INTRODUCTION

The term "genetic counselor" rooted the profession in the medical world as a defined entity: one that filled a role left vacant by other professionals. The creation of the genetic counseling profession was ambitious. Over time, genetic counselors channeled that same ambition and continued to establish themselves and their profession in diverse areas of patient care (Balkite & Smith, 2009). They have established themselves as lifelong learners and the vocation born of familial risk assessment in pediatric clinics branched out to other areas almost immediately (Balkite & Smith, 2009; Zetzsche, Kotzer, & Wain, 2014). Genetic counselors followed the ebb and flow of testing technologies into the obstetric setting as prenatal screening became available (Balkite & Smith, 2009; Garber & Hixon, 1990; Tercyak, Johnson, Roberts, & Cruz, 2001). The transition was so successful that prenatal genetic counseling remains the second...
counseling skill-set. This skill-set is acquired through masters-level genetic counseling training programs centered upon the core competencies of the profession (Accreditation Council for Genetic Counseling, 2015). Genetics expertise, interpersonal communication and counseling, effective education, and professional relationship building are a few examples of the core competencies that can stretch into other medical settings. While this skill-set is acquired during training, there is a responsibility on genetic counselors to continue their education (National Society of Genetic Counselors, 1992, 2006, 2017).

This value of lifelong learning has been reflected in genetic counseling subspecialties. Eighty-one percent of public health genetic counselors reported learning skills necessary for their position on the job (Mc Walter, Sdano, Dave, Powell, & Callanan, 2015; Powell, Hasegawa, & Mc Walter, 2010). Likewise, 86% of cardiovascular genetic counselors reported having to obtain additional knowledge regarding cardiovascular conditions outside of their graduate training (Somers et al., 2014). This is not a criticism of genetic counseling graduate programs, but indicative of the programs’ ability to produce competent and flexible professionals.

1.2 | Specialty and subspecialty practice in genetic counseling

Cancer, pediatric, prenatal, and general genetics are regarded as the core specialty areas central to genetic counseling practice (Accreditation Council for Genetic Counseling, 2013). Three of these core specialties are still the most common areas of clinical practice as described by the 2018 Professional Status Survey (PSS) with 52% of clinical genetic counselors specializing in cancer genetics, 41% specializing in prenatal, and 29% specializing in pediatric genetics (National Society of Genetic Counselors, 2018). Subspecialties refer to the emerging, smaller areas of practice. For example, cardiovascular genetics, neurogenetics, and psychiatric genetics are considered subspecialties for the purposes of this article.

Cardiology, infertility/assisted reproductive technologies, neurogenetics, genomic medicine, and pharmacogenetics all emerged as minor clinical subspecialty areas in the 2018 PSS (National Society of Genetic Counselors, 2018). While these subspecialties occupy, overall, small percentages of clinically active genetic counselors, their presence on this profession-wide survey indicates that subspecialties have established and draw measurable quantities of genetic counselors’ time.

1.3 | Purpose of this study

The skill-set of genetic counselors is adaptable, diverse, and able to be applied to various subspecialties. Some case reports have highlighted genetic counselors’ experiences in subspecialty positions (Inglis et al., 2015; Mc Walter et al., 2015; Powell et al., 2010; Stadler & Mulvihill, 1998). Likewise, some studies have documented how these kinds of positions came to be (Everett, Gustafson, & Raymond, 2014; Inglis et al., 2015; Zetzsche et al., 2014). However, a broad
study of factors that lead to the development and evolution of subspecialty practice in the genetic counseling profession has not been completed. While it is evident that these positions exist, and that the common skill-set genetic counselors possess fosters success in subspecialty medicine, how these subspecialties emerge and evolve is unclear.

It is important that genetic counselors have a deep understanding of what factors are necessary for a subspecialized clinical position to be successful. As a relatively new field, a formula for clinical position viability will be enormously useful as the field, inevitably, expands. This study was designed to investigate and shed light on this aspect of genetic counseling career development. The aim of this study was to answer three questions: (1) What common factors establish a need for a genetic counselor in a subspecialty setting? (2) How do genetic counselors in subspecialties establish their positions? (3) Once established, how do the positions of these genetic counselors evolve as the subspecialty expands?

