

UNIVERSITY OF CINCINNATI

August 14, 2003

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Master of Science
in Medical Genetics
It is entitled Research Values and Practices of
Genetic Counselors

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Research Values and Practices of Genetic Counselors

A thesis submitted to the

Division of Research and Advanced Studies
of the University of Cincinnati

in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Genetic Counseling Program
in the Department of Analytical and Diagnostic Sciences
of the College of Allied Health Sciences

2003

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UMI Number: EP26311

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ABSTRACT

Genetic counselors' clinical expertise continues to expand, and now includes research as a primary component of practice. We designed a comprehensive web-based survey to describe the research values and practices of genetic counselors. We assessed genetic counselors' opinions regarding research and their interest in obtaining additional advanced degrees. Respondents were asked to self-report their current research involvement, their specific roles, and their interest in performing research in the future (N=531). The study showed that a significant number of respondents (84.5%) have conducted research at some point, and 69.4% of respondents plan to perform more research in the future. The study also demonstrates that 34.1% of genetic counselors have high interest in a hypothetical PhD in Genetic Counseling, suggesting that our profession is primed for the development of doctoral degree training programs. Further efforts are needed to provide research training support for genetic counselors, including advanced graduate education.

ACKNOWLEDGEMENTS

I would like to thank the members of my research advisory committee for their guidance and support throughout this project. Nancy Steinberg Warren inspired the original idea for this project and helped me create a formal research proposal from a classroom lecture. She willingly answered my numerous questions and revised numerous drafts of the proposal, survey, and thesis. Jennifer Gamm provided encouragement and feedback throughout the challenges of the research process. Dr. Ralph Buncher was instrumental in developing the study design and provided assistance with data analysis. Dr. Carl Huether continually supported the vision of this project and provided valuable assistance in developing the manuscript. Dr. Ruthann Blough Pfau was always enthusiastic and provided friendly support. Special thanks to Doug Hott, University of Cincinnati webmaster, for development of the web-based survey, server maintenance, and database creation. His computer knowledge and assistance were much appreciated. I would also like to acknowledge Nancy Steinberg Warren for providing financial support by funding this project through a University Research Council grant. I would not have been able to complete this project without the friendship and support of my classmates. I am thankful for their humor, willingness to listen, and ability to find the positive in every situation. Finally, I would like to thank my family for their constant patience and encouragement over the past two years. They understand that I always work on my own time schedule, and I would not have completed this program without their love and support.

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INTRODUCTION

The health care industry is changing rapidly, and budgets at every hospital and medical center have become subject to scrutiny. Simultaneously, new health care practices and professions are emerging as a result of recent scientific and technological advances. Since allied health disciplines are competing for a limited pool of resources, health professions which demonstrate objective evidence of their effectiveness will have a competitive financial advantage.⁶ Since third-party payers increasingly rely on outcome data to justify health care costs, research is an important factor driving a profession's ability to negotiate for reimbursement of clinical services.³ Genetic counseling is a new clinical profession with little empirical evidence to guide its practice.³ There is a lack of scientific data to suggest the most effective counseling strategies or the ways in which clients benefit from genetic counseling services. Genetic counseling is similar to many other allied health professions which are unable to fully accept the responsibility for generating the knowledge base for their own professional practices.²¹ To date, the published literature that addresses the process and outcomes of genetic counseling has been generated primarily by social science researchers.³ Without active involvement in generating these kinds of scientific data, it is difficult for the profession to convincingly demonstrate its importance in the health care system.

The emerging practice of genetic counseling has much to gain from developing a strong foundation in research. Research in counseling theory, process studies, and outcomes requires thorough study.³ Genetic counselors who design and participate in research will be the leaders who advance the discipline and determine its direction. In addition, these genetic counselors will achieve greater professional visibility and are ideal

candidates for faculty positions at academic institutions.^{14, 24} Unfortunately, comprehensive information about the involvement of genetic counselors in research is lacking.

Previous studies from other allied health disciplines have identified a number of factors that influence research practice and productivity. These include cumulative advantage (graduate training, mentoring, academic resources, years of experience), psychological/individual (intrinsic motivation, personal preferences, age, academic rank, gender), and reinforcement (institutional emphasis, contacts with colleagues, early research productivity).²⁴ Other studies from nursing and physical therapy have identified factors such as the relevance of research to the clinical practice, the importance of research to the status of the profession, the ability of the professional organization to support research, and the professional's personal obligation for conducting and generating research.¹² Primary reasons for noninvolvement in research were found to be lack of time, lack of skills, and lack of interest.²⁴

Previous research has demonstrated that it may be very difficult for practicing clinicians to initiate a research career and perform independent research. Often, they must define their own research roles and functions, obtain resources and funding, and establish support networks in the absence of mentors – all while maintaining their well-defined clinical and administrative roles.²⁸ Acquiring funding may prove to be especially difficult for the novice researcher, especially when major funding agencies use an applicant's previous funding record and publications as major evaluation criteria for evaluating applications. Therefore, new researchers without an existing track record may find it very difficult to prioritize and establish their own research interests.¹⁴ In the field

of genetics, additional barriers beyond inexperience must be considered. Ninety-five percent of genetic counselors are women who have achieved the terminal degree of the profession, a M.S. degree. In contrast, established researchers are primarily physicians who have achieved a M.D. or PhD degree. Many genetic counselors are generally unfamiliar with research methods and inexperienced in conducting independent research.⁸ The American Board of Genetic Counseling has only recently instituted a research requirement for accredited programs. The vast majority of genetic counselors are employed in clinical settings in positions that do not include research as a primary role.¹⁰

The genetic counseling literature has a significant void regarding the topic of research. Very few studies have investigated research in genetic counseling, and most of these studies have been conducted by individuals from outside the profession.^{3, 35} One can speculate that studies conducted by genetic counselors regarding the process and outcomes of genetic counseling are likely to have greater significance and be more relevant to the profession. No studies have specifically focused on the type or amount of research that is being conducted by genetic counselors. Particularly absent are studies that focus on factors that may influence genetic counselors to become engaged in research.²⁴

The purpose of this study is to describe the research values and practices of genetic counselors by assessing the amount and types of research activities they perform along with barriers to performing research. We consider that “recent graduates” (referring to genetic counselors who graduated from a training program five years ago or less) may be more likely than “experienced graduates” (referring to those who graduated more than five years ago) to have been taught research methods and to have formally

conducted research during graduate school. In contrast, experienced graduates of genetic counseling programs may be more likely than recent graduates to have the career-related experience, time, and desire to perform research in order to contribute to the profession. Therefore, this study tests the null hypothesis that there is no difference in research involvement between recent graduates and experienced graduates. The study will test this hypothesis by: (1) assessing each respondent's research experiences during graduate school, (2) ascertaining the specific types of research currently conducted by genetic counselors, (3) quantifying the amount of time genetic counselors devote to performing research, and (4) assessing the reasons why genetic counselors do or do not perform research.

METHODS

Study Design and Sample

The project was approved by the University of Cincinnati Institutional Review Board – Social and Behavioral Sciences (UC IRB-S) prior to initiation. The study was cross-sectional in design and the subjects were genetic counselors ascertained through the membership registry of the National Society of Genetic Counselors (NSGC). All full members were eligible for participation. Because nearly all practicing genetic counselors belong to the NSGC, this method of ascertainment is representative of practicing genetic counselors.²⁷

Measures

A self-reported, web-based questionnaire was developed (Appendix A). A webmaster was employed to design the web-based questionnaire, which was hosted on a secure University server. Prior to use, the questionnaire was reviewed by experts in epidemiology, statistics, and genetics. It was also pilot tested with 4 genetic counselors from the Cincinnati Children's Hospital Medical Center. The questionnaire consisted of 42 questions, the majority of which were closed-ended with respondents choosing options from a pre-determined list or using a 5-point Likert scale. Two questions were open-ended. The questionnaire collected data on research experiences, skills, roles, graduate degree training, job characteristics, future advanced training plans, and basic demographics.

Procedures

A list of full members' email addresses was purchased from the NSGC. There are 1346 full members who allow their contact information to be sold on this list. An email cover letter and weblink to the questionnaire was sent to each individual. Excluding returned emails and undeliverable addresses, 1200 emails were sent. After two weeks, we had received 338 responses (28.2%). A follow-up invitation to participate in the study along with the weblink was addressed to all full members and posted on the NSGC listserv. Listserv messages are theoretically sent to all 1623 full members of the organization through email, although there is no way to ensure that each person receives every message. We received a total of 531 responses (theoretical response rate of 32.7%).

