The Genetics Knowledge, Education, and Confidence of Speech-Language Pathologists

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Title: The Genetics Knowledge, Education, and Confidence of Speech-Language Pathologists

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Abstract

The purpose of this research was to survey speech-language pathologists about their genetics understanding and confidence within their practice. Results included statistical analysis of demographics, educational experience, basic genetics knowledge, and confidence. A strong correlation was found between results on the genetics quiz and self-reported measures of confidence; the stronger scores on the quiz correlated to the highest self-reported confidence rating and vice versa. The Internet was also reported to be the most popularly used resource for attaining genetics information. 39% of respondents reported using the Internet as a source for genetics information in their practice. Implications for degree programs and professional development providers will be discussed.
The Genetics Knowledge, Education, and Confidence of Speech-Language Pathologists

INTRODUCTION

The field of genetics has expanded in the past two decades, in part to new advances in DNA sequencing and research aimed at identifying the genetics of specific diseases and disorders. These advances have serious implications for speech-language pathologists. Even though speech-language pathologists will not directly diagnose genetic disorders, the role they play in treating communication disorders and making appropriate referrals to other professionals is very clear. The American Speech-Language-Hearing Association (ASHA) defines the roles of speech-language pathologists to include prevention, screening, identification, assessment, clinical services, rehabilitation, advocacy/consultation, documentation, referral, education, research, and administration (American Speech-Language-Hearing Association [ASHA], 2007). Health-care professionals need to have proper genetics knowledge in order to properly care for patients and counsel their families (Gresty, Skirton, & Evenden, 2007). Despite this obvious need and growing interest in the field of communicative disorders, genetics education is not currently a requirement in the curriculum for speech-language pathology or audiology students (Arnos, Rocca, Karchmer, Culpepper, & Cohn, 2004). A change in curriculum may be necessary to ensure that students are graduating as clinicians who are confident in dealing with patients and their families who are affected by genetic syndromes. For professionals, making genetics information more easily acquired through professional development and continuing education would help to diminish the disparity between education and information about genetics in speech-language pathology.
LITERATURE REVIEW

ASHA states that “it is critical that audiologists and speech-language pathologists understand principles of genetics, genetic testing and genetic counseling” (ASHA, 2011). The normal development of speech and language, as well as patterns in atypical development, can be understood and recognized through genetics education. Knowledge of genetics can also assist speech-language pathologists in making treatment decisions while considering medical conditions (ASHA, 2011). Genetics knowledge and understanding will help to determine treatment goals for these populations, improve education for families and caregivers, and recognize any comorbid or frequently coexisting disorders (Tramontana, Blood, & Blood, 2012).

According to Fisher, Lai, and Monaco (2003), the trait of language acquisition has been attributed to genetic characteristics unique to humans. As more is understood about phenotypic composition, more is understood about the nature of speech and language disorders as well. Current research indicates that, in the body of practicing speech-language pathologists in the nation, there is a paucity of genetics knowledge and confidence, despite the growing need for application (Christianson, McWalter, & Warren, 2005; Blood & Blood, 2005; Tramontana, Blood & Blood, 2012).

Newbury and Monaco (2010) provided an overview of recent developments in the genetic studies of such speech and language disorders as verbal dyspraxia, speech sound disorders, specific language impairment, and stuttering. They reported that future research of the pathways that intersect with FOXP2, the first gene found to be linked to a speech and language disorder, may be able to identify more genes that underlie speech and language disorders and that speech sound disorders may share genetic basis with dyslexia. They concluded that the study of specific language impairment “has enabled the identification of two candidate genes on
chromosome 16 (ATP2C2 and CMIP) and stuttering research has identified the lysosomal enzyme pathway (GNPTAB, GNPTG, and NAGPA) as another candidate mechanism” (Newbury & Monaco, 2010). Although these findings are promising to the field, genetic contributions to speech and language disorders are still considered sparse and more research with larger data sets are necessary.