2 | METHODS

2.1 | Study design

This is a cross-sectional survey-based study. The study was approved by the University of North Carolina at Greensboro (UNCG) Institutional Review Board (IRB).

2.2 | Participants and procedures

Full members of the NSGC were sent a description of the study and link to the consent form and online anonymous survey via the NSGC ListServ (Supporting Information Appendices S1 and S2). Clinical genetic counselors working in subspecialty positions in the United States or Canada were eligible to participate in the study.

2.3 | Instrumentation

As there is limited literature pertaining to genetic counseling subspecialties, qualitative data from ten telephone interviews with subspecialized genetic counselors informed the construction of an online survey which was administered to genetic counselors as the primary data set for this study (for additional information, see Supporting Information Appendix S3). The 59-item unique survey was developed based on both the literature review and the telephone interviews (Supporting Information Appendix S2).

The survey consisted of both closed (45) and open-ended questions (14) grouped into four sections. The survey took between 15 and 30 min to complete. The first section addressed participants’ demographic information, including their identified gender, year of graduation from an ACGC accredited genetic counseling training program, area of practice, state or Canadian province of practice, and distribution of time spent on clinical, research, laboratory, or other duties. The second section targeted information pertaining to participants’ identified subspecialty and addressed the participants’ subspecialty position establishment, previous knowledge of the subject area, subspecialty-specific resources, job description evolution, and overall experience in their subspecialty area. When a participant noted more than one subspecialty area of practice, this survey block would repeat for each area of subspecialty practice identified. The third section addressed the department or division placement and funding for the participants’ subspecialty position. The final section of the survey assessed the participants’ professional meeting attendance, including genetics and non-genetics related meetings. The final survey was created in the Qualtrics computer program licensed by the UNCG. The survey was pilot tested by two practicing genetic counselors and four genetic counseling students.

2.4 | Data analysis

Survey data was analyzed using SPSS software licensed by the University of North Carolina at Greensboro. Basic functions such as frequency calculation and descriptive statistics were utilized to describe the data for each subspecialty reported. Because the most frequently reported subspecialties were cardiovascular genetics and neurogenetics, tests for significance were restricted to these two subspecialties. Chi-square analysis and independent t tests were utilized to test for significant differences between responses from cardiovascular genetics and neurogenetics. Significance level was reported as a p-value and considered significant if the p-value was below 0.05. Open-ended responses to the survey questions were evaluated using the content analysis approach (Elo & Kyngäs, 2008) Responses were coded independently by two members of the study team (VH and NC). A unified set of thematic codes was created by the primary investigator following the independent analyses. Because the open-ended questions invited a variety of responses, some questions did not produce cohesive themes. Therefore, the open-ended responses presented in the results are restricted to those questions in which common themes were evident.

3 | RESULTS

One hundred and forty-four genetic counselors of the estimated 3,266 full members of the NSGC who received the recruitment email consented to the survey between January 8, 2016 and February 11, 2016. After being informed that eligibility required that participants must be (1) currently practicing in an area of subspecialty genetic counseling and (2) working in either the United States or Canada, 42 individuals elected not to continue with the survey. Of the 102 who continued with the survey, 34 either did not currently see patients in a clinical setting or did not meet the defined criteria for subspecialty practice. This led to a final core of 68 participants.

It is important to note that some participants did not provide valid responses for later sections of the survey, thus varying the number of responses (N) for each set of questions. Fifty-eight participants completed every question of the survey, giving the core 68 eligible responses a dropout rate of 14.7%.
As only clinical genetic counselors working in subspecialties were eligible to participate in this study, it is appropriate to calculate participation rates as compared to the results of NSGC Professional Status Surveys (PSS) relevant to the time period when data were collected (January 8, 2016–February 11, 2016). Of the 1,525 participants to the 2016 NSGC PSS working in clinical positions, 650 reported working in subspecialty practice areas (National Society of Genetic Counselors, 2016). Due to the PSS response rate of 54%, the total number of subspecialized genetic counselors (who are members of either NSGC or diplomates of ABGC) is calculated to be 1,204. This extrapolated response rate for this study is 68/1,204 or 5.65%.

