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ORIGINAL RESEARCH

Expanding Roles: A Survey of Public Health Genetic Counselors

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Abstract According to the 2008 National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS), 31 genetic counselor respondents reported spending at least 50% of their time in the area of public health. The NSGC Public Health Special Interest Group (PHSIG) had 49 dues-paying members in 2009. The purpose of this study was to identify the work settings and public health activities in which genetic counselors participate. A novel online survey was disseminated over the NSGC PHSIG Listserv. Forty-one percent ($n=13$) of public health genetic counselor respondents worked in a university medical system, while 53% ($n=17$) were grant-funded and held a non-clinical appointment. The most common public health activities included educating healthcare professionals (82%) and community members (61%), research (55%), grant writing (55%) and grant administration (36%). Most respondents (82%) reported learning certain public health skills outside of their genetic counseling training programs. Differences in work settings were found, with a significantly greater percentage of public health genetic counselors working in government agencies. Genetic counselors have opportunities to become involved in public health activities as the scope of public health genetics grows. Furthermore, genetic counseling competencies are compatible with the Institute of Medicine's "10 Essential Public Health Services." The NSGC and genetic counseling training programs are encouraged to offer more public health learning opportunities for genetic counselors and genetic counseling students interested in this specialty area.

Keywords Public health · Genetic counseling · Genomics · Newborn screening

Introduction

As the field of genetic counseling has evolved, an increasing number of genetic counselors have chosen to specialize. The diversity of genetic counselors' specialty areas suggests that their core skill sets are versatile and transferable. According to the 2008 National Society of Genetic Counselor's (NSGC) bi-annual Professional Status Survey (PSS), clinical genetic counselors now practice in specialty areas such as cancer, cardiology, psychiatric illness, and newborn screening (NBS)/public health, incorporating both clinical and non-clinical roles (NSGC PSS 2008).

Genetic Counseling in the Public Health Arena

In 1994, when the field of genetic counseling was still relatively young, the Public Health Functions Working Group (a committee convened by the Department of Health and Human Services) with representatives from all major public health constituencies, identified the following "10 Essential Public Health Services": (1) Monitor health status to identify and solve community health problems; (2) Diagnose and investigate health problems and health hazards in the community; (3) Inform, educate, and empower people about health issues; (4) Mobilize community partnerships and action to identify and solve health problems; (5) Develop policies and plans that support individual and community health efforts; (6) Enforce laws and regulations that protect health and ensure safety; (7) Link people to needed personal health services and assure

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the provision of health care when otherwise unavailable; (8) Assure competent public and personal health care workforce; (9) Evaluate effectiveness, accessibility, and quality of personal and population-based health services; and (10) Research for new insights and innovative solutions to health problems (Institute of Medicine 2002).

The American Board of Genetic Counseling (ABGC), the credentialing body for the genetic counseling profession, provides Practice-Based Competencies that genetic counselors must successfully demonstrate prior to graduation from an accredited genetic counseling training program (ABGC 2009a, b). The "10 Essential Public Health Services" can be easily linked to the ABGC competencies, as seen in Table 1. Thus, the skills gained during genetic counseling training are transferable to public health settings.

One of the first public health settings to employ genetic counselors was state newborn screening programs (Sylvia Au, personal communication). Over the past decade, NBS panels have expanded greatly beyond the original phenylketonuria testing, aided by the use of tandem mass spectrometry (Crowe 2008). Follow-up, such as the evaluation and management services performed by genetic counselors, has been identified by the Council of Regional Networks for Genetics Services as an important component of the NBS system (Crowe 2008). Genetic counselors' skills and experiences lend themselves well to the challenging considerations surrounding NBS, including issues such as reproductive considerations, the inclusion of disorders on the NBS panels, and consent requirements.

As more genetic counselors specialized in public health genetics, it was recognized that a forum for support and collaboration was needed. In 2002, several genetic counselors founded the NSGC Public Health Special Interest Group (PHSIG) so genetic counselors working in public health could support and network with each other. Since then, the PHSIG has grown, maintained a member listserv, provided educational opportunities through the NSGC Annual Education Conference (AEC), awarded funding to students with theses relating to public health, and created a mission statement (NSGC PHSIG 2009).

