J Genet Counsel (2014) 23:239–253
DOI 10.1007/s10897-013-9655-6

ORIGINAL PAPER

Models of Service Delivery for Cancer Genetic Risk Assessment and Counseling

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Received: 20 May 2013 / Accepted: 30 August 2013 / Published online: 26 October 2013

Abstract Increasing awareness of and the potentially concomitant increasing demand for cancer genetic services is driving the need to explore more efficient models of service delivery. The aims of this study were to determine which service delivery models are most commonly used by genetic counselors, assess how often they are used, compare the efficiency of each model as well as impact on access to services, and investigate the perceived benefits and barriers of each. Full members of the NSGC Familial Cancer Special Interest Group who subscribe to its listserv were invited to participate in a web-based survey. Eligible respondents were asked which of ten defined service delivery models they use and specific questions related to aspects of model use. One-hundred ninety-two of the approximately 450 members of the listserv responded (42.7 %); 177 (92.2 %) had provided clinical service in the last year and were eligible to complete all sections of the survey. The four direct care models most commonly used were the (traditional) face-to-face pre- and post-test model (92.2 %), the face-to-face pretest without face-to-face post-test model (86.5 %), the post-test counseling only for complex results model (36.2 %), and the post test counseling for all results model (18.3 %). Those using the face-to-face pretest only, post-test all, and post-test complex models reported seeing more new patients than when they used the traditional model and these differences were statistically significantly. There were no significant differences in appointment wait times or distances traveled by patients when comparing use of the traditional model to the other three models. Respondents recognize that a benefit of using alternative service delivery models is increased access to services; however, some are concerned that this may affect quality of care.

Keywords Genetic counseling · Service delivery models · Alternative service delivery · Access to services

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Genetic counseling services for cancer predisposition syndromes arose out of the research setting, when families were seen in the context of protocols attempting to identify genes predisposing to hereditary cancer syndromes. In this setting, individuals participating in the research were often initially seen by genetic counselors, research coordinators, and physicians so that appropriate informed consent could be provided before family pedigrees and blood samples were obtained to facilitate genetic research (Eeles et al. 2007). Eventually, the availability of clinical testing for the *BRCA1*, *BRCA2*, and other genes led to the development of clinical risk assessment, counseling and testing service delivery models in a number of academic medical centers. These early programs typically utilized a multidisciplinary team of professionals which included medical geneticists, genetic counselors, and oncology nurses, as well as medical and surgical oncologists (Hoskins et al. 1995). While provision of these services was based on the tenets of traditional pediatric and prenatal genetic counseling services (informed consent, facilitated decision-making, and ensuring confidentiality), the actual approach to delivering the service was more consistent with early Huntington disease genetic counseling and testing protocols (Biesecker et al. 1993; International Huntington Association and the World Federation of Neurology Research Group on Huntington's Chorea 1994; Wham et al. 2010). The Huntington disease genetic testing protocol required a pre-test in person visit, a

second visit for sample collection, and at minimum, at least one more in-person visit for result disclosure.

Thus, early genetic counseling for hereditary predisposition to cancer typically included a face-to-face (in person) counseling session prior to having blood drawn for genetic testing followed by at least one or more in person post-test counseling sessions. In fact, the National Society of Genetic Counselors (NSGC), as well as other professional organizations, described this model as the standard for genetic cancer risk assessment and counseling (American College of Medical Genetics 1999; Berliner and Fay 2007; Trepanier et al. 2004). As such, most genetic counselors have been trained in this two visit model. The rationale for the two visit service delivery approach was that face-to-face pre-test counseling allowed for a controlled situation in which all the elements of informed consent could be reviewed prior to drawing blood for genetic testing. During pre-test counseling visits, genetic professionals could collect relevant family history information; perform a risk assessment; and facilitate discussions about the potential underlying genetic cause for the cancer in the family, whether genetic testing was indicated, who should be tested, accuracy of testing, possible testing outcomes, how test results could affect medical management, and ethical, legal, and social issues. In addition, the face-to-face post-result disclosure optimized the opportunity to discuss and review the accuracy and significance of results, explore the impact of results on the client and their family, and allow for conveyance of medical management recommendations.

As cancer susceptibility gene testing moved out of the research arena and became clinically available, the provision of cancer genetic services expanded beyond academic medical centers into community hospitals and other oncology services. According to the National Society of Genetic Counselors 2010 Professional Status Survey ($NSGC_a$ 2010), while 38 % of genetic counselors who identified cancer genetic services as their primary specialty worked in a University-based medical center, an increasing number reported their primary work setting was a private physician practice, private medical facility, or public medical facility. Additionally, advances in gene identification and genetic testing methods, development of healthcare provider position statements and evidence-based reports, and the advent of direct-to-consumer marketing campaigns have increased demand for cancer genetics services. In one center, cancer referrals contributed to less than 10 % of the overall genetics referrals in 1994 but increased to greater than 50 % in 2004 (Iredale et al. 2007).

Data obtained from one large managed care organization revealed that referrals for cancer genetic services during a direct-to-consumer advertising campaign by Myriad Genetics, Inc., the laboratory in the United States that until recently was the exclusive provider of *BRCA1* and *BRCA2* genetic testing, increased more than 240 %, with referrals being highest toward the beginning of the advertising campaign (Mouchawar et al. 2005). In addition, a study done in 2009 by Bellcross and colleagues, illustrated that genetic testing services for hereditary cancer has moved outside the purview of genetic professionals, finding that among 1250 primary care physicians who provided services for adults, greater than 30 % had ordered at least one genetic test for hereditary breast and ovarian cancer (Bellcross et al. 2011). Other studies also document the growing trend of non-genetic providers ordering genetic testing (Prochniak et al. 2012; Sifri et al. 2003; Wideroff et al. 2003).

It is predicted that demand for genetic testing services will continue to increase and this has led to growing concern that the traditional in-person two visit model adopted as a standard for cancer genetic testing services may ultimately limit or delay patient access to care (Allain et al. 2010; Cohen et al. 2012). One recent study which surveyed members of the National Society of Genetic Counselors Familial Cancer Special Interest Group found that the majority of respondents estimated they were spending 46–60 min with a patient during pre-test counseling and approximately 30.6 % were spending 60–75 min (Wham et al. 2010). In the same study, approximately 59.3 % of genetic counselors stated that they only disclose results during an in-person follow-up visit; spending approximately 31–60 min with the client if the test result was positive and about 16–30 min if the test result was negative. Respondents then estimated that using the traditional model, they were providing services to approximately six clients per week adjusted for amount of full time equivalents spent on clinical work. The limited numbers of patients served and the time intensiveness involved supports the growing concern that the current practice model for the delivery of cancer may be a rate limiting step in the ability to access to cancer genetic services. Indeed, the Institute of Medicine (IOM) Roundtable on Translating Genomic-Based Research into Health convened a workshop on "Innovations in Service Delivery in the Age of Genomic Medicine" in recognition of the need for new genetics practice models to meet the demand created by the growing availability and applications of genomic technology (IOM 2009).