### 3.1 | Survey participant demographics

The majority of the 68 participants identified as female (97.1%) and was certified in genetic counseling (88.2%). There were no significant differences between the two largest subspecialties. Of note, all participants who were not certified (n = 8) had graduated in either 2014 or 2015. Most (45.6%) participants graduated from an accredited genetic counseling program between 2010 and 2015. Twenty-three (33.8%) graduated between 2000 and 2009, 10 (14.7%) between 1990 and 1999, and four (5.9%) between 1980 and 1989. There were no significant differences between the two largest subspecialties.

### 3.2 | The specialties and subspecialties reported

The most commonly reported areas of subspecialty practice were cardiovascular genetics (19 participants or 27.9%) and neurogenetics (15 participants or 22.1%). Lesser reported areas of subspecialty practice included hematology/hemoglobinopathies (8 participants or 11.8%), metabolic genetics (6 participants or 8.8%), ophthalmic genetics (6 participants or 8.8%), and pulmonology/cystic fibrosis (5 participants or 7.4%). Fifteen participants (22.1%) noted other subspecialties including autism, pediatric oncology, craniofacial genetics, gastroenterology, assisted reproductive technologies and/or infertility, whole exome sequencing, disorders of sex development, neurofibromatosis, and skeletal dysplasias. No participants selected psychiatric genetics as their area of subspecialty practice. Five participants (7.4%) noted more than one area of subspecialty practice. Of note, the number of participants in each of these subspecialty areas did not remain consistent across all sections of the survey due to drop out.

As subspecialty practice may not account for all of a participant’s clinical time, participants were asked if they also worked in a broader specialty (such as pediatrics, prenatal genetics, or cancer genetics). Pediatric genetics was the most commonly reported specialty in which participants also provided services (reported by 12 participants or 17.7%). Other specialty areas included prenatal genetics (reported by five participants or 7.4%), cancer genetics (reported by seven participants or 10.3%), and adult genetics (reported by nine participants or 13.3%). There were no significant differences between the two largest subspecialties.

### 3.3 | The circumstances prompting the move to subspecialty practice

Commonly reported coded themes included genetic counselor interest in that subspecialty area, job availability, subspecialist roles added as a component of their existing position, recognition of the value of a genetic counselor by another health care provider (such as a physician), and a genetic counselor’s desire to be an expert in their area of practice. Coded themes that recurred with a lower frequency included the desire for increased autonomy, an interest in research, desire to be challenged, desire to work in a new area of genetic counseling, responding to a clinical need, and proactively seeking subspecialist opportunities. Examples of responses demonstrating these coded themes are shown in Table 1.

### 3.4 | The creation of subspecialty positions

Most participants (45 of 60 participants or 75%) indicated that their position was created as a new position for the institution. There were no significant differences between the two largest subspecialties. Coded themes for the creation of these new positions included interested physicians, recognized institutional need for genetic counselor, response to research funding, and availability of genetic testing. The coded themes of physician interest and institutional need were often seen simultaneously. For example, participants recounted multiple examples of physicians encouraging their institution to hire a genetic counselor to address a need they were seeing within their clinic. Other coded themes included not knowing how their position was created, an increase in patient volume, the creation of a new clinic, and genetic counselor initiative. Examples of responses demonstrating these coded themes are shown in Table 2.

A smaller proportion of participants (15 of 60 participants or 25%) noted that their positions evolved from a previous position through the addition of new responsibilities. Common coded themes for evolution of these positions included an increase of patient load or an increased patient need (n = 4), the hiring of a genetic counselor who brought his/her skill-set to the subspecialized team (n = 3), or the availability of genetic testing and/or screening (n = 3).