Genetic Counseling Opportunities in Public Health

Greater opportunities for genetic counselors in public health are evidenced by results of the NSGC's 2006 and 2008 PSS's. In 2006, 6% (75/1,245) of genetic counselors self-identified as working in public health, but the amount of time spent on these activities was not identified (NSGC PSS 2006). The 2008 PSS asked genetic counselor respondents to identify where they spent ≥50% of their time. That year, 0.7% ($n=12$) of clinical and 7% ($n=19$) of non-clinical genetic counselors reported spending ≥50% of their time in a public health/NBS role (NSGC PSS 2008). The 2008 PSS, however, did not capture individuals with public health roles that make up ≤50% of their time, so the actual proportion of genetic counselors spending time on public health activities is likely even higher.

The advent of genomic medicine programs whose intent is to provide personalized genetic information, including genome wide association studies and direct-to-consumer testing, could further expand opportunities for genetic counselors in public health settings (Geransar and Einsiedel 2008; American College of Medical Genetics 2008; Matloff et al. 2007). These diverse settings have the potential to increase the demand for public health genetic counselors, calling for the multiplicity of skills learned in genetic counseling training programs to be utilized in these roles (e.g., communication, risk evaluation, education, case management, assessment, identification of resources, interpretation, interviewing, advocacy, and research, among others) (ABGC Practice-Based Competencies 2009).

In 2009, the Co-Chairs of the NSGC PHSIG recognized the current and future important opportunities for genetic counselors in public health. To gain more information about the public health activities in which NSGC members currently participate, individuals on the PHSIG Listserv were surveyed. The goal of this study was to identify the work settings and public health activities in which genetic counselors participate. This is the first formal survey to describe the specific public health activities in which genetic counselors participate. The results provide a better understanding of genetic counselor's public health activities and responsibilities. In this paper, we report the work settings and public health activities of participants. We also discuss the participants' best reported sources of learning for their public health positions.

Methods

This project was approved by the Hawaii Department of Health Institutional Review Board.

Sample

The population of interest in this study included genetic counselors whose primary work interest was public health genetics. Members of the NSGC with an interest in public health genetics have the opportunity to become PHSIG members and join the PHSIG listserv. A survey was sent to the 46 members of the NSGC PHSIG who participate in the electronic listserv. Forty-three individuals responded.

Instrumentation

A literature review was conducted to determine the public health activities of genetic counselors within public health

Table 1 ABGC Practice-based Competencies and Their Applications to the Institute of Medicine's "10 Essential Public Health Services"

a. ABGC Competency Domain I: Communication	**Essential Public Health Service**
1. Can establish a mutually agreed upon genetic counseling agenda with the client	7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
2. Can elicit an appropriate and inclusive family history	2. Diagnose and investigate health problems and health hazards in the community
3. Can elicit pertinent medical information including pregnancy, developmental, and medical histories	2. Diagnose and investigate health problems and health hazards in the community
4. Can elicit a social and psychosocial history	2. Diagnose and investigate health problems and health hazards in the community
5. Can convey genetic, medical, and technical information including, but not limited to, diagnosis, etiology, natural history, prognosis, and treatment/management of genetic conditions and/or birth defects to clients with a variety of educational, socioeconomic, and ethnocultural backgrounds	3. Inform, educate, and empower people about health issues
6. Can explain the technical and medical aspects of diagnostic and screening methods and reproductive options including associated risks, benefits, and limitations	3. Inform, educate, and empower people about health issues
7. Can understand, listen, communicate, and manage a genetic counseling case in a culturally responsive manner	8. Assure competent public and personal health care workforce
8. Can document and present case information clearly and concisely, both orally and in writing, as appropriate to the audience	3. Inform, educate, and empower people about health issues
9. Can plan, organize, and conduct public and professional education programs on human genetics, patient care, and genetic counseling issues	3. Inform, educate, and empower people about health issues; 4. Mobilize community partnerships and action to identify and solve health problems; 5. Develop policies and plans that support individual and community health efforts; 6. Enforce laws and regulations that protect health and ensure safety; 8. Assure competent public and personal health care workforce

b. ABGC Competency Domain II: Critical-thinking Skills	**Essential Public Health Service**
1. Can assess and calculate genetic and teratogenic risks	1. Monitor health status to identify and solve community health problems; 2. Diagnose and investigate health problems and health hazards in the community
2. Can evaluate a social and psychosocial history	1. Monitor health status to identify and solve community health problems; 2. Diagnose and investigate health problems and health hazards in the community
3. Can identify, synthesize, organize and summarize pertinent medical and genetic information for use in genetic counseling	1. Monitor health status to identify and solve community health problems; 2. Diagnose and investigate health problems and health hazards in the community
4. Can demonstrate successful case management skills	1. Monitor health status to identify and solve community health problems; 2. Diagnose and investigate health problems and health hazards in the community
5. Can assess client understanding and response to information and its implications to modify a counseling session as needed	2. Diagnose and investigate health problems and health hazards in the community; 3. Inform, educate, and empower people about health issues; 9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services
6. Can identify and access local, regional, and national resources and services	7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable; 10. Research for new insights and innovative solutions to health problems