The email invitation to participate explained the aim of the study and its voluntary nature (Appendix B). Subjects understood that by completing and submitting the survey, they were giving their consent to participate. A direct weblink to the questionnaire was included in the body of the letter. When subjects clicked on the weblink, a separate window showing the questionnaire immediately opened. This window was not connected to the original email message. Subjects completed the questionnaire and submitted their responses when complete. All responses were anonymous. The questionnaires did not request identifying information and could not be traced back to the original email. Each response was stored in a secure database upon submission.

Data Analysis

All data were initially stored in a text file database on the secure University server. Data analysis was performed using the SPSS system for Windows, version 11.0. Descriptive statistics, including frequency distributions, were computed for most questions. All questions were analyzed based on the number of respondents who answered each question. Chi-square analysis was used to examine interactions between key variables and determine the statistical significance of differences between groups. The threshold for statistical significance was set at the $p < 0.05$ level.

RESULTS

Demographics

The characteristics of the study population were compared to demographics from the 2002 NSGC Professional Status Survey²⁷ and are shown in Table I. Differences were not statistically significant; therefore it is assumed that the study sample is representative.

Job Characteristics

As shown in Figure 1, respondents were asked to identify their primary genetic counseling role at their current job ($n=527$). “Clinical” was the most common identified role with 353 responses (67.0%), while the second most common identified role was “Research/Study Coordinator” with 71 responses (13.5%). Chi-square analysis did not identify a statistically significant difference between gender and choice of primary role ($p=0.38$). The majority of respondents (87.0%) reported having regular contact with patients ($n=529$). Out of 524 respondents, 130 (24.8%) indicated that they hold a faculty appointment.

In order to quantify the amount of time genetic counselors are committing to research, respondents were asked to report the amount of work time (based on a 5-point scale of 25% increments) that they commit to each genetic counseling role. Later, they were asked to consider their *ideal* genetic counseling position and indicate how much time they would like to commit to each role. The results are summarized in Table II. Currently, 46.6% of respondents indicated that they are not spending any time performing research. However, only 16.8% would *ideally* want to spend no time on research. The data illustrate that the majority of respondents (77.4%) would like to spend 25%-50% of

their work time performing research, although only 39.0% of respondents are currently devoting effort in this range. Respondents indicated that those who are currently committing 0% or 75%-100% of their work time to performing research tended to gravitate toward the middle 25%-50% range in their *ideal* position (Figure 2).

In order to address our null hypothesis, responses were divided into two groups based on the respondents' year of graduation. "Recent" graduates completed their training within the past 5 years, and "experienced" graduates completed their training 6 or more years ago. Chi-square analysis was conducted to see if graduation year affected the amount of research performed. Table III illustrates that there is no significant difference in research involvement between recent graduates and experienced graduates ($p=0.56$).

Additional advanced degree training

Currently, 13 of 522 respondents (2.5%) are enrolled in a post-masters advanced degree program. However, 125 of 513 respondents (24.4%) reported that they plan to enroll in an additional advanced degree program in the future. Respondents were also asked if they would be interested in pursuing a doctoral degree specifically in genetic counseling, if such a degree existed. This option appealed to even more respondents, with 178 of 522 subjects (34.1%) indicating that they would pursue a PhD in Genetic Counseling. Responses are summarized in Figure 3.

Chi-square analysis showed that recent graduates are significantly more likely to be interested in pursuing a PhD in Genetic Counseling than experienced graduates ($p=0.001$). Genetic counselors who have interest in pursuing an additional advanced

degree in the future are significantly more likely to be interested in pursuing a PhD in Genetic Counseling than genetic counselors who are not interested in pursuing an advanced degree in the future ($p=0.002$). Neither the difference between gender and interest in pursuing an advanced degree ($p=0.65$) nor the difference between gender and interest in a PhD in Genetic Counseling was statistically significant ($p=0.74$). Holding a “Clinical” or “Research” primary genetic counseling role was not significant with respect to interest in a PhD in Genetic Counseling ($p=0.14$). Possession of a faculty appointment did not significantly influence interest in a PhD in Genetic Counseling ($p=0.53$). Responses to these questions are illustrated in Table IV.

As shown in Table V, respondents identified various reasons why they plan to pursue an advanced degree ($n=474$). The most common reason, “For personal fulfillment/satisfaction” was indicated by 237 respondents (50.0%). “For career advancement/promotion” was the second most common reason with 192 responses (40.5%). “I don’t ever plan to pursue an advanced degree” was chosen by 181 people (38.2%).

Chi-Square analysis was performed to measure difference between time of graduation and identified reason to pursue an advanced degree. This analysis shows that recent graduates were significantly more likely to have identified “For career advancement,” “To make more money,” and “To pursue another job within the field” as reasons to pursue an advanced degree, as shown in Table V.

57.9% of the total respondents. Subjects who graduated more than five years ago ($n=219$) were termed “experienced graduates” and made up 42.1% of the total respondents.

Respondents were asked how much emphasis their genetic counseling program placed upon preparing them to perform research after graduation ($n=517$). Responses were selected from a 5-point Likert scale from 1 (no emphasis) to 5 (very strongly emphasized) and are summarized in Table VII. The majority of respondents felt their programs did not emphasize research preparation with 293 responses (56.7%). One-hundred four subjects (20.1%) remained neutral, while 120 respondents (23.2%) felt that research was emphasized in their programs. Respondents were also asked how well they thought their training program prepared them to perform research ($n=518$). Responses were summarized as described above (see Table VII). Most respondents (239, 46.1%) did not feel prepared to perform research upon graduation. One hundred-fifteen respondents (22.2%) were neutral, while 164 people (31.7%) felt that their training program had prepared them well to perform research after graduation. Finally, respondents were asked if they felt it was a genetic counselor’s role to perform research ($n=520$). Eighty-two respondents (15.8%) did not feel that it was a genetic counselor’s role to perform research, 238 respondents (45.8%) remained neutral, and 200 respondents (38.5%) did feel that research is a genetic counselor’s role.

Chi square analysis was conducted for all three of these questions to measure differences in responses based on year of graduation. Table VII illustrates that recent graduates were significantly more likely to have felt that their training program placed an emphasis on research than experienced graduates ($p<0.001$). Recent graduates were also

Outlook for the Future

Ninety-five percent (495/521) of respondents anticipate still working in the genetic counseling field in 2 years. However, only 64.8% (335/517) of subjects anticipate still working in the field in 10 years. Respondents identified various reasons why they anticipate no longer working in the genetic counseling field ($n=194$). The most common reason, “No room for promotion” was indicated by 98 respondents (50.5%). “Burnout” was the second most common reason with 73 responses (37.6%).

Chi-Square analysis was performed to measure difference between time of graduation and these reasons. The analysis in Table VI shows that recent graduates were significantly more likely to have identified “To start a family/raise children” and “Pursuing an advanced degree,” while experienced graduates were significantly more likely to have chosen “Retirement” as reasons that they anticipate no longer working in the field in 10 years.

Graduate Training

Respondents were asked to disclose their year of graduation from a specific genetic counseling training program within a predetermined five-year range ($n=520$). With 301 responses (57.9%), the largest group of subjects graduated within the past five years (1997-2002). Ninety-seven respondents (18.7%) graduated six to ten years ago (1996-1992), 53 respondents (10.2%) graduated eleven to fifteen years ago (1991-1987), and 69 respondents (13.3%) graduated more than fifteen years ago (before 1987). The subjects were divided into two groups based on year of graduation. Subjects who graduated within the past five years ($n=301$) were termed “recent graduates” and made up

significantly more likely to feel that their training program had prepared them well to perform research ($p<0.001$). There was no statistically significant difference between graduation year and opinions about research as a genetic counselor's role ($p=0.63$).

Respondents were asked to describe their various research requirements during graduate training ($n=464$). In terms of coursework, 291 subjects (62.7%) completed a statistics or biostatistics course and 147 people (31.7%) took a research design course. Three hundred-forty-eight respondents (75.0%) completed a required thesis, while 16 respondents (3.4%) completed an optional thesis. Ninety-seven respondents (20.9%) described their independent research as "hypothesis driven," while 93 subjects (20.0%) described their independent research as a "descriptive study." One hundred-twenty respondents (25.9%) learned to write a grant or research proposal and 100 respondents (21.6%) submitted a manuscript for publication in a peer-reviewed journal. We conducted a chi-square analysis to see if these experiences differed based on year of graduation. This analysis showed that recent graduates were significantly more likely than experienced graduates to have taken a research design course ($p<0.001$), to have completed a required thesis ($p<0.001$), and to have learned how to write a grant or research proposal ($p<0.001$).

