

A Survey of Genetic Counselors in Michigan

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Executive Summary

Background:

Due to scientific advances, increased knowledge of genes and genetic pathways, and increased public awareness of inheritable conditions, the demand for genetic counselors has increased. In order to assess whether capacity meets demand in Michigan, all genetic counselors were surveyed in order to develop a detailed profile of genetic counselors currently practicing in the state of Michigan as well as to provide a means to estimate the demographic profile of clients, the types of services provided to clients, and to assess cost reimbursement for genetic counseling and genetic testing. In addition, genetic counselors who counsel on cancer were surveyed to assess the availability and disposition of genetic counselors to address cancer genetic analysis, referral patterns, and appropriateness of referrals to cancer counseling.

Methods:

A web based survey was sent to all genetic counselors and medical geneticists in Michigan in February 2009 to March 2009.

Major Findings:

- Genetic counselors in Michigan are predominately White Non-Hispanic women at a mean age of 36 years who hold a Master of Science degree.
- Clients seen by genetic counselors are predominately women. The distribution by race within the patient population closely reflects the racial distribution in Michigan. Among patient demographics, age distribution of the patient population varied most and relied mostly on the specialty of the genetic counselor being seen.

- The cancers genetic counselors commonly counsel on are cancers that are the leading causes of death among men and women.
- The majority of clients being counseled for breast, ovarian, and colorectal cancer are found at a moderate or high risk of developing cancer.
- The majority of referrals to breast, ovarian and colorectal cancer counseling are deemed by genetic counselors to be appropriate for referral to genetic counseling.
- Only half the client population had complete insurance coverage for genetic counseling and genetic testing services.

Conclusions:

- This study provides insight into the capacity that exists within the State of Michigan for provision of genetic counseling services by specialized professionals.
- The proportion of clients who are classified into higher than average risk categories for developing cancer is not trivial, which calls for continuing efforts to promote and increase public awareness of the need to obtain an assessment of cancer risk and to seek counseling where appropriate.
- It is encouraging to learn that the majority of referrals to genetic counseling for cancer are considered appropriate.
- The gap that exists in insurance coverage of the comprehensive process of genetic counseling and testing is worth examining to ensure adequate access to comprehensive cancer care.

Background

Genetic counseling is a short-term counseling process for individuals and families who have a genetic disease or who are at risk for such a disease. Genetic counseling is a tool to diagnose, confirm, or rule out a genetic condition. Consultation with a genetic counselor, followed by genetic testing when appropriate, is a means to identify those at risk, preferably before the disease manifests. Ultimately, an individual who has a known familial gene mutation can make informed decisions about prevention strategies, disease management, treatment options, or in some cases reproductive options.

Hereditary cancer is the development of cancer due to an inherited gene mutation that has been passed from parent to child upon conception. Someone with an inherited gene mutation also inherited an increased risk to develop cancer in their lifetime that is greater than the risk of someone in the general population. Over the past decade, scientists have discovered specific genes that can contribute to the development of hereditary breast, ovarian, colorectal, endometrial, and prostate cancers as well as other less commonly occurring cancers. Genetic consultation and assessing one's cancer risk provides the opportunity for tailored screening and prevention strategies such as surveillance, chemoprevention, and prophylactic surgery that may reduce the morbidity and mortality associated with hereditary cancer.

Due to scientific advances and increased knowledge of genes and genetic pathways, rapidly developing technologies, and increased public awareness of inheritable conditions, the demand for genetic counselors has increased. Total membership in the National Society of Genetic Counselors (NSGC) has increased 23% from 2003 to 2008.¹ In order to assess whether capacity meets demand in Michigan, a web based survey of all genetic counselors was conducted in order to develop a detailed profile of genetic counselors currently practicing in the state of Michigan as well as to provide a means to estimate the demographic profile of clients, types of services provided to clients and to assess appropriateness of referrals and cost reimbursement for genetic counseling and genetic testing.

Purpose and Objectives

To better serve the population of Michigan, the Michigan Public Health Institute (MPHI) Cancer Control Services Program in collaboration with the Cancer Prevention and Control Section and the Genomics and Genetics Disorders Section of the Michigan Department of Community Health (MDCH) conducted a survey of genetic counselors in the state of Michigan in order to:

1. Assess basic demographics of genetic counselors and the services they provide
2. Assess referral patterns and primary sources of referral to genetic counseling as well as health care provider accuracy and competence in referral to counseling

¹ National Society of Genetic Counselors (2003-2008). Annual Report (online). Retrieved 09 June 2009. <http://www.nsgc.org/about/annualReport.cfm>.

3. Assess demographics of clients utilizing genetic services
4. Assess cost reimbursement for genetic counseling and genetic testing
5. Assess the availability and disposition of genetic counselors throughout Michigan to address cancer genetic analysis
6. Assess the adequacy of genetic counseling services specific to cancer that are available to Michigan residents

Methods

Target Population

The Genomics and Genetics Disorders Section at the MDCH provided a list of all genetic counselors in Michigan as of December 31, 2008. The list of genetic counselors included all genetic counselors as well as medical geneticists. The target population for this survey consisted of 75 genetic counselors and medical geneticists in Michigan.

Survey Instrument

The survey instrument contained questions on the general demographics of counselors in Michigan, the type of services they provide, general demographics of clients served, and questions about cost reimbursement for genetic counseling and genetic testing services. In addition, genetic counselors who counseled on cancer were asked about the types of cancers they counseled on, services offered to clients, and the appropriateness of referrals to genetic counseling specific to breast cancer, ovarian cancer, and colorectal cancer. A copy of the survey instrument is included in Appendix I.

