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ORIGINAL RESEARCH

Identification of Genetic Counseling Service Delivery Models in Practice: A Report from the NSGC Service Delivery Model Task Force

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Abstract Increasing demand for genetic services has resulted in the need to evaluate current service delivery models (SDMs) and consider approaches that improve access to and efficiency of genetic counseling (GC). This study aimed to describe SDMs currently used by the GC community. The NSGC membership was surveyed regarding the use of four SDMs: in-person GC, telephone GC, group GC, and telegenetics GC. Variables related to access and components of use were also surveyed, including: appointment availability, time-per-patient, number of patients seen, billing, and geographic accessiblity. Seven hundred one usable responses were received. Of these, 54.7 % reported using an in-person SDM exclusively. The remainder (45.3 %) reported using multiple SDMs. Telephone, group and telegenetics GC were used often or always by 8.0 %, 3.2 % and 2.2 % of respondents, respectively. Those using an in-person SDM reported the ability to see the highest number of patients per week ($p<0.0001$) and were the most likely to bill in some manner ($p<0.0001$). Those using telegenetic and telephone GC served patients who lived the furthest away, with 48.3 % and 35.8 %% respectively providing GC to patients who live >4 h away. This study shows that genetic counselors are incorporating SDMs other than traditional in-person genetic counseling, and are utilizing more than one model. These adaptations show a trend toward shorter wait time and shorter length of appointments. Further study is indicated to analyze benefits and limitations of each individual model and factors influencing the choice to adopt particular models into practice.

Keywords Service delivery models · Genetic counseling · Access · National Society of Genetic Counselors · In-person genetic counseling · Telephone genetic counseling · Telegenetic counseling · Group genetic counseling

All authors are members of the NSGC Service Delivery Model Task Force.

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Introduction

Traditionally, individuals with rare, Mendelian-inherited disorders comprised the majority of medical genetics patients; however with the increase in understanding of the genetics of common disease, referrals are expanding to the general population. In anticipation of this expansion, there is

a critical need to examine current genetic service delivery models (SDM); evaluate and assess these models; determine key components; and develop new, efficient, and effective models for providing genetic services.

The National Society of Genetic Counselors (NSGC) appointed the Service Delivery Model Task Force (SDMTF) in 2009 as part of its 2010–2011 strategic initiatives. The charge of the SDMTF was to research and assess the capacity of all existing service delivery models to improve access to genetic counseling (GC) in the context of increasing demand for genetic testing and counseling services.

To evaluate service delivery models, the SDMTF proposed definitions for current genetic counseling service delivery models, modes of referral, and components of service delivery (Cohen et al. 2012). It was proposed that current models of service delivery can be defined by: 1) the methods in which GC services are delivered (In-person, Telephone, Group, and Telegenetics), 2) the way they are accessed by patients (Traditional referral, Tandem, Triage, Rescue, and Self -referral), and 3) the components unique to each service setting (ex: documentation, specialty, physician involvement, etc.). These definitions provide a starting point whereby standardized terminology can be used in future studies that assess the effectiveness of described models to overcome barriers to access to GC services.

The traditional in-person model of providing genetic counseling has been shown to involve an hour or longer of clinic visit time and several hours of case preparation, documentation of the genetic counseling provided, and follow-up (Wham et al. 2010; McPherson et al. 2008; Uhlmann et al. 2009). This time intensive model is not well reimbursed by third party payers and is not practical to reach a large population (Tuckson 2006). Improvements in efficiency and access are critical to ensuring that the growing number of patients seeking genetic services receives appropriate care.

Measures of access include wait times (typically measured in the time to the third next available appointment), travel distance as defined by travel time from patient to service location, and ability to get to be reimbursed for services (Hall et al. 2008; Hyndman et al. 1999; Jones et al. 2003; McGrail and Humphreys 2009). Wait times and distance traveled are of particular concern for genetic counseling services since these specialty services tend to be concentrated in academic centers and large cities with relatively small workforces.

This study aims to describe the current landscape of GC service delivery by surveying professional practice nationally. Outcomes of genetic counseling in the context of these different service delivery models will also need to be carefully considered. However, such subjects are beyond the scope of this manuscript. To pave the way for this future work, this manuscript focuses on the service delivery models themselves. Ultimately, identification of the models that effectively integrate and utilize genetic counselors in the healthcare system will improve access to genetic counselors and promote overall visibility of the profession.

Methods

Recruitment

Full members of the NSGC were notified of the study by e-blast in September 2010 (N=2,316 genetic counselors as of the first quarter of 2010). The study was also promoted in the NSGC president's weekly message and on the NSGC listserv. Eligible participants included full members of NSGC who had provided clinical GC services during the preceding year. They were invited to complete a Zoomerang™ multiple-choice online survey of current SDM use.

Survey Instrument

The survey instrument was developed by the research team, which includes individuals with diverse clinical genetics backgrounds and work settings. The survey was piloted with members of the NSGC Access and Service Delivery Committee and feedback was incorporated as appropriate. The final survey included 51 questions, which included 48 multiple choice and rating scale questions, two open ended questions, and one question asking for contact information for future studies. The survey was converted into an online format using Zoomerang™ software.