Table 1 (continued)

7. Can identify and access information resources pertinent to clinical genetics and counseling	7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable; 10. Research for new insights and innovative solutions to health problems
c. ABGC Competency Domain III: Interpersonal, Counseling and Psychosocial Assessment Skills	**Essential Public Health Service**
1. Can establish rapport, identify major concerns, and respond to emerging issues of a client or family	2. Diagnose and investigate health problems and health hazards in the community; 3. Inform, educate, and empower people about health issues; 4. Mobilize community partnerships and action to identify and solve health problems; 7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
2. Can elicit and interpret individual and family experiences, behaviors, emotions, perceptions, and attitudes that clarify beliefs and values	2. Diagnose and investigate health problems and health hazards in the community; 3. Inform, educate, and empower people about health issues
3. Can use a range of interviewing techniques	2. Diagnose and investigate health problems and health hazards in the community
4. Can provide short-term, client-centered counseling and psychological support	2. Diagnose and investigate health problems and health hazards in the community; 3. Inform, educate, and empower people about health issues; 7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
5. Can promote client decision making in an unbiased, non-coercive manner	3. Inform, educate, and empower people about health issues
6. Can establish and maintain inter- and interdisciplinary professional relationships to function as part of a health-care delivery team	4. Mobilize community partnerships and action to identify and solve health problems; 5. Develop policies and plans that support individual and community health efforts; 6. Enforce laws and regulations that protect health and ensure safety; 8. Assure competent public and personal health care workforce; 9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services; 10. Research for new insights and innovative solutions to health problems
d. ABGC Competency Domain IV: Professional Ethics and Values	**Essential Public Health Service**
1. Can act in accordance with the ethical, legal, and philosophical principles and values of the profession	5. Develop policies and plans that support individual and community health efforts; 6. Enforce laws and regulations that protect health and ensure safety; 8. Assure competent public and personal health care workforce; 9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services
2. Can serve as an advocate for clients	4. Mobilize community partnerships and action to identify and solve health problems; 5. Develop policies and plans that support individual and community health efforts; 7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
3. Can introduce research options and issues to clients and families	3. Inform, educate, and empower people about health issues; 10. Research for new insights and innovative solutions to health problems

Table 1 (continued)

4. Can recognize his/her own limitations in knowledge and capabilities regarding medical, psychosocial, and ethnocultural issues and seek consultation or refer clients when needed	7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable; 8. Assure competent public and personal health care workforce
5. Can demonstrate initiative for continued professional growth	8. Assure competent public and personal health care workforce; 9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services; 10. Research for new insights and innovative solutions to health problems

settings. No previous studies assessing the activities, work settings, roles, or skill-sets of genetic counselors in public health settings were identified.

A novel quantitative survey was created (Appendix) to identify the work settings and public health activities of genetic counselors associated with the PHSIG. Two questions were adapted from the NSGC PSS; the remaining questions were developed by the PHSIG Co-Chairs. The survey consisted of 29 questions (22 multiple-choice, four open-ended, and three yes/no). The open ended questions asked respondents 1) their percent full time equivalent (FTE) 2) what percent of their salary was grant funded, 3) their percent FTE if they were involved in both clinical and non-clinical work settings, and 4) to provide their contact information if they were interested in participating in future PHSIG activities.

A skip pattern was imbedded into the survey so participants were not burdened with non-relevant questions, thus taking them less than 5 minutes to complete. Participants were asked about their employment setting, whether their position was clinical or non-clinical, the funding source for their position, public health activities in which they participate, where they learned the skills for those activities, and the public health activities in which they would like to see the PHSIG participate.

The survey was piloted with two genetic counselors working in public health programs. With minor word changes incorporated, the revised survey was administered to the PHSIG Listserv.

Procedures

A link to the survey was posted to the Listserv for 3 weeks in April 2009 and 2 weeks in July 2009 on Zoomerang, an online survey software program. Reminder emails were sent to the Listserv 1 week after each survey link posting.

Data Analysis

Identifying information was removed from the responses during data entry. Quantitative data analysis included descriptive statistics (means, medians, and modes) and common measures of variability (ranges, standard deviations).