Data Collection

A commercial service, SurveyMonkey.com, was used to conduct a web-based survey. The survey instrument was developed in November and December of 2008 and pre-tested in January of 2009. Based on pre-test results, final edits to the survey and final programming into SurveyMonkey were completed in February 2009. An initial invitation to participate in the survey was then emailed to each genetic counselor and a follow up email invitation was sent to all genetic counselors who did not respond to the survey in early March, 2009. A final email reminder to all non-respondents was additionally sent in mid-March, 2009. The survey was closed on March 17, 2009.

Data Analysis

SPSS statistical software 16.0 was used to conduct the analysis. Basic descriptive statistics, such as frequency, mean, and median are presented.

Results

Survey Response

Of the 75 potential respondents identified in the Genetic Counselor Directory, 5 respondents reported that they were no longer working as a genetic counselor, 2 counselors were on maternity leave and 1 person opted out of web-based Survey Monkey. Of the remaining 67 counselors, 56 completed the survey, resulting in an 83.6% response rate (Table 1). Genetic counselors from seven different counties in Michigan completed a survey (Figure 1). Wayne County had the most representation with 25 genetic counselors completing a survey, followed by Washtenaw County (n=9), Kent County (n=7), Ingham County (n=6), Oakland County (n=5), Kalamazoo County (n=1) and Grand Traverse County (n=1).

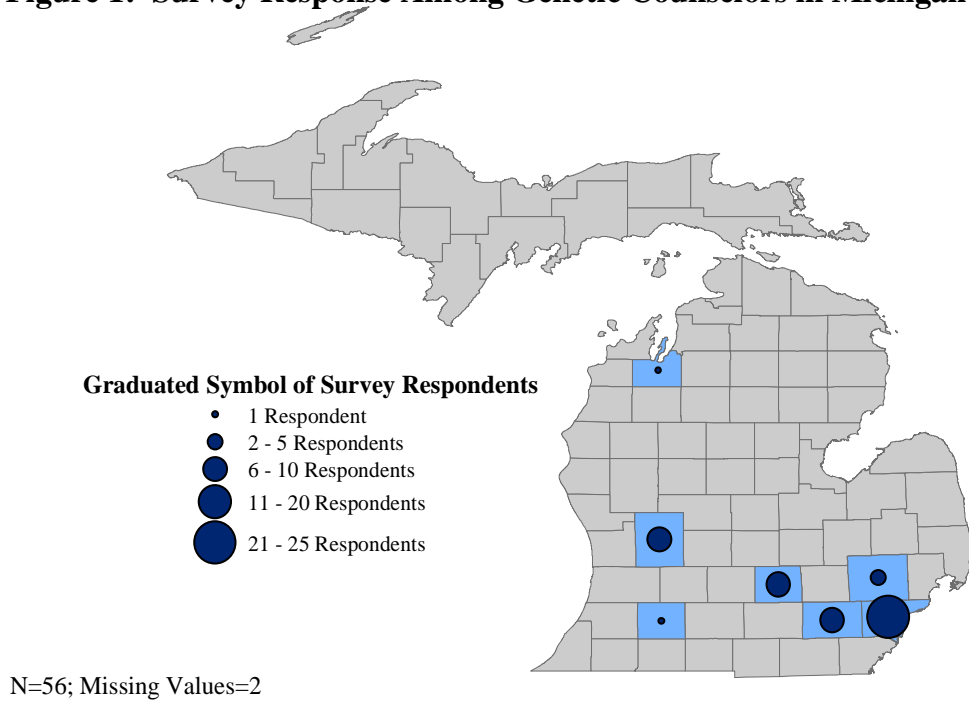
Table 1: Final Response Rate

| Total Cases | Opted Out of Survey Monkey | Maternity Leave | No Longer Working as a Genetic Counselor | Total Lost | Surveys Completed | Percent Lost¹ | Response Rate² |
|--------------------|-----------------------------------|------------------------|---|-------------------|--------------------------|---------------------------------|----------------------------------|
| 75 | 1 | 2 | 5 | 8 | 56 | 10.7% | 83.6% |

¹Percent Lost Calculation: $(8/70)*100 = 10.7\%$

²Response Rate Calculation: $(56/(75-8))*100 = 83.6\%$

Figure 1: Survey Response Among Genetic Counselors in Michigan by Location



Demographics of Genetic Counselors

Table 2 presents the demographic characteristics of the study population. The mean age of respondents is 36 years, ranging from 24 to 62 years. Respondents within the study population are predominantly female (94.4%), of a White Non-Hispanic race (80.0%) and hold a Master of Science degree (87.5%).

Table 3 presents employment demographics for the study population. Of respondents, a majority is an American Board of Genetic Counseling (ABGC) or an American Board of Medical Genetics (ABMG) certified genetic counselor (71.4%) and has several years experience in the field of genetic counseling. Nearly half of genetic counselors work in a University Medical Center (48.2%), followed by a Private Hospital/Medical Facility (26.8%), Public Hospital/Medical Facility (17.9%), State Health Department (3.6%), Diagnostic Laboratory (1.8%), and a Health Plan (1.8%).

Table 4 presents the areas of specialty reported by respondents. Half of all respondents (50.9%) reported specializing in more than one area. Specialty areas include Adult Cancers (43.6%), Pediatrics (43.6%), Prenatal Analysis (40.0%), Adult Genetics (32.7%), Molecular and Biochemical Testing (10.9%), and Research (10.9%).