The concern is that growing demand, in the absence of more efficient service delivery and/or a larger, more geographically diverse workforce, may limit access to genetic counseling services. The Healthy People 2020 initiative defines access as the ability of a patient to obtain health services in a timely manner that allows the patient to achieve the best health outcomes. Access requires that the patient is able to: 1) gain entry to the healthcare system, 2) gain entry to a location where the needed services are provided, and 3) identify a healthcare provider with whom he can communicate and develop a trusting relationship. There are four factors that affect access: health insurance coverage, having an ongoing source of care, having timely access to services, and having a sufficient workforce. Inadequate access can affect a number of outcomes

including overall health, disease prevention, quality of life, and life expectancy U.S. Department of Health and Human Services (HHS), Healthy People 2020 (2011).

To what extent each of the factors mentioned above affects access to cancer genetic counseling services is largely unknown. Beene-Harris et al. (2007) conducted focus groups with consumers and professionals to identify barriers to accessing genetics services. Participants identified lack of workforce, cost and insurance, and distance from services as institutional (healthcare system) barriers as well as healthcare providers' lack of awareness of genetic services and coordination of care/referral (Beene-Harris et al. 2007). Rolnick et al. (2011) surveyed genetic counselors to identify what they perceived as barriers to the identification and referral of patients for cancer genetic risk assessment services. Perceived barriers related to access included distance to appointments and lack of insurance (Rolnick et al. 2011). Cohen et al. (2013) recently evaluated three measures of access in genetic counseling: appointment wait times, drive time traveled for most or all patients, and number of new patients that could be seen per week for various service delivery models. For the majority of respondents providing in-person cancer genetics services, wait time for the third next available appointment was less than 4 weeks. For all in-person genetic counseling services (not cancer-specific), respondents most frequently reported being able to see 6–10 new patients per week (32.9 %) per full time genetic counselor, and that drive time traveled was <30 min (49.2 %) (Cohen et al. 2013). Whether the above-reported patient volumes, appointment wait times, and distance variables are sufficient in providing adequate access to genetic counseling services is unknown.

Many genetic service providers have already begun to proactively explore and evaluate alternative service delivery models for enhancing access. Outside of the traditional, face-to-face model, the other most commonly described service delivery models for cancer genetic services are telephone and group counseling models (Baumanis et al. 2009; Calzone et al. 2005; Chen et al. 2002; Jenkins et al. 2007; Peshkin et al. 2008; Ridge et al. 2009; Rothwell et al. 2012; Shanley et al. 2007). Telemedicine and web-based approaches have also been described as methods for improving access, especially for rural populations (Hilgart et al. 2012a, b; IOM 2009).

With regard to telephone counseling, a survey of the National Society of Genetic Counselors (NSGC) Familial Cancer Risk Counseling Special Interest Group members found that 92.5 % of those who responded ($n=107$) had provided *BRCA1* and *BRCA2* genetic test results by telephone (Baumanis et al. 2009). However, the subset of counselors ($n=99$) who had delivered results by phone in the prior 12 months stated that only 25 % or fewer of their clients received results in this manner. This study also used a survey to assess patient satisfaction with the delivery of *BRCA1* and *BRCA2* test results and found no significant difference in satisfaction between individuals who received results in person versus by telephone. However, it was noted that those who received results by telephone were more likely to have negative genetic test results. An earlier study surveying over 600 subjects who had undergone genetic testing, found that approximately 40 % had received results by telephone and were more likely to have negative genetic test results (Chen et al. 2002). Again, satisfaction did not differ among the cohort of patients receiving results by telephone when compared to those patients who received results in person. Factors that were not assessed by these studies include why telephone counseling was implemented, what the advantages to this delivery method were, and what barriers exist to the utilization of this service delivery model.

Satisfaction and effectiveness of group genetic counseling has also been evaluated in several studies. In 2005, Calzone et al. randomly assigned 142 individuals at risk for having *BRCA1* or *BRCA2* mutations to either a group or individual pre-test education/counseling session (Calzone et al. 2005). Knowledge and Impact of Event Scales (IES) were administered at baseline, and several other time points, and satisfaction with the education and counseling process was measured at the completion of the initial session. No differences in knowledge, IES scores, or satisfaction were found between the two groups. Another study found that when given the option to attend a group genetic counseling session, 40 % of clients declined, citing concerns about the group setting and need for personalized counseling (Ridge et al. 2009). Among those who elected to undergo group counseling there were no significant differences in satisfaction when compared to those who had individual counseling. A more recent study assessing the feasibility and acceptability of group counseling for HBOC also concluded that when given the option, most clients preferred individual counseling, but among those who elected to undergo group counseling there were no differences in outcomes on psychological sequelae or satisfaction (Rothwell et al. 2012). Ridge and colleagues were the only ones who addressed efficiency of the model, finding that with the group counseling model they could serve 4 patients in a group counseling session in the same amount of time required for one in-person individual counseling session (Ridge et al. 2009).

There are other cancer genetic service models utilized by genetic counselors described in the literature (Allain et al. 2010; Cohen et al. 2009). These include service delivery models described as modified traditional counseling, post-test results only counseling, complex-case pre-test counseling, collaborative counseling, consultant model, and the public health model. However, the efficacy of these models and satisfaction among patients utilizing these models has not been well studied. There is also significant overlap and varying interpretations about these different service delivery models leading to confusion when attempting to define and assess the impact of these models on provision of care. In fact,

the National Society of Genetic Counselors Service Delivery Model Task Force (SMDTF), charged with researching and assessing the capacity of all existing service delivery models, recently proposed definitions for models, modes of referral and components of service delivery in order to begin standardizing discussions of models (Cohen et al. 2012).

Purpose of the Study

The objectives of this exploratory study were to assess what types of service delivery models cancer genetic counselors are using, to characterize how they are used, and to determine perceived barriers and benefits of their use. Specifically, the aims were 1) to determine which of ten defined service delivery models cancer genetic counselors are using and to potentially identify novel service delivery models, 2) to assess what proportion of the genetic counselors' clinical time is spent using each model, 3) to compare and contrast the efficiency of each model and 4) to identify the perceived benefits and barriers of using each model. Of note, this study was designed and implemented prior to the publication of the NSGC's Service Delivery Model Task Force's proposed definitions of service delivery models (Cohen et al. 2012). As such, the definitions used in this study differ to some extent from those proposed. The implications of this will be reviewed in the discussion.