### 3.5 | The evolution of subspecialty positions

Four main coded themes were present among the 43 responses. Fifteen participants (34.9%) identified that there had been an increase in their professional responsibilities since starting their position. Often, participants noted that these additional responsibilities related to clinic coordination roles. Thirty-three participants (30.2%) noted an increase in referrals to their services. Additionally, 11 participants (25.6%) noted that there had been an increase in research responsibilities since starting their position. Additional, less frequent coded themes included an increase in teaching responsibilities, an increase in ordering testing, an increased need to remain current on subspecialty-specific knowledge, increased autonomy, and an overall feeling of increased respect as a genetic counselor. Of note, the
TABLE 1  The move to subspecialty practice

<table>
<thead>
<tr>
<th>Theme</th>
<th>N</th>
<th>%</th>
<th>Example of response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal interest of genetic counselor</td>
<td>22</td>
<td>42.3</td>
<td><em>Maintained a self-directed interest in CV Genetics in graduate school. Despite having no exposure to it in the program, I personally read textbooks. It was during my first job that I carved out part of my time to do CV Genetics. There I learned from clinical experiences.</em>—Participant R_9oYk; Cardiovascular Genetics</td>
</tr>
<tr>
<td>Job availability</td>
<td>13</td>
<td>25</td>
<td><em>Honestly, I didn’t purposely choose neurogenetics. The job was in the location I was looking for and I was also hoping for a research component, which my initial position offered.</em>—Participant R_1MPP; Neurogenetics and Whole Exome Sequencing</td>
</tr>
<tr>
<td>Part of the position</td>
<td>10</td>
<td>19.2</td>
<td><em>This was part of the clinical caseload I was assigned when hired by an academic pediatric hospital in 1999.</em>—Participant R_2xPr; Hematology</td>
</tr>
<tr>
<td>Value of a genetic counselor was recognized</td>
<td>8</td>
<td>15.4</td>
<td><em>I saw the way genetics could make a real impact in this area, actually changing their medical care, directing with those MDs who provide the care to these patients! I was very intrigued by being a unique and valued member of the care team in my specialty, providing complementary care alongside the distinct care of other providers.</em>—Participant R_bINe; Ophthalmology</td>
</tr>
<tr>
<td>Desired to be an expert</td>
<td>7</td>
<td>13.5</td>
<td><em>During my peds/adult genetics rotation as a student, I always felt like I was a jack of all trades but master of none. I hated feeling like all I could do was regurgitate what I read about a condition on GeneReviews.</em>—Participant R_bINe; Ophthalmology</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>44.2</td>
<td><em>It was also attractive to be able to ‘create’ my own position depending on the needs of the patients. A lot of autonomy which was great.</em>—Participant R_1F52; Cystic Fibrosis and Pulmonary</td>
</tr>
</tbody>
</table>

Note. Total number of responses = 52 and percent does not equal 100 because some participants gave responses that were coded into more than one category. N = Number of responses coded into each category.

TABLE 2  The creation of a new position

<table>
<thead>
<tr>
<th>Theme</th>
<th>N</th>
<th>%</th>
<th>Example of response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interested physicians</td>
<td>17</td>
<td>46</td>
<td><em>The physicians wanted to order more testing and reached out to another specialty at the institution which was ordering lots of genetic testing, and not working with the traditional medical genetics department. The other specialty had a genetic counselor who suggested my division hire a genetic counselor.</em>—Participant R_qDyP; Cardiovascular Genetics</td>
</tr>
<tr>
<td>Institution recognized need for genetic counselor</td>
<td>11</td>
<td>29.7</td>
<td><em>Within a two year period six alpha thalassemia major pregnancies occurred. An institutional response was necessary.</em>—Participant R_9X14; Hematology</td>
</tr>
<tr>
<td>Response to research funds</td>
<td>7</td>
<td>18.9</td>
<td><em>From what I have been told, we the department was given a grant from the department of public health and they decided to use the funds to pay for a genetic counselor to assist in newborn screening follow-up for sickle cell disease and hemoglobin traits...</em>—Participant R_7VVD; Hematology</td>
</tr>
<tr>
<td>Related to genetic testing</td>
<td>7</td>
<td>18.9</td>
<td><em>Since we recommend genetic testing on all children with a new or standing diagnosis of autism (if it had not been completed previously), a need for someone to help explain the testing to the families and to interpret the results was identified. It was just not practical to expect that Genetics would be able to see all of these families since our department evaluates over 30 new patients each week...</em>—Participant R_wQYe; Autism</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>32.4</td>
<td><em>The HD clinic was created by the State Legislature and was awarded to our institution. The Director of the Division of Genetics, where I was working part-time, had known me for many year and knew of my long standing interest in adult genetics. He offered me the position...</em>—Participant R_C9zO; Neurogenetics</td>
</tr>
</tbody>
</table>