Table 2: Personal Demographics of Study Population (n=56)

| | N | % |
|---|----|------|
| Age¹ (years) | | |
| Mean | 36 | -- |
| Median | 35 | -- |
| Min | 24 | -- |
| Max | 62 | -- |
| Gender² | | |
| Male | 3 | 5.6 |
| Female | 51 | 94.4 |
| Race | | |
| White Non-Hispanic | 44 | 80.0 |
| White-Hispanic | 7 | 12.7 |
| Asian/Pacific Islander | 3 | 5.5 |
| Black/African American | 2 | 3.6 |
| Advanced Degree Held | | |
| Master of Science (M.S.) | 49 | 87.5 |
| Doctor of Philosophy (PhD) | 5 | 8.9 |
| Doctor of Medicine (M.D.) | 4 | 7.3 |
| Other ³ | 2 | 3.6 |
| ¹ Missing values=3 | | |
| ² Missing values=2 | | |
| ³ 'Other' responses include "Doctor of Osteopathic Medicine" and "Master of Management". | | |

Table 3: Employment Demographics of Study Population (n=56)

| | N | % |
|--|----|------|
| Certification Status | | |
| ABGC or ABMG certified genetic counselor | 40 | 71.4 |
| ABGC eligible genetic counselor | 9 | 16.4 |
| ABMG certified PhD or MD medical geneticist | 3 | 5.4 |
| ABMG certified clinical geneticist | 2 | 3.6 |
| Other ¹ | 2 | 3.6 |
| Number of Years Working as a Genetic Counselor¹ | | |
| Less than one year | 5 | 9.1 |
| 1 to less than 3 years | 10 | 18.2 |
| 3 to less than 5 years | 5 | 9.1 |
| 5 to less than 10 years | 9 | 16.4 |
| 10 to less than 15 years | 11 | 20.0 |
| 15 years or more | 15 | 27.3 |
| Primary Employment Setting | | |
| University Medical Center | 27 | 48.2 |
| Private Hospital/Medical Facility | 15 | 26.8 |
| Public Hospital/Medical Facility | 10 | 17.9 |
| State Health Dept | 2 | 3.6 |
| Diagnostic Lab | 1 | 1.8 |
| Health Plan | 1 | 1.8 |
| ¹ 'Other' responses include "ABMG-certified MD clinical geneticist and biochemical geneticist" and "I am not certified and do not plan to unless they create a certification specifically for cancer genetics". | | |
| ² Missing Value=1 | | |

Table 4: Specialty Area of Genetic Counselors¹ (n=56)

| | N | % |
|--|----|------|
| Specializes in Multiple Areas | | |
| Specialize in One Area | 27 | 49.1 |
| Specialize in More than One Area | 28 | 50.9 |
| Areas of Specialty² | | |
| Adult Cancer | 24 | 43.6 |
| Pediatrics | 24 | 43.6 |
| Prenatal | 22 | 40.0 |
| Adult Genetics | 18 | 32.7 |
| Molecular/Cytogenetics/Biochem Testing | 6 | 10.9 |
| Research | 6 | 10.9 |
| Pediatric Cancer | 5 | 9.1 |
| Administrative | 3 | 5.5 |
| Education | 2 | 3.6 |
| PreConception/ART-PGD | 2 | 3.6 |
| Public Health | 2 | 3.6 |
| Cardiovascular Disease | 1 | 1.8 |
| Metabolic Disorders | 1 | 1.8 |
| Neurogenetics | 1 | 1.8 |
| Specialty Disease | 1 | 1.8 |
| ¹ Missing Values=1 | | |
| ² Specialty area categories are not exclusive | | |

Average Number of Hours Worked

Three-quarters of study respondents reported working at a full time status (75.0%) and 21.4% of respondents reported working at a part time status (Table 5). The mean number of hours worked in an average week for a full time employee is 44 hours, ranging from 32 to 60 hours per week. The mean number of hours worked in an average week for a part time employee is 27 hours, ranging from 5 to 40 hours per week.

The mean number of hours spent working directly with clients for all respondents is 15 hours per week (Table 6). Genetic counselors who worked 40 hours or more per week spent an average of 17 hours working per week working directly with clients, ranging from 2 to 40 hours per week. Counselors who worked less than 40 hours per week spent an average of 11 hours per week with clients, ranging from 4 to 25 hours per week.

Table 5: Average Hours Worked per Week by Employment Status (n=56)

| | Full Time | Part Time | Other¹ |
|---|------------------|------------------|--------------------------|
| Total N (%) | 42 (75.0) | 12 (21.4) | 2 (3.6) |
| Avg Hrs Worked/Week² | | | |
| Mean | 44 | 27 | 30 |
| Median | 44 | 30 | 30 |
| Min | 32 | 5 | 25 |
| Max | 60 | 40 | 35 |
| ¹ 'Other' responses include "Mid-time" and "Hourly contracted for ~25 hours per week". | | | |
| ² Missing Values=1 | | | |

Table 6: Average Number of Hours per Week Spent Directly with Clients by Average Hours Worked per Week¹ (N=51)

| | Total | 40 Hrs or more/week | Less than 40 Hrs/week |
|---|--------------|----------------------------|------------------------------|
| Mean | 15 | 17 | 11 |
| Median | 15 | 15 | 10 |
| Min | 2 | 2 | 4 |
| Max | 40 | 40 | 25 |
| ¹ Respondents who said that they did not currently counsel clients were excluded (n=5); Missing Values=1 | | | |

Client Load and Source of Referrals

Of survey respondents, 91.9% counsel patients in their current position (Table 7). The yearly patient volumes range from 10 to 600 clients, with respondents reporting an average of 240 clients per year (Figure 2). On average, 30.0% of genetic counselors reported client volumes of 101 to 200 clients per year and 28.0% of genetic counselors reported client volumes of 201 to 300 clients per year.