Research Practices

The majority of respondents (84.5%) have performed research with 441 of 522 people indicating that they have performed research at some point in the past. Eighty-one respondents (15.5%) have never performed research. However, 359 of 517 respondents (69.4%) plan to perform research in the future, while 158 respondents (30.6%) do not.

Respondents ($n=508$) classified their various research activities as: clinical research (209, 41.1%), case study/report (175, 34.4%), medical literature review (172, 33.9%), patient or professional education materials (171, 33.7%), quantitative research/survey (155, 30.5%), qualitative research/interviews (147, 28.9%), laboratory-based research (138, 27.2%), natural history of a genetic condition (85, 16.7%), single gene identification study (70, 13.8%), multiple/complex genes identification study (62, 12.2%), counseling theory/outcome study (55, 10.8%), and “other” (28, 5.5%). Forty respondents (7.9%) indicated “none of these responses.”

In Table VIII, respondents indicated the various research roles that they have participated in ($n=514$). The most common roles were “data collection/management” (353, 68.7%), “reporting/presenting results” (330, 64.2%), “manuscript writing” (276, 53.7%), and “subject recruitment” (275, 53.5%). Sixty-two respondents (12.1%) indicated that they have not performed any of these research roles.

Respondents were asked how they gained the afore-mentioned research skills ($n=513$). Most respondents (329, 64.1%) indicated that they learned how to perform these skills “on the job.” Two hundred-thirty-four respondents (45.6%) learned their skills in their genetic counseling training program, 136 people (26.5%) learned them through personal reading/research, 82 (16.0%) attended a conference or workshop, and 83 genetic counselors (16.2%) indicated an “other” means of learning research skills. Fifty-eight respondents (11.3%) do not feel that they possess any of these research skills.

Respondents identified various reasons why they perform research, summarized in Table IX ($n=478$). The most common reason, “Interest in the subject” was chosen by 276 respondents (57.7%). “To contribute to the field” was indicated by 231 respondents

(48.3%) and “Personal development/satisfaction” had 220 responses (46.0%). “I do not perform research” was indicated by 113 respondents (23.6%).

A number of Likert-scale questions addressed various barriers to performing research, writing grants, and writing scientific papers. Responses were selected from a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree) and are summarized in Table X. We analyzed the responses by classifying them into three groups: 1 and 2 as “disagree,” 3 as “neutral,” and 4 or 5 as “agree.” The most common barriers cited were “I don’t have time to do research” with 327 of 502 respondents (65.1%) agreeing, “I don’t have time to write a grant” with 317 of 472 respondents (67.2%) agreeing, and “I don’t have time to write a scientific paper” with 288 of 493 respondents (58.4%) agreeing.

DISCUSSION

Genetic counselors’ interest in conducting independent research and their attitudes toward obtaining a potential doctoral degree in genetic counseling has not been assessed in more than a decade.¹³ The goal of this study was to describe the research values and practices of genetic counselors by assessing their current research involvement, their specific roles, and their interest in performing research in the future. The study also examined genetic counselors’ opinions regarding their future professional plans and their interest in obtaining advanced degrees, including a hypothetical PhD in Genetic Counseling.

Genetic Counselors and Research

Our null hypothesis, that there is no difference in research involvement between recent graduates and experienced graduates, was not rejected. The study showed that there is no significant difference in the amount of time that each group devotes to research; nor is there a significant difference in the amount of time each group would *ideally* like to devote to research. We speculated that recent graduates are significantly more likely to have been taught research methods and to have formally conducted research during graduate school than experienced graduates. The data showed that this assumption is true, as recent graduates are significantly more likely to have taken a research design course, to have completed a required thesis, and to have learned to write a grant or research proposal. We also presumed that experienced graduates would be significantly more likely to have the career-related experience, time, and greater desire to participate in research in order to contribute to the profession. Clearly, experienced graduates have had time to gain professional expertise. However, they do not feel that they have time to perform research, and indicated this as their major barrier to performing research. Although the most common reason to perform research identified was “To contribute to the field,” this response was equally divided between recent and experienced graduates.

This study showed that the vast majority of genetic counselors (84.5%) had performed research at some time in the past or present, including research performed in graduate school. Our results showed that recent graduates are significantly more likely to feel that their genetic counseling training program placed an emphasis on performing research and were significantly more likely to feel prepared to perform research after

graduation than experienced graduates. This suggests that genetic counseling training programs have adapted their research requirements and didactic curricula over the past few years to be more inclusive of research. Indeed, the American Board of Genetic Counseling (ABGC) recently included “research opportunities” as part of the required criteria for genetic counseling program accreditation (www.abgc.net, 2003).

When asked to describe the types of research they are conducting, genetic counselors provided a variety of responses. The most common classifications were clinical research, case study, or review of the medical literature. It appears that many genetic counselors are engaged in research related to patient care. These research findings will need to be incorporated into practice, so that we can provide our patients with the services that have been shown to be effective. This research will establish a scientific basis for the practice of genetic counseling.

We made an effort to quantify the amount of time genetic counselors are committing to research (in 25% increments), and to assess their opinions about this research time. Currently, just under half of all respondents are not spending any time performing research. However, the majority of that group indicated that their *ideal* job would have more research time than is present in their current job. A total of 83.2% of genetic counselors indicated that they would like to spend at least 25% of their work time on research. Most of this group (77.4%) would like to devote 25% to 50% of their work time to performing research. The data also showed that respondents who are currently spending 75% to 100% of their work time would ideally like to be spending only 25% to 50%. It appears that the ideal amount of research work time tends to gravitate toward the mean of 25%. A limitation of this assessment is that respondents were required to choose

their amount of work time from a 5-point scale of set percentages (0%, 25%, 50%, 75%, and 100%). A few respondents indicated that the interval scale was too large, and that they had difficulty using the available responses.

Over two-thirds of genetic counselors (69%) plan to perform research at some point in the future, while 31% of respondents do not have any research plans for the future. Previous studies from other allied health disciplines identified the primary reasons for noninvolvement in research to be lack of time, lack of skills, and lack of interest.²⁴ However, our data shows that genetic counselors' main barrier to conducting research is lack of time. The majority of respondents felt that they possessed research skills and had interest in performing research. Lack of time was also the most frequently-cited barrier to writing a scientific paper for publication. However, the majority of respondents identified additional barriers to grant writing. Besides lack of time to write grants, the majority of the respondents indicated that they did not know how to write a grant, did not have interest in writing grants, or had not had the opportunity to write a grant. These findings are consistent with previous studies that have found that acquiring funding to support scholarly efforts may be especially difficult for novice researchers.¹⁴

Doctoral Degree History

Relevant literature on the topic of developing a new doctoral degree in an allied health profession comes from the fields of nursing, physical therapy, and occupational therapy. The nursing field offers advanced training in the form of a PhD or clinical doctorate. The PhD is considered to be an academic degree and there is no higher degree awarded by a university. It is a research-oriented degree that involves disciplined

learning and depth of knowledge. Nurses with this degree are often principal investigators who conduct research to expand nursing's knowledge base.¹¹ A clinical doctorate is a professional degree, which emphasizes advanced clinical practice with the integration of research.¹¹ The fields of physical therapy and occupational therapy offer the Doctor of Physical Therapy and Doctor of Occupational Therapy degrees, respectively. Literature from these fields noted that these clinical doctorates were considered by the professions to be another pathway to better serve the patient, the profession, and society as a whole.³⁴ For each of these fields, the creation of a doctoral degree helped to expand the profession beyond the clinical realm.

