

# A Time Study of Cancer Genetic Counselors Using a Genetic Counselor–Only Patient Care Model Versus a Traditional Combined Genetic Counselor Plus Medical Geneticist Care Model

Brandie Heald, MS<sup>a,b,c</sup>; Shanna Gustafson, MS<sup>d</sup>; Jessica Mester, MS<sup>a,b</sup>; Patricia Arscott, MS<sup>e</sup>; Katherine Lynch, MS<sup>f</sup>; Jessica Moline, MS<sup>a,b,c</sup>; and Charis Eng, MD, PhD<sup>a,b,c,g,h</sup>

## Abstract

Analyses of time-based effort have determined that clinical genetic services are labor-intensive, although these data derive primarily from studying geneticists' efforts in the pediatric model. No studies have investigated the time and patient care activities of cancer genetic counselors (GCs) in traditional clinics with a medical geneticist (GC/MD) compared with genetic counselor–only (GCO) appointments. In this study, 6 GCs prospectively tracked time spent in patient care activities in both clinical settings. The authors found that overall, GCs' time spent per patient was lower for GCO versus GC/MD visits. No differences were seen in time spent on results disclosure, but differences were noted in case preparation, face-to-face, and follow-up times. Furthermore, no differences were seen in number of case preparation activities or topics covered during a session. These data suggest that GCO visits result in better use of GCs' time, without a trade-off in number of patient-related activities. (*JNCCN* 2013;11:1076–1081)

Analyses of time-based effort have historically determined that clinical genetic services are labor-intensive.<sup>1–3</sup> The limited analyses have focused primarily on geneticists' efforts in a pediatric model. One study examined real-time work flow of medical geneticists and genetic counselors (GCs), and found that the average amount of professional time was 7 hours for new patients and 3.5 hours for follow-up cases.<sup>3</sup> In a more recent study, cancer GCs of the National Society of Genetic Counselors (NSGC) were surveyed on their clinical practices.<sup>4</sup> Participants were given an example of the typical patient encountered in a cancer genetics clinic and asked to estimate the amount of time they would spend on an initial patient encounter. Half of the respondents estimated they would spend more than 60 minutes with the patient.<sup>4</sup> They also reported that approximately 50% of GCs had some level of direct physician involvement in their patient care, and in most cases (81.6%) for billing purposes.<sup>4</sup>

With the inception of CPT code 96040 and licensure, GCs have an avenue for professional recognition within their scope of practice. Furthermore, increased awareness of cancer genetic counseling services has created a higher demand for appointments. Thus, expansion of these services is required and must be achieved in a manner that efficiently provides care, without sacrificing quality, in the context of limited workforce.

No prospective studies have examined the time and labor efforts of cancer GCs. This study investigated the actual time spent on patient-related activities (visit and pre- and post-visit time) for GCs providing services in

From the <sup>a</sup>Genomic Medicine Institute; <sup>b</sup>Taussig Cancer Institute; and <sup>c</sup>Sanford R. Weiss M.D. Center for Hereditary Colorectal Cancer, Digestive Diseases Institute, Cleveland Clinic, Cleveland, Ohio; <sup>d</sup>Departments of Internal Medicine and Human Genetics and <sup>e</sup>Cardiovascular Center, University of Michigan Health System, Ann Arbor, Michigan; <sup>f</sup>GeneDx, Gaithersburg, Maryland; <sup>g</sup>Stanley Shalom Zielony Institute of Nursing Excellence, Cleveland Clinic, Cleveland, Ohio; and <sup>h</sup>Department of Genetics and Genome Sciences, CASE Comprehensive Cancer Center, Case Western Reserve University, Cleveland, Ohio.

Submitted January 14, 2013; accepted for publication April 23, 2013.

The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors. Dr. Eng is the Sondra J. and Stephen R. Hardis Chair of Cancer Genomic Medicine at the Cleveland Clinic and is an American Cancer Society Clinical Research Professor, generously funded in part, by the F.M. Kirby Foundation.