As the field of genetics continues to grow, SLPs are often the first referral for families experiencing speech, language, hearing, and feeding difficulties. However, many graduate programs for speech-language pathology still do not require a genetics course in the curriculum. When surveyed, 79% of communication sciences and disorders graduates rated their basic knowledge of genetics as “marginal” or “none” (Christianson, McWalter, & Warren, 2005). Another survey of 1,958 health professionals was conducted by Lapham, Kozma, Weiss, Benkendorf, and Wilson (2000) in regards to this gap between their practices and genetics education. Many of these professionals stated they have a variety of job responsibilities involving the topic. However, most stated a lack of confidence in their genetics knowledge (only 17% reported high confidence) and “nearly two-thirds of the respondents said they would be interested in attending continuing education workshops in genetics at their professional conferences” (Lapham, et al., 2000). Their lack of confidence was typically attributed to a lack of prior genetics education. Chermak and Wagner-Bitz (1993) conducted a survey of 147 speech-language pathologists and audiologists with similar results to the aforementioned study in that respondents lacked general knowledge of genetics, genetic conditions, and counseling. These survey results, as well as other surveys and academic papers, highlight that genetics education is of current interest to many types of health professionals who need to be competent in genetics for their careers as well as for their clients’ care (Farndon & Bennett, 2008).
Speech-language pathologists will need to gain a broader knowledge of genetics as well as acquire resources to give appropriate information to their clients and know when a referral to other professionals is needed (Garrett et al., 2005; Harvey, Stanton, Garrett, Neils-Strunjas, & Warren, 2007). A number of resources have been developed and are available for practicing speech-language pathologists. ASHA is a member of the National Coalition for Health Professional Education in Genetics (NCHPEG), an organization that promotes health education and provides information regarding advances in genetics. NCHPEG lists core competencies for genetics education. These items include understanding basic genetics terminology and information, understanding basic patterns of biological disorders, understanding biological similarities amongst families and populations, and resources to aid in identification of genetic variations and how these variations facilitate and impact development (NCHPEG, 2007).

NCHPEG provides the website *Genetics in the Practice of Speech-Language Pathology*, as a resource that addresses relevant genetic concepts. The most crucial areas of the website include information for practicing SLPs about taking a family history, syndrome identification, and connexin 26 and hearing loss (Harvey, Stanton, Garrett, Neils-Strunjas, & Warren, 2007). Along with NCHPEG’s contributions to genetics education, the National Center for Biotechnology Information (NCBI) has also developed a website (www.ncbi.nlm.nih.gov) that serves as a genetics resource for all health professionals to find biomedical and genomic information. NCBI is part of the United States National Library of Medicine, a branch of National Institutes of Health. NCBI is responsible for researching, as well as creating and upkeeping biomedical databases (National Center for Biotechnology Information, 2012). The NCHPEG and NCBI databases are informative and accurate web-based resources for professionals.

Online mediums for health care resources have become more popular since the amount of
medical, specifically genetics, information synthesized is rapidly expanding. Gresty, Skirton, and Evendon (2007) examined the implication of genetics education and e-learning or learning conducted via electronic media, specifically the internet. Kennedy (2001) examined the benefits of web-based learning methods, specifically to nurses. Benefits included that courses could be taken and information gathered regardless of geographical proximity, but based on need, easy access, and access to cross-cultural learning. However, disadvantages included time and space to support this type of learning and management and support issues. Current literature regarding web-based learning in speech-language pathology is limited. More research is needed to establish the importance of utilizing web-based learning in curriculums as well as for professional development.

