delivery models offer convenience for both the patients and the genetic counselors; and 2.) Logistical issues are a major barrier to implementing alternative service delivery models into clinical practice. Results of this research will give genetic counselors and other health care professionals a way to better assess and evaluate the genetic counseling service models that are currently being used. This work also has public health relevance. By researching and understanding alternative service delivery models, the hope is to make genetic counseling services more accessible by creating increasing access to genetic counseling by addressing the increasing demand for genetic testing and counseling among the population.

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PREFACE

First and foremost, I would like to thank the Genetic Counselors who took the time to participate in this interview. I know genetic counselors have such hectic schedules, and I truly appreciate these 20 individuals who allowed me to flood their email inbox for weeks at a time. I would also like to thank the NSGC Service Delivery Models Task Force for allowing me to work on this project, and providing me with assistance from the beginning. Their enthusiastic and encouraging check-in emails always made me feel supported.

I would also like to extend gratitude to Dr. Robin Grubs for approaching me to work on this project, and supplying constant guidance and support, without which I would not have been able to complete this project. Robin has been a fantastic director, as well as an excellent mentor. I would also like to thank Betsy Gettig for being a part of my thesis committee as well as an exceptional director and mentor to me throughout the last two years.

I would also like to acknowledge Dr. Jessica Burke for being a part of my thesis committee. I really appreciate the continued support and direction.

I would like to thank my classmates for always listening and providing much needed pep talks and checklists to make sure everything was done correctly and on time. I could not have done this without them.

Lastly, I would like to thank my family for making me the person that I am today. My sisters for providing their constant distractions, often when I needed them most. My dad for always being proud of me, no matter what. And most importantly, to my mom, who has been a constant source of support in my life. She has always been there for me and is definitely my biggest fan.

1.0 INTRODUCTION

Because genetic counseling is a relatively young field, there is little research on how genetic counseling services are delivered. The majority of the literature on genetic counseling models comes from Great Britain and Wales, so 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). Because of this, the National Society of Genetic Counselors (NSGC) formed a Service Delivery Models (SDM) Task Force to help accomplish one of their 2010 strategic initiatives to research, identify, and promote genetic service delivery models that maximize the integration of genetic counselors into healthcare services. The overall goal of the Service Delivery Models Task Force is to research genetic counseling service delivery models including: in-person counseling, telephone counseling, telemedicine, and group counseling. The work of the Task Force focused on identifying the alternative service delivery models, particularly how often and in which situations these models are being used.

To accomplish this goal, the appointed NSGC SDM Task Force sent an online survey to all currently practicing genetic counselors. The survey addressed different service delivery models (SDMs) and asked the participating genetic counselors questions relating to limitations of certain SDMs used in their practices. Limitations addressed included: wait time for new patients, average distance patient had to travel to receive services, whether an MD had to be present at time of

service, and if and how the service was billed. The survey also sought to identify how the majority of genetic counselors were providing services.

Results from this survey showed that 95.7% of genetic counselors are using in-person genetic counseling either “always” or “often,” while only 8.4% are using telephone counseling, 3.2% are using group counseling and 2.3% are using telemedicine. Genetic counselors using telephone counseling reported the shortest wait time for their patients, as well as the least amount of time in consultation. Telemedicine and telephone genetic counseling were reported to be used for patients who live furthest away (Cohen, 2011).

Results also showed that in-person genetic counseling was most likely to be billed for, while telephone counseling was least likely to be billed for. However, limitations of this initial survey included that the participants were not using the accurate definition of telephone counseling to complete the survey questions. In other words, participants were including results disclosure as using telephone counseling, while the SDM Task Force was defining telephone counseling as doing an entire session(s) via the telephone (Cohen, 2011).

The initial survey showed that genetic counselors are incorporating additional models of service delivery into their practices. However, further research was needed to identify components of service delivery that improve access, increase efficiency and improve billing practices. Therefore, the SDM Task Force decided they wanted to follow-up with their quantitative survey results with a qualitative study exploring the alternative service delivery models in richer detail.

Thus, the goal of this study was to provide information regarding service delivery models used in the practice of genetic counseling and to identify advantages and limitations of these models. To fulfill this goal, a qualitative thematic analysis was done. Interviews were

conducted with practicing genetic counselors that utilize unique service delivery models. The interviews were analyzed and themes relating to the research question were identified and are presented and explored in this paper.

2.0 BACKGROUND AND SIGNIFICANCE

Genetic counseling is a relatively young field, with training programs devoted to the profession having originated only since the 1970s (Uhlmann et al., 2009). Historically, genetic counseling has been provided face-to-face; however, different service delivery models have begun to evolve in recent years due to challenges encountered within face-to-face counseling. Some of the challenges produce barriers to providing genetic counseling services and include: access (geographic and socioeconomic), billing and reimbursement and too few genetic counselors to meet the rising demand for genetic counseling services, especially in rural areas. Because of these barriers, genetic counselors have been looking for other appropriate alternative models of service delivery to address these issues.

Following is a more in-depth discussion of in-person genetic counseling (the traditional face-to-face model) and the barriers that have been experienced with this model.

2.1 IN-PERSON GENETIC COUNSELING

In-person genetic counseling is the traditional model used to provide this service in health care. Patients are seen in-person for face-to-face counseling, usually in a health-care facility or doctor's office. According to Cohen (2011) in a survey administered to all practicing genetic counselors, more than 95% use in-person counseling either always or often. Thus research has

been done assessing the efficacy and success of in-person genetic counseling. This model may be provided with different types of referral (either physician or self-referred), and a physician may or may not be present for all or part of the session. Some of the above variables (i.e. referral method and whether or not the physician is present) are dependent on the clinical setting, specialty and billing practices.

2.1.1 Benefits of In-Person Genetic Counseling

Benefits of in-person genetic counseling include the use of highly trained professionals to deliver the service in a session that is tailored for each patient. In-person genetic counseling has been well documented. It has been shown to increase patient knowledge, while providing psychosocial support and facilitating improved communication among family members (Bernhardt et al., 2000).

Traditional, in-person genetic counseling has also been shown to decrease patient distress. A study by Keller et al. (2008) analyzed the psychosocial outcomes in families with suspected hereditary non-polyposis colorectal cancer (HNPCC), and found that following genetic counseling these individuals had significant reductions in general anxiety, distress specific to colorectal cancer and general cancer worry. This study showed the beneficial effects of genetic counseling.

In-person genetic counseling has also been shown to accurately identify patient risk so appropriate options can be presented (Cohn et al., 1996; Frezzo et al., 2003). For example, a study by Cohn et al. (1996) analyzed the use of a three-generation family history (pedigree) and compared its accuracy of identifying genetic risk to a prenatal questionnaire attempting the same goal. This study found that a detailed pedigree provides more information regarding genetic

concerns by accurately identifying patient risk. Having accurate risk information enables patients to seek appropriate options for themselves and other family members.