Correspondence: Charis Eng, MD, PhD, Cleveland Clinic Genomic Medicine Institute, 9500 Euclid Avenue, NE50, Cleveland, OH 44195. E-mail: engc@ccf.org

a traditional cancer genetics clinic with a medical geneticist (GC/MD) compared with cancer clinics staffed only by a genetic counselor only (GCO). This study sought to address the hypothesis that time spent per patient encounter for GCs would be lower in the GCO visits versus the GC/MD visits.

## Methods

### Patient Tracking

Between July 2009 and March 2010, 6 cancer GCs (years of experience at the beginning of the study ranged from 0 months to 10 years) prospectively tracked time spent and activities performed relevant to outpatient-related care and direct patient interaction. This study was conducted with the approval of the Cleveland Clinic Institutional Review Board. All sessions were noted as either GCO appointments or GC/MD appointments. Most patients were randomly scheduled as GCO or GC/MD appointments based on their preferred date and clinic location, except for patients referred for a PTEN hamartoma tumor syndrome (PHTS) evaluation, which tended to be scheduled upfront as a GC/MD appointment. Items recorded included whether a genetic counseling student was involved, the reason for referral, suspected genetic diagnoses, ICD-9 code applied to the visit, and type of genetic testing pursued.

For each patient, the GCs documented in minutes the amount of time spent on case preparation, with the patient (including, when appropriate, time spent waiting for and with the GC/MD), in follow-up activities, and, when applicable, disclosing genetic test results and subsequent documentation. Within the time spent on case preparation, on topics covered in the session, and for post-initial visit follow-up, GCs also tracked the activities they completed. These activities are listed in Table 1. If genetic testing was ordered, the GCs noted if the results were discussed over the telephone and/or in person, and if a telephone encounter was documented in the electronic medical record, a patient letter was written, and/or a family letter was written.

### Statistical Analyses

The patient visits were divided into 2 groups for comparison: GCO visits and GC/MD visits. Two-tailed unpaired *t* tests and Fisher exact test were

used to make comparisons between the groups. *P* values less than .05 were considered significant.

## Results

During the study period, 351 unique patients were tracked (242 in GCO clinics and 109 in GC/MD clinics). The most common reason for referral was a personal and/or family history of breast cancer ( $n=190$ ). Figure 1 summarizes the suspected diagnoses, based on risk assessment of reported personal and family history information, for the patients seen at each visit type. Aligned with the greatest reason for referral, hereditary breast-ovarian cancer syndrome (HBOC) from *BRCA1* and *BRCA2* mutations was the most commonly suspected diagnosis ( $n=176$ ). GCO visits trended toward seeing significantly more breast cancer referrals ( $P=.065$ ) and suspected HBOCs ( $P=.0008$ ) compared with GC/MD visits. A greater percentage of suspected PHTS cases were seen in GC/MD encounters (19.3%) than GCO visits (10.7%;  $P=.04$ ). Overall, average time spent per patient was lower for GCO visits (105.5 minutes) than GC/MD visits (157.5 minutes;  $P<.0001$ ).

### Case Preparation

GCs performed a significantly greater number of preparatory activities on average for patients seen in the GC/MD clinic compared with GCO visits (2.2 and 1.6 activities, respectively;  $P<.0001$ ). GCs also spent more time on case preparation in the GC/MD clinic (29.8 vs 16.2 minutes;  $P<.0001$ ; Table 2).

### Patient Encounter

GCs spent significantly less time with patients in the GCO visits than the GC/MD visits (52.3 vs 77.0 minutes;  $P<.0001$ ; Table 2). However, the same number of items was covered during each type of visit (9.7 items for GC/MD and 9.8 for GCO;  $P$ =not significant [NS]), and no differences were observed in which topics were covered by GCs.