Results

Sample Demographics

At the time of survey distribution, the PHSIG had 49 dues-paying members with "Full" or "New Genetic Counselor" status. Of the 49 members, 46 received Listserv postings. "Student" members of the NSGC who have an interest in public health genetics can also participate on the PHSIG Listserv, but they were not eligible to participate in the survey.

A total of 43 responses were received. Eleven surveys were excluded due to partial completion (n=6), completion by a graduate student (n=1) or participants responding twice (n=4). Therefore, 32 completed surveys were received from the 46 eligible Listserv members, for a usable response rate of 70% (32/46).

Three percent of the NSGC PHSIG respondents were male, compared to 5% of the NSGC general membership (2008 NSGC PSS). Seventy two percent (23/32) of respondents work full time. Ethnicity of the PHSIG respondents is not known.

Characteristics of Primary Work Settings

Forty-one percent (13/32) of respondents worked in a University Medical Center, which is similar to the NSGC PSS finding of 39% of NSGC general members working in this setting. While the work settings of PHSIG genetic counselors have similarities to those of the general membership, there are also differences, as seen in Table 2. The PHSIG respondents were significantly more likely than 2008 PSS respondents to work in a Government Agency or health care center (p=0.031, 95% confidence). Of the 32 respondents, 53% (17/32) were funded by grants or appropriated funds, compared to general NSGC members, only 5% of whom are wholly and 13% of whom are partially grant funded. Forty-seven percent (8/17) of respondents with

Table 2 Work Setting Comparisons Between the 2008 NSGC PSS and the PHSIG

Primary work setting	NSGC PSS (%)	NSGC PHSIG (%)
University medical center	37	41
Private hospital/medical facility	19	9
Public hospital/medical facility	14	6
Diagnostic laboratory	9	9
Physician's private practice	6	3
Health maintenance organization	4	0
Not-for-profit organization (not otherwise specified)	2	6
University/non-medical center	2	9
Government organization or agency	2	16
Research development/ biotechnology company	0.7	0
Pharmaceutical company	0.6	0
Private practice—self-employed	0.4	0
Internet/website company	0.4	0
Outreach/satellite/field clinic	0.4	0
Health advocacy organization	0.2	3

grant-funded positions were 100% grant-funded. Grant-funded positions were primarily funded by federal grants (71% or 12/17), most commonly by the Centers for Disease Control and Prevention (CDC) (58% or 7/12), National Institutes of Health (NIH) (42% or 5/12), or Health Resources and Services Administration (HRSA) (33% or 4/12). Positions were also funded by foundations (5/12) and state funds (3/12). Five positions were funded by more than one grant.

Fifty-three percent (17/32) of respondents had a non-clinical (i.e., does not counsel patients) position, 28% (9/32) had a mixture of clinical and non-clinical responsibilities, and 19% (6/32) had clinical positions. In contrast, the 2008 NSGC PSS indicates that 18% of general NSGC members hold a non-clinical position, while 82% counsel patients. Of those respondents in positions with a mixture of clinical and non-clinical work, the ratios varied from 20/80 to 80/20 (clinical/non-clinical). Of the 17 respondents in a strictly non-clinical position, 24% (4/17) work on a grant that researches a specific disease group or condition, while 76% (13/17) do not.

Of the nine respondents whose positions included a mixture of clinical and non-clinical work, 56% (*n*=5) worked in a genetics clinic, 44% (*n*=4) worked in a specialty clinic, 22% (*n*=2) worked in a genetic counseling private practice, and 11% (*n*=1) provided genetic counseling over the telephone. Of the nine respondents, 56% (*n*=5) counseled adult patients, 44% (*n*=4) counseled pediatric patients, and 20% (*n*=2) counseled prenatal and/or preconception patients. Of the nine respondents who worked in a mixed clinical/non-clinical role, 67% (*n*=6) worked on a grant that researches a specific disease group or condition, while 33% (*n*=3) did not. Respondents could choose more than one answer.

In the clinical/non-clinical mixed work category, three of the five respondents who counseled adult patients said the most common referral indication was cancer. All three saw patients for breast/ovarian cancer and colorectal cancer and two of the three also saw patients with other cancer syndromes (e.g., Li-Fraumeni, Multiple Endocrine Neoplasm). All four respondents in this category who saw pediatric patients counseled patients with developmental delay, and three also counseled patients with chromosome disorders. The two respondents in this category who counseled prenatal and/or preconception patients reported advanced maternal age and serum screening as the most common indications.