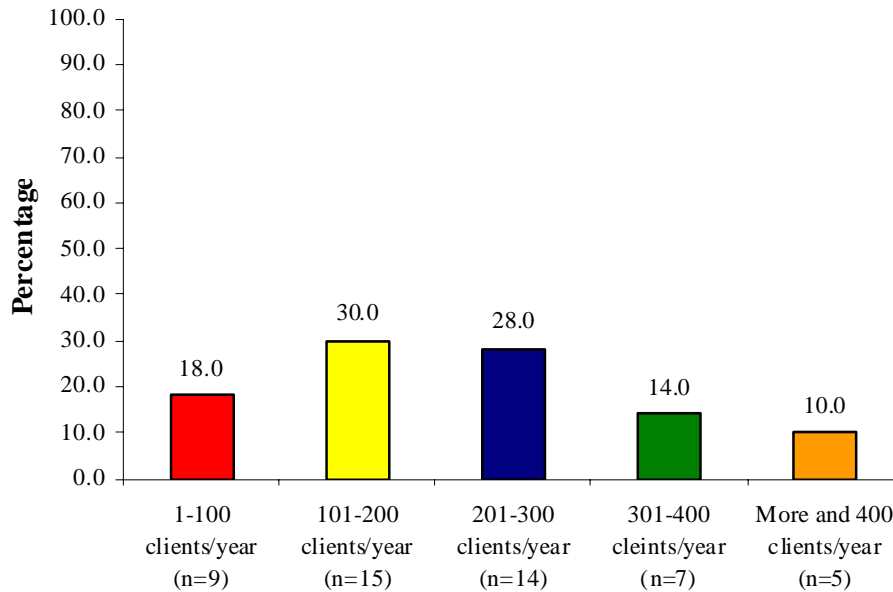
Respondents reported a mean of 6 new clients per week, ranging from 1 to 15 new clients, and a mean of 2 returning clients per week, ranging from 0 to 10 returning clients (Table 8). Table 9 presents the average weekly client load by specialty area of the genetic counselor. Genetic counselors specializing in pre-conception or artificial reproductive technologies and preimplantation genetic diagnosis (ART-PGD) reported the greatest number of new and returning clients per week with an average of 10 returning clients per week and an average of 5 new clients per week. Counselors specializing in prenatal genetics reported an average of 8 new clients per week and an average of 1 returning client per week. Counselors specializing in adult cancer, pediatrics, and adult genetics all reported an average of 6 new clients per week and 2 returning clients per week.

Table 10 displays the primary source of client referrals. Genetic counselors report that the primary source of client referrals in the past year was from Obstetricians/Gynecologists (30.0%), followed by Pediatricians (26.0%), Oncologists (18.0%), and Primary Care Doctors (14.0%). Only four percent of referrals to genetic counseling were self-referrals.

Table 7: Counsel Patient in Current Position (n=56)

| | N | % |
|-----|----|------|
| Yes | 51 | 91.9 |
| No | 5 | 8.9 |

Figure 2: Average Number of Clients Counseled per Year* (n=51)



*Mean=240, Median=210, Min=10, Max=600; Missing Values=1

Table 8: Average Weekly Client Load (n=51)

| | New Clients/Week ¹ | Returning Clients/Week ¹ |
|-------------------------------|-------------------------------|-------------------------------------|
| Mean | 6 | 2 |
| Median | 6 | 1 |
| Min | 1 | 0 |
| Max | 15 | 10 |
| ¹ Missing Values=1 | | |

Table 9: Average Weekly Client Load by Specialty Area of Genetic Counselor (n=51)*

| | Adult Cancer (n=24) | Pediatrics (n=24) | Prenatal (n=22) | Adult Genetics (n=18) | Other (n=11) | Molecular/Cytogenetics/Bio-Chemical (n=6) | Pediatric Cancer (n=5) | Pre-Conception/ART-PGD (n=2) |
|--|---------------------|-------------------|-----------------|-----------------------|--------------|---|------------------------|------------------------------|
| New Clients/Week | | | | | | | | |
| Mean | 6 | 6 | 8 | 6 | 5 | 5 | 4 | 10 |
| Median | 6 | 4 | 8 | 4 | 5 | 5 | 3 | 10 |
| Minimum | 2 | 1 | 3 | 3 | 1 | 3 | 3 | 6 |
| Maximum | 15 | 15 | 15 | 15 | 10 | 8 | 8 | 13 |
| Missing Values | 2 | 1 | 0 | 0 | 3 | 0 | 0 | 0 |
| Returning Clients/Week | | | | | | | | |
| Mean | 2 | 2 | 1 | 2 | 1 | 2 | 1 | 5 |
| Median | 1 | 1 | 1 | 2 | 1 | 2 | 1 | 5 |
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Maximum | 8 | 6 | 6 | 6 | 2 | 6 | 2 | 10 |
| Missing Values | 2 | 1 | 0 | 0 | 3 | 0 | 0 | 0 |
| *Specialty area categories are not exclusive | | | | | | | | |

Table 10: Primary Source of Client Referrals¹ (n=51)

| | N | % |
|---|----|------|
| Obstetricians/Gynecologists | 15 | 30.0 |
| Pediatricians | 13 | 26.0 |
| Oncologists | 9 | 18.0 |
| Primary MD/Internists | 7 | 14.0 |
| Other ² | 4 | 8.0 |
| Self Referral | 2 | 4.0 |
| ¹ Missing Values=1 | | |
| ² 'Other' includes "Surgeons", "Reproductive Endocrinologist", "Ophthalmologist", and "all refer". | | |

Client Demographics

Based on respondent reports, females made up approximately 70% of clients who received genetic counseling in the past year (Table 11). Table 12 presents the race of clients as reported by the genetic counselor. Clients of a White Non-Hispanic race (mean=62%; min=3%, max=97%) accounted for the majority of the clientele population in the past year. Black/African American clients accounted for an average of 19% (min=0%, max=80%) and White Hispanic clients accounted for an average of 11% (min=0%, max=95%) of the clientele population in the past year. American Indian, Asian/Pacific Islander, and clients of other races made up less than 5% of the clientele population, on average.