In 1989, the Education Committee of the National Society of Genetic Counselors (NSGC) met to discuss a variety of issues, including the need and desirability of additional advanced graduate education in genetic counseling.³⁵ This meeting identified potential advantages and disadvantages of the doctoral degree. The advantages included greater opportunity in academic settings to acquire teaching roles and grant funding, the development of research skills, and personal satisfaction/professional recognition. The disadvantages included devaluing the master's-level genetic counselor, replacing the master's degree as the terminal degree for clinical practice, diverting practicing clinical counselors into school again, and creating genetic counselors who have doctoral training but no clinical experience.³³ That same year, a survey of full NSGC members assessed the perceived need for a doctoral degree and individual interest in pursuing a doctoral degree.¹³ At that time, 54.4% of respondents indicated a need for a doctoral degree in genetic counseling, and 44.3% of respondents indicated they would pursue such a degree. The reasons most often cited for seeking a PhD in Genetic Counseling were professional

recognition, a desire to specialize in a particular area, and greater depth of knowledge. The authors concluded that the creation of a doctoral degree would be a natural progression for the profession and would strengthen the position of genetic counseling within the academic community.¹³ However, further discussions regarding the feasibility of a doctoral degree in genetic counseling have not been published.

Current Thoughts on a PhD in Genetic Counseling

Currently, only a very small group of respondents (2.5%) are in the process of pursuing an additional advanced degree. The degrees included MPH, MBA, MSc, JD, and PhD in Genetics, Epidemiology, or Psychology. However, almost a quarter of all respondents are planning to pursue an additional advanced degree in the future. Many indicated that they are considering the fields of public health, epidemiology, psychology, counseling, business, ethics, and education. This is a large number of genetic counselors who plan to formally return to school someday, and shows that they are motivated to work within current confines to continue their education. It is of importance that an even greater number of respondents (34.1%) would pursue a PhD in Genetic Counseling, if this degree existed. This high level of interest may be due to the specificity of this degree to the profession.

Almost 70% of respondents plan to conduct research in the future, and 40% of this group of genetic counselors would pursue a PhD in Genetic Counseling. Respondents indicated that their main reasons for conducting research were (1) to contribute to the field, (2) for personal satisfaction/development, and (3) to diversify their job responsibilities. Although this research performance will help the profession grow

and advance within the healthcare and academic arenas, it will also serve to fulfill genetic counselors' desire for intellectual development and possibly improve job satisfaction.

The study showed that recent graduates are significantly more likely to be interested in pursuing a PhD in Genetic Counseling than experienced graduates. We speculate a few reasons why this may be true. The data show that recent graduates had better research experiences in graduate school than experienced graduates. Also, because the role of a genetic counselor is constantly changing, it is possible that recent graduates have a different vision for their future within the profession than experienced graduates. In addition, experienced graduates have been out of school for a longer time and may have families and be established in their communities. The idea of moving and enrolling in a specialized doctoral training program may be less appealing.

Future Directions of the Profession

One-third of respondents do not anticipate still working in the field in 10 years. It is of concern that 54.2% of this group consists of recent graduates. Respondents identified the main reasons to leave the profession as (1) no room for promotion, (2) burnout, and (3) anticipate a career change. The most common write-in reason was "limited salary potential." We believe that these genetic counselors are expressing that they need something "more" from the profession, and are willing to leave the profession in order to find it. A doctoral degree specifically in genetic counseling may help retain this group of genetic counselors, as they would have opportunities to advance their position within the field.

Limitations

A limitation of this study is the possibility of response bias, since the personal characteristics of the respondents may be different from non-respondents. The study also has the potential for self-report bias, since the design relies solely on the subjects' responses. If the subjects report inaccurate data, then the responses may not correlate with the actual population data. Another possible limitation is a halo effect. The subjects may report what they perceive to be desirable actions rather than their actual activities. As mentioned earlier, there was a limitation in the assessment of the amount of time that each respondent devoted to each genetic counseling role because the 25% interval scale was large. This problem could have been alleviated by using a 10% interval scale or using a range of percentages rather than a predetermined response scale.

Implications for Future Research

Although interest in the doctoral degree by practicing genetic counselors is evident, further studies should investigate more details regarding the feasibility of this degree. It would be interesting to investigate if genetic counselors would prefer a PhD in Genetic Counseling to the alternate advanced degrees they are currently planning to pursue, in terms of what they plan to do with these additional degrees. Further studies are needed to determine how the role of a PhD genetic counselor will differ from a MS genetic counselor and if employers are interested in hiring doctoral-trained genetic counselors. Another important direction for future research is to determine if the level of job satisfaction would be improved by the attainment of a doctoral degree.

Conclusion

In 1989, Gaupman *et al.* commented that doctoral training programs would help solidify the genetic counseling profession in academia.¹³ They also recommended that doctoral programs be formally endorsed by the NSGC and predicted that doctoral training programs would be established within the next 10 years. The results of this study demonstrate that a significant number of genetic counselors are currently conducting research, and that many more plan to perform research in the future. These results reflect the maturation of our field, in that a large sector of NSGC members considers active involvement in research to be a core genetic counseling role. Fostering genetic counselors' desire to generate research will facilitate our understanding of genetic counseling professional practices. The study also demonstrates that a significant number of genetic counselors have high interest in a hypothetical doctoral degree in genetic counseling, suggesting that our profession is primed for the development of doctoral degree training programs. Genetic counselors, academic institutions, the NSGC, and the ABGC need to work together to craft our academic future.

TABLE I.
Demographic Comparisons of Genetic Counselors Responding to Current Study
and 2002 Professional Status Survey

	Current Study (<i>n</i> =531)	2002 PSS (<i>n</i> =856)
REGION	%	%
Region 1	10 (<i>n</i> =54)	8
Region 2	24 (<i>n</i> =129)	23
Region 3	12 (<i>n</i> =64)	12
Region 4	24 (<i>n</i> =125)	26
Region 5	10 (<i>n</i> =55)	11
Region 6	20 (<i>n</i> =104)	20
GENDER		
Female	96 (<i>n</i> =509)	94
Male	4 (<i>n</i> =20)	6
AGE		
< 30	38 (<i>n</i> =203)	31
30-39	39 (<i>n</i> =208)	40
40-49	15 (<i>n</i> =81)	21
50-59	6 (<i>n</i> =31)	7
≥60	1 (<i>n</i> =6)	1

TABLE II.
Current versus Ideal Work Time Commitment of Genetic Counselors

	Clinical Practice/Coordination		Research		Teaching/Supervising Students	
	Current (n=489)	Ideal (n=491)	Current (n=290)	Ideal (n=327)	Current (n=355)	Ideal (n=434)
Work Time (in 25% increments)						
0%	50 (10.2%)	17 (3.5%)	135 (46.6%)	55 (16.8%)	100 (28.2%)	31 (7.1%)
25%	71 (14.5%)	115 (23.4%)	87 (30.0%)	194 (59.3%)	228 (64.2%)	329 (75.8%)
50%	93 (19.0%)	191 (38.9%)	26 (9.0%)	59 (18.0%)	19 (5.4%)	64 (14.7%)
75%	189 (38.7%)	139 (28.3%)	32 (11.0%)	17 (5.2%)	6 (1.7%)	6 (1.4%)
100%	86 (17.6%)	29 (5.9%)	10 (3.4%)	2 (0.61%)	2 (0.56%)	4 (0.92%)

TABLE II. (continued)

	Administration		Other	
	Current (<i>n</i> =298)	Ideal (<i>n</i> =216)	Current (<i>n</i> =115)	Ideal (<i>n</i> =86)
Work Time (in 25% increments)				
0%	123 (41.3%)	110 (50.9%)	58 (50.4%)	49 (57.0%)
25%	142 (47.7%)	90 (41.7%)	16 (13.9%)	17 (19.8%)
50%	23 (7.7%)	13 (6.0%)	15 (13.0%)	13 (15.1%)
75%	7 (2.3%)	3 (1.4%)	13 (11.3%)	1 (1.2%)
100%	3 (1.0%)	0 (0%)	13 (11.3%)	6 (7.0%)

TABLE III.
 Research Involvement of Genetic Counselors
 Chi-Square Analyses

	Recent Grads (≤5 years)	Experienced Grads (> 5 years)
Current Research Time/Involvement	<i>(n=181)</i>	<i>(n=102)</i>
0%	90 (49.7%)	42 (41.2%)
25%	48 (26.5%)	35 (34.3%)
50%	15 (8.3%)	11 (10.8%)
75%	21 (11.6%)	11 (10.8%)
100%	7 (3.9%)	3 (2.9%)
Chi Square	<i>p=0.56</i>	
Ideal Research Time/Involvement	<i>(n=196)</i>	<i>(n=129)</i>
0%	37 (18.9%)	18 (14.0%)
25%	113 (57.7%)	80 (62.0%)
50%	32 (16.3%)	26 (20.2%)
75%	13 (6.6%)	4 (3.1%)
100%	1 (0.5%)	1 (0.8%)
Chi Square	<i>p=0.41</i>	