2.2 BARRIERS TO GENETIC COUNSELING/TESTING SERVICES

2.2.1 Access (Geographic and Socioeconomic)

Access to services has been reported in the literature as a potential barrier to individuals who need or desire genetic counseling services. The majority of genetic services are located in urban areas, which can produce challenges for patients living in rural areas who may not have the means to access such services (Coelho et al., 2005; Lea et al., 2005; Abrams and Geier 2006; Koil et al., 2003). Geographic location of services may inhibit patients from having the ability to travel to their genetic counseling appointment due to long travel distances that cannot be overcome because of the inability to take time off from work or because of other financial reasons associated with traveling long distances. Additionally, physicians who practice in rural settings are less likely to refer patients for genetic services, citing barriers that include: distance and lack of awareness of services (Koil et al., 2003).

Socioeconomic barriers may also lead to a decrease in access for some populations. For example, studies have shown that possible socioeconomic barriers exist in the utilization of amniocentesis, and genetic counseling is often provided prior to amniocentesis. In a study by Khoshnood et al. (2004), they found that these socioeconomic barriers also exist to women making informed decisions regarding maternal serum screening for Down syndrome.

Additionally, differential access to and utilization of genetic counseling and genetic testing of minority groups compared to the white population has led to growing health care disparities, especially in clinical cancer genetics (Hall and Olopade, 2006). Reasons behind this have been explored, and possible contributions to this disparity include: poor communication of family history, inaccurate risk perception and lack of awareness of genetic counseling and testing services (Hall and Olopade, 2006). Underserved populations may also face access and financial barriers to seeking genetic services, especially because most services are located in urban areas and may require multiple appointments, and thus missed work adding additional costs (Hall and Olopade, 2006; Wang and Watts 2007).

2.2.2 Billing and Reimbursement

Another barrier that has been documented with in-person genetic counseling is billing and reimbursement. Limitations on billing by genetic counselors have been commonly reported (McPherson, 2008; Irons, 2008; Wham et al., 2010). McPherson et al., (2008) reported documentation of the workflow in a general genetics department, including the activities performed by both the clinical geneticists and the genetic counselors. In this analysis, they found that 85% of the time spent on each patient is non-billable. Put in other words, only 15% of the time spent on patient care was billable with the potential for reimbursement (Irons, 2008). Because this study was only based on one clinical genetics clinic, and in which the genetic counselors were not able to bill for their services, the results are not able to be generalized to all centers, yet highlight the challenges some clinical genetic centers are facing. Challenges with reimbursement limit the integration of trained genetic service providers into the health care system as well as access to their services (Harrison et al., 2010).

In 2006, the National Society of Genetic Counselors working with the AMA Health care Professional Advisory Committee developed a CPT billing code (96040) to be specifically used by non-physician, trained genetic counselors (Harrison et al., 2010). This code does not require that the physician be present and is meant to cover every 30 minutes of the genetic counselor's face-to-face time with the patient. In a national survey by Harrison et al., (2010) only 69% of genetic counselors surveyed reported billing for genetic services (either under the physician's name, the genetic counselor's name, or the patient directly). 26% reported not billing for services, while the remaining 5% was unsure of billing practices at their institution. Of those who bill, only 24% reported using code 96040. Reported reasons why they were not billing with this code included: genetic counselors were not credentialed and thus not able to bill independently, the level of reimbursement for the code was lower than other billing procedures and/or the genetic counseling was billed as a bundled fee and had yet to be discussed with the billing staff at their institution.

2.2.3 Limited number of Genetic Counselors

In-person genetic counseling is limited by both number of qualified health care professionals, as well as by financial and time constraints associated with the lengthy interaction (Calzone et al., 2005). A limitation of in-person genetic counseling is that it is time consuming, and studies have shown that significantly more time is spent per patient in individual sessions compared to alternate delivery models (Calzone et al., 2005). Because of these factors, individuals may experience long wait times to schedule a genetic counseling appointment. In the case of cancer genetic counseling for hereditary breast and ovarian cancer, after deciding on pursuing genetic

counseling, women wait on average 4 or more weeks to have their initial genetic counseling session (Mikkelsen et al., 2008). This may lead to an increase in psychosocial distress.

2.3 INCREASE IN NEED FOR GENETIC COUNSELING/TESTING SERVICES

The rapidly increasing demand for genetic counseling, as well as the barriers experienced with the traditional in-person model, has prompted investigation of alternative methods of service delivery, particularly for outreach and rural areas. Models that have been evaluated include telephone counseling, group counseling, telemedicine, the use of decision-aids and computer-assisted learning (Zilliacus 2010). Telephone counseling, group counseling, and telemedicine will be described further.

2.4 TELEPHONE COUNSELING

Telephone counseling is an alternative genetic counseling service delivery model, with some similarities and differences to the traditional in-person genetic counseling model. In this model, genetic counseling for a new cause or concern is delivered to patients by telephone, with the session(s) completed entirely on the telephone. Literature is limited regarding this model of delivery, especially regarding the efficacy and patient outcomes (Peshkin et al., 2008; Ormond et al., 2000; Wang, 2000).

Historically, telephone counseling developed from psychiatric services and medical triage experiences. In the late 1950s, crisis hotlines, typically focusing on suicide prevention, rapidly

evolved into telephone triage and counseling, which spread to the use of telephone counseling for teratogen information services (Ormond et al., 2000).

Empirical studies have demonstrated that telephone counseling can be utilized effectively in many settings, including to manage health conditions, to facilitate behavioral or management changes in individuals and to deliver sensitive information regarding disease status (Peshkin et al., 2008).

Within genetic counseling, the telephone has been used for many years in performing certain components of a genetic counseling session such as intakes, triage, assessment and follow-up (Ormond et al., 2000; Peshkin et al., 2008). In a report from 1993, the majority of genetic counselors interviewed indicated that they use the telephone for tasks such as teratogen services, follow-up, and reporting of normal genetic test results (Peshkin et al, 2008; Young, 1993). Although it is common for genetic counselors to use the telephone to complete different components of sessions, there is overall little research regarding how to deliver entire session(s) via the telephone (i.e. with no face-to-face component) (Ormond et al, 2000).

2.4.1 Benefits of Telephone Counseling

A major advantage of telephone counseling is the convenience and flexibility it offers to the client. Telephone counseling enables individuals who would not be able to attend an in-person genetic counseling session because of socioeconomic or geographic reasons the ability to receive genetic counseling services. By reducing barriers to service and increasing accessibility, telephone counseling could ultimately provide a reduction in health disparities (Ormond et al., 2000; Sangha et al., 2003).

Another benefit of telephone counseling is that it has the potential to allow the patient to feel more comfortable and safe given the private nature of the interaction, allowing her/him to express feelings in an open manner, and thus making the genetic counseling exchange more productive (Sangha et al., 2003; Wang, 2000). The patient may feel like she/he has more control over the interaction when compared to seeing the health care professional in an office setting (Wang, 2000).

Telephone counseling may also reduce costs for both the patient and the genetic counselor. For the patient, reduced travel and negation of additional expenses from taking time off from work and possible accommodations can help to save money. For the genetic counselor or health care professional, costs may be reduced because telephone counseling requires less time and there are less overhead costs (Platten et al., 2012; Ormond et al., 2000; Peshkin et al., 2008).