Due to the increase in genetics research, a change in the education of health-care professionals may be required. As speech-language pathologists are often the first referral for children experiencing speech, language, hearing, and feeding difficulties, a certain level of confidence in genetic issues, as well as awareness of genetic counseling, could be required of the clinician. Aforementioned research indicates that a change in curriculum and a new requirement of genetics education may be necessary for many healthcare professionals, including speech-language pathologists. Tramontana, Blood, and Blood (2012) conclude that more research is required to determine the level of education and information required for speech-language pathologists. The purpose of this research was to measure the current knowledge of genetics in practicing SLPs to determine if there is a need for change in genetics curriculum.
RESEARCH QUESTIONS

The following research questions around genetics knowledge and confidence were addressed in this study: 1) What are the reported confidence levels of genetics knowledge compared to the size of the individual’s caseload? 2) What are the reported confidence levels compared to work settings? 3) What are the reported confidence levels compared to university attended? 4) What are the reported confidence levels compared to the number of years the professional practiced? 5) How do reported confidence levels compare to survey scores? 6) How does percent correct on the genetics quiz compare to number of years practicing as a speech-language pathologist? 7) How do professionals acquire genetics information when needed?
METHODS

Procedures

A 48-question survey was created to assess four areas: demographics, educational experiences, basic genetics knowledge, and genetic confidence. Questions were adapted from multiple sources to allow for comparison to previous research studies (Abouelmagd & Ageely, 2009; Haydon, 2008; Scheuerle, 2005; Shprintzen, 2000; Tramontana, Blood, & Blood, 2012). The research project was approved by the University of Northern Iowa Institutional Review Board. The Iowa Speech-Language-Hearing Association (ISHA) distributed the cover letter, informed consent information, and survey link via email. Due to a lack of responses from the initial distribution, the survey was sent out a second time. Participants responded to the confidential survey hosted on Survey Monkey. Results were tabulated within each of the four areas (genetics quiz results shown in Table 3). Statistical analyses for number of years practicing, education and certification, caseload size, and number of clients served who had genetic disorders were conducted. In the area of educational experience, data about degree programs and attainment as well as specific courses were collected. A Likert Scale was used to measure confidence levels reported by respondents. The 5-point scale was as follows; 1 - not at all confident, 2 - somewhat unconfident, 3 - unsure, 4 - somewhat confident, 5 - confident. SLPs were asked to rank their perceived confidence for the following six items: their current knowledge of genetics, ability to discuss the genetic components of speech, language, and hearing problems, ability to communicate general knowledge in the area of genetic syndromes and/or genetic disorders, ability to obtain critical information in the area of genetic syndromes or genetic disorders in order to provide high quality services, ability to provide counseling for parents and guardians of children with genetic syndromes or genetic disorders, and ability to
make referrals for genetic counseling. The respondents’ rankings to these six items were summed for a total score out of six (not at all confident) to 30 (confident on all six items). Discussion comparing the results of this study compared to others will be shared. Implications for undergraduate and graduate programs as well as professional development providers are included in the discussion.

Data Analysis

Data was analyzed using SPSS predictive analytics software. Descriptive statistics were computed for demographic data, percent correct on a basic genetics knowledge quiz, and self-perceived confidence ratings. Statistical analysis Pearson correlation test was conducted examining the relationship between the number of correct answers on the genetics quiz compared to the number of years the SLPs have practiced. Also, statistical analyses Pearson correlation tests were conducted evaluating the relationship between confidence levels and caseload numbers, work settings, universities attended, years practiced, and genetics quiz scores.
RESULTS

Participants and Demographics

Thirty people attempted the survey, one of which did not complete the quiz portion. This data was excluded therefore answers from 29 respondents were used for this study. Out of the 29 participants, 27 reported that they lived and worked in Iowa. One respondent lived and worked in Missouri, and the other lived and worked in Nebraska. Of 29 respondents, all received a Master’s degree, 25 had their Certificate of Clinical Competence (CCCs), and two had Doctorate degrees.