The survey instrument included a description of the four major SDMs, including in-person (previously referred to as face-to-face traditional), telephone, group, and telegenetic GC per the definitions previously defined by the SDM taskforce (Table 1) (Cohen et al. 2012). In-Person genetic counseling involves cases where the patient is seen in-person, typically within a healthcare facility of private office. Historically this has been referred to as "face-to-face" however to accurately delineate from telegenetic counseling utilizing video conferencing, the new up to date definition was proposed. Telephone genetic counseling occurs when a patient is provided genetic counseling for a new indication or concern and the session is completed entirely via telephone. Group genetic counseling involves multiple individuals seen for genetic counseling together, usually for a common indication. This model has been reported typically occurring in-person in a health care setting or private office. Telegenetic counseling has also been described as web-based or videoconferencing genetic counseling. In this model genetic counseling is provided remotely via video-conference or web-link, including visual and audio access.

The survey asked how often participants used these models and all questions were asked in relation to new patients appointments, not return visits. Measures of access for each model were

Table 1 Definitions of service delivery models and referral patterns

Service Delivery Models (SDMs)	
In-Person	Genetic Counseling is provided in-person. Follow up and results disclosure may occur by telephone of other means
Telephone	Genetic Counseling is provided remotely by telephone. The telephone call may be supplemented by written, online or other resources.
Group	Patients are educated in a group setting by a genetic counselor, which may be followed by individual assessment, counseling etc. This model has been reported typically occurring in-person.
Telegenetic	Genetic Counseling is provided remotely using videoconferencing
Referral Patterns	
Traditional	An MD or other health care provider recognizes an indication for genetic counseling and refers patient
Tandem	A collaborative relationship in which the initial genetic counseling is done by another health care provider. Select patients are then referred to a genetic counselor for follow up
Triage	A collaborative relationship in which the initial genetic counseling is done by another health care provider. Select patients are then referred to a genetic counselor as needed based on complexity
Rescue	Healthcare providers refer select patients to genetic counselors in the absence of a collaborative relationship and after they have encountered difficulty
Self-referred	Referral initiated by a patient

Cohen et al. (2012)

assessed, including wait time, drive time from patient to GC site, and mode of referral. Other measures of access assessed for each model included billing practices, and the number of patients that could be seen by one full time genetic counselor per week for each model used. Demographic information was collected, including work setting, clinical specialty, number of years of experience, certification, credentialing, and licensure status. Willingness of the individual to participate in a future interview analysis of service delivery was also determined.

Data Analysis

Use of each of the SDMs was analyzed separately in relation to the measures of access (wait time to third next appointment and drive time, number of new patients, referral method) and components of the models (length of time in consultation, limitations of scheduling, supervision and billing practices). Cross tabulations and chi-square analyses for significance were performed on the multiple-choice questions using Statistical Package for the Social Sciences (SPSS) software. Open-ended comments to the survey were reviewed by the authors for underlying themes. A formal qualitative analysis of the open-ended responses was not performed.

This study was approved by the St. Vincent Hospital Institutional Review Board (Indianapolis, IN) and the University of Michigan Medical Institutional Review Board (Ann Arbor, MI).

Results

There were 820 respondents to the survey for an overall response rate of 35.4 %. This is our best estimate, since not all NSGC members may have received the e-blast or known about the study invitation. Of the total respondents, 715 indicated that they had provided clinical genetic counseling services within the last year and, of these, 701 provided complete responses that were used in data analysis. The demographic data of respondents did not differ significantly from the demographics of the respondents of the 2010 NSGC Professional Status Survey (PSS) with regard to training, certifications, specialty, and work setting. There were 21 respondents who indicated they worked outside of the United States of America.

As expected by the number of states that require licensure, most genetic counselors responding to the survey were not licensed (84.3 %) and most did not report being credentialed by their institution (63 %) or payers (75.5 %). Almost 17 % did not know their credentialing status. The payer mix for clinical services in order of most to least common was: private 3rd party payer, Medicaid, Medicare, uninsured/out of pocket, integrated health care plan, uninsured/charity care/grant support, socialized health care (Supplemental Table A).

In-Person (Face-to-Face Traditional) Genetic Counseling

Overall, 95.7 % (671/701) of respondents indicated that they have used in-person GC "always" (65.3 %) or "often" (30.4 %) over the past 5 years. A breakdown of these responses for use of service delivery model by specialty is presented in Table 2.