In small pilot studies done to date, there is no significant difference in patient satisfaction, understanding, or anxiety when genetic counseling was conducted via telephone versus in person (Sangha et al., 2003; Platten et al., 2012).

2.4.2 Limitations of Telephone Counseling

Genetic counselors commonly use visual aids to help convey key genetic concepts during a genetic counseling session (Baty et al., 1997). Therefore, a possible limitation of telephone counseling is the inability of the genetic counselor to use visual aids, such as diagrams and schematics, in providing information, which may result in a lower level of comprehension for the client (Sangha et al., 2003). However, a study by Peshkin et al., (2008) is seeking to address this issue by mailing participants visual aids prior to a telephone genetic counseling session.

A major critique of telephone counseling is that it inhibits the health care professional from seeing and thus addressing visual cues from the patient (Sangha et al., 2003; Platten et al., 2012; Ormond et al., 2000; Wang, 2000). This could add difficulty in maintaining focus and attention of the patient. Distractions may also be a risk for both the patient and the counselor, further inhibiting a rich exchange (Wang, 2000).

The logistics of arranging for necessary genetic testing is another barrier that can arise in this alternate service delivery model. Because the genetic counselor or other health care professional is not present in the session, the patient must go to a blood draw center (either a lab or primary care physician's office) and may be required to do their own packing/shipping of the sample to send to the genetic testing lab, which can produce additional confusion (Peshkin et al., 2008).

Another barrier to implementation of telephone counseling is there is a lack of documented reimbursement for this model of service delivery. Young (1993) reports that fewer than 25% of counselors bill clients for telephone counseling, and reimbursement is poor. This raises the question of whether or not unbilled telephone counseling sessions are a cost-effective use of the counselor's time (Ormond et al., 2000).

2.5 GROUP COUNSELING

Group counseling is another alternative service delivery model in which multiple, unrelated individuals are seen for genetic counseling, usually for a common indication, which can include: hereditary breast and ovarian cancer, advanced maternal age, abnormal maternal serum

screening, etc. Individual, in-person meetings may occur following a group session, although typically such meetings are brief and not a necessary component of this model.

2.5.1 Benefits of Group Counseling

A benefit of group counseling is that it may provide more efficient use of a genetic counselor's time. More patients can be seen in a shorter amount of time and there is less repetition of information provided during genetic counseling for common indications. Since more patients can potentially be seen with group genetic counseling, this may increase access to services and decrease wait time for appointments. A study by Ridge et al., (2009) calculated that as many as four patients could be seen by group counseling in the same amount of time required for one individual appointment.

The client may potentially benefit from other group participants raising questions that they may not have considered asking. Additionally, an advantage of group counseling may be shared experience and patient sharing. Individuals have been shown to be quite open and supportive of each other because of their shared experience, which is a finding that has previously been supported in the field of psychosocial therapy (Ridge et al., 2009; Gladding 1994; Wilson 1997).

Overall, studies have found that the level of patient satisfaction with group genetic counseling was similar to that of individual, in-person genetic counseling (Ridge et al., 2009; Hunter et al., 2005; Calzone et al., 2005)

2.5.2 Limitations of Group Counseling

Group counseling may be less personal and possibly intimidating for the client in a group setting to pose questions. Measures need to be taken to ensure that individuals' needs are met in the group setting. There may be privacy and confidentiality issues in a group setting, requiring that the genetic counselor stress the need for these aspects throughout the session (Ridge et al., 2009; Gladding 1994). Additionally, billing practices are not well defined within this model, leaving questions about sustainability with this model.

Some studies have shown that group counseling can lead to group influence on decision making (Ridge et al., 2009). In the situation of genetic testing, group members may be influenced on whether or not to pursue testing depending on what other group members decide to do. It has been suggested that group counseling is best utilized when followed with a brief in-person, individual meeting, as follow-up is generally more common following group counseling than in individual counseling (Calzone et al., 2005; Ridge et al., 2009).

Scheduling may also be a barrier experienced by centers attempting to offer group genetic counseling services (Ridge et al., 2009). Booking appointments for group counseling sessions requires coordinating the schedules of multiple individuals, which can prove to be difficult and time consuming (Calzone et al., 2005)

2.6 TELEMEDICINE

Telemedicine, or telehealth, can be broadly defined as the use of electronic communication and information technologies to provide or support clinical care at a distance (Volkert et al., 2000). Telemedicine is currently being used to aid in patient care and professional and patient education, as well as in research and public health applications. Telemedicine providers are expanding into the full realm of health care, including: cardiology, trauma medicine, dentistry, toxicology, gynecology, and ophthalmology (Volkert et al., 2000). There are currently over 450 telehealth programs worldwide; including over 350 in the United States and this number is expected to rise (Abrams and Geier, 2006).

Telemedicine or telehealth use in clinical genetics is referred to as telegenetics and offers an alternative model for delivery genetic counseling services through videoconferencing. In this model of delivery, genetic counseling is provided remotely via videoconference or web-link, including visual and audio access. Web-based genetic counseling is also included as this type of service delivery, since it follows the same basic principle of providing genetic counseling remotely via electronic equipment with visual and auditory access. Telegenetics is a relatively new field with few research studies assessing its acceptability and efficacy (Zilliacus et al., 2010). Therefore, there is a deficiency of research into the patient's experience with these services, especially in the field of genetic counseling (Abrams and Geier 2006).

Research done in the United Kingdom has shown that telemedicine is a useful alternative to provide cancer genetic counseling services (Coelho et al., 2005). In this study, Coelho (2005) evaluated cancer genetic counseling when conducted via telemedicine compared to face-to-face consultations. Participants receiving counseling via telemedicine experienced a significant

reduction in cancer related anxiety levels and high satisfaction with their experience, mirroring the experiences of the individuals who received face-to-face counseling.

There has also been successful implementation of telegenetics in Maine, providing pediatric, adult, and reproductive genetic counseling (Lea et al., 2005). Lea et al. (2005) describe their three-year pilot project of using telemedicine throughout the state of Maine. Partnered with 24 rural clinical sites, they were able to evaluate 125 patients who had received telemedicine services. Surveys from both patients and the genetic counselors offering the telemedicine services showed positive responses to this alternative service delivery model.

2.6.1 Benefits of Telemedicine

This model allows for access to genetic services in remote areas, which in turn decreases travel time for the genetic counselor, geneticist and the client. As specialists are usually located primarily in urban settings, telemedicine can be employed to reduce possible discrepancies in health care, making it possible to offer genetic counseling services to individuals in rural and underserved areas (Coelho et al., 2005; Lea et al., 2005; Abrams and Geier 2006).

Telemedicine provides convenience for individuals. One particular convenience is a reduction in travel necessary. This provides continuity of care, either for individuals in rural areas or for individuals who are not able to have extended time off from work.

Additionally, telemedicine has been associated with a reduction in costs. Costs can include: gasoline for travel (or costs associated with public transportation), costs for accommodations if requiring an overnight stay, and/or costs associated with taking time off from work. In comparison to telephone counseling, telemedicine provides the genetic counselor the

ability to see the patient via the web conferencing. Therefore, he or she can see and thus respond to visual cues from the patient(s).