### Follow-Up Activities

GCs also spent significantly less time on follow-up activities in the GCO visits than the GC/MD visits (27.0 vs 40.3 minutes, respectively;  $P<.0001$ ; Table 2). However, the same average number of follow-up activities was performed regardless of visit type (2.6 vs 2.4 activities, respectively;  $P$ =NS).

Heald et al

**Table 1** Data Points Documented for Encounters

Case Preparation Activities	Topics Covered in the Session	Follow-Up Activities
Review electronic medical records	Contracting	Write clinic note
Obtain pedigree from medical records	Medical history	Write patient letter
Obtain pedigree from patient phone call	Family history	Complete genetic testing requisition form
Review electronic pedigree submitted by patient	Natural history	Package up genetic testing kit
Request/review outside records	Basic genetics	Write letter of medical necessity
Review literature/resources	Risk assessment/inheritance	Additional research/literature review
Complete genetic testing requisition forms	Psychosocial assessment	Debrief with genetic counseling student
Run risk models	Psychosocial counseling	Other
Explore research options	Genetic testing options	
Student meeting	Medical management options	
Other	Resource identification/referral	
Nothing	Other	

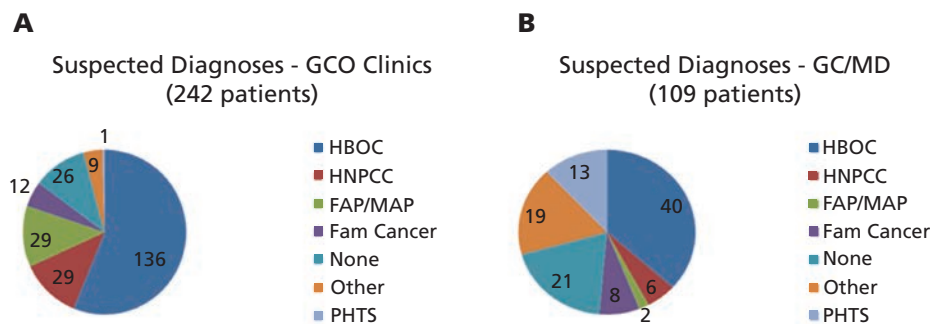
### Genetic Testing and Results Disclosure

Figure 2 provides the distribution of the number of patients who proceeded with clinical testing, received results by telephone or in person, and returned for a follow-up visit. Over the course of the study, 69% of patients seen in GCO clinics underwent genetic testing, which was significantly more than the 54% seen in GC/MD clinics ( $P=.011$ ). No differences were noted in the time of the results disclosure or number of patients who elected to receive genetic test results by telephone versus follow-up visit.

### HBOC Cases

To ensure that the time difference observed between GC/MD and GCO visits was not a measure of the complexity of cases that were seen in the GC/

MD clinic, a subanalysis was performed on cases for which HBOC was the suspected diagnosis. As noted in Table 2, no difference was seen in the amount of time spent on case preparation between the GC/MD and GCO visits (12.0 vs 16.8;  $P=.11$ ). The average amount of time spent on follow-up activities and discussing results via telephone between the 2 models trended toward being significantly longer in the GC/MD group ( $P=.052$  and  $P=.057$ , respectively). A significantly shorter amount of time was spent on the patient encounter during the GCO visits compared with those in the GC/MD clinic (56.8 vs 69.8 minutes;  $P<.0001$ ). No differences were observed in the number of activities performed for case preparation or follow-up, topics covered during the session, or the number of genetic tests ordered ( $P>.05$ ).



**Figure 1** Breakdown of the suspected diagnoses for patients seen in genetic counselor–only (GCO) clinics (A) and medical genetics clinics (B). Abbreviations: Fam Cancer, familial cancer; FAP/MAP, familial adenomatous polyposis or MYH-associated polyposis; GC/MD, genetic counselor and medical geneticist visit; HBOC, hereditary breast–ovarian cancer syndrome; HNPCC, hereditary nonpolyposis colorectal cancer; PHTS, PTEN hamartoma tumor syndrome.