Wait time for most in-person appointments was less than 2 weeks. Sixty-five percent (65 %) of respondents indicated that their third next available GC appointment for a new patient was <1 week (35 %) or 1–2 weeks (30 %) (Table 3). Stratifying by specialty, the prenatal specialty had the highest response rate for appointments at <1 week (59 %)

Table 2 Use of genetic counseling service delivery models

Overall usage	In-person	Telephone	Group	Telegenetics
Genetic Counselors reporting use of this model "always" or "often"	95.7 % (671/701)	8.0 % (46/572)	3.2 % (19/593)	2.2 % (13/570)
By specialty	**In-person**	**Telephone**	**Group**	**Telegenetics**
Cancer	98.2 % (157/160)	3.9 % (6/153)	1.9 % (3/160)	1.3 % (2/160)
Cardiac	100.0 % (16/16)	6.2 % (1/16)	−(0/16)	−(0/16)
General genetics	90.2 % (37/41)	12.1 % (5/41)	4.9 % (2/41)	7.3 % (3/41)
Prenatal	99.0 % (200/202)	3.5 % (7/199)	3.0 % (6/202)	1.5 % (3/202)
Pediatrics	100 % (80/80)	6.9 % (5/72)	−(0/80)	2.5 % (2/80)
Other	24.6 % (16/65)	24.6 % (16/65)	7.7 % (5/65)	1.5 % (1/65)
By years of experience	**In-person**	**Telephone**	**Group**	**Telegenetics**
<5 years	97.8 % (181/185)	4.8 % (9/185)	−(0/185)	1.0 % (2/185)
5–10 years	96.6 % (175/181)	8.9 % (16/179)	3.0 % (6/181)	2.0 % (5/181)
11–15 years	94.3 % (67/71)	9.0 % (6/67)	5.0 % (4/71)	1.0 % (2/71)
>15 years	96.0 % (122/127)	8.0 % (10/125)	4.0 % (6/127)	2.0 % (3/127)
By work setting	**In-person**	**Telephone**	**Group**	**Telegenetics**
University Medical Center	97.5 % (240/246)	3.8 % (9/238)	1.0 % (3/246)	2.0 % (7/246)
Private hospital	98.3 % (121/123)	1.7 % (2/121)	2.0 % (3/123)	−(0/123)
Public hospital	100 % (93/93)	3.3 % (3/92)	3.2 % (3/93)	2.1 % (2/93)
Diagnostic laboratory	72.7 % (8/11)	36.3 % (4/11)	−(0/11)	18.1 % (2/11)
Integrated health plan	91.3 % (21/23)	43.4 % (10/22)	4.3 % (4/23)	−(0/23)
Physicians private practice	97.5 % (39/40)	2.5 % (1/40)	−(0/40)	−(0/40)
Private practice	94.4 % (17/18)	16.7 % (3/18)	−(0/18)	−(0/18)
Government	100.0 % (8/8)	−(0/8)	12.5 % (1/8)	25.0 % (2/8)
Not for profit organization	94.7 % (18/19)	15.8 % (3/19)	−(0/19)	−(0/19)

and 1–2 weeks (36 %). Pediatrics had the lowest response rate for appointments at <1 week (8 %) and 1–2 weeks (8 %). The remaining specialties (cancer, cardiac, general, and other) had similar response rates with 1–2 weeks being the most common (Table 3).

About one half of patients accessing in-person GC had less than a 30-min drive (Table 3). Patients utilizing in-person GC rarely had a 2–4 h drive or greater than 4 h drive. The number of new patients one full time clinical genetic counselor could see using in-person GC per week was reported to be 6–10 for 33 % of respondents, 11–15 for 23 % of respondents, and 16–20 for 18 % of respondents (Table 3). This is similar to the 2010 PSS, with the average clinical genetic counselor reporting 8.3 new patients per week. Referral patterns indicate that most in-person genetic counseling sessions are initiated by a healthcare provider (94.5 % always or often) in a traditional mode of referral (Table 3).

Seventy two percent (72 %) of respondents indicated that they spent on average 31 to 60 min with patients for in-person genetic counseling (Table 4). With regard to the scheduling of new patients for in-person GC, only 19.4 % indicated that they were "always" or "frequently" limited by the availability of a procedure (ultrasound, amniocentesis, etc). The largest reported limitation in scheduling was the physician availability with 23.5 % reporting "always or frequently" being limited by needing a physician under the same roof, and 22.2 % reporting being limited by requirement for a physician available for part of the visit (Table 4).

Nearly half of respondents (49.4 %) definitively reported billing for in-person GC services, and 31.1 % indicated that they do not bill at all (Table 4). An additional 11.2 % reported "other" strategies of billing and 8.4 % did not know if they were billing. When billing for in-person GC services, the most commonly used code was the 96040 GC code, followed by consultation codes 99241–99245 or 99251–99255 and evaluation and management codes 99201–99205 or 99211–99215.