Methods

Participants

All members of the National Society of Genetic Counselors' (NSGC) Familial Cancer Risk Counseling Special Interest Group (Cancer SIG) who were subscribers of the group's listserv from July-August 2010 were invited to take part in this study. The Cancer SIG members are those who have self-identified as providing and/or being interested in cancer genetic risk assessment and counseling. There were 612 Cancer SIG members by the close of the year in 2010; an estimated 450 were listserv subscribers at the time the survey was conducted (74 % of the 2010 membership). All Cancer SIG members were eligible; however, only those who had provided clinical care in the last year were approached to complete the full survey. Those not providing clinical service just completed the demographic portion.

Instrumentation

A novel survey instrument was developed by the investigators with significant input from Stephanie Cohen, Chair of the NSGC's Service Delivery Model Task Force. The final instrument contained 13 sections with a total of 121 questions. The first section included questions about demographic variables, modeled after those included in the National Society of Genetic Counselors 2010 Professional Status Survey and Cancer Professional Status Survey ($NSGC_a$ 2010; $NSGC_b$ 2010) so that comparisons could be made between our study participants and the larger cancer genetic counselor population. In addition to standard questions about age, gender, race/ethnicity, work setting, and region of employment, the demographic section included questions on country of practice, licensure status, credentialing status, years of experience as a genetic counselor, and years of experience as a cancer genetic counselor. These additional variables were included because we wanted to investigate any were associated with model use. The last question in the demographic section asked participants to indicate whether they had provided clinical cancer genetics service (patient care) in the last year. Those who answered "no" to this question were directed to the last page of the survey which explained that they were only eligible to take part in the demographic portion and as such, their participation was complete.

The second section of the survey listed and described ten service delivery models (Table 1). The list of models was generated based on 1 ½day discussion on service delivery that took place between nine genetic counselors (including the two authors) from various practice settings and five genetic counselors in leadership positions at Myriad Genetics Laboratories (Allain et al. 2010). A review of the medical literature was also conducted to identify additional service delivery models and to help develop clear definitions of each model (Baumanis et al. 2009; Calzone et al. 2005; Chen et al. 2002; Cohen et al. 2009; IOM 2009; Jenkins et al. 2007; Peshkin et al. 2008; Ridge et al. 2009; Rothwell et al. 2012; Shanley et al. 2007; Wham et al. 2010). Participants were asked to indicate which of these models they use and what proportion of their patient care time (0–100 %) they spend using each one. Participants were also invited to write in up to two additional models that they use or are aware that others are using.

Sections three through twelve asked detailed, multiple choice-type questions about factors associated with the individual service delivery models. We modeled some of the detailed questions after those used in other surveys such as that conducted by Wham et al. (2010) and the NSGC 2010 Professional Status Survey: Cancer Genetics ($NSGC_b$ 2010). The first question in each of these ten sections asked participants whether they use the particular model. Those who responded "no" were directed to the next section. As a result, only a subset of participants completed each individual section. One purpose of the detailed questions in these sections was to determine how efficient each model is in terms of the following categorical measures: time spent in genetic counseling sessions (1–15 min, 16–30, 31–60, 61–90, >90 min); number of

Table 1 Defined service delivery models

Traditional face-to-face pre-test and post-test counseling (Traditional)
Face-to-face pre-test without face-to-face post-test counseling (Face-to-face Pre-test Only)
Telephonic pre-test with or without post-test counseling (Telephonic)
Videoconferencing/telemedicine pre-test with or without post-test counseling (Video)
Post-test counseling only- all: Clients are referred to genetic counselor after genetic testing for all/most test results. Pre-test counseling provided by other health care provider (Post-test All)
Post-test counseling- complex: Clients are referred to genetic counselor after genetic testing for complex cases only. Routine results managed by ordering provider (Post-test Complex)
Consultant model: Genetic counselor helps individual provider with risk assessment, provider provides genetic counseling/direct patient care for most cases (Consultant)
Collaborative model: Genetic counselor helps health care provider with risk assessment, provider manages low risk cases and refers high/moderate risk to genetic counselor (Collaborative)
Group genetic counseling: Genetic counselor provides counseling to groups of clients with or without follow up individual sessions (Group)
Public health model: Counselor educates a community of providers (within a practice, hospital, etc.) through group education with expectation they will manage routine and refer complex cases (Public Health)

new clients served per week(1–4, 5–7, 8–10, 11–13, 14–16, 17–19, 20–22, >22); and number of return clients served per week. Another purpose was to collect information related to how accessible services are based on the following measures: average distance clients travel (<10 miles, 10–25 miles, 25–50 miles, 50–100 miles, >100 miles) and third next available appointment, a standard measure of appointment availability (<2 weeks, 2–4 weeks, 4–6 weeks, 6–8 weeks, 2–3 months, 3–6 months, >6 months). Participants were also asked to indicate the greatest benefit of each model they used and the greatest barrier to utilizing it. The last section of the survey included one open-ended question that gave participants an opportunity to comment on the survey or to provide more information about their answers.

A draft of the survey was piloted with several members of the NSGC Cancer SIG and the NSGC's Service Delivery Model Task Force. The feedback obtained was incorporated and a final version of the survey was developed.

Procedures

An invitation to take part in a research study with a link to a web-based survey (SurveyMonkey©) was posted to the NSGC Cancer SIG listserv in July 2010. The email message explained that listserv members were being asked to take part in a research study that involves evaluating which service delivery models are commonly employed in providing cancer genetic risk assessment and counseling services and the perceived benefits, limits, and barriers of these models. Those who chose to access the survey link were instructed to read an informed consent information sheet. Those who chose to participate by selecting "yes" after reading the information sheet were directed to the survey. Those who choose "no" were directed to the end of the survey. Two weeks after the initial email invitation to participate was posted, a reminder email was sent. The survey was open for a total of 4 weeks. The study was approved by the institutional review boards at Wayne State University and The Ohio State University.

Data Analysis

Descriptive and inferential statistics were generated using IBM SPSS Statistics Version 19 (2010). Frequencies were generated for demographic variables, overall model use, and proportion of time spent using each model as well as for model-specific characteristics, benefits, and barriers of the most commonly used models. Fisher's exact test was used to determine if years employed as a cancer genetic counselor, credentialing status, or licensure status were associated with model use. Wilcoxon signed rank tests were used to assess differences in efficiency (time spent in sessions and number of clients served) between the traditional (face-to-face pre- and post-test) model and the other most commonly used models. The chi-square goodness of fit test was used to assess differences between the traditional model and other commonly used models in terms of the dichotomous variables of distance traveled and third next available appointment. Because we conducted multiple univariate analyses, only alpha values ≤ 0.0019 (Bonferroni correction) were considered significant.

Results

Out of an estimated 450 subscribers to the NSGC Cancer SIG listserv there were 192 responses for an estimated overall response rate of 42.7 %. This represents approximately one-third (192/612; 31.3 %) of the 2010 Cancer SIG membership. Nine of 186 respondents (4.8 %) indicated that they had not seen patients in the last calendar year and as such were only eligible to complete the demographic portion of the survey.

The remaining 177 respondents were eligible to complete the rest of the survey. This represents an estimated 39.3 % of those originally invited to take part.