The mean number of years working as an SLP was 22.14 with a range of less than one year to 44 years. Table 1 shows SLPs reported work settings. The average caseload size was 24.18 (SD=15.98; range 0 to 54). Table 2 shows participants’ caseload sizes. All participants consented to the use of their answers for the purposes of this study. There was no compensation given to respondents for participating in this study.
Table 1
Participants’ Reported Work Settings

<table>
<thead>
<tr>
<th>Work Settings</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>School</td>
<td>10</td>
</tr>
<tr>
<td>Hospital</td>
<td>10</td>
</tr>
<tr>
<td>Skilled Nursing Facility</td>
<td>7</td>
</tr>
<tr>
<td>Long Term Care Facility</td>
<td>4</td>
</tr>
<tr>
<td>Rehabilitation Center</td>
<td>2</td>
</tr>
<tr>
<td>Private Practice</td>
<td>2</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>3</td>
</tr>
<tr>
<td>College/University</td>
<td>4</td>
</tr>
<tr>
<td>Retired</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2
Participants’ Reported Caseload

<table>
<thead>
<tr>
<th>Number of Participants</th>
<th>Number of People on Caseload</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>0-10</td>
</tr>
<tr>
<td>4</td>
<td>11-20</td>
</tr>
<tr>
<td>3</td>
<td>21-30</td>
</tr>
<tr>
<td>5</td>
<td>31-40</td>
</tr>
<tr>
<td>4</td>
<td>41-50</td>
</tr>
<tr>
<td>1</td>
<td>51-60</td>
</tr>
</tbody>
</table>
Descriptive Analyses

SLPs’ percentages of correct and incorrect responses on the 22-item genetics quiz were tabulated (Table 3). The mean number of questions correctly answered was 16.5517 (S.D. = 2.59) with a range from 10 to 22. These scores converted to a range of 45-100%, with a mean score of 75% correct responses on 22 items.

SLPs were asked to report their confidence in counseling, educating, making referrals, and working with individuals that have genetic disorders. Confidence levels were obtained through a 5-item scale from 1 (not at all confident) to 5 (confident). The mean confidence summary score for participants was 17 (S.D.=7.5) with a range from 7 to 33.
### Table 3