Telephone Counseling

It should be noted that upon review of the comments sections of this survey, some respondents appear to have

Table 3 Measures of access by service delivery model

Wait time to third next appointment using this model	In-Person	Telephone	Group	Telegenetics
	Of Genetic Counselors who report any use of these models			
< 1 week	34.9 % (204/584)	77.0 % (151/196)	21.3 % (17/80)	23.3 % (14/60)
-Cancer	22.1 % (35/158)	70.6 % (36/51)	7.4 % (2/27)	16.6 % (3/18)
-Cardiac	18.7 % (3/16)	55.5 % (5/9)	−(0/3)	−(0/1)
-General Genetics	21.0 % (8/38)	60.0 % (9/15)	−(0/3)	12.5 % (1/8)
-Prenatal	59.4 % (120/202)	85.0 % (51/60)	38.5 %(10/26)	40.0 % (8/20)
-Pediatrics	7.5 % (6/80)	76.2 % (16/21)	−(0/5)	10.0 % (1/10)
-Other	32.8 % (20/61)	86.5 % (32/37)	26.6 % (4/15)	25.0 % (1/4)
1–2 weeks	29.6 % (173/584)	12.7 % (25/196)	27.5 % (22/80)	25.0 % (15/60)
-Cancer	34.8 % (55/158)	17.6 % (9/51)	25.9 % (7/27)	33.3 % (6/18)
-Cardiac	25.0 % (4/16)	−(0/9)	−(0/3)	−(0/1)
-General genetics	28.9 % (11/38)	20.0 % (3/15)	33.3 % (1/3)	−(0/8)
-Prenatal	36.1 % (73/202)	11.6 % (7/60)	30.7 % (8/26)	50.0 % (10/20)
-Pediatrics	7.5 % (6/80)	14.2 % (3/21)	20.0 % (1/5)	−(0/10)
-Other	26.2 % (16/61)	8.1 % (3/37)	33.3 % (5/15)	−(0/4)
2–4 weeks	15.2 % (89/584)	6.1 % (12/196)	22.5 % (18/80)	20.0 % (12/60)
-Cancer	24.7 % (39/158)	5.8 % (3/51)	29.6 % (8/27)	22.2 % (4/18)
-Cardiac	25.0 % (4/16)	22.2 % (2/9)	66.6 % (2/3)	−(0/1)
-General genetics	28.9 % (11/38)	20.0 % (3/15)	−(0/3)	50.0 % (4/8)
-Prenatal	3.5 % (7/202)	1.6 % (1/60)	19.2 % (5/26)	5.0 % (1/20)
-Pediatrics	17.5 % (14/80)	9.5 % (2/21)	20.0 % (1/5)	30.0 % (3/10)
-Other	16.4 % (10/61)	2.7 % (1/37)	13.3 % (2/15)	25.0 % (1/4)
1–2 months	8.6 % (50/584)	1.5 % (3/196)	7.5 % (6/80)	15.0 % (9/60)
-Cancer	12.0 % (19/158)	1.9 % (1/51)	18.5 % (5/27)	16.6 % (3/18)
-Cardiac	6.25 % (1/16)	22.2 % (2/9)	−(0/3)	−(0/1)
-General genetics	10.5 % (4/38)	−(0/15)	−(0/3)	25.0 % (2/8)
-Prenatal	−(0/202)	−(0/60)	−(0/26)	−(0/20)
-Pediatrics	21.2 % (17/80)	−(0/21)	20.0 % (1/5)	20.0 % (2/10)
-Other	11.5 % (7/61)	−(0/37)	−(0/15)	50.0 % (2/4)
>2 months	11.6 % (68/584)	2.5 % (5/196)	21.3 % (17/80)	16.7 % (10/60)
-Cancer	6.3 % (10/158)	3.9 % (2/51)	18.5 % (5/27)	11.1 % (2/18)
-Cardiac	25.0 % (4/16)	−(0/9)	33.3 % (1/3)	100.0 % (1/1)
-General genetics	10.5 % (4/38)	−(0/15)	66.6 % (2/3)	12.5 % (1/8)
-Prenatal	0.9 % (2/202)	1.6 % (1/60)	11.5 % (3/26)	5.0 % (1/20)
-Pediatrics	46.3 % (37/80)	−(0/21)	40.0 % (2/5)	40.0 % (4/10)
-Other	13.1 % (8/61)	2.7 % (1/37)	26.6 % (4/15)	−(0/4)
Drive time traveled for “most” or “all” Traveled by patients using this model	In-Person	Telephone	Group	Telegenetics
<30 min	49.2 %(282/573)	15.5 % (28/181)	59.2 % (45/76)	1.7 % (1/58)
30–60 min	33.4 % (191/571)	8.2 % (15/182)	30.2 % 23/76)	1.7 % (1/58)
1–2 h	8.2 % (46/558)	12.5 % (23/183)	10.5 % (8/76)	16.3 % (10/61)
2–4 h	4.9 % (27/549)	16.9 % (31/183)	5.4 % (4/74)	38.7 % (24/62)
>4 h	9.4 % (51/539)	35.8 % (66/184)	5.5 % (4/73)	48.3 % (29/60)
Number of new patients could be seen per week using this model	In-Person	Telephone	Group	Telegenetics
1–5	12.7 % (74/581)	27.9 % (55/197)	27.5 % (22/80)	53.2 % (33/62)
6–10	32.9 % (191/581)	10.1 % (20/197)	20.0 % (16/80)	9.7 % (6/62)

Table 3 (continued)