2.6.2 Limitations of Telemedicine

Some studies have reported concerns that telegenetics may result in a reduced ability for the genetic counselor and geneticist to build rapport with the client, but current studies have shown this not to be the case (Zilliacus et al., 2010).

Other studies suggest that a limitation of telemedicine may be technical difficulties experienced with the equipment. There are a few studies that have been conducted that have identified technological difficulties as a significant limitation, which can result in the inability to complete a genetic counseling appointment. However, the studies that have been conducted found that participants and counselors did not experience problems with technology leading to a decrease in satisfaction with services (Abrams and Geier 2006).

Another potential barrier to this model is the need for trained medical staff in both locations. Additionally, significant technology and equipment are required in both locations, adding to the costs. Lea et al. (2003) identified barriers to utilization of a telegenetics model of genetic counseling. These barriers included: a lack of knowledge of telemedicine and how it is used, lack of understanding of the role genetic services can play in patient care, the location of ITV unit (which was often still located remotely and thus not easily assessable to clients seeking services), and unanticipated issues of hospital credentialing and the privileging process at remote, unaffiliated sites. Some of these barriers to implementation of telegenetic services may be unique to this clinical site, while others could be barriers experienced globally. This group

did assess patient and provider satisfaction to be high and the service was well accepted and utilized, suggesting that telegenetics may be a useful alternative to in-person genetic counseling.

2.7 METHODOLOGY OF THE AFOREMENTIONED STUDIES

The majority of the studies discussed above were quantitative studies, utilizing surveys to identify potential limitations and advantages of alternative service delivery models. Although quantitative studies are useful, they do not allow researchers to discover and characterize issues that researchers do not anticipate, as can be done with qualitative research (Beeson, 1997). The body of literature on alternative service delivery models in genetic counseling is sparse, especially in regards to qualitative studies.

3.0 AIM OF THE STUDY

The current study served as a qualitative analysis to identify the benefits and limitations of various genetic counseling service delivery models.

4.0 METHODS AND PROCEDURES

Stephanie A. Cohen, MS, CGC conducted the initial survey, Phase 1 of the Service Delivery Task Force study, under Institutional Review Board (IRB) approval from an outside center. Data from Phase 1 was presented at the 30th National Society of Genetic Counselors Annual Education Conference (2011) and is being analyzed for publication. The University of Pittsburgh IRB (PRO11020128) approved the study being reported in this thesis, Phase 2 of the Service Delivery Task Force study. See Appendix A.

4.1.1 Interviews with research participants

The qualitative research design conducted in this study included e-mail interviews with practicing genetic counselors. See Appendix C for outline of interview questions. Email interviews have been described as an appropriate alternative to in-person or telephone interviews, as outlined by Hamilton and Bowers (2006). Email interviews were conducted by sending participants 3-5 questions at a time for 6-7 cycles of questions. Participant responses were reviewed and then probes based on their answers to questions and additional questions were sent to participants within 24 to 48 hours.

Email interviewing has been identified to be more convenient for both the researcher and participants, and gives both parties time to reflect on questions (Hamilton & Bowers, 2006).

This has the benefit of allowing the researcher to perform a degree of analysis concurrently with his or her questioning. Generally, email interviews are shorter than in-person or telephone interviews. However, responses tend to be more reflective as participants can respond to the questions on their own accord, often after having given them some thought (Hamilton & Bowers, 2006).

Email interviews are more cost effective than in-person or telephone interviews. Data from the interview emails are generated in electronic format, requiring little editing or reformatting before analysis. Therefore costs are saved on transcription, as it is not needed (Meho, 2006). Additionally, email interviews allow for equivalency of context for both the researcher and participants (Hamilton & Bowers, 2006).

A disadvantage 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 & Bowers, 2006). From an ethical standpoint, there is a potential increased hazard for loss of confidentiality when interviews are conducted via the Internet (Hamilton & Bowers, 2006; Meho, 2006).

Email interviews were considered to be an appropriate method of data collection. The population of genetic counselors are highly educated, motivated, and are connected to email. All of these factors were considered when choosing this as the appropriate data collection technique.

The author performed all interviews.

4.1.2 Participant Recruitment

Study participants were recruited in three different ways. A group of the participants used in this study had previously participated in the Phase 1 Internet survey administered by the National Society of Genetic Counselors (NSGC) Service Delivery Models Task Force. These participants were given the option to either agree or disagree to having future contact from group members. The contact information of individuals who gave their consent was given as potential participants for phase 2 of the study. Participants were selected so that there would be genetic counselors from the most common genetic counseling specialties (e.g., prenatal, pediatric, cancer and general genetics). In addition, participants were chosen so that each type of service delivery model was represented. A description of the study was also posted on the NSGC discussion board, requesting that interested genetic counselors contact the author. Lastly, a flyer was posted at the 30th NSGC Annual Education Conference requesting that interested genetic counselors contact the author. (See Appendix B). All participants gave informed consent prior to being interviewed.

4.1.3 Transcription

Email interviews did not require transcription. They were copied and pasted into Microsoft Word to be analyzed. No revisions were made to the transcripts in order to retain the integrity of the email interview.

4.1.4 Thematic analysis as the method of analysis

Thematic analysis, a type of qualitative research, was used to analyze the interview transcripts. Qualitative research has the advantage of capturing complexity in research by explaining not only what people do, but also why they do it (Besson, 1997). Qualitative research can be used when there is not much known about a topic. Although there is a growing body of literature on alternative service delivery models in genetic counseling, there is not yet a robust body of literature on this topic. Therefore, qualitative research was chosen for the basis of analysis for this study.

Mixed methods can be defined in a variety of ways; however, it involves the use of combining quantitative and qualitative analysis. One potential advantage of mixed methods is that it enables the researcher to simultaneously answer confirmatory and exploratory questions, therefore verifying and generating theory in the same study (Teddlie and Tashakkori, 2004). By combining and increasing the number of research strategies utilized within a study, the researcher may be able to develop a more complete picture of human behavior and experience (Morse, 2004). Phase 1 of this study utilized survey data for quantitative analysis. The purpose of this qualitative study is to complement the previous research.

Thematic analysis was the qualitative method chosen for analysis of the interview data. Thematic analysis is a widely used, yet somewhat poorly documented qualitative method (Boyatzis, 1998; Braun and Clarke, 2006). Thematic analysis is a method for identifying, describing, analyzing and reporting themes and patterns within a data set in rich detail (Braun and Clarke, 2006). This method of analysis was chosen because of its flexibility and because it is a relatively easy and quick method to learn and do for a novice qualitative researcher (Braun and Clarke, 2006). A potential limitation of thematic analysis is that the methodology is poorly

documented so is open to interpretation, especially in higher-level analyses (Braun and Clarke, 2006). However, the aforementioned benefits of using thematic analysis for this research study outweighed this reported drawback.