## Cancer Genetic Counselor Time Study

**Table 2** Average Time Spent on Activities for Each Encounter

	Average Time (min)		
	GCO	GC/MD	P Value
<b>All Cases</b>			
Case preparation	16.2	29.8	<.0001
Patient encounter	52.3	77.0	<.0001
Follow-up	27.0	40.3	<.001
Telephone results disclosure	10.0	10.4	NS
<b>HBOC Cases</b>			
Case preparation	16.8	12.0	.11
Patient encounter	56.8	69.8	<.0001
Follow-up	24.3	33.1	.052
Telephone results disclosure	10.4	13.0	.057

Abbreviations: GCO, genetic counselor–only visit; GC/MD, genetic counselor and medical geneticist visit; HBOC, hereditary breast–ovarian cancer syndrome; NS, not significant.

## Discussion

Traditional cancer genetics services are provided by both a GC and medical geneticist. Approximately 50% of cancer GCs of the NSGC have some level of physician involvement in their patient encounters, with 22.2% requiring physician involvement in all consultations.<sup>4</sup> Almost certainly, some redundancies occur between the services provided by a GC and a geneticist when both professionals are involved in a patient encounter. Reasons for physician involvement vary, but include billing purposes, providing medical management recommendations, performing physical examinations, and physician preference.<sup>4,5</sup> Currently, many challenges and opportunities are facing the field of medical genetics that beg the question, is it necessary for a GC *and* a geneticist to be involved in every patient encounter?

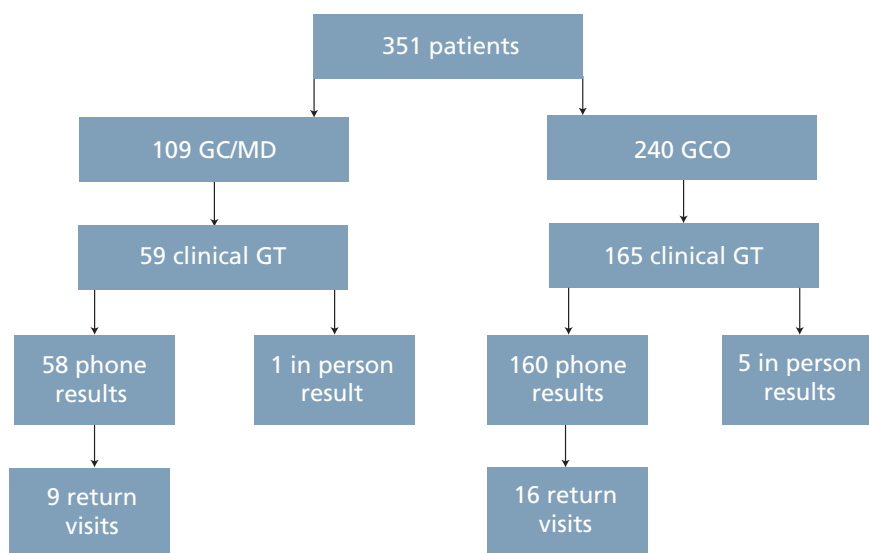
Providers in the field of genetics recognize that with advancements in genomic testing and decreased cost of genetic testing, an anticipated demand in clinical genetics services will occur.<sup>5,6</sup> As of 2011, a total of 1419 medical geneticists were certified through the American Board of Medical Genetics, with a decreasing trend of physicians obtaining certification in this field.<sup>7</sup> Funneling patients through this limited number of physicians can lead to longer wait times for appointments and decreased access to services. Survey responses from

cancer GCs of the NSGC suggested that they believed patient volumes were lower when a greater number of consultations required the presence of both a geneticist and a GC.<sup>4</sup> Additionally, approximately half of the respondents had a wait time of 3 weeks to more than 2 months.<sup>4</sup> This length of time for an initial consultation could be particularly problematic, especially for patients who plan to use genetic test results in their surgical decision-making. To create greater access, alternative service delivery models have been developed, including telephone<sup>8</sup> and group<sup>9,10</sup> genetic counseling and telegenetics.<sup>11–13</sup> Despite these models, most patients are still seen over 1 or 2 visits as in-person consultations.