Wait time to third next appointment using this model	In-Person	Telephone	Group	Telegenetics
	Of Genetic Counselors who report any use of these models			
11–15	22.7 % (132/581)	8.1 % (16/197)	10.0 % (8/80)	9.7 % (6/62)
16–20	18.4 % (107/581)	3.5 % (7/197)	8.8 % (7/80)	3.2 % (2/62)
21–30	10.5 % (61/581)	4.1 % (8/197)	8.8 % (7/80)	4.8 % (3/62)
>30	2.8 % (16/581)	2.5 % (5/197)	3.8 % (3/80)	−(0/62)
Not sure	−(0/581)	43.6 % (86/197)	21.3 % (17/80)	19.4 % (12/62)
Referral method reported "always" or "often" in this model	In-Person	Telephone	Group	Telegenetics
Traditional	94.5 % (550/582)	52.1 % (99/190)	75.3 % (58/77)	82.0 % (50/61)
Tandem	3.0 % (17/555)	6.0 % (11/182)	7.9 % (6/76)	5.0 % (3/59)
Triage	3.8 % (21/556)	5.7 % (10/179)	1.3 % (1/75)	5.0 % (3/59)
Rescue	8.0 % (44/556)	9.3 % (17/182)	−(0/75)	10.0 % (6/60)
Self-referred	9.1 % (52/571)	29.0 % (54/186)	28.6 % (2/77)	10.0 % (6/60)

interpreted the definition of telephone GC to include results disclosure following an in-person visit, despite the definition provided that telephone counseling referred to a new patient consultation completed by telephone. Twelve responses were removed as a result of a comment made either in the telephone section (usually in the billing comments) or at the end of the survey that telephone counseling is only used to provide results. These 12 individuals removed from the analysis included 3 who reported using the model "often" and 9 that reported using the model "rarely" (4) or "sometimes" (5). After removing those 12 individuals, telephone genetic counseling was reported to be in use by 41.3 % of respondents, and only 8.0 % reported "always" or "often" using telephone genetic counseling (Table 2). The average wait to the third next available appointment was <1 week among 77.0 % of all respondents (Table 3). Patients accessing telephone GC showed a trend towards longer drive time, with a range of reported patient drive times of 1–2 h, 2–4 h, and over 4 h. Of patients served using telephone GC, the largest proportion served (35.8 %) lived over a 4-h drive away. The most frequently reported number of new patients that could be seen per week by one full time clinical genetic counselor with telephone GC was 1–5 (27.9 %) and 6–10 (10.1 %); however, 43.6 % of respondents reported uncertainty and did not report a range (Table 3). A traditional mode of referral was the most commonly reported for telephone GC (52.1 %), followed by self-referral (29.0 %) (Table 3).

Average amount of time spent per patient in telephone GC is less than 30 min (50.3 %), closely followed by 31–60 min (45.6 %) (Table 4). The telephone SDM was not highly limited by availability of a physician or support staff, with the largest limitation reported being the number of available genetic counselors (9.9 % reported this as "frequently" or "always" the limitation in arranging telephone GC). For telephone GC, 84.8 % reported no requirements for physician supervision (under the same roof or on the same telephone call as services are delivered). Most genetic counselors reported not billing for the telephone SDM (67.5 %). Only 7.5 % reported using some method of billing (Table 4).

Group Counseling

Only 16.8 % of respondents reported ever using group GC and 3.2 % of genetic counselors responded that they use group counseling "always" or "often" (Table 2).

The third next available appointment for group counseling ranged between <1 week and 4 weeks, with similar responses for each of the time ranges therein (Table 3). A wait time of 2–4 months was reported by 13.8 % of respondents and 7.5 % had a wait time of greater than 4 months for group GC. Most or all patients who access group GC live within a 30-min drive (59.2 %). Genetic counselors who use group GC reported being able to see between 1 and 5 patients per week (27.5 %) or 6–10 patients per week (20 %). Patients accessed group GC most often through a traditional mode of referral and least often through a rescue mode (Table 3).

Most genetic counselors report spending less than 30 min in one-on-one counseling associated with a group GC session (58.0 %) (Table 4). Time spent in the group setting was not assessed. The most commonly reported limitation in scheduling new patients for group GC was physical space (reported by 19.2 % as "always" or "frequently" a limitation) and the least common reported limitation was lack of support staff (reported as "always"