There are two primary ways themes or patterns are identified in thematic analysis: an inductive approach and a theoretical deductive approach. In the former approach, the researcher seeks to code data without trying to fit it into a pre-existing coding frame or the researcher's analytic preconceptions. In this method, thematic analysis allows for a rich description of the data set related to a broad research question, enabling the specific research question to evolve through the coding process (Braun and Clarke, 2006). In the latter approach, the analysis is more explicitly analyst-driven. This form of thematic analysis tends to provide a less rich description of the data overall and instead focuses on a more detailed analysis of some aspect of the data, coding for a specific research question (Braun and Clarke, 2006). In general, thematic analysis seeks to provide a description and interpretation of themes, often relating to previous studies reported in the literature (Braun and Clarke, 2006).

For this study, an inductive thematic analysis approach was utilized because few studies have analyzed alternative service delivery models in genetic counseling, especially seeking to identify the limitations and barriers, as well as the advantages of these models. The thematic analysis allowed the researcher to identify themes within the interviews with the genetic counselors related to this overall question.

Below is a description of the steps followed to perform the thematic analysis in this research study.

4.1.4.1 Becoming familiar with data and background literature

The author read all transcripts at least two times to gain familiarity with them. The repeated reading of the data was done in an active way, as suggested by Braun and Clarke (2006), in order to begin searching for meaning and patterns in the data. After actively reading through the data one time, during the next reading, notes were taken on the data that could be used in later steps.

A comprehensive literature review was also done in this step, and a summary can be found in the background/significance section. The literature review was done to sensitize the author to potential themes embedded in the data that may not have been identified without having done so (Braun and Clarke, 2006).

4.1.4.2 Generating initial codes

The next phase in thematic analysis was to generate initial codes with the data. Codes are essentially labels, using few words that are conceptually meaningful to the data (Boyatzis, 1998). This phase begins after the researcher has become familiarized with the data and what is interesting about them (Braun and Clarke, 2006). The process of coding is the first analytic step in thematic analysis, as the data is being organized into meaningful groups (Braun and Clarke, 2006). Coding depends somewhat on whether the themes are data driven or theory driven, as well as whether the aim is to code the content of the entire data set or just particular features of the data set (Braun and Clarke, 2006). Coding can be done either manually or through use of a software program.

Coding was facilitated by several strategies adapted from Braun and Clarke (2006). Some of these tips included: coding for as many potential themes/patterns as possible,

remembering to keep some of the surrounding data when coding so the context was not lost and coding individual pieces of data into as many codes as was relevant.

For the current study, line-by-line coding was chosen. Line-by-line coding gives at least one code to each phrase, line, or sentence in the data set. This encouraged careful detail and attention to each line, thus capturing every detail within the transcripts. Notes were taken in the text, and segments of data were identified using different colors of highlighters, as suggested by Braun and Clarke (2006).

4.1.4.3 Memo writing

An additional phase was writing memos, as it is recommended that researchers should often write down their thoughts as they are coding and characterizing themes throughout the process of thematic analysis. Memo writing can be thought of as pre-writing, or free writing. It consists of taking grouping of codes apart by breaking them into their components and spurs researchers to start digging into implicit, unstated, and condensed meanings (Charmaz, 2004). This phase occurred throughout the course of thematic analysis. Memos were written from the beginning of the process, when first conducting and re-reading the interview transcripts, to the final steps of identifying and describing the themes.

4.1.4.4 Identifying and characterizing themes

A theme in qualitative research is defined by Braun and Clarke (2006) as an idea that captures an important aspect of the data in relation to the research question. A theme often represents a patterned response or meaning within the data set. A theme can arise within a data set despite how often it is discussed. Therefore, Braun and Clarke (2006) advise researchers not

to relate the importance of a theme to quantifiable measures, but to how it relates to the research question.

Identification and characterization of themes was a process that began early in this study, and continued until the final phase. 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 often included under more than one theme. Possible thematic categories were identified, and codes were arranged to illustrate the themes in the best manner.

Upon completion of coding and classifying themes, they were written in a memo that showed the connections between each theme on a thematic map. The themes discussed in this paper were selected from this thematic map and are described in more detail in the Results section.

5.0 RESULTS

5.1 CHARACTERIZATION OF THE SAMPLE

The analysis involved 20 participants, all practicing genetic counselors in the United States. All 20 participants were female. Genetic counseling specialty breakdown of the participants included: 35% cancer, 15% pediatrics, 15% general genetics, 15% cardiac genetics, 10% prenatal, and 10% cancer/prenatal. Of the participants, 25% had less than 5 years of experience as a genetic counselor. 30% of the participants had between 5 to 9 years of experience, 35% of participants had between 10-15 years of experience, and 10% of the participants listed more than 15 years of experience.

With regards to service delivery models, 75% of participants use some degree of in-person genetic counseling. Of the 20 participants, 30% use an in-person model of genetic counseling only and 25% of participants use telephone counseling only. Some participants reported using a combination of different models: 20% use in-person and telephone counseling, 10% use telephone and telemedicine counseling, 10% reported using in-person and group counseling, and 5% reported using a combination of in-person and telemedicine counseling. Table 1 summarizes the characteristics of the participants and the service delivery models used.

Table 1. Participant Demographics

Participant	Specialty	Years of Experience	Primary Model	Secondary Model
GC01	Cancer	10	In-Person	
GC02	Cancer	5	In-Person	
GC03	Prenatal	15	In-Person	
GC04	General Genetics	7	In-Person	
GC05	Cardiac	7	In-Person	
GC06	Pediatrics	2	In-Person	Telephone
GC07	Cancer	10	In-Person	Telephone
GC08	Cancer/Prenatal	6	Telephone	Telemedicine
GC09	Cancer	10	In-Person	Telephone
GC10	Pediatrics	2	Telephone	
GC11	General Genetics	27	Telephone	
GC12	Cardiac	5	Telephone	
GC13	General Genetics	3	Telephone	
GC14	Pediatrics	1	Telephone	Telemedicine
GC15	Prenatal	1	Telephone	
GC16	Cancer	6	In-Person	Telemedicine
GC17	Cancer	12	In-Person	Group
GC18	Cancer	>15	In-Person	Group
GC19	Cardiac	10	In-Person	
GC20	Cancer/Prenatal	13	In-Person	Telephone

5.2 THEMES IDENTIFIED IN THE ANALYSIS

The thematic analysis identified two major themes relating to the use and limitations of alternative service delivery models in genetic counseling. This paper will focus on these two themes and how they are distinct entities, but yet are related to each other.

5.2.1 Theme #1: Convenience of alternative service delivery models

Alternative service delivery models, either 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. Below, the concept of convenience will be described.

5.2.1.1 Reducing travel distance

A major convenience that telephone and telemedicine counseling offers is the reduced travel it offers. This was a common reason for why such services were adopted into practice. Participant GC09 adopted telephone counseling into her practice after realizing that only offering in-person counseling was not right for the population/geography of the patients she serves. 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 goes 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 addresses the issue of distance from the standpoint of the genetic counselor.

Interviewer: Does distance [from the services] play a role for those patients who choose to pursue telephone counseling?