Billing purposes are the most commonly cited reason for physician involvement in patient care. In 2006, CPT code 96040 was created to bill for genetic counseling encounters provided by a GC. The intent of this code development was to permit GCs to bill for services provided by the GC without a physician present, which can allow for independence from the medical geneticist's schedule and availability. As of 2010, an estimated 69% of NSGC survey respondents were billing for genetic counseling services, but of these individuals, only 24% were using CPT 96040.<sup>14</sup> Reasons reported for not using this code varied, and reflected limitations set in place by lack of licensure or institutional credentialing, and concerns regarding reimbursement rates.<sup>14</sup> Study of this code at the authors' institution, a large academic medical center, revealed that 63% of encounters billed under CPT 96040 had some level of reimbursement by private payers.<sup>15</sup> Reimbursement level for genetic counseling services varies nationally because of inconsistent state and federal recognition of GCs. As of September 2012, 16 states had licensure for GCs, with an additional 17 introducing or preparing to introduce bills.<sup>16</sup>

This is the first prospective study of cancer GCs that examines time and activities related to patient care, compared with a traditional approach to patient care involving a GC and a geneticist. The authors found that, on average, GCO visits were shorter than appointments in which the GCs worked with a GC/MD (105 vs 157 minutes, respectively). Potentially, some of this time difference can be attributed to the GCs waiting for the geneticist to complete other patient encounters and/or in the time spent in the room with the geneticist, which

Heald et al



**Figure 2** Flow diagram of the patients who pursued clinical genetic testing (GT) in both types of clinics. Abbreviations: GCO, genetic counselor–only visit; GC/MD, genetic counselor and medical geneticist visit.

could be a redundancy of services. This is not an insignificant time difference. If this approximately 50-minute difference occurs with the average number of patients (~6) seen per week as reported by Wham et al,<sup>4</sup> then that is an additional 5 hours per week that could be used by the GCs for patient encounters. The last Annual Report of the NCCN estimated that more than 160,000 new cancer cases per year are seen at NCCN Member Institutions.<sup>17</sup> If approximately 5% of those cases are hereditary, then 8000 patients at these centers would need to undergo a genetic risk assessment and, potentially, genetic testing in the setting of genetic counseling. Using the data from this study, a GCO model would be 30% more efficient than a GC/MD seeing this number of patients.

The authors found that GCs were performing similar activities for case preparation and follow-up, and covering the same number of topics in a session across both appointment types, suggesting that they did not vary the care they provided between GCO and GC/MD visits. Although this study was carried out at a single large academic institution, the authors suspect that similar results would be found at varying institutions. This study did not address patient satisfaction or understanding, which are important follow-up studies. Additionally, it would be interesting to see whether similar results were obtained for GCs who practice in GC/MD clinics with oncologists and surgeons rather than medical geneticists.

A potential confounder is that more complex patients, such as those with a suspected diagnosis of PHTS, were seen in the GC/MD clinics. To show that this dataset as a whole was not a reflection of complexity, a subanalysis was performed on cases in which HBOC was the suspected diagnosis. These data showed that GCs still performed the same tasks in a timelier manner. Interestingly, across all cases, clinical genetic testing was ordered more often in GCO visits than GC/MD visits. The reason for this is unclear and warrants further study.