TABLE IV.
Interest in a PhD in Genetic Counseling
Chi-Square Analyses

	Total	Interest in a PhD in Genetic Counseling	
		YES	NO
Graduation Group			
Recent	298	120 (40.3%)	178 (59.7%)
Experienced	216	57 (26.4%)	159 (73.6%)
Advanced Degree			
Plan to Pursue	125	56 (44.8%)	69 (55.2%)
Do Not Plan to Pursue	384	115 (29.9%)	269 (70.1%)
Gender			
Female	509	171 (33.6%)	338 (66.4%)
Male	20	6 (30.0%)	14 (70.0%)
Primary Role			
Clinical	353	132 (37.4%)	221 (62.6%)
Research	71	20 (28.2%)	51 (71.8%)
Faculty Appointment			
Yes	130	41 (31.5%)	89 (68.5%)
No	394	136 (34.5%)	258 (65.5%)

TABLE V.
Reasons Genetic Counselors Would Pursue an Advanced Degree
Chi-Square Analyses

	For Personal Fulfillment/ Satisfaction	For Career Advancement/ Promotion	To Make More Money	To Increase Level of Autonomy	To Specialize in a Certain Field/Area	To Pursue Another Job Within the Field	To Change Careers	Other
Graduation Group								
Recent (<i>n</i> =301)	146 (48.5%)	122 (40.5%)	112 (37.2%)	85 (28.2%)	52 (17.3%)	48 (15.9%)	37 (12.3%)	4 (1.3%)
Experienced (<i>n</i> =219)	90 (41.1%)	67 (30.6%)	48 (21.9%)	47 (21.5%)	31 (14.2%)	18 (8.2%)	25 (11.4%)	8 (3.7%)
Chi-Square	<i>p</i> =0.09	<i>p</i> =0.02 *	<i>p</i> <0.001 *	<i>p</i> =0.08	<i>p</i> =0.34	<i>p</i> =0.01 *	<i>p</i> =0.76	<i>p</i> =0.08

* Statistically Significant at the *p*<0.05 level

TABLE VI.
 Anticipated Reasons for Leaving Genetic Counseling (in 10 years)
 Chi-Square Analyses

	No Room for Promotion	Burnout	Anticipate a Career Change	Start a Family/ Raise Children	Lack of Personal Satisfaction	Personal/Family Commitment
Graduation Group						
Recent (n=301)	60 (19.9%)	40 (13.3%)	42 (14.0%)	43 (14.3%)	29 (9.6%)	11 (3.7%)
Experienced (n=219)	36 (16.4%)	33 (15.1%)	28 (12.8%)	13 (5.9%)	17 (7.8%)	14 (6.4%)
Chi-Square	<i>p</i> =0.31	<i>p</i> =0.56	<i>p</i> =0.70	<i>p</i> =0.002 *	<i>p</i> =0.46	<i>p</i> =0.15
	Lack of Flexibility	Retirement	Pursue Advanced Degree	Plan to Move	Other	
Graduation Group						
Recent (n=301)	14 (4.7%)	3 (1.0%)	19 (6.3%)	7 (2.3%)	12 (4.0%)	
Experienced (n=219)	10 (4.6%)	19 (8.7%)	5 (2.3%)	5 (2.3%)	13 (5.9%)	
Chi-Square	<i>p</i> =0.96	<i>p</i> <0.001 *	<i>p</i> =0.03 *	<i>p</i> =0.97	<i>p</i> =0.31	

* Statistically Significant at the *p*<0.05 level

TABLE VII.
Graduate School Research Experiences of Genetic Counselors

	Recent Grads (≤5 years)	Experienced Grads (> 5 years)
Program Emphasis on Research	<i>(n=299)</i>	<i>(n=217)</i>
1 (<i>none</i>)	44 (14.7%)	89 (41.0%)
2	94 (31.4%)	66 (30.4%)
3	73 (24.2%)	30 (13.8%)
4	56 (18.7%)	23 (10.6%)
5 (<i>very much</i>)	32 (10.7%)	9 (4.1%)
Chi Square		<i>P</i> <0.001 *
Preparedness to Perform Research	<i>(n=298)</i>	<i>(n=219)</i>
1 (<i>not at all</i>)	30 (10.1%)	75 (34.2%)
2	73 (24.5%)	61 (27.9%)
3	76 (25.5%)	39 (17.8%)
4	71 (23.8%)	30 (13.7%)
5 (<i>very well</i>)	48 (16.1%)	14 (6.4%)
Chi Square		<i>P</i> <0.001 *
GC's Role to Perform Research	<i>(n=297)</i>	<i>(n=219)</i>
1 (<i>not at all</i>)	5 (1.7%)	7 (3.2%)
2	42 (14.1%)	28 (12.8%)
3	140 (47.1%)	95 (43.4%)
4	70 (23.6%)	53 (24.2%)
5 (<i>very much so</i>)	40 (13.5%)	36 (16.4%)
Chi Square		<i>P</i> =0.63

* Statistically Significant at the *p*<0.05 level

TABLE VIII.
Research Roles of Genetic Counselors

Research Roles	Response Frequency (%) (n=514)
Data Collection/Management	353 (68.7%)
Reporting/Presenting Results	330 (64.2%)
Manuscript Writing	276 (53.7%)
Subject Recruitment	275 (53.5%)
Research Coordinator/Conducting Project	263 (51.2%)
Project Design	192 (37.4%)
Data Analysis/Statistical Computation	151 (29.4%)
Grant Writing	147 (28.6%)
Investigator (Principal or Co-)	142 (27.6%)
Budget Oversight	87 (16.9%)
None of These Roles	62 (12.1%)

TABLE IX.
Reasons Why Genetic Counselors Perform Research

Reasons to Perform Research	Response Frequency (%) (<i>n</i> =478)
Interest in the Subject	276 (57.7%)
Contribute to the Field	231 (48.3%)
Personal Development/Satisfaction	220 (46.0%)
Diversify Job Responsibility	175 (36.6%)
Job Requirement	142 (29.7%)
Lack of Research on the Subject	125 (26.2%)
Career Advancement	94 (19.7%)
Responsibility to a Professional Organization	45 (9.4%)
Flexibility/Work from Home	24 (5.0%)
Increase Salary	15 (3.1%)
Create a Job in a New Area	15 (3.1%)
Other	19 (4.0%)
I Do Not Perform Research	113 (23.6%)

TABLE X.
Research Barriers Expressed by Genetic Counselors

	Total (n)	(disagree) Likert Scale Responses (agree)		
		1/2	3	4/5
RESEARCH BARRIERS		(%)	(%)	(%)
I don't know how to do research	501	272 (54.3)	112 (22.4)	117 (23.4)
I don't have time to do research	502	102 (20.3)	73 (14.5)	327 (65.1)
It is not my job to do research	500	285 (57.0)	70 (14.0)	145 (29.0)
Research doesn't really interest me	500	328 (65.6)	88 (17.6)	84 (16.8)
It is not necessary for me to do research	497	313 (63.0)	105 (21.1)	79 (15.9)
I don't know what to do research on	499	291 (58.3)	114 (22.8)	94 (18.8)
I have not had the opportunity to do research	499	257 (51.5)	110 (22.0)	132 (26.5)
GRANT BARRIERS		(%)	(%)	(%)
I don't know how to write a grant	470	135 (28.7)	78 (16.6)	257 (54.7)
I don't have time to write a grant	472	86 (18.2)	69 (14.6)	317 (67.2)
It is not my job to write grants	473	176 (37.2)	79 (16.7)	218 (46.1)
Grant writing doesn't really interest me	472	164 (34.7)	86 (18.2)	222 (47.0)
It is not necessary for me to write grants	469	219 (46.7)	110 (23.5)	140 (29.9)
I don't know where to apply for grants	470	185 (39.4)	114 (24.3)	171 (36.4)
I have not had the opportunity to write a grant	475	166 (34.9)	90 (18.9)	219 (46.1)

TABLE X. (continued)