Note. Total number of responses = 37 and percent does not equal 100 because some participants gave responses that were coded into more than one category. N = Number of responses coded into each category.

coded theme of no change in responsibilities was present in some responses. However, this was often because they had been in their position for a short time. Examples of responses demonstrating these coded themes are shown in Table 3.

3.6  The funding of subspecialty positions

Almost half of the participants (28 of 58 participants or 48.3%) reported their position was based out of a non-genetics department or division. The second most common area of position placement was exclusively within a genetics department or division (13 of 58 participants or 22.4%). There were no significant differences between the two largest subspecialties. These responses are shown in Figure 1. Almost three-fourths of the participants (43 of 58 participants or 74.1%) reported that their position was funded by a hospital department/division. Other commonly reported sources of funding for subspecialty positions included research funds (23 of 58 participants or 39.7%) and direct billing for genetic counseling services (16 of 58...
participants or 25.9%). Eight participants (13.8%) identified other sources of funding including, but not limited to, donation funds, endowments, industry, and public health grants. Two participants (3.5%) stated they did not know how their position was funded. Of note, participants could provide multiple answers to this question.

Of the 58 participants, 17 (29.3%) stated funding for their position had changed over time, 33 (56.9%) stated it had not changed, and 8 (13.8%) did not know if funding had changed over time. Commonly reported coded themes were increased departmental funding over time and decreased research and/or grant funding over time. Lesser reported coded themes included increased government funding, increased laboratory funding, and transition of funding between departments. Of note, there were several responses that were coded for more than one theme. Examples of responses demonstrating these coded themes are shown in Table 4.

4 DISCUSSION

The results of this study begin to shed light on the development of niche roles in clinical genetic counseling. It is paramount that genetic counselors understand what factors lead to success in sub-specialized positions so that patients continue to be served in these settings. This study addressed three research questions: (1) What...
common factors establish a need for a genetic counselor in a subspecialty setting? (2) How do genetic counselors in subspecialties establish their positions? (3) Once established, how do the positions of these genetic counselors evolve as the subspecialty expands?

### 4.1 Factors establishing the need for a subspecialty genetic counseling position

Clinical need and genetic testing were often seen together as factors prompting the need to create a subspecialty genetic counseling position. Many participants reported that positions were created as a response to serve a growing patient population and to accommodate increased disease-specific referrals. Regarding genetic testing, the data suggest that a base contributing factor to the clinical need for subspecialty genetic counselors is the availability of genetic testing for that disease scope. This conclusion aligns with the genetic counselor competencies related to integration of appropriate genetic testing into the process of genetic counseling and providing personalized patient education (ACGC, 2015). This conclusion is reminiscent of genetic counselors’ movement into prenatal testing, hereditary cancer risk assessment, and precision oncology roles (Balkite & Smith, 2009; Everett et al., 2014; Garber & Hixon, 1990; Stadler & Mulvihill, 1998; Tercyak et al., 2001).