Figure 1 displays the comparison of the median race estimates of the client population to the racial distribution of the population in Michigan. The median estimates of the client population compares closely to racial estimates from the US Census. The White racial category in the US Census considers Hispanic origin separately from race and may not be directly comparable to the White Non-Hispanic estimate in this survey however.

Table 13 presents the race of clients receiving genetic counseling in the past year by the race of the genetic counselor. Client populations that were made up of 50% or greater of White-Hispanic clients or Black/African American clients were counseled by White-Non Hispanic genetic counselors. One Black/African American genetic counselor did report having a client population that was 26%-50% Black/African American.

The age distribution within the client population counseled in the past year varied greatly among genetic counselors (Table 14). Clients 18 years or less comprised an average of 32% of the client population (min=0%, max=99%). Clients aged 30 to 39 years comprised an average of 23% of clients, ranging from 0% to 70%. Clients aged 18 to 29 years comprised an average of 14% of the client population, ranging from 0% to 40% and clients 40 to 49 years comprised an average of 14% of clients in the past year, ranging from 0 to 60%.

Table 11: Gender Distribution of Clients in Past Year as Reported by Genetic Counselor (n=51)*

| | Male | Female |
|-------------------|-------------|---------------|
| Mean | 30% | 70% |
| Median | 28% | 73% |
| Minimum | 0% | 5% |
| Maximum | 95% | 100% |
| *Missing Values=1 | | |

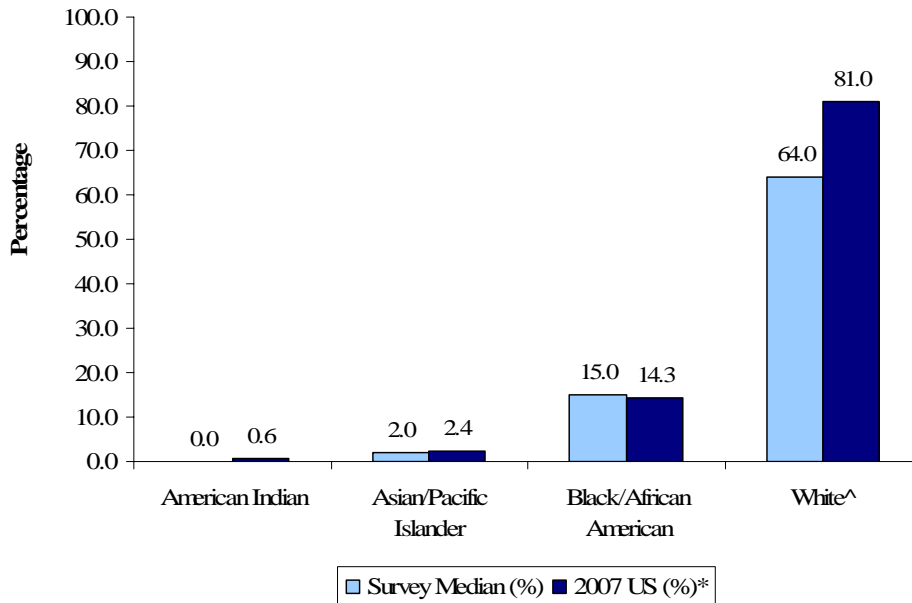
Table 12: Race Distribution of Clients in Past Year as Reported by Genetic Counselor (n=51)*

| | American Indian | Asian/Pacific Islander | Black/African American | White Non-Hispanic | White Hispanic | Other Race |
|-------------------|------------------------|-------------------------------|-------------------------------|---------------------------|-----------------------|-------------------|
| Mean | 1% | 4% | 19% | 62% | 11% | 4% |
| Median | 0% | 2% | 15% | 64% | 5% | 1% |
| Minimum | 0% | 0% | 0% | 3% | 0% | 0% |
| Maximum | 5% | 25% | 80% | 97% | 95% | 25% |
| *Missing Values=2 | | | | | | |

Table 13: Race of Clients in Past Year by Race of Genetic Counselor (n=56)*

| | | Race of Genetic Counselor | | | | | | | |
|--|---------|----------------------------------|-------|-------------------------------|-------|---------------------------|-------|-----------------------|-------|
| | | Asian Pacific Islander | | Black/African American | | White-Non Hispanic | | White-Hispanic | |
| | | N | % | N | % | N | % | N | % |
| % of Clients that are White-Hispanic | 0-25% | 3 | 100.0 | 2 | 100.0 | 36 | 90.0 | 5 | 100.0 |
| | 26-50% | 0 | 0.0 | 0 | 0.0 | 2 | 5.0 | 0 | 0.0 |
| | 50-75% | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| | 76-100% | 0 | 0.0 | 0 | 0.0 | 2 | 5.0 | 0 | 0.0 |
| % of Clients that are Black/African American | 0-25% | 1 | 33.3 | 1 | 50.0 | 29 | 72.5 | 5 | 100.0 |
| | 26-50% | 2 | 66.7 | 1 | 50.0 | 10 | 25.0 | 0 | 0.0 |
| | 50-75% | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| | 76-100% | 0 | 0.0 | 0 | 0.0 | 1 | 2.5 | 0 | 0.0 |
| % of Clients that are Asian/Pacific Islander | 0-25% | 3 | 100.0 | 2 | 100.0 | 40 | 100.0 | 5 | 100.0 |
| | 26-50% | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| | 50-75% | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| | 76-100% | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| *Race category of genetic counselor is not exclusive; Missing Values=7 | | | | | | | | | |

Figure 3: Racial Distribution of Client Population versus Michigan Population



^"White" racial category within this survey contains those who self reported as White Non-Hispanic only and "White" racial category within the US Census data considers Hispanic origin separately from race and may not be directly comparable.