Demographic Profile

The sample was primarily female (94.1 %), less than 40 years old (68.8 %, 128/186), had been employed as a genetic counselor for less than 10 years (60.3 %, 111/184), and as a cancer genetic counselor for less than 10 years (73.9 %, 136/184). Most worked for either a university medical center, a private hospital/medical center, or a public hospital (90.3 %. 167/185). About one third (32.8 %) were credentialed by their institution, and about one fifth (20.8 %) were licensed. Additional details about the study population are reviewed in Table 2.

The demographic profile of this study population was compared to that of respondents of the National Society of Genetic Counselor's 2010 Professional Status Survey- Cancer Genetics (NSGC$_b$ 2010), using the difference in proportions test. There were no statistically significant differences between the samples with regard to gender or the most common work settings. However, those who responded to this study were older (31.2 % versus 19.3 % were over 40 years old) and likewise, had been employed longer as genetic counselors (39.7 % versus 18.9 % had more than 10 years experience) than the PSS-Cancer respondents (95 % confidence level).

Use of Identified Models

The percentage of respondents using each model and the proportion of their clinical time spent using them is reported in Table 3. For a review of the definitions of each model, see Table 1. The two most commonly used models were the traditional model and face-to-face pretest only model, used by 92.2 % and 86.5 % of respondents, respectively. When asked what proportion of their clinical time was spent using these models, 51.9 % (81/156) of those using the traditional model and 48.6 % (72/148) of those using the face-to-face pretest only model indicated that they used them ≥50 % of the time. However, a sizable proportion used these models only 5–10 % of the time (26.9 % and 29.7 %, respectively) and a small proportion never used the traditional model (7.8 %). The post-test counseling for complex test results model was the third most commonly used model (36.2 %); post-test counseling for all results was used less often (18.3 %) and was the fifth most common model. However, most of those who used either of the post-test models only used them 5–10 % of the time, and no one reported using either model more than 50 % of the time. The collaborative model, which is not a direct patient care model, overall was the fourth most used model (22.4 %). As with the post-test models, most used it only 5–10 % of the time. The remaining five models were only used by a small proportion of respondents.

Table 2 Repondents' demographic profile (N=186)

	Percent	*n*
Gender (*n=186*)		
Female	94.1	175
Male	5.9	11
Age (years) (*n=186*)		
20–24	1.6	3
25–29	25.3	47
30–34	26.9	50
35–39	15.1	28
40–44	9.1	17
45–49	7.0	13
50–54	5.9	11
55–59	6.5	12
60+	2.7	5
Years employed as a genetic counselor (*n=184*)		
1–4 years	28.3	52
5–9 years	32.1	59
10–14 years	19.6	36
15–19 years	9.2	17
20+ years	10.1	20
Years employed as a cancer genetic counselor (*n=184*)		
1–4 years	43.5	80
5–9 years	30.4	56
10–14 years	18.5	34
15–19 years	4.3	8
20+ years	3.3	6
Work setting (*n=185*)		
University Medical Center	38.9	72
Private Hospital/Medical Center	29.7	55
Public Hospital/Facility	21.6	40
Diagnostic Laboratory	1.6	3
Health Maintenance Organization	1.1	2
Not for Profit, not otherwise specified	3.2	6
University Non-Medical Center	2.2	4
Federal/State/County Office	0.5	1
Private Practice	1.1	2

Fisher's exact test was used to determine if there were any associations between years employed as a cancer genetic counselor (<10 years or >10 years), credentialing status or licensure status and model use. There was no association between years as a cancer genetic counselor and use of the post-test complex, post-test all, or the collaborative model. No conclusions could be drawn regarding the remaining models because of insufficient sample size or insufficient diversity of responses within the sample. Credentialing status was not associated with use of the face-to-face pretest only, post-test counseling, collaborative, telephonic or public health models. With regard

Table 3 Used of defined service delivery models

Model	Use model		Proportion of clinical time spent using the model		
	Percent	*n*	Proportion of time (%)	Frequency selected (%)	*n*
Traditional	92.2	153/166	None	2.6	4/156
			5–10 %	26.9	42/156
			20–40 %	18.6	29/156
			50–70 %	14.1	22/156
			80–100 %	37.8	59/156
Face-to-face pre-test only	86.5	134/155	None	8.1	12/148
			5–10 %	29.7	44/148
			20–40 %	13.5	20/148
			50–70 %	16.2	24/148
			80–100 %	32.4	48/148
Post-test complex	36.2	51/141	None	53.6	59/110
			5–10 %	44.5	49/110
			20–40 %	1.8	2/110
Collaborative	22.4	32/143	None	73.0	81/111
			5–10 %	24.3	27/111
			20–40 %	0.9	1/111
			50–70 %	1.8	2/111
Post-test all	18.3	26/142	None	73.6	78/106
			5–10 %	23.6	25/106
			20–40 %	2.8	3/106
Public health	12.3	17/138	None	83.2	89/107
			5–10 %	16.8	18/107
Video	10.6	15/141	None	87.6	92/105
			5–10 %	9.5	10/105
			20–40 %	2.9	3/105
			50–70 %	–	–
			80–100 %	–	–
Telephonic	10.1	14/139	None	85.8	91/106
			5–10 %	8.5	9/106
			20–40 %	3.8	4/106
			50–70 %	1.9	2/106
			80–100 %	–	–
Group	7.9	11/139	None	89.5	94/105
			5–10 %	8.6	9/105
			20–40 %	1.9	2/105
Consultant	3.6	5/138	None	93.1	95/102
			5–10 %	4.9	5/102
			20–40 %	–	–
			50–70 %	1.0	1/102
			80–100 %	1.0	1/102

to credentialing status and the videoconferencing model, 21.6 % (11/51) of those credentialed used this model in comparison to 4.5 % (4/88) of those not credentialed; this finding approached but did not meet statistical significance (Fisher's exact test, 2-sided, $p<0.003$). Comparisons could not be made with the traditional, consultant or group models. There was no association between licensure status and use of either post-test counseling model or the collaborative model. Comparisons could not be made with the remainder of the models.

Clarification of Model Use and Newly Identified Models

Twenty-one respondents wrote in a total of 22 responses that either clarified how or why a specific model was used or described other service delivery models. Seven respondents clarified how they use the traditional model versus the face-to-face pre-test without face-to-face post test model (face-to-face pre-test only) with regard to results disclosure. Three indicated they only disclose negative results by telephone, whereas two others mentioned that all results are given by telephone. Another respondent indicated s/he used either face-to-face or telephonic post-test counseling, but did not mention how this decision was reached. One respondent clarified that when s/he does not see a client for face-to-face post-test counseling, the counseling is provided by telephone. Five respondents also described variations of the traditional model in terms of who provides pre- and post-test counseling (genetic counselor alone, with physician, physician alone). With regard to other models, three respondents indicated that they used the post-test only counseling models not by design but at the behest of the ordering health care provider. Two respondents clarified how they used the telephonic service delivery model. One provides telephonic genetic counseling only for those who do not meet criteria for genetic testing. The second provides telephonic risk assessment but does not offer genetic testing. One respondent commented on her use of group counseling clarifying that it is limited to counseling groups of family members.