GC04: For telephone counseling, distance is the issue on our end. For example, we serve a maternal/fetal medicine practice in upstate NY but do not have a physical office there (and all of us [genetic counselors] are 2.5 hours from [there]). We run in-person clinics once or twice a month in upstate NY, 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.

In GC04's situation, telephone counseling is offered so they do not have to travel to their satellite clinic weekly, thus adding to their practice's convenience.

GC15 also discusses the convenience that telephone counseling provides to the counselors in her practice. She says: "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 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)."

These examples show the convenience that alternative service delivery models offer not only to patients, but to the counselors as well, by decreasing (or eliminating) the distance to receive and offer services.

5.2.1.2 Reducing long wait times

Genetic counselors who participated in this interview often cited that the adoption of alternative models of service delivery was a result of the long wait times they were experiencing in their centers. This was the case for one participant, GC01. GC01's practice provides an in-person service delivery model; however, their practice has been adapted to be more of a

community-based approach. The genetic counseling practice that GC01 is a part of consists of 13 cancer clinics throughout the state of Wisconsin, with one central scheduler “who is knowledgeable about what we do and is the patient’s first point of contact.” GC01 states: “She [central scheduler] will find an appointment at a location and time that is most convenient for that patient. With this process we can see patients urgently and patients do not have to wait months, weeks, or even days to see us, unless they choose to.” In this scenario, the genetic counseling practice evolved the traditional in-person counseling approach, and made modifications to provide convenience to the patients they serve in the community.

Participant GC16 utilizes telemedicine to decrease wait times for her patients:

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.

By adopting telemedicine and avoiding the time required to travel, GC16 has been able to reduce the referral wait time for patients seen at a satellite clinic.

Group counseling was an alternative service delivery model adopted by another participant to decrease the wait time that her cancer patients were experiencing:

Interviewer: What brought you to use the models you are currently using? Were they already in place when you started at the position, or have you modified them in some way?

GC17: The general model of the regular new visits with MDs was already in place, and initially all patients were returning for in person follow-ups, including negative results. 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, addresses 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 at an earlier convenience. GC08 says: “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.” This is increasing convenience for the patient, while decreasing the time they must wait to speak to a genetic counselor.

5.2.1.3 Enhancing access to services by providing convenience for patients

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 genetic counseling model was implemented in order to increase access for their patients. GC04 discusses the community-based approach to their in-person genetic counseling model.

We try to make the setting as comforting as possible and meet the client’s needs- for instance if they need us to make a house call or organize a family meeting, we will do that. We also feel very fortunate that our model allows us to see anyone, regardless of ability to pay- so everyone has access to genetic services, not just those who can get to a major medical center. Where we live in upstate New York, it is quite rural and some folks live hours from a major city so our program offers them services without having to travel.

This traditional, yet modified, model was set up the way it is to improve patient access by overall increasing the convenience they can offer to their patients. Similarly, GC08 states: “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.”

Participant GC12 provides cardiac genetic counseling services using a telephone model. She says, “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.” GC12 and the other genetic counselors in her practice offer genetic counseling services to individuals who would otherwise not have access to such services.

GC18 also discussed that she developed group sessions to provide access for patients who would not otherwise have been able to seek genetic counseling services.

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.

Her model of delivery evolved to allow more individuals the ability to have genetic counseling regarding their breast cancer diagnoses.

5.2.1.4 Convenience identified to outweigh limitations of service delivery model

There was an overall feeling that despite any barriers that were experienced with implementing alternative service delivery models, the benefits the models offered outweighed any of these potential barriers. This sentiment is expressed by GC15 when she says: “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. In an interview

with GC14, she describes the limitations and benefits she experiences in her telephone counseling model, and then goes on to describe her satisfaction with these services offered.

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 (no judgment/bias based on a person's appearance, flexible scheduling, disclosure of information a person might not say in a face to face session, etc). 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).

Thus, GC14 expresses her satisfaction with the telephone model of genetic counseling despite the limitations she encounters on a daily basis.

5.2.2 Theme #2: Logistical issues as major barrier in implementation of alternative service delivery models

The second major theme identified in this study is that the logistics of implementing an alternative service delivery model in practice was often a barrier. The following sections describe several instances where logistical issues were a hurdle that genetic counselors had to overcome before beginning to successfully offer an alternative model of delivery or instead could not be overcome and the alternative service delivery model was not offered.

5.2.2.1 Billing and reimbursement as a logistical barrier to implementation of alternative service delivery models

The genetic counselors identified that the inability to bill for services was a major limitation with their service delivery model, and having the ability to bill would be something they would change to increase their satisfaction with the model utilized. When asked why these

individuals are not able to bill, responses typically involved issues such as: there was not enough time to begin the process with the billing department, the genetic counselors were “told” they could not bill (but were not sure why) or the state did not have licensure. Additionally, of the counselors interviewed who employ in-person genetic counseling and an alternative delivery model, they were more likely to bill for their in-person counseling than the alternative model.

The participants who do bill for their genetic counseling services were often unsure of the logistics behind the billing. Additionally, when asked about reimbursement level for services, the answer was not known.

GC03’s response to describe the billing practices at her center demonstrates some of the challenges:

This is a long story. But currently, NO, the GC’s [genetic counselors] do not bill for genetic counseling. We are licensed and I am credentialed as a non-billing provider. However, due to contractual agreements with third party payers, my compliancy and contract office have decided it is not worth the bother to bill for a little fish like me when they are uncertain of the reimbursement. They claim they are waiting for CMS. However they keep changing their story...

GC03 has a similar story to some of the other participants.

Other counselors were only able to bill incident to a physician. GC17 addresses this situation encountered in her practice.

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.

Overall, billing was noted to be a challenge encountered in providing genetic counseling services.

5.2.2.2 Equipment set-up and arranging for genetic testing noted as a logistical barrier to implementation of alternative service delivery models

Availability and set up of necessary equipment seems to be a major barrier to implementing telemedicine services. Also, the logistics to this may increase wait time for this model in some instances. GC16 says in regards to her telemedicine services:

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.

Also, a barrier for counselors who are able to offer these services may be low patient uptake of telemedicine services. I asked GC08 what her experiences have been in offering telemedicine services.

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.

Another issue that adds complications for genetic counselors in implementing alternative service delivery models is having to arrange for genetic testing. When individuals are counseled via telephone counseling or telemedicine services, and decide to pursue genetic testing, the counselor must have a process in place for how and where the individual(s) can have their sample collected. This was often noted in the interviews as a major limitation of these alternative service delivery models.

GC11 uses a web-based telephone-counseling model. She stated in the interview that the major limitation in her delivery of telephone counseling is with specimen collection and shipment details for individuals choosing to pursue testing. Where the patient will have their

blood drawn and how the specimen will get to the genetic testing laboratory provide complications in implementing this type of model.

GC16 provides telemedicine services to her patients and encounters similar challenges as GC11. She says: “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.”