	Total (n)	(disagree) Likert Scale Responses (agree)		
		1/2	3	4/5
MANUSCRIPT BARRIERS		(%)	(%)	(%)
I don't know how to write a scientific paper	488	325 (66.6)	75 (15.4)	88 (18.0)
I don't have time to write a scientific paper	493	103 (20.9)	102 (20.7)	288 (58.4)
It is not my job to write scientific papers	486	278 (57.2)	94 (19.3)	114 (23.5)
Writing scientific papers doesn't really interest me	492	305 (62.0)	99 (20.1)	88 (17.9)
It is not necessary for me to write scientific papers	486	320 (65.8)	101 (20.8)	65 (13.4)
I don't know what to write a scientific paper on	489	306 (62.6)	109 (22.3)	74 (15.1)
I have not had the opportunity to write a scientific paper	490	274 (55.9)	90 (18.4)	126 (25.7)

FIGURE I.
Primary Genetic Counseling Roles (*n*=527)

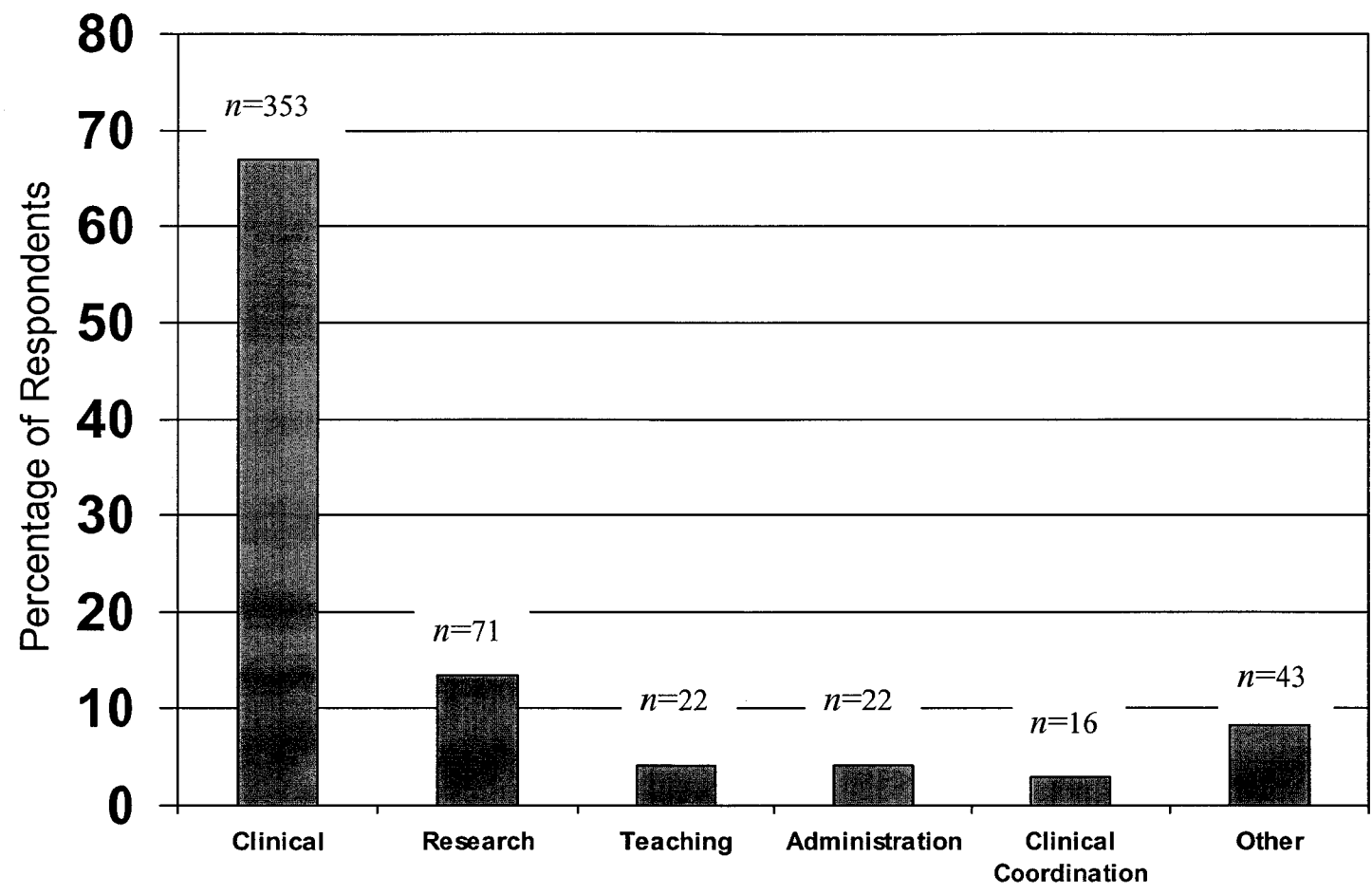


FIGURE 2
Current versus Ideal Effort that Genetic Counselors Commit to Research

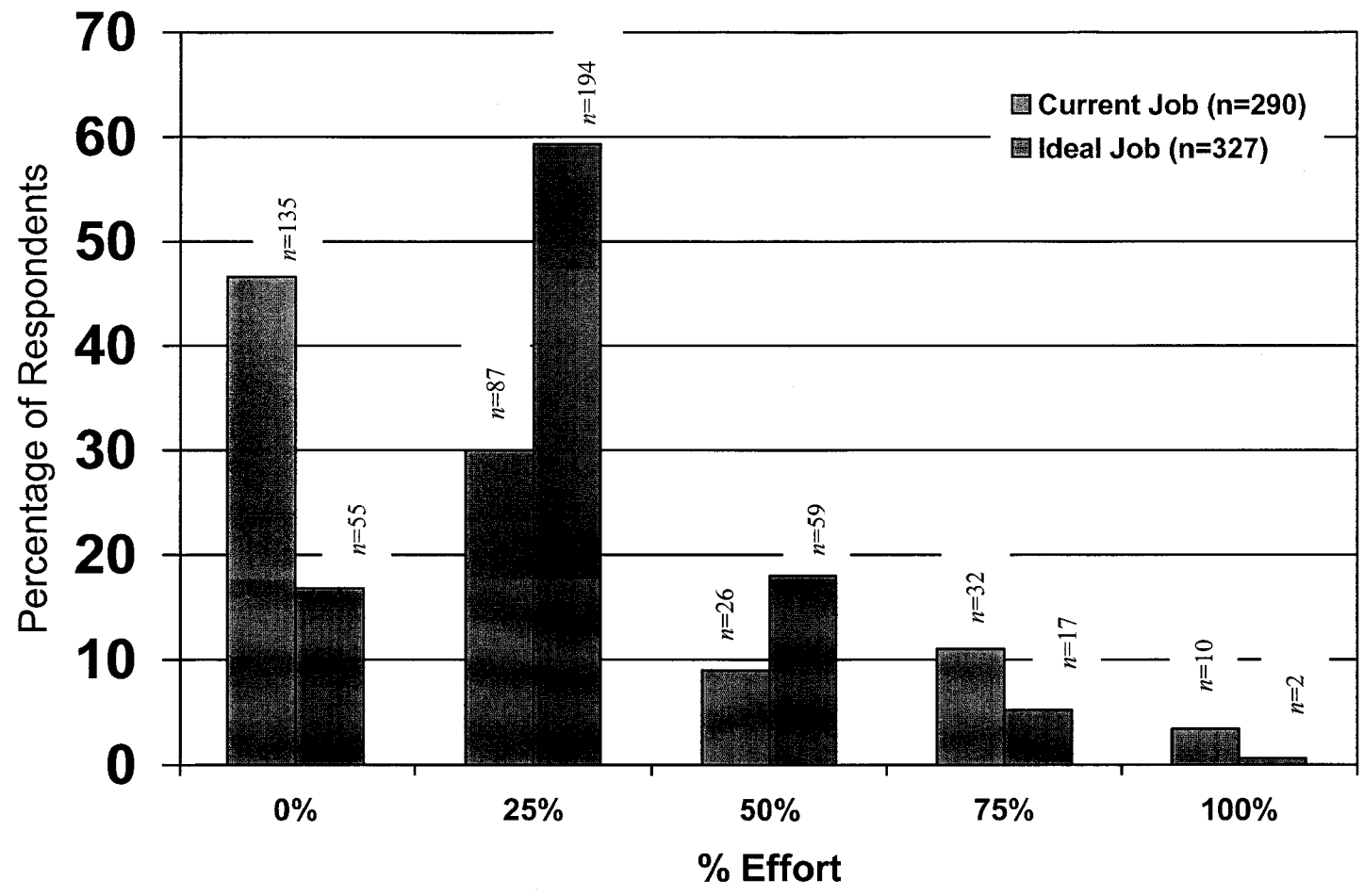
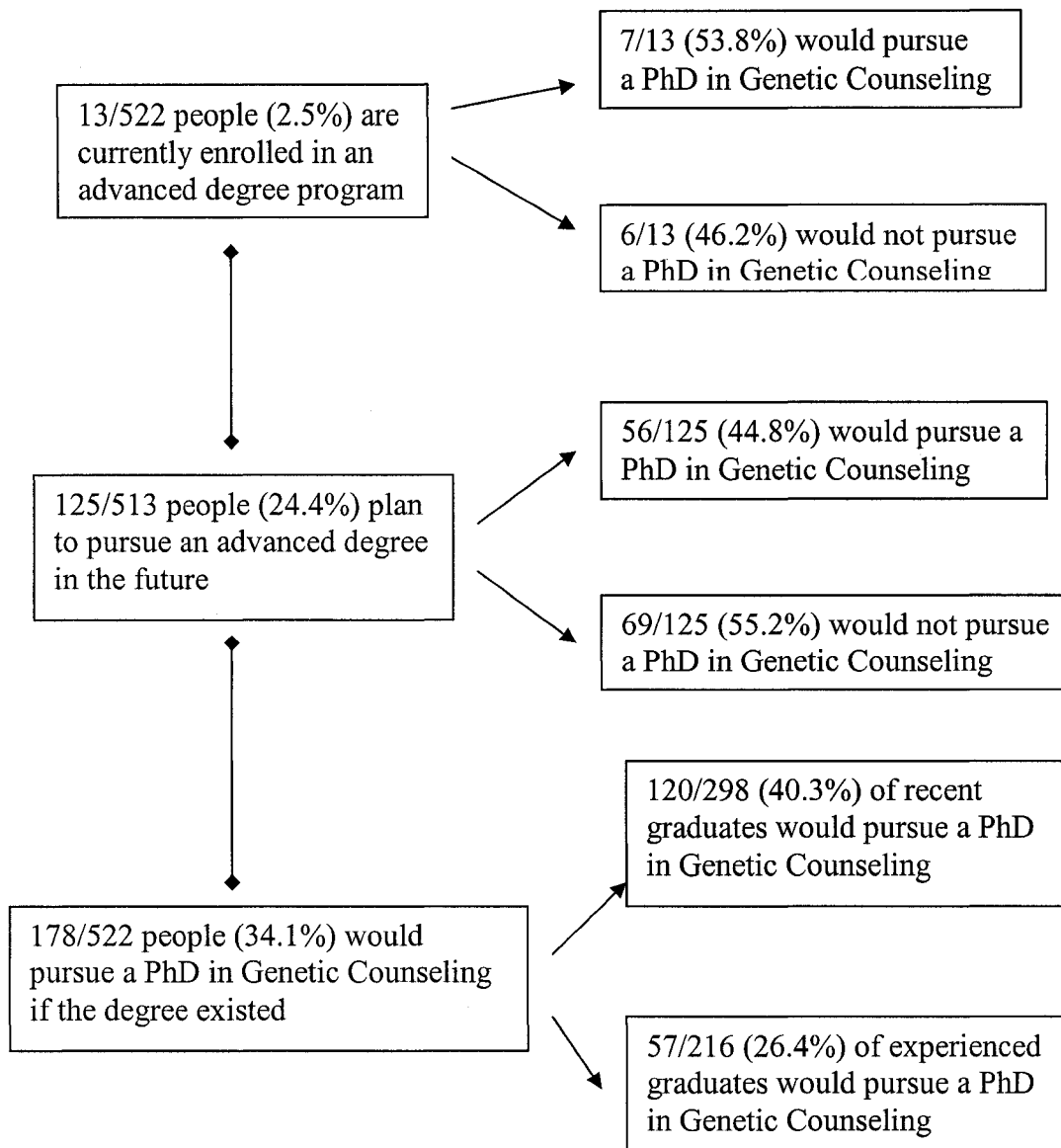


FIGURE 3.
Interest in a PhD in Genetic Counseling



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APPENDIX A

Genetic Counselor's Professional Activities Survey

1. What NSGC region do you work in?
 - Region 1: *CT, MA, ME, NH, RI, VT, Canadian Maritime Provinces*
 - Region 2: *DC, DE, MD, NJ, NY, PA, VA, VW, Quebec, Puerto Rico, Virgin Islands*
 - Region 3: *AL, FL, GA, KY, LA, MS, NC, SC, TN*
 - Region 4: *AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario*
 - Region 5: *AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan*
 - Region 6: *AK, CA, HI, ID, NV, OR, WA, British Columbia*

2. What is your gender? female male

3. What is your age? < 30 years 30-39 40-49
 50-59 ≥60

4. What degrees do you hold? (*Check all that apply*)
 - BS/BA (*Field:* Biology Genetics Psychology Education Other)
 - MS/MA (*Field:* Medical Genetics Human Genetics Genetic Counseling Other)
 - MPH PhD Other

5. What is your primary work setting? (*Choose only one*)
 - University Medical Center University/Non-Medical Center
 - Private Hospital/Medical Facility Public Hospital/Medical Facility
 - Federal/State/County Office Health Maintenance Organization
 - Diagnostic Laboratory Physician's Private Practice
 - Self-Employed/Private Practice Other

6. In your current position, do you have regular contact with patients? yes no

7. If yes, do you interact with patients:
 - In a clinic setting
 - As part of a research protocol (*obtaining informed consent, etc.*)
 - In both settings