Four new models of service delivery were identified through the write-in responses. One respondent described a genetic counselor physician partnership model. In this model, the genetic counselor provides risk assessment and genetic counseling. The counselor then works with the client's physician/other health care provider to help coordinate testing. The physician/health care provider orders the test and provides post-test counseling which includes management. A second respondent described a quick triage model. In this model, the genetic counselor performs risk assessments in a high risk clinic in 15 min or less and then triages those at increased risk for additional services. A third respondent described a multidisciplinary model where a genetic counselor works with a gynecologic oncologist and breast surgeon to evaluate and counsel patients as a team. A fourth respondent identified an underserved population mixed model. The genetic counselor conducts in person pre-test sessions alone for underserved clients. Then, post-test counseling is provided by the genetic counselor in person at an offsite clinic in conjunction with a physician via videoconference.

Model Use and Efficiency

Table 4 shows two elements of efficiency- the time spent in pre-test and post-test genetic counseling sessions (when applicable) and the estimated number of clients that could be seen in a 40 h work week- across four of the five most commonly used models. Those using the traditional model most commonly reported spending between 61 and 90 min in a pre-test session (48.3 %). In comparison, those using the pre-test only model most commonly reported spending 31–60 min (55.0 %). However, the overall difference in time spent was not statistically significant. With regard to time spent in post-test counseling, those using the traditional model most commonly reported spending 16–30 min in the post test session (64.5 %). In contrast, the most frequently selected response for those using the face-to-face pre-test only model was <15 min (82.3 %). Only 4.6 % of those using the pre-test face-to-face only model indicated that they spent no time doing post-test counseling. For both the post-test all and post-test complex models, the most frequently selected response was 31–60 min (50.0 % and 54.4 %, respectively). The differences between time spent in post-test sessions for the face-to-face pre-test only, post-test all, and post-test complex were compared to that of the traditional model using Wilcoxon signed ranks test. Those using the face-to-face pre-test only model spent significantly less time in post-test sessions than those using the traditional model ($Z=-8.488$, $p=0.000$). Those using the post-test all and post-test complex models spent significantly more time in post-test sessions ($Z=-4.326$, $p=0.000$; $Z=-4.985$, $p=0.000$, respectively).

In terms of the number of new patients that could be served in a 40 h week, those using the face-to-face pretest only, post-test all and post-test complex models reported being able to see more patients than those using the traditional model and this difference was statistically significant ($Z=-5.101$, $p=0.000$; $Z=-3.736$, $p=0.000$; $Z=-3.172$, $p<0.0015$, respectively). Only 39.0 % (57/146) of those using the traditional model reported being able to see eight or more new patients per week, in comparison to 62.0 % (75/121), 81.5 % (22/27), and 68.4 % (26/38) of those using the face-to-face pre-test only, post-test all and post-test complex models, respectively. With regard to the number of return patients that could be seen in a 40 h week, those using the face-to-face pretest only model reported being able to see more returns than those using the traditional model, and this difference was significance ($Z=-5.670$, $p=0.000$). Only 18.0 % (25/139) of those using the traditional model were able to see eight or more return patients in a week in comparison to 40.2 % (45/112) of those using the face-to-face pretest only model.

The collaborative model, which was the fourth most commonly used model, could not be compared to the others because it is a triage model rather than a direct care one. Those who described their use of the collaborative model ($n=29$) estimated that in a 40 h week they could triage a range of 1–5 cases to 71–80 cases. The most frequent response to this question, however, was "cannot estimate" (39.3 %, 11/28 respondents). When asked how quickly a case could be triaged once submitted for review, most selected the response, "within 24 h" (75.0 %, 21/28 respondents). When asked what service delivery model they used for those clients at moderate or high risk, 48.3 %% (14/29) indicated that they use the traditional model, 34.5 % (10/29) use

Table 4 Service delivery model specific characteristics

	Traditional	Face-to-face pre-test only	Post-test all	Post-test complex
Time spent in pre-test sessions -% (*n*)	*n=149*	*n=129*	*N/A*	N/A
<15 min	–	–		
16–30 min	1.3 (2)	0.8 (1)		
31–60 min	46.3 (69)	55.0 (71)		
61–90 min	48.3 (72)	41.1 (53)		
>90 min	4.0 (6)	3.1 (4)		
Time spent in post-test sessions -% (*n*)	*n=138*	*n=130*[a]	*n=27*	*n=44*
No time/no post test	–	4.6 (6)	N/A	N/A
< 15 min	9.4 (13)	82.3 (107)	–	–
16–30 min	64.5 (89)	13.1 (17)	11.1 (3)	4.5 (2)
31–60 min	23.9 (33)	–	51.9 (14)	54.5 (24)
61–90 min	2.2 (3)	–	33.3 (9)	38.6 (17)
>90 min	–	–	3.7(1)	2.3 (1)
New clients could serve in 40 h week - % (*n*)	*n=146*	*n=124*[b]	*n=27*	*n=40*
N/A	–	2.4 (3)	–	–
1–4	17.1(25)	7.3 (9)	11.1 (3)	10.0 (4)
5–7	43.8 (64)	29.8 (37)	7.4 (2)	20.0 (8)
8–10	19.9 (29)	29.0 (36)	25.9 (7)	22.5 (9)
11–13	13.7 (20)	19.4 (24)	25.9 (7)	17.5 (7)
14–16	2.1 (3)	4.0 (5)	7.4(2)	12.5 (5)
17–19	–	2.4 (3)	3.7 (1)	5.0 (2)
≥20	3.5 (5)	5.6 (7)	18.5 (5)	12.5 (5)
Return clients could serve in 40 h week-% (*n*)	*n=139*	*n*=119[b]	N/A	N/A
N/A	-	5.9 (7)		
1–4	40.3 (56)	21.0 (25)		
5–7	41.7 (58)	35.3 (42)		
8–10	12.2 (17)	23.5 (28)		
11–13	0.7 (1)	10.1 (12)		
14–16	2.9 (4)	1.7 (2)		
17–19	–	0.8 (1)		
≥20	2.2 (3)	3.4 (2)		
3rd next available appointment-% (*n*)	*n=141*	*n=127*	*n=23*	*n=42*
<2 weeks	46.1 (65)	58.3 (74)	65.2 (15)	66.7 (28)
>2 weeks	53.9 % (76)	41.7 %(53)	34.8 % (8)	33.3 (14)
Distance traveled by average client- % (*n*)	*n=149*	*n=126*	*n=27*	*n=41*
<10 miles	22.8(34)	23.0 (29)	22.2 (6)	26.8 (11)
>10 miles	77.2 (115)	77.0 (97)	77.7 (21)	73.2 (30)

Table represents the four most commonly reported direct patient care models used. Information regarding the collaborative model is provided in the text

[a] Six individuals indicated spending no time in a post-test session and were excluded from statistical analyses since the traditional model by definition requires a post-test session; thus the sample used for the Wilcoxon signed ranks test was 124

[b] Three individuals endorsed N/A for new clients served in a 40 h work, and seven endorsed N/A for return patients served. They were excluded from statistical analyses. The sample size used for the Wilcoxon signed ranks test was 121 and 112, respectively

the face-to-face pre-test model, 6.9 % (2/29) use the telephonic model and 10.3 % (3/29) use the post-test counseling only complex model.