### 4.2 The creation of subspecialty genetic counseling positions

A subspecialized genetic counseling position needs a genetic counselor willing to fill that role. Genetic counselors reported moving to subspecialty practice to, in part, expand upon their previous disease-specific interest and to become an expert in a narrower scope of clinical practice. Participants also commented on the increased autonomy associated with their subspecialty role. Therefore, it can be inferred that genetic counselor interest is an important, though not wholly required, component of the creation of a subspecialty genetic counseling position.

While some participants described genetic counselor-initiated position creation, most participants reported that the position was institution-created or physician-created in response to a variety of needs. Creation of these new positions seemed to depend on physician interest, clinical need, and availability of genetic testing for disorders in the subspecialty. Most of the described subspecialty positions were created as new positions for subspecialized purposes and did not evolve from existing, and possibly more general, positions.

Over half of survey participants reported that their subspecialty position was not exclusively based within a genetics department or division. Rather, their position was based either entirely or in part in a non-genetics department or division. This implies that most subspecialty genetic counseling positions are based within the department relevant to their subspecialty, rather than based in a general genetics department and receiving disease-specific referrals.

### 4.3 The evolution of subspecialty genetic counseling positions

An increase in disease-specific referrals was noted by many participants. The continued collaboration between physicians and genetic counselors is vital to the growth and sustainability of genetic counseling positions. Frequent and direct collaboration between genetic counselors and physicians has been documented in oncology and cardiovascular genetics (Somers et al., 2014; Stopfer, 2000). Regardless of whether they contributed to the creation of a subspecialized genetic counselor position, physician referrals still play a major role in subspecialized genetic counselors’ patient volume.

Over one-third of participants noted that their responsibilities had increased over time. The increase in responsibilities included a wide variety of administrative, educational, and clinical roles. The expansion of subspecialized genetic counselors’ job scope suggests that they are not acting in a strictly consultative capacity. A certain amount of ownership of patient care seems to have become a component of subspecialized positions as they have evolved. Addition of responsibilities to genetic counselors in subspecialized positions further supports the idea that the genetic counseling skill-set is applicable to other areas of patient care and appreciated by non-genetics departments.

A common theme regarding the evolution of subspecialty positions was the importance of research funding when starting a
position. Intuitively, it makes sense that a hospital would not fund a genetic counseling position in a subspecialty until a clinical utility was identified. Positions at least partially supported by research funds seemed to serve as an avenue to demonstrate the utility of genetic counseling in a new setting.

In addition, many participants noted the funding for their position had transitioned from external funding (such as a research grant) to internal funding (such as direct funding through their hospital department). A department’s ownership of a genetic counselor’s salary is perhaps the best evidence for position utility as the institution is no longer relying on an external entity to support the position. The subspecialty genetic counseling position is perceived as valuable enough to be supported by the institution itself. Of note, many participants maintained responsibilities in other primary areas of genetic counseling practice (pediatrics, adult genetics, etc.) suggesting that subspecialty genetic counseling positions may still be in a period of transition at some institutions and are not yet entirely self-sustainable.

4.4 | Implications for practice

As the purpose of this study was to examine subspecialties outside of the core specialty areas, documented success of subspecialty genetic counseling positions further supports the adaptability of the genetic counselor skill-set. Genetic counseling programs should continue to encourage their students to be lifelong learners and, if desired, repurpose their skill-set into new areas of clinical practice. Teaching students to recognize opportunities for professional growth, cultivate interdisciplinary relationships, and network will further support genetic counselors branching into new areas of medicine. Likewise, the results of this study should provide guidance to genetic counselors in traditionally based genetics clinics to branch out to other departments and market their skill-set. Genetic counselors eager to branch out may benefit from educating subspecialized providers in their hospital about the services genetic counselors may provide their patients.