*Source: US Census Bureau (2007), State and County QuickFacts (online), retrieved 09 June 2009, <http://quickfacts.census.gov/qfd/states/26000.html>.

Table 14: Age Distribution of Clients in Past Year as Reported by Genetic Counselor (n=51)*

| | < 18 yrs | 18-29 yrs | 30-39 yrs | 40-49 yrs | 50-59 yrs | 60-69 yrs | 70+ yrs |
|-------------------|----------|-----------|-----------|-----------|-----------|-----------|---------|
| Mean | 32% | 14% | 23% | 14% | 10% | 5% | 3% |
| Median | 10% | 10% | 20% | 15% | 6% | 1% | 0% |
| Minimum | 0% | 0% | 0% | 0% | 0% | 0% | 0% |
| Maximum | 99% | 40% | 70% | 60% | 40% | 20% | 20% |
| *Missing Values=3 | | | | | | | |

Cancer Counseling

Among respondents who provide counseling, 55.1% of respondents counseled patients for cancer in the past year (Table 15). The types of cancer that genetic counselors provided counseling for in the past year are displayed in Table 16. Breast cancer (96.3%), colorectal cancer (92.6%), and ovarian cancer (92.6%) are the most common cancers where counseling is provided, followed by pancreatic cancer (88.9%), endometrial cancer (88.5%) and prostate cancer (73.1%).

Over half of all genetic counselors that counsel patients on cancer have a formalized tracking system to assure that recommended testing is performed (Table 17). Eleven percent of genetic counselors have a formalized tracking for some patients and 14.8% of counselors have no ability to follow up with clients.

Table 15: Counseled Clients on Cancer in Past Year¹ (n=51)

| | N | % |
|-------------------------------|----|------|
| Yes | 27 | 55.1 |
| No | 22 | 44.9 |
| ¹ Missing Values=2 | | |

Table 16: Types of Cancer Patients are Counseled for at Facility of Employment (n=27)

| Cancer Type ¹ | N | % |
|--|----|------|
| Breast Cancer | 26 | 96.3 |
| Colorectal Cancer | 25 | 92.6 |
| Ovarian Cancer | 25 | 92.6 |
| Pancreatic Cancer | 24 | 88.9 |
| Endometrial Cancer | 23 | 85.2 |
| Prostate Cancer | 19 | 70.4 |
| Lung Cancer | 6 | 22.2 |
| Other ² | 6 | 22.2 |
| Renal | 6 | 22.2 |
| Thyroid | 6 | 22.2 |
| Any type of cancer | 5 | 18.5 |
| Skin Cancer | 4 | 14.8 |
| Brain | 4 | 14.8 |
| Gastric/Stomach | 3 | 11.1 |
| ¹ Multiple answers given | | |
| ² 'Other' includes "adrenal", "head and neck", "paraganglioma", "retinoblastoma", "malignant nerve sheath tumors", and "sarcoma". | | |

Table 17: Have Formalized Tracking System to Assure Recommended Testing is Performed (n=27)

| | N | % |
|--|----|------|
| Yes, for all patients | 16 | 59.3 |
| Yes, for some patients | 3 | 11.1 |
| No, no ability to follow up | 4 | 14.8 |
| Do not receive lab results | 1 | 3.7 |
| Other ¹ | 3 | 11.1 |
| ¹ 'Other' includes "we personally track all recommended testing, but nothing formalized", "We recommend and track genetic testing results; we do not track other recommended testing and are often not cc'ed results", and "We track each patient that decides to have testing-as to what results are. We don't recommend any testing- the patient makes the decision so sometimes they just want to think about it and are welcome to call us back if interested". | | |

Breast Cancer Risk

Of genetic counselors that counsel on cancer, 92.6% of counselors counsel on breast cancer risk (Table 18). Of clients who were counseled on breast cancer risk in the past year, a mean of 12% of clients were at an average risk for developing breast cancer, a mean of 47% of clients were at a moderate risk for developing breast cancer, and a mean of 41% of clients were at a high risk for developing breast cancer (Table 19). Based on the counselors' assessment of the clients' risks for developing breast cancer, approximately 91% of client referrals were appropriate referrals to counseling (Table 20).