The study findings support that GCs can see patients independently while still covering the same information that would be discussed during a combined encounter, which may be a better use of a GC's time in clinic. This model of patient care could allow for greater access to medical genetics services, because it would give GCs the opportunity to see patients in clinic alongside medical oncologists and surgeons. Additionally, this model could help to alleviate the geneticist's schedule of more routine cases, and allow greater time to be dedicated to more complex cases. The authors propose that a GC could independently see patients for an initial risk assessment. If sufficient information in the patient's personal and/or family history warrants testing, this could be accomplished at the first visit. If a physical examination is indicated to determine whether testing is appropriate, then the GC could triage the patient to either a combined appointment or separate visit with the geneticist. If

## Cancer Genetic Counselor Time Study

necessary, the patient could be seen for a follow-up visit with the geneticist to receive medical management recommendations, because these visits have historically been shown to take less time.<sup>1-3</sup> These data support the adaptation of GCO visits that may be beneficial for GCs, geneticists, and patients.

## Acknowledgments

The authors wish to thank Emily Edelman, MS, CGC, for her input on the study design and helpful discussions.

## References

- Bernhardt BA, Weiner J, Foster EC, et al. The economics of clinical genetics services. II. A time analysis of a medical genetics clinic. *Am J Hum Genet* 1987;41:559-565.
- Cooksey JA, Forte G, Flanagan PA, et al. The medical genetics workforce: an analysis of clinical geneticist subgroups. *Genet Med* 2006;8:603-614.
- McPherson E, Zaleski C, Benishek K, et al. Clinical genetics provider real-time workflow study. *Genet Med* 2008;10:699-706.
- Wham D, Vu T, Chan-Smutko G, et al. Assessment of clinical practices among cancer genetic counselors. *Fam Cancer* 2010;9:459-468.
- Cohen SA, Gustafson SL, Marvin ML, et al. Report from the National Society of Genetic Counselors Service Delivery Model Task Force: a proposal to define models, components, and modes of referral. *J Genet Couns* 2012;21:645-651.
- Irons M. The genetics clinic: where does the time go? *Genet Med* 2008;10:657-658.
- American Board of Medical Genetics I. Numbers of certified specialists in genetics. Available at: [www.abmg.org](http://www.abmg.org). Accessed July 9, 2012.
- Sutphen R, Davila B, Shappell H, et al. Real world experience with cancer genetic counseling via telephone. *Fam Cancer* 2010;9:681-689.
- Ridge Y, Panabaker K, McCullum M, et al. Evaluation of group genetic counseling for hereditary breast and ovarian cancer. *J Genet Couns* 2009;18:87-100.
- Calzone KA, Prindiville SA, Jourkiv O, et al. Randomized comparison of group versus individual genetic education and counseling for familial breast and/or ovarian cancer. *J Clin Oncol* 2005;23:3455-3464.
- Coelho JJ, Arnold A, Nayler J, et al. An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations. *Eur J Cancer* 2005;41:2257-2261.
- Gattas MR, MacMillan JC, Meinecke I, et al. Telemedicine and clinical genetics: establishing a successful service. *J Telemed Telecare* 2001;7(Suppl 2):68-70.
- Zilliacus EM, Meiser B, Lobb EA, et al. Are videoconferenced consultations as effective as face-to-face consultations for hereditary breast and ovarian cancer genetic counseling? *Genet Med* 2011;13:933-941.
- Harrison TA, Doyle DL, McGowan C, et al. Billing for medical genetics and genetic counseling services: a national survey. *J Genet Couns* 2010;19:38-43.
- Gustafson SL, Pfeiffer G, Eng C. A large health system's approach to utilization of the genetic counselor CPT(R) 96040 code. *Genet Med* 2011;13:1011-1014.
- Counselors NSoG. States issuing licenses for genetic counselors. Available at: <http://www.nsgc.org/Advocacy/StatesIssuingLicensesforGeneticCounselors/tabid/347/Default.aspx>. Accessed July 9, 2012.
- National Comprehensive Cancer Network. Strategy for a stronger future: NCCN annual report 2012. Available at: [http://www.nccn.org/about/annual\\_report/files/assets/basic-html/page1.html](http://www.nccn.org/about/annual_report/files/assets/basic-html/page1.html). Accessed April 23, 2013.