Beyond professional growth, genetic counselors in subspecialty positions have a unique opportunity to improve the care of patients. The profession of genetic counseling grew out of a desire to fill an unmet need in patient care. Since then, genetic counselors have identified and reacted to needs in prenatal care, cancer care, and even psychiatric care (Balkite & Smith, 2009; Biesecker et al., 1993; Garber & Hixon, 1990; Inglis, et al., 2015; Stadler & Mulvihill, 1998; Tercyak et al, 2001). With newly discovered (or suspected) genetic mechanisms emerging in increasing diverse fields, these unmet needs are becoming increasingly common. By understanding the factors needed to create and sustain a viable subspecialty position, genetic counselors may continue to support a more integrated and seamless method of patient care.

4.5 | Limitations and suggestions for future research

This research study was the first to examine the factors contributing to the expansion of clinical subspecialty genetic counseling positions and, therefore, was intended to be general. As expected, a substantial portion of participants identified as specializing in cardiovascular genetics or neurogenetics. It is possible that the preponderance of these responses skewed the data to be more representative of these subspecialties’ establishments, rather than the establishment of subspecialties as a whole. Additionally, the small sample size limits comparisons of significance between subspecialties.

The subspecialty of psychiatric genetic counseling was not represented in this study. This factor could have skewed the role of available clinical genetic testing in subspecialty position creation and viability.

Although the number of participants in this study was relatively small, we estimate that it represents up 5.65% of genetic counselors working in subspecialty practice as reported in the 2016 PSS. Nonetheless, the generalizability of the results is limited. Further research in the form of a broader survey could contribute to the understanding of subspecialty expansion in genetic counseling. However, given the samples for studies of this type are innately limited by small numbers of genetic counselors in subspecialties, a larger study may be dependent upon subspecialties growing to provide a larger survey base.

The results of this study suggest that the creation of subspecialist positions depends, in part, on the hospitals’ and physicians’ interest in hiring a genetic counselor. An area of future research could be examining the formation of these positions from the hospitals’ or physicians’ perspective.

This study suggested, but did not explicitly show, that clinical research roles for genetic counselors could serve as an avenue for subspecialty position establishment. An area of future research could examine whether the utilization of a genetic counselor in a research role leads to a more traditionally clinical role in the future.

4.6 | Conclusion

This study sought to better understand the development and evolution of niche roles in clinical genetic counseling. Interested genetic counselors, supportive physicians, clinical need, and available genetic testing were components in the establishment and viability of subspecialized genetic counseling positions. These positions sometimes began as components of a research project or were created outright in response to an increased clinical need. Over time, departmental funding of these positions increased as did subspecialized genetic counselors’ responsibilities and clinical roles. Overall, this study showed that genetic counselors are adaptable professionals capable of bringing their transferrable skill-set into subspecialty practice. The results of this study can encourage genetic counselors to market their skill-set outside of the traditional genetics department and into the ever-expanding branches of medicine.

COMPLIANCE OF ETHICAL STANDARDS

Conflict of interest

Victoria C.E. Haverbusch declares that she is an employee of Progenity, Inc. Nancy P. Callanan declares that she has no conflict of interest. Elizabeth M. Heise is an employee of GeneDx Inc., a wholly
owned subsidiary of OPKO Health, Inc. Ann Katherine M. Foreman declares that she has no conflict of interest.

**Human studies and informed consent**

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. This article does not contain any studies with animals performed by any of the authors. Informed consent was obtained from all individual participants included in the study. The study was approved by the University of North Carolina at Greensboro (UNCG) Institutional Review Board (IRB).

**ACKNOWLEDGEMENTS**

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**AUTHOR CONTRIBUTIONS**

V.H., the principle investigator, made substantial contributions to the conception of this study, data acquisition, analysis, and interpretation. V.H. was responsible for drafting and revising this study and approving the final version to be published. V.H. agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. N.C. made substantial contributions to the conception of this study and its design. N.C. contributed to the qualitative data analysis. N.C. was responsible for critically reviewing drafts of this study and approving the final version for publication. E.H. made substantial contributions to the conception of this study and its design. E.H. was responsible for critically reviewing drafts of this study and approving the final version for publication. A.F. made substantial contributions to the conception of this study and its design. A.F. was responsible for critically reviewing drafts of this study and approving the final version for publication.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.