Of the six respondents reporting a strictly clinical position, five worked in a specialty clinic, two worked in a genetics clinic, and one worked in a primary care practice. All six counseled adult patients and saw patients referred for cancer indications. The types of cancer specified were breast/ovarian cancer, colorectal cancer, and "other", including rare syndromes, kidney, gastric and thyroid cancers. Three of the six respondents reporting a strictly clinical position counseled pediatric patients. Indications for referral included developmental delay, chromosome disorders, single gene disorders, and cancer. One respondent in this category counseled prenatal and/or preconception patients. Referrals included advanced maternal age, serum screening and ultrasound findings.

Public Health Activities

Thirty-two respondents reported participation in a number of public health activities. In descending order of frequency, they include: educating healthcare professionals (84%, *n*=27); educating community members (62%, *n*=20); participating in research (53%, *n*=17); writing grants (53%, *n*=17); administering grants (38%, *n*=12); developing genetics public policy (34%, *n*=11); participating in state genetics needs assessments (31%, *n*=10); developing research protocols (28%, *n*=9); participating in chronic disease programs (22%, *n*=7); providing technical assistance of public health activities (22%, *n*=7); participating in newborn screening (19%, *n*=6); and involvement with lobbying (9%, *n*=3). "Other" responses (*n*=5) included quality assurance of prenatal genetic services, birth defects prevention month campaign, education of students and researchers, and cancer genetic counseling for underserved residents.

Learning Public Health Skills

When asked if their public health positions necessitated learning new skills that were not taught in their genetic counseling training program, 81% (26/32) of respondents said "Yes." When asked what the best sources of information that helped the respondents learn their skills, the top two sources were reported to be public health colleagues (58%, 15/26) and "going to a meeting" (54%, 14/26).

The 14 respondents who reported that going to a meeting was a good source of information for learning new skills identified 17 different types of meetings: NSGC AEC (*n*=8); American College of Medical Genetics (*n*=4); American Society of Human Genetics (*n*=3); National Coalition of Healthcare Professional Education in Genetics (*n*=3); American Public Health Association (*n*=2); The Institute of Medicine (*n*=2); Collaborative Group of the Americas on Inherited Colorectal Cancer (*n*=1); International Society for Gastrointestinal Hereditary Tumours (*n*=1); Ethical, Legal and Social Issues (*n*=1); Society of Maternal Fetal Medicine (*n*=1); The American Institute of Ultrasound in Medicine (*n*=1); Council of Regional [Genetic] Networks (CORN) including Great Plains Genetic Services Network (GPGSN) and Heartland Genetics (*n*=1); Academy Health (*n*=1); Maternal Serum Screening by Foundation for Blood Research (*n*=1); Newborn Screening Collaborative (*n*=1); State licensure meetings (*n*=1); and, Local training (*n*=1).

Additional sources for learning a new skill mentioned by respondents included lab directors, physicians, researchers, the Internet, other genetic counselors, an additional graduate degree (specifically a degree in public health), non-genetic counseling colleagues or non-provider colleagues, literature searches or federal/regional public health genetics publications, continuing education, writing/editing training, training in statistical methods, Institutional Review Board training sessions, committee experience, and networking outside of the field.

Discussion

This is the first formal survey to identify the specific work settings and public health activities of genetic counselors who work in the public health specialty area. As more genetic counselors enter public health settings, it will be important to further delineate their participation in public health activities, including the skills needed to be successful at these activities and where/how those skills can be learned. Responses to this survey provide insight into some of the current activities of public health genetic counselors, as well as the resources they used to learn new knowledge and skills respondents did not believe were taught in genetic counseling training programs.

Public health genetics is a growing field. In the past, public health genetics was mainly defined by NBS programs. More recently, genetics professionals have forged their way into different applications of public health genomics, including disease surveillance, epidemiological studies, program and policy development, education of the public and providers, assuring access to genetic services in underserved populations, and genetic test and service evaluation (Centers for Disease Control and Prevention 2009). The diversity of opportunities for genetic counselors interested in pursuing a career in public health reflects both the expansion of public health genetic programs from the original NBS programs, as well as the adaptability of genetic counselors' skill-sets into this setting.

Given the sheer numbers (almost all of the 4 million infants born each year in the United States are screened) NBS has arguably been the most successful public health initiative to be integrated with genetics (The President's Council on Bioethics 2008). However, only six survey respondents indicated that they work in NBS programs, with one respondent working on a grant pertaining to metabolic conditions/NBS. The majority of respondents were involved in education of healthcare providers and community members, with a smaller number involved in grant writing and administration, research, developing public policy, conducting state genetics needs assessments, developing research protocols, providing technical assistance for public health activities (e.g., grant writing, lobbying) and providing genetic counseling and/or technical assistance within chronic disease programs. Counselors providing genetic counseling and/or technical assistance within chronic disease programs were most commonly providing counseling or education about cancer. This indicates a greater range of roles for public health genetic counselors than the more "traditional" NBS responsibilities would encompass.