Table 4 Components of service delivery model use

Average time spent in consultation using this model	In-Person	Telephone	Group	Telegenetics
None	−(0/582)	−(0/195)	8.0 % (6/77)	−(0/62)
< 30 min	6.0 % (35/582)	50.2 % (98/195)	58.0 % (45/77)	12.0 % (7/62)
31–60 min	72.0 % (395/582)	45.6 % (89/195)	17.0 % (13/77)	77.0 % (46/62)
61–90 min	20.0 % (110/582)	3.6 % (7/195)	14.0 % (11/77)	12.0 % (7/62)
> 90 min	1.0 % (7/582)	0.5 % (1/195)	3.0 % (2/77)	−(0/62)
Limitations in scheduling reported "always" or "frequently" using this model	In-Person	Telephone	Group	Telegenetics Remote site = R GC site = H
Procedure	19.4 % (110/569)	NA	10.3 % (8/78)	NA
Physician under same roof	23.5 % (136/578)	2.6 % (5/192)	14.1 % (11/78)	11.7 % (7/60)
Physician for part of visit	22.2 % (127/573)	0.5 % (1/191)	15.6 % (12/77)	13.3 % (8/60)
# Clinical GC's	17.8 % (103/576)	9.9 % (19/191)	17.9 % (14/78)	16.7 % (10/60)
Support Staff	6.8 % (39/573)	2.6 % (5/191)	7.7 % (6/78)	*R* 25.8 % (16/62) *H* 12.9 % (8/62)
Physical space	12.6 % (73/578)	N/A	19.2 % (15/78)	*R* 24.2 % (15/62) *H* 25.0 % (15/60)
Requirement for Physician supervision in this model?	In-Person	Telephone	Group	Telegenetics
No	39.3 % (242/615)	84.8 % (168/198)	55.1 % (48/87)	59.0 % (36/61)
Yes, in room/on phone	0.4 % (3/615)	0.4 % (1/198)	1.1 % (1/87)	4.9 % (3/61)
Yes for physical exam	10.7 % (66/615)	N/A	5.7 % (5/87)	4.9 % (3/61)
Yes, for part of visit	19.3 % (119/615)	−(0/198)	14.9 % (13/87)	11.4 % (7/61)
MD Readily available	21.9 % (135/615)	6.1 % (12/198)	17.2 % (15/87)	9.8 % (6/61)
Other	8.1 % (50/615)	8.5 % (17/198)	5.7 % (5/87)	9.8 % (6/61)
Billing methods used in this model	In-Person	Telephone	Group	Telegenetics
In GC's name and NPI	8.6 % (50/582)	3.5 % (7/200)	5.1 % (4/78)	1.6 % (1/63)
Incident to Physician	24.1 % (140/582)	1.5 % (3/200)	15.4 % (12/78)	11.1 % (7/63)
Facility Fee	11.0 % (64/582)	0.5 % (1/200)	5.1 % (4/78)	−(0/63)
Bundled Charge	5.7 % (33/582)	2.0 % (4/200)	1.3 % (1/78)	4.8 % (3/63)
No Billing	31.1 % (181/582)	67.5 % (135/200)	41.0 % (32/78)	47.6 % (30/63)
Do Not know	8.4 % (49/582)	8.5 % (17/200)	10.3 % (8/78)	12.7 % (8/63)
Other	11.2 % (65/582)	16.5 % (36/200)	21.8 % (17/78)	22.2 % (14/63)
Billing Codes used in this model	In-Person	Telephone	Group	Telegenetics
CPT 96040	27.4 % (158/576)	3.6 % (7/193)	13.3 % (10/75)	8.2 % (5/61)
HCPS S0265	0.2 % (1/576)	−(0/193)	−(0/75)	−(0/61)
CPT E&M Codes (99201–99205,99211–99215)	9.2 % (53/576)	−(0/193)	6.7 % (5/75)	−(0/61)
CPT Consultation Codes (99241–99245, 99251–99255)	16.0 % (92/576)	1.0 % (2/193)	9.3 % (7/75)	8.2 % (5/61)
Other CPT Codes	−(0/576)	9.8 % (19/193)	4.0 % (3/75)	−(0/61)

or "frequently" a barrier by 7.7 %). Most genetic counselors reported that they had no physician supervision requirements when counseling new patients by group GC (55.1 %), although 17.2 % reported needing to have a physician readily available under the same roof and 14.9 % reported that a physician needed to be in the room for part of the visit (Table 4).

Although many genetic counselors reported not billing for their services (41.0 %), 26.9 % of genetic counselors report some form of billing for group GC services (Table 4). An additional 21.8 % reported "other" strategies of billing and 10.3 % did not know if they were billing. When billing for group GC services, the most commonly used code was the 96040 GC code, followed

by consultation codes 99241–99245 or 99251–99255 and evaluation and management codes 99201–99205 or 99211–99215.

Telegenetic Counseling

Overall, genetic counselors in this survey used the telegenetic model least frequently (2.2 % reported using this "often;" none reported using it "always"). Most genetic counselors (88 %) reported never using this model (Table 2).

The third next available appointment for telegenetic counseling ranged between <1 week to over 2 months (Table 3). A wait time of less than 4 weeks was reported by more than two thirds of respondents (68.3 %). The frequency of accessing telegenetic genetic counseling is directly proportional to the patient drive time, with 87.0 % of patients living over 2 h away from the GC location (Table 3). Most genetic counselors reported the ability to see 1–5 new patients per week with telegenetic counseling. Patients access telegenetic counseling most often through a traditional mode of referral and least often through a tandem or triage mode (Table 3).

During the telegenetics appointment, most genetic counselors reported spending an average of 30–60 min (77.0 %) (Table 4). Most genetic counselors reported that a physician was never required to be under the same roof for a telegenetic consultation (59.0 %). Only 11.7 % reported that a physician "always "or "frequently" was required to be under the same roof and 13.3 % reported that the availability of a physician for part of the visit was "always" or "frequently" a limitation in scheduling new patients (Table 4). The most often reported limitations for the telegenetic model were support staff at the remote site (25.8 %) and physical space at both the host (25.0 %) and remote location (24.2 %) (Table 4).