Model Use and Access

Table 4 also shows elements of access: third next available appointment and average distance clients travel. Overall, a higher proportion of those using the face-to-face pretest only, post-test all, and post-test complex models reported having a 3rd next available appointment in <2 weeks in comparison to those using the traditional model. However, these differences were not statistically significant. With regard to distance traveled, there were no significant differences for any of the three models when each was compared to the distances traveled by patients seen using the traditional model.

Benefits of Models

Respondents were asked to select what they perceived as the greatest benefit of each service delivery models they use given the following choices: provides high quality care, enhances

access to services, adequate reimbursement, an efficient way to provide care, other (please specify) (Fig. 1). For the traditional model (79.6 %, 117/145) indicated that it provides high quality care. Sixteen respondents selected "other" (10.9 %). Most of the responses described the circumstances under which the model provided the highest quality care: for positive or complicated results, when provided at the client's request, for clients with high risk features such as mental illness, when the counselor has gauged that face-to-face results disclosure is in the best interest of the client, or when clients have other scheduled appointments at the medical center (for screening or treatment). One respondent commented that the traditional model is a high quality model but not for all clients. Another responded that it afforded the "ability to educate and gauge understanding of complex issues in the most efficient way."

For the face-to-face pretest without face-to-face post-test model, the most commonly selected benefit was "an efficient way to provide care" (53.1 %; 69/130). Fourteen respondents chose "other." Several of these respondents indicated a benefit of the model is that it is more convenient for clients or promotes client satisfaction. Others variously indicated that it decreases client stress, respects the client's time especially when the client is recovering from surgery or has many other appointments, allows for quick disclosure of straightforward results, and allows the counselor to see more clients on clinic days.

The most commonly selected benefit for the post-test counseling all model was that it "enhances access to services" (44.4 %; 12/27). Seven respondents selected "other" (25.9 %). One noted that the model was convenient for clients. A second indicated that it provided clients access to a genetic counselor even in absence of pre-test access. Five respondents indicated that they did not see a benefit of this model. Some specified that this is because clients are not adequately informed prior to testing.

Similarly, the most commonly selected benefit for the post-test counseling complex model was that it "enhances access to services" (41.9 %; 18/43). Ten respondents selected "other." Other benefits included convenient for client, good use of genetic counseling skills, ensures clients receives accurate interpretation of test result, referring provider feels they are "…getting the ball rolling," and allows for fastest turn-around time. Three respondents did not see any benefit. Two indicated that they do not like the model, one because it is no less time consuming than the traditional model, and the second because clients are often not adequately counseled before testing.

"Enhances access to services" was also the greatest perceived benefit of the collaborative model (53.6 %; 15/28). Only one respondent selected "other" indicating that the model helps educate/train the health care team about the role of cancer genetics in their setting.

Barriers to Model Use

Respondents were asked to select what they perceived as the greatest barrier of each service delivery models they use given the options of: poor/no reimbursement, time consuming/low efficiency, limits client access to services, reduces quality of cancer genetics services, or other (please specify) (Fig. 2). Respondents identified "time consuming/low efficiency" as the greatest barrier to the traditional model (47.6 %; 69/145).