5.2.2.3 Inability to see the patient provides complications with alternative service delivery models

A limitation often noted of telephone counseling is that the genetic counselor is unable to see the patient and may miss out on visual clues as to what the patient is thinking or feeling. Therefore, it may be more difficult to ascertain client emotions/understanding over the telephone than it is with in-person counseling. However, there were additional challenges noted with not having the ability to see the patient in-person for a counseling session. The majority of counselors use visual aids to help increase the understanding of complex genetic/medical information for their patients. Performing a session via the telephone provides a barrier to the use of visual aids. GC14 provides a description of the way her center seeks to overcome this barrier.

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

Additionally, a limitation with not seeing the patient(s) in person was noted that it decreases the ability of the counselor to rely on physical features to help with diagnostic evaluation. This was also noted to be a potential challenge in the participants providing telemedicine services for their patients. GC10 illustrates this point:

Of course, another limitation is that we are not using clinical features (physical examination) as a way to guide the most appropriate test. This is not a possibility given our model, so we do run the risk of performing an array in a girl who, for instance, has Rett syndrome caused by an MECP2 mutation.

The inability to see the patient(s) for an in-person genetic counseling session was mentioned to provide barriers in delivering effective genetic counseling services.

6.0 DISCUSSION

6.1 STUDY FINDINGS IN THE CONTEXT OF PREVIOUS WORK

This study provides an investigation into alternative service delivery models in genetic counseling, as there is little research on the limitations and barriers experienced in implementing such models in the United States. Thematic analysis from semi-structured interviews with 20 practicing genetic counselors revealed two major themes that were the focus of this paper. The first theme is that alternative service delivery models offer convenience to patients and to the genetic counselors utilizing the models. The second theme is that logistical issues are a major barrier in implementing alternative service delivery models.

In following section, these themes are compared to findings from previous studies looking at the limitations and barriers of alternative genetic counseling models. The implications for genetics professionals are discussed, as well as the limitations of the study and areas for future research.

6.1.1 Theme #1: Convenience of alternative service delivery models

Previous studies have discussed some of the conveniences associated with adopting alternative service delivery models in genetic counseling, as outlined in the Background and Significance section (Calzone et al., 2005; Hunter et al., Wilson, 1997; Ridge et al., 2009; Lea et al., Zilliacus

et al., Abrams and Geier, 2006; Coelho et al., 2005; Peshkin et al., 2008; Ormond et al., 2000; Wang, 2000; and Sangha et al., 2003). Therefore it was not surprising to find that the convenience associated with telephone, telemedicine, and group counseling was a common reason they were implemented into a genetic counseling practice.

Reducing travel distance is a convenience to patients and providers often cited in the literature as a benefit to offering telephone and telemedicine services (Platten et al., 2012; Ormond et al., 2000; Peshkin et al., Coelho et al., 2005; Lea et al., 2005; Abrams and Geier 2006). Reduction in travel time or distance was also cited by the participants in the study as a major convenience of their service model. For some of the genetic counselors interviewed, offering such models was often directly related to travel distances. GC09 lives in a large state, and some of the individuals would not be able to seek her genetic counseling services if she was unable to offer telephone counseling. Telephone counseling enables genetic counselors who work for a company to offer their services nation-wide, as noted by participant GC15.

Long wait times are also addressed by the adoption of alternative service delivery models. This is a convenience cited in a study by Ridge et al. (2009) evaluating group genetic counseling for hereditary breast and ovarian cancer. Wang (2000) also suggests that the convenience provided by telephone counseling may enable patients to have such services at an earlier time than if they were required to attend an in-person genetic counseling session. Participants in this study showed a reduction in wait times for their patients when they used alternative models. For example, participant GC16 is able to see patients at a satellite clinic using telemedicine services. These patients typically had to wait up to six weeks for GC16 to travel to the clinic; however, telemedicine has enabled her to bring services to this population upon time of referral. Participant GC17 began to utilize group counseling in her cancer genetics

practice after the wait time for scheduling a new appointment reached seven months. Offering the option of group counseling successfully reduced the wait time in her clinical practice, as she was able to see more patients in a shorter amount of time. Reducing wait times may also cause a decrease in psychosocial distress, as this can be an occurrence for women waiting for cancer genetic counseling (Mikkelsen et al., 2008).

This study also elicited the theme that alternative service delivery models enhance access to patients who would not otherwise be able to have counseling services. Previous studies have identified that the majority of genetic services are located in urban areas, which can produce challenges for patients living in rural areas who may not have the means to access such services (Coelho et al., 2005; Lea et al., 2005; Abrams and Geier, 2006; Koil et al., 2003). Participant GC12 offers cardiac genetic counseling to patients all over the country, often to individuals who are not located near hospitals that offer these services. Socioeconomic barriers may also be addressed by implementing alternative service delivery models. GC18 utilizes group counseling and education for her patients that would not otherwise have the financial means to seek these services.

Overall, the participants interviewed were satisfied with the genetic counseling models used in their practices, despite any barriers they may have encountered while implementing or executing the alternative service delivery model.

6.1.2 Theme #2: Logistical issues as major barrier in implementation of alternative service delivery models

Many participants in the current study described logistical barriers that were challenges to them when trying to incorporate telephone, telemedicine or group counseling into their clinical

practices. Logistical issues, such as challenges with billing and reimbursement, not having the necessary equipment to offer services and the inability to see visual cues in telephone counseling have all been identified in literature to be barriers in implementing alternative service delivery models (Harrison et al., 2010; Sangha et al., 2003; Peshklin et al., 2008; Platten et al., 2012; Ormond et al., 2000; Wang 2000; Lea et al., 2003).

Billing was often noted by participants to be a major limitation in their model of genetic counseling. Billing issue concerns were not unique to the counselors using only alternative service delivery models but remain a universal concern for all genetic services. For the participants who were offering more than one model of genetic counseling, they were more likely to bill for the in-person genetic counseling than for the alternative service delivery model.

Another barrier associated with telemedicine was having equipment set-up available. Some participants had the ability at their center to offer telemedicine services; however, these services were not often used because of lack of equipment on the other end. In some cases the clinical center did not have the telemedicine equipment, and in other cases, the patient themselves did not have access to a computer with a camera. Or, as noted by participant GC08, it was more convenient for the patients to talk on their cell phone than it was to deal with setting up video conferencing on their computer. Other concerns experienced with telephone and telemedicine counseling was having to arrange for blood draws should the patient chose to pursue genetic testing. This is a challenge that has been identified in previous studies (Peshkin et al., 2008; Lea et al., 2005).

The inability to see the patient in person also provides complications when providing telemedicine and telephone genetic counseling services. Several studies looking at the utility of telephone counseling have addressed the concern of not being able to use visual diagrams, as

well as not having the ability to see and thus address visual cues from the patient (Sangha et al., 2003; Platten et al., 2012; Ormond et al., 2000; Wang, 2000). Many of the participants cited that the inability to respond to visual cues when discussing complex information over the telephone was a challenge that they experienced with this model. There are reports in the literature that discuss how rapport building may be hindered by the lack of visual cues available to both the counselor, and also the patient. Telephone counseling may have the potential to impede the emotional connection and could result in higher anxiety level for the patient following telephone counseling compared with in-person counseling (Sangha et al., 2003).