Only 17.5 % of genetic counselors report some form of billing for telegenetic services, while many genetic counselors reported not billing for their services (47.6 %) (Table 4). An additional 22.2 % reported "other" strategies of billing and 12.7 % did not know if they were billing. When billing for telegenetic services, the only codes reported to be used were the 96040 GC code and consultation codes 99241–99245.

General Comparisons

Almost half of genetic counselors surveyed (43.4 %) use more than one SDM. Of those who use one SDM exclusively (54.7 %), 98 % (383/391) use the in-person SDM exclusively and 2 % (8/391) use the telephone SDM exclusively . The longer a genetic counselor has been in the profession, the more likely they are to use more than one SDMs ($p=0.024$), although there was no statistically significant difference for any of the models in years experience and use of each model. Certified genetic counselors are significantly more likely to use multiple SDMs or SDMs other than in-person ($p=0.001$).

Comparison analysis of use of SDMs by specialty and work setting was performed; however sample size for SDMs other than in-person GC limited the ability to assess for significance. Trends in data, however, were noted. Cardiac, cancer and prenatal genetic counselors and those who work in a diagnostic laboratory or an integrated health plan appeared more likely to use multiple SDMs than those who work in a university medical center or private practice setting (Table 2). Genetic counselors working for diagnostic laboratories and integrated health plans reported the highest proportional use of telephone GC.

In-person GC was the most utilized model, and estimated capacity to see new patients per week per full time genetic counselor was also highest in this model, compared to other SDMs ($p<0.0001$) (Table 3). Genetic counselors using telegenetic and telephone SDMs report a significantly longer drive time from patient to GC location compared to those who use in-person or group counseling ($p<0.0001$) (Table 3). Time spent in consultation using the telephone SDM was significantly shorter than reported in other models ($p<0.0001$) (Table 4).

Referral patterns indicate that most GC sessions, regardless of SDM, are initiated by a health care provider using a traditional mode of referral. Self-referral, the second most commonly reported mode, was reported most frequently for group and telephone SDMs (Table 3).

Discussion

As expected, in-person GC is the model used most often by respondents. However, almost half of genetic counselors report using more than one SDM. This suggests that genetic counselors are expanding the way in which they provide services, presumably to improve access and/or efficiency. This will require further study, and genetic counselors who indicated they would be willing to answer more specific questions will be contacted as part of another study to more fully explore their use of SDMs, what led them to use different SDMs and nuances of the models they have chosen.

The overall frequency of genetic counselors reporting use of telegenetics is low, likely due to the fact that the technology is fairly new, and equipment may be expensive or inaccessible. Interestingly, genetic counselors working for government agencies and diagnostic laboratories reported the greatest use of telegenetic counseling. Further investigation is needed to confirm and explore why this less traditional model is selected more often within these settings.

Past literature describes long wait times to access genetic services (McPherson et al. 2008). Wham et al. report that 46 % of cancer genetic counselors surveyed had a wait time of 3 weeks or longer (Wham et al. 2010). In contrast, this survey found that 57 % of cancer genetic counselors who provide in-person genetic counseling reported a wait time of

less than 2 weeks (Table 3). This is a vast improvement over past reports, and may reflect a trend of improved access. The study was not able to ascertain why these wait times are less than previous studies reported, and it may be worthwhile to investigate what components of service delivery contributed to these improvements. With regard to in-person genetic counseling in our data set, prenatal genetic counselors reported the shortest wait time, with 95 % reporting that their 3rd next available appointment is in less than 2 weeks (Table 3). Similar to cancer genetic counselors, 43 %–59 % of general, cardiac and other specialty genetic counselors reported their 3rd next available appointment within 2 weeks (Table 3). In contrast, pediatric genetic counselors reported the longest wait time with 46 % reporting a wait time over 2 months. Given that pediatric genetic counselors are the specialty most often working in collaboration with board certified geneticists, a limited resource, these extended wait times are not surprising. This study demonstrates adaptations across other specialties that can inform efforts to improve wait times in the pediatric genetic counseling specialty.

The number of patients seen per week was the highest among genetic counselors providing in-person GC. Since the time spent per patient was reported as the shortest with telephone GC, this is somewhat surprising. Participants were asked to estimate the number of patients one full time genetic counselor could see per week by each model. It is possible that respondents may have been misinterpreted this question to mean "how many DO you see" versus "how many CAN you see". Additionally, there may be an inability for genetic counselors to estimate how many patients could be seen with one particular model, since they were often using more than one different model in practice. These comparisons included a "not sure" response, which was "0" among genetic counselors providing in-person genetic counseling, but 43.7 % among genetic counselors who provided telephone genetic counseling. This suggests that genetic counselors have difficult estimating a model that they perhaps don't use as often. Limiting analysis to just the 12 genetic counselors who reported using telephone counseling "always", none were unable to estimate number of patients that could be seen per week, suggesting that experience allows for a better estimate. Of these, 27.3 % reported being able to see 11–15 patients per week, and 18.2 % reported being able to see >30, 21–30, 16–20 and 6–10 patients each. Although these numbers are small, they do suggest that telephone counseling may be able to reach a larger number of patients and that a targeted survey of genetic counselors using this model solely may provide further data.