**Percentage of Correct and Incorrect Responses on the Quiz**

<table>
<thead>
<tr>
<th>Item</th>
<th>Correct Response</th>
<th>Incorrect Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The four basic chemical components of DNA are: adenine (A), guanine (G), cytosine (C), thymine (T)</td>
<td>72.4%</td>
<td>27.6%</td>
</tr>
<tr>
<td>2. DNA is found in: cell nucleus</td>
<td>62.1%</td>
<td>37.9%</td>
</tr>
<tr>
<td>3. Genes: both are contained within chromosomes and are made of DNA</td>
<td>89.7%</td>
<td>10.3%</td>
</tr>
<tr>
<td>4. Genetics is the study of heredity and how traits are passed down through generations: True</td>
<td>89.7%</td>
<td>10.3%</td>
</tr>
<tr>
<td>5. During interphase, the cell is in normal cell division: True</td>
<td>75.9%</td>
<td>24.1%</td>
</tr>
<tr>
<td>6. The order of the phases of mitosis are: prophase, telephase, interphase, anaphase, metaphase</td>
<td>51.7%</td>
<td>48.3%</td>
</tr>
<tr>
<td>7. Homozygous refers to the state of having ______ of a gene to be identical: both alleles</td>
<td>65.5%</td>
<td>34.5%</td>
</tr>
<tr>
<td>8. Most people have 46 chromosomes in every cell of their body that contain the genetic information that their body needs to develop, grow, and function: True</td>
<td>75.9%</td>
<td>24.1%</td>
</tr>
<tr>
<td>9. Who has XY chromosomes?: Males</td>
<td>65.5%</td>
<td>34.5%</td>
</tr>
<tr>
<td>10. The majority of all health problems are NOT believed to have both a genetic component and an environmental component: False</td>
<td>79.3%</td>
<td>20.7%</td>
</tr>
<tr>
<td>11. What is the chance that two parents who are carriers for an autosomal recessive genetic disorder will have a child with that condition? : 25%</td>
<td>48.3%</td>
<td>51.7%</td>
</tr>
<tr>
<td>12. When cells contain changes or variance in the information in their genes, it is called a gene mutation: True</td>
<td>89.7%</td>
<td>10.3%</td>
</tr>
<tr>
<td>13. Cri-du-chat syndrome is recognized in the neonatal period by the individual’s ______: high-pitched cry</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>Question</td>
<td>Percentage Correct</td>
<td>Percentage Incorrect</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>14. In individuals with Fetal Alcohol Syndrome, what major system(s) are affected?: growth, central nervous system, and musculoskeletal</td>
<td>86.2%</td>
<td>13.8%</td>
</tr>
<tr>
<td>15. Trisomy 21 is also known as ______: Down Syndrome</td>
<td>100%</td>
<td>0%</td>
</tr>
<tr>
<td>16. What term refers to “present at birth”?: congenital</td>
<td>100%</td>
<td>0%</td>
</tr>
<tr>
<td>17. In a family history, _______ share half of their genetic material with the person with the condition: primary relatives</td>
<td>72.4%</td>
<td>27.6%</td>
</tr>
<tr>
<td>18. In a pedigree, the darkened circle symbol represents _______: female who does have condition</td>
<td>31%</td>
<td>69%</td>
</tr>
<tr>
<td>19. What is the importance of obtaining a family history?: get a pattern of affected individuals in the family, avoid unnecessary referrals, and help develop rapport with client</td>
<td>62.1%</td>
<td>37.9%</td>
</tr>
<tr>
<td>20. Which of the following are ways in which genetic testing can impact clinical care?: make an early diagnosis, reduce morbidity and mortality, guide patient planning and decision making, reduce anxiety, and alter future</td>
<td>100%</td>
<td>0%</td>
</tr>
<tr>
<td>21. A health care professional has a duty to warn their patients about other family members who may be at risk of developing genetic diseases and assist patients in the process of informing family members: True</td>
<td>89.7%</td>
<td>10.3%</td>
</tr>
<tr>
<td>22. Which of the following roles do genetic counselors perform?: both assess the risks an individual will have a genetic disorder based on family history and data from genetics studies and provide information about inheritance, medical management, social support, testing options, and research to families with a genetic condition</td>
<td>79.3%</td>
<td>20.7%</td>
</tr>
</tbody>
</table>
Participants were also asked what sources they use to find genetics information. They were allowed to submit more than one source. The following sources were reported: Internet (39%), textbooks/books (16%), case history/medical/other reports (16%), journal articles/publications (13%), or professional development courses (3%). 5% reported no use of genetics and 8% of respondents did not provide an answer.

**Statistical Analyses**

Pearson correlations were calculated examining the relationship between confidence levels and caseload numbers, work settings, and years practiced. It was found that in all three cases there were weak correlations that were not significant. A Pearson correlation was
calculated examining the relationship between participants self-reported confidence levels and their correct number of responses on the genetics quiz. A strong correlation that was significant was found \( F(2, 26) = .002, p = .557 \). A one-way ANOVA was used to test the relationship for confidence compared to university attended. No significant main effect of the university attended on genetics knowledge was found \( F(2, 26) = .537, p = .591 \). Finally, a one-way ANOVA was used to test the relationship for confidence compared to work setting. A relationship was not found \( F(5, 22) = .528, p = .753 \).
DISCUSSION

A strong correlation was found between the participants’ score on the genetics quiz and the self-reported measure of confidence. This is in accordance with the research conducted by Tramontana, Blood, and Blood (2012). Research by Tramontana, Blood, and Blood (2012) found that there was a strong positive correlation between greater knowledge of genetics information and a greater confidence in genetics knowledge. Data from the survey of Midwest speech-language pathologists also suggests that confidence in genetics knowledge is correlated to aptitude in genetics knowledge. SLPs reporting a lower confidence tended to score lower on the genetics quiz. As reported by Tramontana, Blood, and Blood (2012) as well, greater knowledge in genetics information may lead to stronger confidence in working with individuals with genetic disorders therapeutically, in assessment and prevention, and in communication with parents and caregivers.