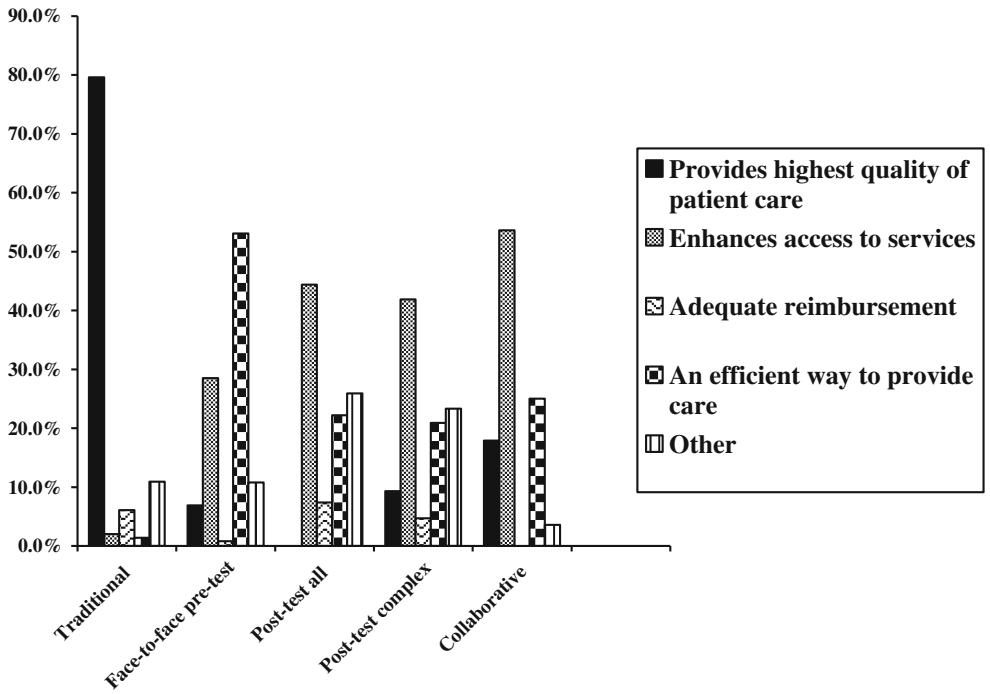

Fig. 1 Perceived benefits of five most frequently used models

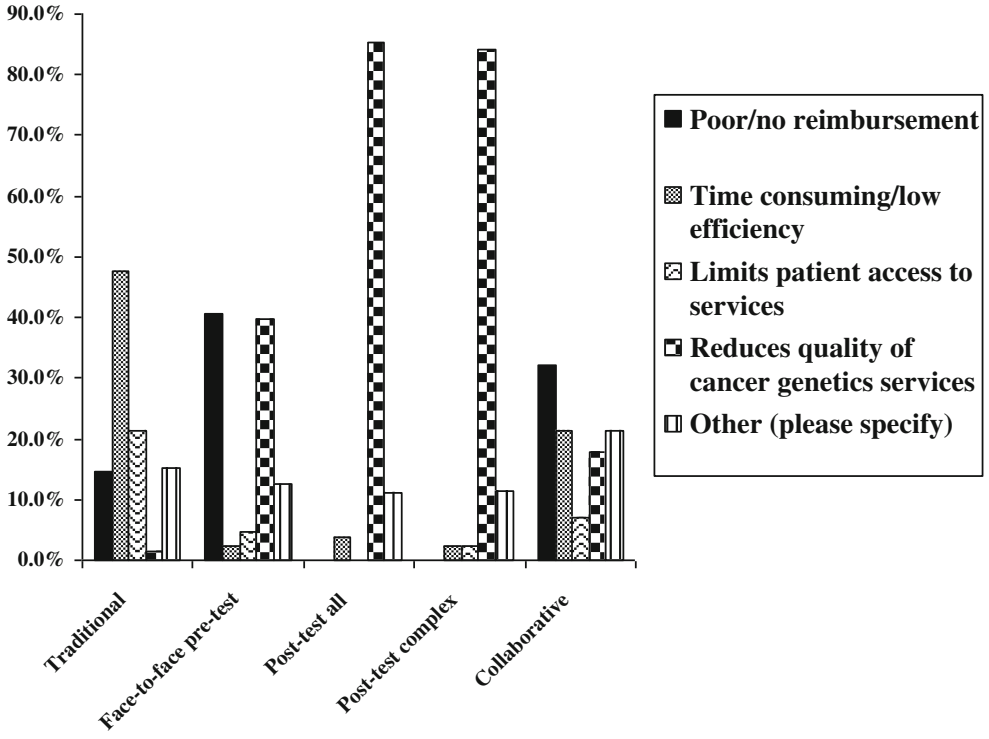

Fig. 2 Perceived barriers of five most frequently used models

Twenty-two respondents selected "other" for this model. Other barriers identified included physician availability ($n=2$), client reluctance to return/inconvenience to the client ($n=12$), time consuming/limits access ($n=2$), low efficiency if genetic counselor's time is an issue ($n=1$), client distress while waiting for results appointment ($n=1$), professional pressure to change ($n=1$), (need for a) referral by other professional ($n=1$), and lack of awareness of benefit of face-to-face counseling ($n=1$). One respondent indicated that there were no barriers to using this model.

The greatest barriers identified for the face-to-face pre-test only model were poor/no reimbursement (40.6 %; 52/128) and reduces quality of services (39.8 %; 51/128). Sixteen respondents selected "other." Four indicated that there were no barriers, especially if face-to-face post-test counseling is available for those who want it. Three respondents indicated that it is more difficult to determine whether the client understands when post-test counseling is done by telephone. Other barriers included not reimbursable, still time consuming (documentation), may be difficult to reach client by telephone, testing may be touted as a "quick blood test," client may have trouble dealing with result, and client may multitask while getting results. One person clarified that although positive/ambiguous results are provided by telephone, clients are scheduled for follow up appointments. Two respondents indicated that lack of awareness of this model and/or perception that post-test counseling has to be done face-to-face is a barrier.

For the post-test counseling only all and post-test counseling only complex models, the greatest perceived barrier was "reduces quality of cancer genetics services" (85.2 %, 23/27; and 84.1 %, 27/44, respectively). "Other" barriers to using these models included poorly educated clients, client anxiety or difficulty adjusting to new information (related to poor pre-test education), no control over what was said in pre-test counseling, and no rapport with clients. Two respondents did not perceive any barriers to using these models but indicated that they were less than ideal.

For the collaborative model, the greatest barrier identified was "poor/no reimbursement" (32.1 %; 9/28). Six respondents selected "other." Additional barriers identified by these respondents included potential misclassification of client risk, training physician/health care provider, and time commitment in absence of reimbursement.

Discussion

The aims of this study were to investigate which of ten defined service delivery models are used in providing cancer genetic counseling services and how often they are used. We also sought to compare and contrast the efficiency of the traditional, face-to-face pre- and post-test model with other commonly used models as well as genetic counselors' perceptions of the benefits and barriers of such models. Finally, we wanted to identify novel service delivery models.

While cancer genetic counselors still primarily use in person service delivery models, there appears to be a shift away from the two visit model. Our data suggest that genetic

counselors are providing fewer result disclosure sessions in person and are instead utilizing the telephone for at least a subset of result disclosures. This finding is consistent with Wham and colleagues' (2010) assessment of cancer genetic counselor practice which found that about one third of genetic counselors surveyed had adopted a one visit model. It is also reflective of the current NSGC cancer genetic risk assessment and counseling practice guideline which states that while disclosure of results in person is often helpful, utilization of telephone disclosure can be appropriate (Riley et al. 2012).

While pre-test counseling models are still most commonly used, a sizable minority of cancer genetic counselors are also engaging in post-test counseling only models and/or in a collaborative service delivery model. Those who employ these models tend to spend about 5-10 % of their clinical time using them. In some cases, it appears the use of the post-test models occurs by default rather than by choice. The remaining five models, including the group, telemedicine, and telephonic models, are relatively infrequently used by the respondents to this study.

National guidelines such as the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group recommendations to offer Lynch syndrome genetic testing to all newly diagnosed colorectal patients (2009), the Association of Community Cancer Center's Cancer Program guidelines stating that genetic counseling and testing be available for all appropriate individuals (2012), and the United States Preventive Services Task Force evidence-based guidelines for genetic risk assessment and *BRCA* mutation testing (Nelson et al. 2005) are increasing awareness of and potentially demand for services. In fact, evidence of increasing demand has been reported (Iredale et al. 2007; Mouchawar et al. 2005). As such, it is particularly important to identify strategies, including alternative service delivery models, that ensure adequate access to cancer genetic counseling and testing services. In this study, respondents who used the face-to-face pretest only model reported spending less time in post-test genetic counseling sessions and seeing more new and return patients than when counseling using the traditional model. Although those using the post-test all or post-test complex models spent more time in their post-test sessions (the only counseling session) than when using the traditional model, they, too, reported enhanced efficiency with regard to patients served per week. These findings are substantiated by counselors' perceptions that the greatest benefit of the face-to-face pretest model is that "it is an efficient way to provide care"; the greatest perceived benefit of the post-test models are that they "enhance access to services".