Eighty-one percent of participants reported learning skills related to their public health activities outside their genetic counseling training programs. This is not surprising, given the limited time available for elective learning, the already full course schedules in training programs, and the fact that many genetic counselors continue to gain specialized knowledge and skills after they graduate. While the ABGC practice-based skills learned in genetic counseling training programs are compatible and transferable to the public health realm, adaptation of these skills based in the gain of public health knowledge is essential. It may not be realistic for training programs to provide in-depth education to their students in every specialty area. However, as public health genetics continues to expand, it will be important to increase opportunities for interested students to learn about public health genetics and how to adapt their skill set to participate in this specialty area. This includes providing educational opportunities on more specialized topics, in the form of informal rotations, funding for attendance at public health meetings/conferences, encouragement to volunteer within state public health genetics programs, internships within public health genetics programs, development of thesis topics relating to public health genetics, and visits to non-traditional sites.

Participants identified their colleagues and meetings as the best sources of information that helped them learn new public health skills; they gained knowledge from their colleagues and meetings that aided them in the development of a new public health skill. For example, attending a meeting could provide information about the Department of Health and Human Services federal grants portal (grants.gov) and the required components of a grant application. The individual could then use this knowledge when they are working on their skill (i.e., grant writing) in their public health role. The NSGC mentoring program, a service that matches genetic counselors wanting to establish relationships with other genetic counselors for networking or professional development, may be a good avenue for students to gain exposure to genetic counselors already experienced in public health. This program could help students form relationships with their future public health colleagues, from whom they will gain new knowledge with which to adapt their skill set for a public health position.

The NSGC's AEC was one venue mentioned frequently as a resource for genetic counselors to learn new skills. Genetic counselors working in more specialized areas, such as public health, could use this venue to educate others about their roles and public health activities where a genetic counseling skill set can be utilized. The NSGC's PHSIG has taken on an educational role in several ways, including AEC offerings, the development of a grant opportunity for students with a thesis project relating to public health genetics, an open-invitation for students to attend the PHSIG meeting at the AEC, informal one-on-one mentoring for students interested in public health, and an invitation for students to join the PHSIG Listserv without cost. Other continuing education opportunities that could be considered include working with public health colleagues and reading public health publications and journal articles.

In addition to identifying the public health activities of genetic counselors, this survey highlights the differences between the respondents to the 2008 NSGC PSS and the respondents to the PHSIG survey. The work settings of the PHSIG survey respondents had both similarities to and differences from those of the general NSGC membership. While 41% of the PHSIG survey participants worked in a university medical center (similar to the 2008 NSGC PSS results of the general membership) PHSIG respondents were significantly more likely to work for a government agency. Additionally, PHSIG respondents were more likely to work in a university non-medical center or health advocacy program/non-profit, and PHSIG respondents were less likely to work for a private or public hospital. As public health is an approach to medicine that concerns the community as a whole, it is understandable that public health genetic counselors hold a higher percentage of positions located within government agencies, health advocacy programs and non-profits. This may also explain the higher percentage of PHSIG survey respondents, compared to general NSGC members, with non-clinical roles: 81% of PHSIG survey respondents had non-clinical roles while only 18% of the NSGC general membership has a non-clinical role.

Limitations and Research Recommendations

The survey appraised a convenience sample of individuals associated with the PHSIG. The survey did not generate detailed information on all of the roles assumed by genetic counselors in a public health genetics setting. While respondents were asked about the public health activities in which they participated, they were not asked detailed information about their day-to-day functions in order to fully assess their specific public health skills. Participants may have confused "skills" with "knowledge". Participants were not given a list of skills from which to endorse, nor were they given a definition of a "skill". While it is possible that participants did learn new skills, the survey design did not quantify or describe how much more they needed to learn to do their public health jobs.

While this is the first survey of public health genetic counselors to assess their public health activities and work settings, a planned future study will further delineate the necessary skills and knowledge needed to work in a public health setting. Future studies should investigate genetic counselors' post-degree experience and how their experience relates to their perceptions about being prepared for public health responsibilities. Research is also needed to determine how genetic counselors assume public health responsibilities (for instance, voluntarily or mandated; gradually or all at once) and whether these factors affect their perceptions of their professional preparation.