Some of the participants are aware of this barrier to telephone counseling, and they provide either a binder with visual aids to their patients, or provide their patients with a web site that they can go to and see visuals that are then discussed with the genetic counselor. However, one limitation that was identified by the participants with the inability to see the patient in-person was not having the option of doing a physical exam to aid in diagnosis. This is a concern when providing both telephone and telemedicine counseling, and is not one that has been addressed in the literature examining these alternative service delivery models.

6.2 IMPLICATIONS FOR GENETIC PROFESSIONALS

This study has implications for genetic counselors and other genetic professionals, as they may benefit from having the awareness of alternative service delivery models and some of the reasons why genetic counselors adopt such models. This study identifies many of the conveniences that can be associated with alternative service delivery models, which may be encouraging for genetic professionals to begin the process of implementing such models into their clinical

practices. Also, this study identified some of the challenges genetic counselors were experiencing with their in-person genetic counseling models (travel distance, wait times, etc.) causing them to initiate an alternative model into practice. This may provide genetic professionals with the awareness and information to implement alternative models.

Knowing the barriers that may be encountered when implementing an alternative model may be beneficial for genetic professionals who are beginning this process, and help them to avoid such barriers, or at least be aware of the barriers so they can have the tools to address them. The participants interviewed were generally satisfied with their model of genetic counseling, despite any barriers they encountered. This is an important aspect for genetic counselors to consider when deciding whether or not to implement an alternative service delivery model.

This could also have implications for genetic counseling training programs. As alternative service delivery models are being used in more clinical practices, it may be necessary to begin training genetic counseling graduate students on telephone, telemedicine, and group counseling procedures to remain more competitive in the job market. Additionally, this may become a necessary component of training programs where the clinical rotation sites themselves are utilizing alternative models.

6.3 STUDY LIMITATIONS AND FUTURE RESEARCH

This study aimed to elucidate themes found within interviews and is not meant to be generalized, as the sample size is too small to do so. Therefore, more research needs to be done to identify other themes and to find significance with the themes. Additionally, although some information

was ascertained as to how genetic counselors overcame the barriers to implementing their alternative service delivery model, more research needs to be done in this area to enable other genetic counselors the ability to employ such models into their clinical practices. Future studies could do more targeted interviews of genetic counselors who began using alternative service delivery models to overcome some barrier they were experiencing in their clinics. Interviews could be focused on what these barriers were and the specifics of how they were overcome. (e.g., who was involved, what was involved, how was this accomplished etc.) This could shed more light on the specifics surrounding how these challenges were overcome.

6.3.1 Limitations with recruitment

The principal investigator was able to select some of the participants from the initial survey administered by the National Society of Genetic Counselors (NSGC) Service Delivery Models (SDM) Task Force who agreed to future contact; however, these individuals were less likely to consent to and complete an interview. The majority of genetic counselors interviewed for this study were self-recruited, either from the NSGC discussion board post or the flyer posted at the 30th NSGC Annual Education Conference. This approach seemed to work more efficiently in identifying participants who utilize unique service delivery models, as only the individuals who used an alternative model would contact the principal investigator. The approved IRB protocol did not allow the principal investigator to contact individuals who did not initially complete the survey and agree to future contact or who did not directly contact her.

It may be beneficial in future studies to have IRB permission to contact individuals directly that utilize unique alternative service delivery models. This would enable the researcher more control over who participates in the interviews, allowing for a more diverse group of

genetic counselors. Additionally, there were genetic counselors identified by the SDM Task Force who would have been exceptional additions to the study; however, these individuals could not be contacted. Having the ability to contact such individuals could potentially allow for a richer analysis.

6.3.2 Thematic analysis and email interview methodology

There were potential limitations with the email interviews utilized in this study. Because there was not one telephone call or one time set aside for the participants to complete the interview, there were several who began answering interview questions and then stopped. The participant was emailed one additional time requesting their continued participation. If a response was not received at that point, the interview was considered to be concluded.

Additionally, some participants replied with a lack of detail, even after probing from the interviewer. These participants may have given more detailed responses if the interviews had been conducted over telephone or in person. However, the majority of the participants did give fairly robust responses that were helpful for analysis. Despite these potential limitations, the email interviews provided convenience and cost effectiveness, and thus were thought to be overall effective.

7.0 CONCLUSIONS

There is little research on alternative service delivery models in genetic counseling, especially in regards to real-life experiences of genetic counselors utilizing these models in their clinical practices. This study sought to provide an overview of the some of the limitations and barriers, as well as the advantages that are experienced from implementing alternative service delivery models into practice. The genetic counselors interviewed provided insight into the conveniences both they and their patients experienced upon employing an alternative service delivery model, as well as discussed some of the barriers and challenges in doing so. More research needs to be done to examine concrete ways to overcome the barriers with implementing these models in order to make adoption of such models applicable to clinical practice.

APPENDIX A

INSTITUTIONAL REVIEW BOARD LETTER APPROVAL



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1490
(412) 383-1508 (fax)
<http://www.ibr.pitt.edu>

Memorandum

To: Rachelle Christie
From: Sue Beers, PhD, Vice Chair
Date: 4/12/2011
IRB#: [PRO11020128](#)
Subject: An Exploration of Service Delivery Models in Genetic Counseling: A Thematic Analysis

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2)

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B

RECRUITMENT MATERIALS: FLYER FOR NSGC

Please Help The Genetic Counseling Profession

Tried something different in your delivery of genetic counseling?



Photo courtesy of: <http://www.itswrittenow.com/649/dare-to-be-different/>

If so, your input is needed for this NSGC approved study:

An Exploration of Service Delivery Models in Genetic Counseling

The purpose of this research study that is being conducted at The University of Pittsburgh is to provide information regarding service delivery models used in the practice of genetic counseling and to investigate methods used to improve access and minimize barriers to these models.

APPENDIX C

GUIDED INTERVIEW QUESTIONS

1. Demographic Information
 - Example Questions
 1. Name
 2. Gender
 3. Years in Specialty
2. General Questions about Practice
 - Example Questions:
 1. How is your position funded?
 2. How many hours per week do you spend providing genetic counseling services?
3. Service Delivery Models
 - Example Questions
 1. How would you describe the model(s) you use in your genetic counseling practice?
 2. Using this model, how much time do you spend with patients?
4. Number of People Served Using Model(s)
 - Example Questions
 1. How many patients do you see with this model?
 2. What is the average wait time to schedule a new appointment?
5. Patient Characteristics
 - Example Questions
 1. What is the average distance that patients have to travel to see you?
 2. What is the maximum distance that patients have to travel to see you?
6. Billing
 - Example Questions
 1. Do you bill?
 2. How do you bill?
7. Outcome Measures
 - Example Questions

1. How would you describe the efficiency of the model(s) used?
 2. What percentage of the amount billed is actually reimbursed?
8. Overall Utility of Model(s) Used
- Example Questions
 1. What are some benefits to the model(s) used?
 2. What are some limitations/barriers to the model(s) used?

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