It is important to note that the use of alternative methods may come at a cost. In particular "reduced quality of services" was identified by respondents as a barrier to the post-test counseling models. There are several studies which have documented errors in provision of cancer genetic services and interpretation of genetic test results by non-genetic providers (Bensend et al. 2013; Brierley et al. 2010; Culver et al. 2009; Giardiello et al. 1997). The most commonly cited study by Giardiello and colleagues (1997) found that approximately 17 % of individuals who had undergone genetic testing for mutations in the *APC* gene did not have a valid indication for testing. In addition, several studies have found that some healthcare providers report being unprepared or uneasy providing cancer genetic testing services (Bellcross et al. 2011; Brierley et al. 2010; Culver et al. 2009; Freedman et al. 2003; Mehnert et al. 2003; Wideroff et al. 2003). Specifically, Freedman et al. (2003) found that only 29 % of U.S. physicians surveyed felt qualified to provided genetic counseling to their patients; Mehnert et al. (2003) found that approximately 66 % of German gynecologists surveyed felt knowledgeable enough to offer basic genetic counseling services. It is possible that the risks of inadequate pre-test informed consent and inappropriate genetic testing may outweigh the benefit of increased efficiency generated by post-test counseling models.

A recent study of 795 female *BRCA* carriers found that although cancer risk management uptake was high regardless of the type of health care professional providing genetic counseling, uptake was highest when counseling was provided by a genetics professional (Pal et al. 2013). In addition, the investigators found that genetic counseling sessions were longer when performed by a genetics professional, and longer sessions were associated with greater uptake of most cancer risk management strategies. In light of these findings, it will be important to investigate whether use of alternative delivery models by genetic professionals affects the patient uptake of management recommendations, one measure of the efficacy of services.

Another barrier to utilization of alternative delivery models, particularly the use of telephone disclosure of results, is the ability to obtain reimbursement for services. Although respondents stated that provision of results by telephone after face-to-face in person counseling was more efficient, allowing them to see more patients overall, there is currently no means by which to obtain reimbursement for this service. Therefore, it is imperative to look at the difference in revenue generated by the two visit in-person model versus the other models to determine if the increase in patient volume leads to increased revenue or at least no net loss in revenue. This may allow for justification of using a one visit model despite inability to bill for services from telephone result disclosure. Alternatively, lobbying for reimbursement of genetic counseling services delivered via telephone may lead to increased access to genetic counseling and testing services.

In this study we defined service delivery in terms of how the genetic counseling was provided (in-person face-to-face, by telephone, by videoconferencing, or through consultation/collaboration with health care professionals), for whom the service was delivered (individual clients versus groups), when services were provided (pre-and/or post- genetic testing) and

under what circumstances this occurred (post-test for all results or post-test complex). The NSGC Service Delivery Model Task Force (SDMTF) recently proposed a framework for defining models. They identified four models of service delivery: telephone, in person, group, telegenetics (Cohen et al. 2012). The most commonly used models in our study fall under the SMDTF's in-person category. We also evaluated the other three models they describe: telephone, group, and telegenetic counseling; however, these models were used infrequently by our respondents.

It is when the SMDTF begins to define the modes of referral and the components of genetic service that we see variability between our definitions. For example, the SDMTF defines tandem referral as a collaborative relationship in which the initial genetic counseling is provided by another healthcare provider and then referred to a genetic counselor for follow-up; a triage referral as a collaborative relationship in which the service is provided by another healthcare provider and then select patients are referred on to a genetic counselor as needed based upon complexity; and the rescue referral occurring when a health care professional refers certain patients to genetic counselors in the absence of a collaborative relationship. Utilizing the SDMTF definitions, our post-test all and post-test complex only service delivery models would be categorized as in-person models with mixed referral modes, including tandem, triage, and rescue, rather than separate service delivery models. This differentiation will be important as efforts move forward to better delineate which models are directly related to maximizing efficiency, access, and efficacy of cancer genetic counseling services.

There is a general belief that there is need to reevaluate genetic counseling service delivery models in the face of increasing demand (IOM 2009), and an apparent willingness by genetic counselors to do so. What is missing are definitive data documenting to what extent, if any, these practices are limiting access. Using the traditional two-visit model, almost one half of patients could be scheduled for an appointment in less than two weeks; the remainder had longer wait times. At what point a delay in scheduling a cancer genetics consultation affects the patient's willingness to attend or a provider's willingness to refer is unknown. Further, there may be factors other than time spent in sessions that have a bigger impact on efficiency, such as inadequate support staff, redundancy in documentation, and dependence on physician for billing (Wham et al. 2010). These factors are what the NSGC SDMTF labels as components of service delivery (Cohen et al. 2012) and their impact on access needs to be evaluated. Demand for genetic/genomic services is very likely to increase, and genetic counselors should continue to investigate innovate ways to provide services to meet this demand. However, it is imperative to evaluate what constitutes adequate access to genetics services and what elements of access are most affected (e.g., health insurance coverage, accessible location, adequate workforce, timely appointments, appropriate referrals) in determining how to provide sufficient access to effective, efficient services.

Study Limitations and Research Recommendations

The results of this study are based on respondents' impressions of how many patients they see per week, how many they could see, and how much time is spent in sessions, depending on which service delivery model is used. As such, these are estimates of time spent and efficiency. To more accurately evaluate these variables, a time study would need to be performed. Further, since this study utilized a newly-developed survey instrument, its validity and reliability have not been determined. In addition, for two questions - the third next available appointment and distance traveled questions-the responses were worded such that we could only do a limited examination of the data. Specifically, we could only compare wait times in terms of those less than or greater than 2 weeks. We could only compare distance traveled in terms of distances less than or greater than 10 miles. This limited our ability to fully investigate the range of each variable and the potential impact on access.

Although the response rate in this study was reasonable for a web-based survey, there was some drop out in later sections of the survey, which reduced the number of responses upon which analyses could be performed. This potentially affects the generalizability of the results to cancer genetic counseling practice. Further, the study participants were more experienced than those cancer genetic counselors that responded to the Cancer Genetic Counselor Professional Status Survey. Thus, whether the trends reported herein apply to all cancer genetic counselors or specifically to those with more experience is unclear.

Finally, this study was conducted before the SDMTF developed their definitions of service delivery models. As such, we were not able to fully evaluate the significance of our findings in the context of the different modes of referral and how these impact the perceived benefits of and barriers to using specific service delivery models.

Conclusions

This study explored the various models by which genetic counselors provide cancer genetic counseling services. The results showed that in person models still predominate; however, a majority no longer uses only the traditional two visit model. Providing results disclosures by means other than face-to-face visits and taking part in post-test counseling only sessions increase the efficiency of genetic counseling and potentially access to services. However, this may come at some costs. The cost benefit ratio of the more efficient models needs to be explored. Other factors that can affect access warrant evaluation as well.

Acknowledgments We would like to acknowledge Stephanie A. Cohen, MS, CGC, Genetic Counselor, St. Vincent Hospital, Indianapolis, IN for her significant contributions to study design and survey development. We would also like to thank the members of the National Society of Genetic Counselors' Service Delivery Model Task Force and Cancer SIG who piloted the draft survey. Another acknowledgement goes out to Rachel Orlowski, MS, from the Wayne State University Center for Urban Studies for her assistance with the statistical analyses performed on the data set. Finally, we would like to thank all the members of the Cancer SIG who completed the survey.

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