No correlation was found between self-reported measurements of confidence and number of years practicing or the number of years practicing and percent correct on the genetics quiz. These findings suggest that recently graduated SLPs are not necessarily more equipped to deal with the new genetic findings in our field. This also suggests that SLPs that have been working longer do not necessarily acquire more knowledge from their practice. These findings are consistent with previous research conducted (Blood & Blood, 2005; Christianson, McWalter, & Warren, 2005; Tramontana, Blood & Blood, 2012). Research by Christianson, McWalter, & Warren (2005) suggested that knowledge of and training in genetics information also correlates to confidence in delivering these skills clinically. However, this research also reported that education in genetics knowledge is not sufficient and that educational interventions for allied health students are still required.
After an ANOVA was calculated, no relationship was found between the work setting of the professional and the confidence level that individual reported. This suggests that confidence levels do not vary based on different work places and the type of experiences gained in different settings. No correlation was found for the university attended and the self-reported confidence level as well.

Knowledge Acquisition

Participants reported several sources they used to gain their genetics knowledge, with the internet being the most reported with 39% usage. There are credible sources on the internet, but there are also sources that are not evidence based. Professionals need to use caution when deciding which websites to use for their practice. Ilic (2010), found that the concerning factor with gaining medical information from the internet is the variance in the quality of information. Through a systematic review, it was found that there is a significant lack of quality websites that offer accurate information (Ilic, 2010). Despite this, there are a few useful and evidence based websites available to clinicians. Two of the main websites were developed by The National Coalition for Health Professional Education in Genetics (NCHPEG) and the National Center for Biotechnology Information (NCBI).

Limitations

One important limitation of this study that should be noted was the small sample size. The Iowa Speech-Language Hearing Association (ISHA) database that was used for this study contains 384 members on their list serve. Out of this total, there were only 29 respondents. Also, due to time constraints, the survey was only distributed to Midwest speech-language pathologists, therefore there wasn’t a representative sample of the total SLP population. As graduate student researchers, approval through the University of Northern Iowa Institutional
Review Board (IRB 12-0198) was mandatory to conduct research. After an amendment to the IRB approval for this project, the researchers were allowed to follow up with participants only once. Lastly, the University of Northern Iowa Communication Science and Disorders program offers a genetics and syndromes class to undergraduate and graduate students. This university is the only one in the state of Iowa to provide a specific course on this topic in the curriculum. As researchers, we were especially interested to see any impact this had on data. However, the course is new and has only been offered three times, therefore a small number of former students who had taken the course responded to the survey. To see any impact of this course on data, a larger sample size would need to be surveyed.

**Future directions**

More research is needed to substantiate the consideration of the addition of genetics to the speech language pathology core curriculum at a national level. Future studies should be done to determine what specific skills speech pathologists need in order to confidently provide services to individuals with genetic disorders. Studies should examine how effective a course in genetics would be at increasing confidence levels in professionals in this field. Studies need to also investigate how effective a genetics course during college would be at increasing confidence levels of SLPs after graduation.

**Conclusion**

Speech-language pathologists are often the first referral for families experiencing speech, language, hearing, and feeding difficulties in addition to a genetic diagnoses. However, many graduate programs for speech-language pathology still do not require a genetics course in the curriculum. With a rapidly expanding body of genetics information applicable to healthcare practices, the need for including genetics within curriculums continue to grow. This research
examined the genetics knowledge and confidence of speech-language pathologists within the state of Iowa. The purpose of the research was to examine the levels of confidence these practitioners have in regards to delivering genetic information and counseling to individuals on their caseloads. The majority of respondents reported a lack of confidence within this realm of their practice. This preliminary research, as well as similar studies conducted on the national level, is finding substantial reasons to include a genetics course within the curriculum for speech-language pathologists.
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