8. Indicate your **PRIMARY** role as a genetic counselor at your current job. (*choose only one*)
 - Clinical Clinical Coordination
 - Teaching/Education/Supervising Students Administration
 - Research/Study Coordinator Other

9. Indicate the percentage of work time you commit to **each** of the following genetic counseling roles you currently perform at your job. (*Percentages should add up to 100%*)

- | | | | | | |
|---|-----------------------------|------------------------------|------------------------------|------------------------------|-------------------------------|
| Clinical Practice/Coordination | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Teaching/Education/Supervising Students | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Research | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Administration | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Other _____ | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |

10. If you see patients, indicate the percentage of time you commit to each of the following clinical specialty areas. (*Percentages should add up to 100%*)

- | | | | | | |
|-------------|-----------------------------|------------------------------|------------------------------|------------------------------|-------------------------------|
| Prenatal | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Pediatrics | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Cancer | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Other _____ | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |

11. Indicate your current employment status:

- Full-time, one position
- Full-time; combination of part-time positions
- Part-time (_____ hours per week, based on a 40-hour work week)
- Not currently employed

12. Do you currently hold a university faculty appointment?

- Yes, at the institution where I work
- Yes, at an institution other than where I work
- No faculty appointment, although I am eligible for one (*skip to #15*)
- No, I am not eligible for a faculty appointment (*skip to #15*)

13. If you currently hold a university faculty appointment, what type of position is it?

- Tenure track Clinical track Research track Volunteer

14. If you are in a tenure-track position, do you currently have tenure? yes no

15. Please consider your **ideal** genetic counseling position. (Indicate the percentage of time you **wish** you could commit to each of the following roles at your **ideal** job.