Table 18: Counsel Clients on Breast Cancer Risk in Past Year (n=27)

| | N | % |
|-----|----|------|
| Yes | 25 | 92.6 |
| No | 2 | 7.4 |

Table 19: Clients' Risk Level for Developing Breast Cancer as Reported by Genetic Counselor (n=25)

| | Average Risk | Moderate Risk | High Risk |
|--------|--------------|---------------|-----------|
| Mean | 12% | 47% | 41% |
| Median | 10% | 50% | 30% |
| Min | 0% | 5% | 15% |
| Max | 50% | 75% | 90% |

Table 20: Estimated Percent of Appropriate Referrals in the Past Year Based on Counselors' Assessment of the Clients' Risk of Developing Breast Cancer (n=25)

| | % Referrals that Were Appropriate |
|--------|-----------------------------------|
| Mean | 91% |
| Median | 95% |
| Min | 50% |
| Max | 100% |

Ovarian Cancer Risk

Of genetic counselors that counsel on cancer, 88.9% of counselors counsel on ovarian cancer risk (Table 21). Of clients who were counseled on ovarian cancer risk in the past year, a mean of 14% of clients were at an average risk for developing ovarian cancer, a mean of 50% of clients were at a moderate risk for developing ovarian cancer, and a mean of 37% of clients were at a high risk for developing ovarian cancer (Table 22). Based on the counselors' assessment of the clients' risks of developing ovarian cancer, approximately 90% of client referrals were appropriate referrals to counseling (Table 23).

Table 21: Counsel Clients on Ovarian Cancer Risk in Past Year (n=27)

| | N | % |
|-----|----|------|
| Yes | 24 | 88.9 |
| No | 3 | 11.1 |

Table 22: Clients' Risk Level for Developing Ovarian Cancer as Reported by Genetic Counselor (n=24)

| | Average Risk | Moderate Risk | High Risk |
|--------|--------------|---------------|-----------|
| Mean | 14% | 50% | 37% |
| Median | 5% | 55% | 25% |
| Min | 0% | 0% | 10% |
| Max | 75% | 85% | 100% |

Table 23: Estimated Percent of Appropriate Referrals in the Past Year Based on Counselors' Assessment of the Clients' Risk of Developing Ovarian Cancer (n=24)

| | % Referrals that Were Appropriate |
|--------|-----------------------------------|
| Mean | 90% |
| Median | 95% |
| Min | 50% |
| Max | 100% |

Colorectal Cancer Risk

Of genetic counselors that counsel on cancer, 92.6% of counselors counsel on colorectal cancer risk (Table 24). Of clients who were counseled on colorectal cancer risk in the past year, a mean of 12% of clients were found to be at average risk for developing colorectal cancer, a mean of 49% of clients were at a moderate risk for developing colorectal cancer, and a mean of 39% of clients were at a high risk for developing colorectal cancer (Table 25). Based on the counselors' assessment of the clients' risk of developing colorectal cancer, approximately 92% of client referrals were appropriate referrals to counseling (Table 26).

Table 24: Counsel Clients on Colorectal Cancer Risk in Past Year (n=27)

| | N | % |
|-----|----------|----------|
| Yes | 25 | 92.6 |
| No | 2 | 7.4 |

Table 25: Clients' Risk Level for Developing Colorectal Cancer as Reported by Genetic Counselor (n=25)

| | Average Risk | Moderate Risk | High Risk |
|--------|---------------------|----------------------|------------------|
| Mean | 12% | 49% | 39% |
| Median | 10% | 50% | 35% |
| Min | 0% | 0% | 0% |
| Max | 50% | 80% | 100% |

Table 26: Estimated Percent of Appropriate Referrals in the Past Year Based on Counselors' Assessment of the Clients' Risk of Developing Colorectal Cancer (n=25)

| | % Referrals that Were Appropriate |
|--------|--|
| Mean | 92% |
| Median | 95% |
| Min | 50% |
| Max | 100% |

Insurance Coverage for Genetic Counseling and Genetic Testing

Based on estimations provided by genetic counselors, a mean of 54% of clients who receive genetic counseling have complete insurance coverage for genetic counseling, a mean of 22% of clients have partial insurance coverage, and a mean of 24% of clients have no insurance coverage for genetic counseling (Table 27). Based on genetic counselor estimations, a mean of 53% of clients have complete insurance coverage for genetic testing, a mean of 29% have partial coverage, and a mean of 18% of clients have no insurance coverage for genetic testing (Table 28).

Table 27: Percentage of Clients That Have Insurance Coverage for Genetic Counseling as Reported by the Genetic Counselor (n=51)¹

| | Complete Coverage | Partial Coverage | No Coverage |
|-------------------------------|--------------------------|-------------------------|--------------------|
| Mean | 54% | 22% | 24% |
| Median | 70% | 15% | 10% |
| Min | 0% | 0% | 0% |
| Max | 100% | 85% | 100% |
| ¹ Missing Values=8 | | | |

Table 28: Percentage of Clients That Have Insurance Coverage for Genetic Testing as Reported by the Genetic Counselor (n=51)¹

| | Complete Coverage | Partial Coverage | No Coverage |
|-------------------------------|--------------------------|-------------------------|--------------------|
| Mean | 53% | 29% | 18% |
| Median | 60% | 30% | 10% |
| Min | 0% | 0% | 0% |
| Max | 99% | 75% | 100% |
| ¹ Missing Values=5 | | | |

Discussion

The demographic profile of genetic counselors from this study indicates that genetic counselors in Michigan are predominately White Non-Hispanic women at a mean age of 36 years who hold a Master of Science degree. Over 60% of genetic counselors in Michigan have more than 5 years experience working as a genetic counselor and the majority work in a University Medical Center. Based on results from the National Society of Genetic Counselors (NSGC) Professional Status Survey, genetic counselors in Michigan are very similar to other counselors throughout the United States.²

However, compared to the United States, genetic counselors in Michigan are more racially diverse. In Michigan, White-Hispanic counselors comprise 12% of all counselors while National estimates indicate White-Hispanic counselors comprise only 2% of the genetic counselor population. The percentage of Black/African American genetic counselors in Michigan is also slightly greater than National estimates (3.6% vs. 1%). Even though Michigan shows a more racially diverse genetic counselor population, findings indicate that clients within the various racial groups are being counseled by genetic counselors within the same racial category to only a small extent. There has been a conscious effort to increase racial diversity within the genetic counselor profession³, yet study findings indicate that even with a more racially diverse genetic counselor population, clients are not counseled by same race counselors to a great degree.