Conclusion

The work settings and activities of public health genetic counselors were compared with those of the NSGC general membership. Differences in work settings were found, with significantly more public health genetics counselors working in government agencies. Genetic counselors involved in public health activities have expanding opportunities as the scope of public health genetics grows. While public health genetic counselors reportedly learn some of their public health skills outside their training programs, the genetic counseling skills that they do learn in formal training (communication, writing, education, data collection) appear to be very transferable to public health settings. These genetic counseling skills can be adapted through the application of knowledge gained through the best sources of learning identified by participants: colleague consultation and attendance at meetings. The NSGC and genetic counseling training programs are encouraged to offer more public health learning opportunities for genetic counselors and genetic counseling students interested in this specialty area.

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Appendix

Survey questions without the embedded skip pattern

1. In what primary employment setting do you work? (Please check one)
    - o University Medical Center
    - o Private Hospital/Medical facility
    - o Public Hospital/Medical facility
    - o Diagnostic Laboratory
    - o Physician's private practice, Specialty: __________________
    - o HMO
    - o University/Non-medical school
    - o Office in a government agency/health care center
    - o Self employed/ Private Practice
    - o Research Development/Biotechnology Company
    - o Pharmaceutical Company
    - o Outreach/Satellite/Field Clinic
    - o Internet/Website Company
    - o Bioinformatics Company/Health Advocacy Organization
    - o Other (please specify): _____________________

2. What is your %FTE? _____%

3. Are you funded by a grant?
    - o Yes
    - o No

4. Please specify the proportion of your salary that is grant funded? ____________%

5. What type of grant is your position funded by? (choose all that apply)
    - o State grant
    - o Federal grant
    - o Foundation (Please specify): _________________________________
    - o Other (please specify): ____

6. Which federal program(s) funds your grant? (check all that apply)
    - o DoD
    - o HRSA
    - o NIH
    - o NIEHS
    - o CDC
    - o Other (please specify): _________________________________

7. What public health activities do you participate in? (choose all that apply)
    - o Lobbying,
    - o Newborn screening,
    - o State genetics needs assessments,
    - o Involvement in chronic disease programs,
    - o Development of genetics public policy,
    - o Research,
    - o Provision of technical assistance
    - o Grant writing
    - o Grant administration
    - o Develop research protocols
    - o Education of healthcare professionals
    - o Education of community members
    - o none
    - o Other (please specify): ____

8. Did you need to learn new skills that were not taught in your genetic counseling training program to participate in these public health activities (e.g. Lobbying, business practices/negotiation)?
    - o Yes
    - o No

9. What were the best sources of information that helped you learn those new skills? (check all that apply)
   - ○ Went to a meeting, which one(s)? (please specify): ____________
   - ○ Internet
   - ○ Other genetic counselors
   - ○ Physicians
   - ○ Laboratory directors
   - ○ Researchers
   - ○ Public health colleagues
   - ○ Other (please specify): ______________________________________

10. Is your position: (choose one)
    - ○ Clinical
    - ○ Non-clinical
    - ○ Both

11. What is your %FTE in the following (proportion should add up to 100%):
    - ○ Clinical _______%
    - ○ Non-clinical (e.g. research, education, etc…) _____%

Clinical questions:

12. Where do you conduct your genetic counseling sessions? *(check all that apply)*
    - ○ Primary Care Practice
    - ○ Genetics Clinic
    - ○ Genetic Counseling Private practice (e.g.my own office off site of the referring physician)
    - ○ Specialty clinic (e.g. cancer, neurology, hematology, etc.)
    - ○ Over the phone
    - ○ Other (please specify): ______________________________

13. What is your patient population? (check all that apply)
    - ○ Adult
    - ○ Pediatric
    - ○ Prenatal
    - ○ Preconception
    - ○ Other (please specify): _________________________________

14. What type of adult patients do you counsel? (*Check all that apply)*
    - ○ Cancer
      - ○ Breast/Ovarian cancer
      - ○ Colorectal cancer
      - ○ Other cancer (please specify): __________________________
    - ○ Cardiovascular disease
    - ○ People who pursued direct-to-consumer genetic testing
    - ○ Diabetes
    - ○ Research participants (e.g. Genome-wide-association study results, disease specific research)
    - ○ Thrombophilia
    - ○ Hemachromatosis
    - ○ Eye diseases
    - ○ Other (please specify)______________________________

15. What type of pediatric patients do you counsel? (*Check all that apply)*
    - ○ Developmental Delay
    - ○ Chromosome disorders
    - ○ Single Gene Disorders
    - ○ Metabolic conditions (newborn screening)
    - ○ Specialty clinics
    - ○ Other (Please specify): ____