Percentages should add up to 100%)

- | | | | | | |
|---|-----------------------------|------------------------------|------------------------------|------------------------------|-------------------------------|
| Clinical Practice/Coordination | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Teaching/Education/Supervising Students | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Research | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Administration | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |
| Other _____ | <input type="checkbox"/> 0% | <input type="checkbox"/> 25% | <input type="checkbox"/> 50% | <input type="checkbox"/> 75% | <input type="checkbox"/> 100% |

16. Are you currently enrolled in an advanced degree program? yes no
If yes, what degree in which field? _____

17. Do you plan to pursue an advanced degree in the future? *(Choose only one)*
- No
- Yes, an additional Masters degree (Field: _____)
- Yes, a Doctoral degree (Field: _____)
- Yes, other type of degree: (_____)

18. If there was a doctoral training program specifically in genetic counseling, would you pursue a PhD in Genetic Counseling? yes no

19. What are the primary reasons that you are currently/plan to pursue an advanced degree? *(Check all that apply)*
- To pursue another job within the field To change careers
- To make more money To specialize in a certain field/area
- For career advancement/promotion For personal fulfillment/satisfaction
- To increase level of autonomy I don't plan to pursue an advanced degree
- Other _____

20. Do you anticipate still working in the genetic counseling field in 2 years? yes no
In 10 years? yes no

If no, why not? *(Check all that apply)*

- To start a family/raise children Personal/family commitment
- Anticipate a career change Planning to move
- No room for promotion Lack of flexibility
- Burnout Lack of gratification/personal satisfaction
- Retirement Pursuing an advanced degree
- Other _____

21. Which genetic counseling training program did you attend?
- | | |
|---|---|
| <input type="checkbox"/> Arcadia University (formerly Beaver College) | <input type="checkbox"/> University of California at Irvine |
| <input type="checkbox"/> Brandeis University | <input type="checkbox"/> University of Cincinnati |
| <input type="checkbox"/> California State University at Northridge | <input type="checkbox"/> University of Colorado |
| <input type="checkbox"/> Case Western Reserve University | <input type="checkbox"/> University of Maryland |
| <input type="checkbox"/> Howard University | <input type="checkbox"/> University of Michigan |
| <input type="checkbox"/> Indiana University | <input type="checkbox"/> University of Minnesota |
| <input type="checkbox"/> Johns Hopkins University/NIH | <input type="checkbox"/> University of North Carolina |
| <input type="checkbox"/> McGill University | <input type="checkbox"/> University of Pittsburgh |
| <input type="checkbox"/> Medical College of Virginia/VCU | <input type="checkbox"/> University of South Carolina |
| <input type="checkbox"/> Mount Sinai | <input type="checkbox"/> University of Texas |
| <input type="checkbox"/> Northwestern University | <input type="checkbox"/> University of Toronto |
| <input type="checkbox"/> Sarah Lawrence College | <input type="checkbox"/> University of Wisconsin |
| <input type="checkbox"/> University of Arizona | <input type="checkbox"/> Wayne State University |
| <input type="checkbox"/> University of British Columbia | <input type="checkbox"/> Other |

22. When did you graduate from your genetic counseling training program?

- Within the past five years (1997 – 2002)
- Six to ten years ago (1996 – 1992)
- Eleven to fifteen years ago (1991 – 1987)
- More than fifteen years ago (before 1987)

23. How do you define the term “independent research”?

24. How well did your genetic counseling training program prepare you to perform independent research after graduation? *(circle the most appropriate choice)*

not prepared 1 2 3 4 5 **very well prepared**

25. How much emphasis did your genetic counseling training program place upon preparing you to perform independent research after graduation? *(circle the most appropriate choice)*

no emphasis 1 2 3 4 5 **very strongly emphasized**

26. Which of the following requirements did you complete during your genetic counseling training? *(Check all that apply)*

- | | |
|---|--|
| <input type="checkbox"/> Research design course | <input type="checkbox"/> Independent research |
| <input type="checkbox"/> Statistics or Biostatistics course | <input type="checkbox"/> hypothesis driven |
| <input type="checkbox"/> Thesis | <input type="checkbox"/> descriptive study |
| <input type="checkbox"/> Required | <input type="checkbox"/> Learned to write a grant/proposal |
| <input type="checkbox"/> Optional | <input type="checkbox"/> Manuscript for publication in a peer-reviewed journal |

27. In your opinion, is it a genetic counselor’s role to perform independent research?

not at all 1 2 3 4 5 **very much so**

28. Have you ever performed independent research *(includes current research)*?

- yes no

If yes, please describe your **primary** field/area of research _____

29. How would you categorize your past and present research activities? *(Check all that apply)*

- | | |
|---|---|
| <input type="checkbox"/> Laboratory-based research | <input type="checkbox"/> Clinical research |
| <input type="checkbox"/> Single gene identification study | <input type="checkbox"/> Multiple/complex genes identification |
| <input type="checkbox"/> Case study/case report | <input type="checkbox"/> Natural history of genetic condition |
| <input type="checkbox"/> Review of the medical literature | <input type="checkbox"/> Patient/professional education materials |
| <input type="checkbox"/> Quantitative research/survey | <input type="checkbox"/> Counseling theory/outcome study |
| <input type="checkbox"/> Qualitative research/interviews | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> None of these activities | |

30. Which research design and development roles have you assumed? *(Check all that apply)*

- | | |
|--|---|
| <input type="checkbox"/> Investigator (Principal or Co-) | <input type="checkbox"/> Project design |
| <input type="checkbox"/> Grant writing | <input type="checkbox"/> Budget oversight |

- Research coordinator/conducting project
- Data collection/management
- Manuscript writing
- None of these roles
- Subject recruitment
- Data analysis/statistical computation
- Reporting/presenting results

31. Where did you gain your skills to perform these roles? *(Check all that apply)*

- In genetic counseling training
- Conference/workshop
- Other _____
- On the job
- Personal reading/research
- I do not have these skills

32. Would you like to perform independent research in the future? yes no

33. Why do you perform independent research? *(Check all that apply)*

- Job requirement
- Interest in the subject
- To diversify job responsibility
- To create a job in a new area
- Contribute to the field
- Personal development/satisfaction
- I do not perform independent research
- Increase salary
- Lack of research on that subject
- Flexibility/work from home
- Career advancement
- Responsibility to a professional organization
- Other _____

34. Have you faced any of the following barriers to performing independent research?

I don't know how to do research.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't have time to do research.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
It is not my job to do research.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
Research doesn't really interest me.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't think it is necessary for me to do research.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't know what to do research on.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I have not had the opportunity to do research.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>

35. In your professional career, have you:

- Served on a journal editorial board
- Served as a journal manuscript reviewer
- Served on a grant proposal review committee
- Served on an Institutional Review Board
- Written/submitted a grant
- Awarded a grant/managed a grant budget
- Written/developed IRB-approved research protocols

36. In your professional career, approximately how many grants have you written and submitted?

- 0
- 1
- 2 – 5
- 6 – 10
- > 10

37. Of these submitted grants, on how many were you named as an investigator?
 0 1 2 – 5 6 – 10 > 10

38. How many of these grants were funded?
 0 1 2 – 5 6 – 10 > 10

39. Have you faced any of the following barriers to writing a grant? (*please indicate for each choice*)

I don't know how to write a grant.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't have time to write a grant.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
It is not my job to write grants.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
Grant writing doesn't really interest me.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't think it is necessary for me to write grants.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't know where to apply for grants.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I have not had the opportunity to write a grant.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>

40. In your professional career, please indicate your publications (and the number of each):

Abstracts	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Article for lay publication/newsletter	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Article on case report	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Article on original research	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Review article	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Brochure/pamphlet/video	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Book	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Book Chapter	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10
Other _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2 – 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> > 10

41. Have you ever presented at a professional meeting?
 Yes, poster presentation Yes, platform presentation/workshop No

42. Have you faced any of the following barriers to writing a manuscript for publication?

I don't know how to write a scientific paper.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't have time to write a scientific paper.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
It is not my job to write scientific papers.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
Writing scientific papers doesn't really interest me.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't think it is necessary for me to write papers.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I don't know what to write a scientific paper on.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>
I have not had the opportunity to write a paper.	<i>disagree</i>	1	2	3	4	5	<i>agree</i>

APPENDIX B

Cover Letter Email

Dear Genetic Counselor,

Researchers at the University of Cincinnati would like to invite you to participate in a study assessing the professional activities of genetic counselors. Our research focuses on current professional roles, activities, graduate school training, as well as ideals and future directions for our profession. Although the 2002 NSGC Professional Status Survey provided a vast amount of significant information, we believe there are numerous areas where a more detailed analysis would be enlightening.

In order to make your participation as easy as possible, the survey can be completed online and will be available for completion for two weeks. Please click on the website link listed below. It will take you 10-15 minutes to complete the survey.

By completing and submitting the survey, you are giving your consent to participate in the study. All responses will be kept anonymous. Once you submit the survey, there is no way to trace responses back to you. Your email address has not been connected to your name and, in accordance with NSGC mailing list policy, all records of email addresses will be destroyed after this mailing. The study will not result in a direct benefit to you, but will provide valuable data on various professional issues relevant to genetic counselors.

Please accept this email as an invitation to participate in our survey. **Your participation is crucial to our research; please ensure that your opinion is heard!**

If you have any questions or have trouble accessing the survey, please contact us for assistance. If you would prefer to complete a paper version of the survey, please call or email one of us and a paper copy will be mailed to you.

<http://www.grad.uc.edu/survey2/active/genetics.html>

Sincerely,

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