Of the genetic counselors surveyed, over 90% of genetic counselors counsel patients in their current position. A majority of counselors have between 100 and 300 clients per year, with an average of 240 clients per year and spend an overall average of 15 hours per week working directly with clients. Counselors who specialize in ART-PDG reported the greatest number of returning and new clients per week followed by counselors in the prenatal specialty. Although with more than half of genetic counselors specializing in more than one area, there is some overlap between the preconception/ART-PGD and prenatal specialty categories.

The demographic profile of patients seeking genetic counseling indicate that clients are predominately White Non-Hispanic women and between the ages of 30 and 39 years. The number of women seeking genetic counseling is much greater than that for males. This gender disparity could reflect the gender-specific conditions that are counseled for such as prenatal counseling and counseling for breast, ovarian, and endometrial cancers. Based on study findings it is unclear whether or not males are under utilizing genetic services for specific reasons, but previous findings indicate that a majority of men do not pursue genetic counseling even when a mutation has been identified in the family.⁴ The distribution by race within the patient population remarkably reflects the racial

² National Society of Genetic Counselors (2007). Professional Status Survey 2006 (online). Retrieved 09 June 2009, http://www.nsgc.org/career/pss_index.cfm.

³ Suez Mittman, H & Downs, K. (2008). Diversity in genetic counseling: Past, present and future. *Journal of Genetic Counseling*, 17, 301-313.

⁴ Daly Mary. (2009). The Impact of Social Roles on the Experience of Men in BRCA1/2 Families: Implications for Counseling. *Journal of Genetic Counseling*, 18, 42-48.

distribution in Michigan. Age distribution of the patient population varied most among patient demographics. Age in particular relied on specialty of the genetic counselor as some counselors reported patient populations comprising nearly 100% within particular age groupings.

More than half of the survey population reported counseling on cancer in the past year. The most common cancers counseled on are breast, colorectal, ovarian, pancreatic, endometrial, and prostate cancers. These cancers coincide with the leading causes of cancer deaths among men and women in the United States.⁵ However, cancers that affect females may be counseled for more frequently because females comprise 70% of the patient population. The leading cause of death for both men and women, lung cancer, is less commonly counseled for but the mechanism of how genetic factors increase the risk for developing lung cancer is fairly new, not fully understood, and still under research.⁶

The majority of genetic counselors who counsel for cancer do counsel patients on breast, ovarian, and colorectal cancer risk. For all three cancer sites, nearly 90% of the patient population is determined to be at a moderate or high risk for developing breast, ovarian, or colorectal cancer by the genetic counselor. Similarly, counselors reported approximately 90% of referrals for breast, ovarian, and colorectal cancer risk assessment to be appropriate for referral. Approximately 10% of patients counseled for breast, ovarian, or colorectal cancer risk are found to be at average risk for developing cancer. Also, genetic counselors reported that approximately 10% of referrals are not appropriate for referral to genetic counseling.

On average, more than half of clients receiving genetic counseling or genetic testing have complete insurance coverage. However, estimates of insurance coverage for genetic services varied by counselor with some counselors reporting 100% of clients with complete coverage and other counselors reporting 0% of clients with complete coverage for genetic counseling and testing. Cost and/or insufficient insurance coverage has been indicated as a factor influencing a patient's decision for not pursuing genetic counseling or genetic testing.^{7,8,9,10} It is clear that insurance coverage for genetic services remains a potential barrier for patients' obtaining these services and is an essential component of discussion when counseling clients.

⁵ American Cancer Society. (2009). *Cancer Facts and Figures 2009*. Atlanta: American Cancer Society.

⁶ Amos C.I., Wu X., Broderick P., *et al.* (2008). Genome-wide association scan of tag SNPs identifies a susceptibility locus for lung cancer at 15q25.1. *Nature Genetics*, 40, 616-622.

⁷ Lacour R.A., Daniels M.S., Westin S.N., *et al.* (2008). What women with ovarian cancer think and know about genetic testing. *Gynecologic Oncology*, 111, 132-136.

⁸ Wang G., Watts C., (2007). Genetic counseling, insurance status and elements of medical home: analysis of the National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal*, 11, 559-567.

⁹ Kausmeyer D.T., Lengerich E.J., Kluhsman B.C., *et al.* (2006). A survey of patients' experiences with the cancer genetic counseling process: recommendations for cancer genetics programs. *Journal of Genetic Counseling*, 15 (6), 409-431.

¹⁰ Peterson E.A., Milliron K.J., Lewis K.E., *et al.* (2002). Health insurance and discrimination concerns and BRCA1/2 testing in a clinic population. *Cancer Epidemiology, Biomarkers & Prevention*, 11, 79-87.

Conclusion

This study provides insight into the capacity that exists within the State of Michigan for provision of genetic counseling services by specialized professionals. The proportion of clients who are classified into higher than average risk categories for developing cancer is not trivial, which calls for continuing efforts to promote and increase public awareness of the need to obtain an assessment of cancer risk and to seek counseling where appropriate. It is encouraging to learn that the majority of referrals to genetic counseling for cancer are considered appropriate. The gap that exists in insurance coverage of the comprehensive process of genetic counseling and testing is worth examining to ensure adequate access to comprehensive cancer care.

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