The time spent in a genetic counseling session reported in this survey was also substantially less than reported in past publications. Most genetic counselors using in-person GC reported spending 31–60 min in consultation. In this survey, 58.2 % of cancer genetic counselors reported spending less than or equal to 60 min in consultation, compared to 46.3 % of cancer genetic counselors who reported spending less than or equal to 60 min in 2008 (Wham et al. 2010). Therefore, in just 2 years, there appears to be a trend toward shorter in-person consultations, possibly an indication of a step toward greater efficiency. It is important to note that the type and complexity of a genetic counseling visit likely has implications to the time spent in a genetic counseling session. This survey specified that responses should reflect new-patient visits only, however complexity can vary dependent upon diagnosis. While the ability to assess visit complexity was not within the scope of this study, the planned follow-up study utilizing interviews of willing respondents may allow for further analysis.

The telegenetic and telephone SDMs appear to fill a need for improved access for patients who live far away from a genetics provider, as the drive times from patient to GC site are significantly longer for genetic counselors who use either of these models. The telegenetics model users reported a longer average wait time for scheduling than for the other models, possibly due to the reported limitations of physical space and support staff. Specifics on equipment used for telegenetics services was not collected, and may contribute to this difference in wait times and issues with the physical space limitations.

It was interesting to note that most patients accessing group genetic counseling had less than a 30-min drive. Although the numbers are small, this suggests that group genetic counseling is not used to improve distance access, but may be used in an attempt to improve efficiency and shorten consultation time, as previously documented (Calzone et al. 2005).

Continued efforts to improve billing for the reimbursement for services provided by genetic counselors are critical to the sustainability of any service delivery model. Respondents using in-person GC were most likely to bill. For those genetic counselors who did report billing for services, most reported billing for physician time only. This may reflect institution-specific billing structures and may dictate, in some cases, the involvement of a physician in the consultation. Over 2/3 of those using telephone GC, and almost half of those using group or telegenetic counseling reported not billing for this service. These models were most often in use in laboratories, integrated health plans and government agencies. It may be that these institutions calculate downstream costs to fund these services, or that the genetic counseling service is part of a grant, or contracted service price; however this is speculative, as this data was not obtained within the scope of this study.

Individual members of the NSGC were asked to respond on their personal use of the four currently defined service delivery models; in-person, group, telephone and telegenetic

counseling. Participants were not selected by state, location or institution. It is possible that this may have resulted in multiple respondents from the same center or institution. While this may have resulted in similar responses to the survey questions, it is felt that isolating respondents to only one or two genetic counselors per center would not allow for proper representation of use as even within individual centers, the choices and use of a service delivery model can vary between specialty clinics. Additionally, opening up the survey to the entire membership resulted in a better representative sampling of the population of currently practicing genetic counselors.

Data regarding use of telephone GC should be interpreted cautiously. Again, it became clear upon review of the comment section at the end of the survey that some participants had interpreted the definition of telephone GC to include results disclosure following an in-person visit, contrary to the definition provided in the survey. Although we did remove 12 individuals from the analysis who specifically mentioned using telephone GC only for providing results, it is possible that others interpreted this incorrectly but did not comment. This particular confusion stresses the need for clear definition and language when discussing SDM, which has been attempted in a prior publication from this group (Cohen et al. 2012). We suspect that the use of telephone GC as a primary SDM may be lower than reported here, however recent literature is demonstrating increased use and acceptance of telephone genetic counseling (Bradbury et al. 2011; Doughty Rice et al. 2010; Graves et al. 2010; Shanley et al. 2007; Sutphen et al. 2010).

Conclusions

These data demonstrate that many genetic counselors are incorporating models other than traditional in-person GC and that these newer models are reaching patients who live at greater distances from GC locations and are associated with shorter wait times, improving the efficiency of genetic counseling services. Each practice setting and specialty will likely have unique needs, thus the determination of which SDM(s) best fit a given organization or practice may vary. Additionally, the ability to sustain any of these models will be dependent on improved billing and reimbursement for these services. Approximately half (50 %) of respondents using each of the models were not billing or were unsure of how they were billing. This trend has been recognized in previous study (Harrison et al. 2010) and has led to multiple NSGC initiatives to increase genetic counselor education and awareness of billing issues. This data affirms the need for these programs as well as ongoing local and national initiatives to improve professional recognition and reimbursement for GC services.

This study provides an overview of the SDMs currently used by genetic counselors to deliver GC services and provides insight into how they impact access. These data provide the foundation for further exploring the nuances of each SDM considered when adopting a model for use and the components that allow for improved access, increased efficiency, and sustainability. More analysis is necessary to identify individual best practices, limitations, barriers and benefits of each model. Furthermore, as the landscape of genetic counseling service delivery evolves, additional research is needed to assure that all SDMs provide similar quality of care and patient outcomes.

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