16. What type of prenatal or preconception patients do you counsel? (*Check all that apply)*
    - ○ Advanced maternal age
    - ○ Serum screening
    - ○ Ultrasound findings
    - ○ Infertility
    - ○ Other (please specify): ____

Non-clinical questions:

17. Do you work on a grant that researches a specific disease group or condition?
    - Yes
    - No

18. Which disease group or condition do you research?
    - Cancer
        - Breast/Ovarian cancer
        - Colorectal cancer
        - Other cancer (please specify): ________________________
    - Cardiovascular disease
    - People who pursued direct-to-consumer genetic testing
    - Diabetes
    - Research participants (e.g. Genome-wide-association study results, disease research)
    - Thrombophilia
    - Hemachromatosis
    - Eye diseases
    - Developmental Delay
    - Chromosome disorders
    - Single Gene Disorders: please specify: _____________
    - Metabolic conditions (newborn screening)
    - Other (Please specify): ____

Both clinical and non-clinical questions:

19. Where do you conduct your genetic counseling sessions? *(check all that apply)*
    - Primary Care Practice
    - Genetics Clinic
    - Genetic Counseling Private practice (e.g. my own office off site of the referring physician)
    - Specialty clinic (e.g. cancer, neurology, hematology, etc.)
    - Over the phone
    - Other (Please specify): ____

20. What is your patient population? (check all that apply)
    - Adult
    - Pediatric
    - Prenatal
    - Preconception
    - Other (Please specify): ____

21. What type of adult patients do you counsel? (*Check all that apply)*
    - Cancer
        - Breast/Ovarian cancer
        - Colorectal cancer
        - Other (please specify): ____________________________
    - Cardiovascular disease
    - People who pursued direct-to-consumer genetic testing
    - Diabetes
    - Research participants (e.g. Genome-wide-association study results, disease specific research)
    - Thrombophilia
    - Hemachromatosis
    - Eye diseases
    - Other (please specify)____________________________ consult

22. What type of pediatric patients do you counsel? (*Check all that apply)*
    - o Developmental Delay
    - o Chromosome disorders
    - o Single Gene Disorders
    - o Metabolic conditions (newborn screening)
    - o Specialty clinics
    - o Other (Please specify): ____

23. What type of prenatal or preconception patients do you counsel? (*Check all that apply)*
    - o Advanced maternal age
    - o Serum screening
    - o Ultrasound findings
    - o Infertility
    - o Other (Please specify): ____

Non-clinical questions:

24. Do you work on a grant that researches a specific disease group or condition?
    - o Yes
    - o No

25. Which disease group or condition do you research? (choose all that apply)
    - o Cancer
        - o Breast/Ovarian cancer
        - o Colorectal cancer
        - o Other cancer (please specify): ________________________
    - o Cardiovascular disease
    - o People who pursued direct-to-consumer genetic testing
    - o Diabetes
    - o Research participants (e.g.Genome-wide-association study results, disease specific research)
    - o Thrombophilia
    - o Hemachromatosis
    - o Eye diseases
    - o Developmental Delay
    - o Chromosome disorders
    - o Single Gene Disorders: please specify: ________________
    - o Metabolic conditions (newborn screening)
    - o Other (Please specify): ____

SIG activities:

26. In which activities would you like to see the Public Health SIG participate? (choose all that apply)
    - o Speakers bureau
    - o Development of practice guidelines
    - o Educational Breakout Session at the annual conference
    - o Preconference symposium at the annual conference
    - o Lobbying
    - o Writing peer review articles
    - o Writing articles for *Perspectives in Genetic Counseling*
    - o None
    - o Other (Please specify): ____

27. Do you have experience with: (choose all that apply)

○ Creating or participating in a speakers bureau
○ Creating practice guidelines
○ Submitting and coordinating an Educational Breakout Session
○ Submitting and coordinating a Preconference symposium
○ Lobbying for a particular topic
○ Writing peer review articles
○ Writing articles for *Perspectives in Genetic Counseling*
○ None
○ Other (please specify): ____

28. Would you be willing to participate in: (choose all that apply)

○ Creating or participating in a speakers bureau
○ Creating practice guidelines
○ Submitting and coordinating an Educational Breakout Session
○ Submitting and coordinating a Preconference symposium
○ Lobbying for a particular topic
○ Writing peer review articles
○ Writing articles for *Perspectives in Genetic Counseling*
○ None
○ Other (please specify): ____

29. Please list your name and email address if you wish to be contacted should the Public Health SIG pursue an activity of your interest

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