Exploring the Intersection of Pediatric Genetic Counseling and the U.S. Foster Care System

Master's Thesis

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Brandeis University
Graduate Program in Genetic Counseling
Cassandra Buck, MS, CGC, Advisor

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by
Talia Flamos

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ABSTRACT

Exploring the Intersection of Pediatric Genetic Counseling and the U.S. Foster Care System

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Talia Flamos

Six percent of children in the United States spend some time in the foster care system by their 18th birthday. Previous research has reported that children in the foster care system have an increased incidence of medical and developmental concerns, and that children with complex medical needs tend to have poorer long-term outcomes of placement and more transient care. Given that medically complex cases are often appropriate to consider a referral to a genetics clinic, a genetic counselor may be one part of the healthcare system that a child in foster care may encounter. Since much of a pediatric genetic counseling session relies on access to family and developmental history information, often gleaned from the biological parents, this study aimed to determine the impact that the unique aspects of foster care have on a genetic counseling session. Pediatric genetic counselors, who had previously counseled at least one patient in the foster care system, were recruited from the NSGC email listserv to participate in an anonymous online survey. Of the 125 respondents, 40% reported seeing a patient in foster care at least twice a month, most commonly for developmental delay or intellectual disability/autism spectrum disorders evaluations. The majority (70.4%) of respondents stated that the referral reasons for their patients in foster care were similar to the rest of their practice. However, over 75% of respondents reported that there are aspects of their counseling
that are different when a patient is in foster care. These differences presented in both in the logistical aspects, such as access to patient history, and the psychosocial features of the genetics evaluation, such as determining who is involved in the decision-making or navigating family dynamics. Over 50% of respondents ranked access to history information as a factor that had a high impact on their sessions. More than 60% of respondents agreed that incomplete history information may make it difficult to determine the most appropriate testing strategy, and over 80% agreed that it can lead to a fair amount of uncertainty about the genetic contribution to a child’s developmental or health concerns. The perspectives of the genetic counselors that participated in this research highlighted the need for increased education on the foster care system for providers, increased awareness of the specific psychosocial issues that may need to be addressed, and revealed the lack of knowledge of any standardized protocols for providers and specific resources for foster families.

KEYWORDS: pediatric; genetic counseling; genetic counselor; foster care
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INTRODUCTION

The United States foster care system was originally developed in the late 19th century as an improved substitute for the institutionalization of children who were surrendered or unable to receive adequate care from their biological families. It was designed to provide a system of care for these children while aiding in their adjustment, monitoring their progress, and working towards a sufficient permanent home (Child Welfare League of America, 1975; Simms, 1991). Six percent of all children in the United States spend at least some time in foster care before their 18th birthday, with nearly 500,000 children currently enrolled (American Academy of Pediatrics, 2000; Turney & Wildeman, 2016). Over 70% of these children are placed in state custody due to neglect, abuse, unstable living environments, poverty, family violence, and parental substance abuse, criminal activity, and/or mental illness (Szilagyi, Rosen, Rubin, & Zlotnik, 2015; US Department of Health and Human Services & Administration on Children Youth and Families, 2013).

Children in foster care that have experienced adversity early in childhood have consistently been found to have more mental and physical health concerns than non-maltreated non-foster children controls, and therefore their health and development often requires more preventative and reparative support from the health care system (Bruce et al., 2013; Perry, Pollard, Blakley, Baker, & Vigilante, 1995; Ringeisen, Casanueva, Urato, & Cross, 2008; Turney & Wildeman, 2016). The proportions of children with developmental delays and Autism Spectrum Disorder are significantly higher in children within the foster care system than those who are not (Cidav, Xie, & Mandell, 2018; Drillien, Pickering, & Drummond, 1988;
Leslie et al., 2005). As many as 10% of foster children are classified as medically complex cases, which has been shown to independently correlate with poor outcomes of placement including increased length of stay and number of placement transfers, and decreased placement stability and sense of permanency (Cohen et al., 2011; Seltzer, Dodge, & Boss, 2018).

Current medical decision making for children in foster care involves many intricate and variable parts – the legal system, child welfare system, and the healthcare system. Lack of cohesive cooperation between these systems, coupled with the presence of incomplete or uncertain relevant medical and family history may make it difficult to establish and maintain a cohesive and comprehensive standard of care for children in foster care (Simms, Dubowitz, & Szilagyi, 2000; Szilagyi et al., 2015). Information gaps combined with frequently changing placements and medical providers can reduce health care consistency, coordination, and efficacy (Digiuseppe & Christakis, 2003; Szilagyi et al., 2015).

Given that the agendas of many pediatric genetic counseling sessions revolve closely around information about the biological family history and medical history of the child, which is not always available, sessions with children in foster care may be difficult to conduct. Traditionally, a pediatric genetic counseling appointment emphasizes pregnancy history, family history, and medical history to guide examination, investigation, genetic testing, and long-term follow-up care. When working with the foster care population, there is often limited history information available and complex confidentiality issues and social situations. This can lead to a fair amount of uncertainty about the genetic contribution to a child’s health or developmental concerns and may leave a large gap in comprehensive care and overall understanding of the patient’s case (Douglas, 2017; Parker & Teasdale, 2016). Further research and recognition of the challenges health care professionals encounter in providing complete care for this cohort
can help drive future policy and solutions to ensure these children receive top quality care and work towards alleviating some of the disparities they face.

A genetic counselor is one specific part of a healthcare team that a child in foster care may encounter given their increased incidence of medical and developmental concerns, and one that may be critical in the improved coordination of their overall health care. Prior research has highlighted a need for improvement in the health care delivery of children in foster care, but there has been limited research into the specific interactions of genetic counselors and this cohort. The intention of this research is to better understand the process and impact of genetic counseling within the U.S. foster care system via the current perspectives of pediatric genetic counselors in order to explore their challenges, and gather insight on prospective ways the genetics field can better serve this pediatric population and their families.
METHODS

This project was deemed exempt by the Brandeis University Human Research Protection Program’s Institutional Review Board.

Participants

All members of the National Society of Genetic Counselors (NSGC) that are signed up to receive listserv emails were invited to participate in the study. In order to be eligible to participate, participants were required to be certified or board-eligible genetic counselors, who have practiced in a pediatric setting within the last 5 years, and have counseled at least one case involving a child in foster care.

Instrumentation

The survey was developed and hosted on a Qualtrics survey platform and made available online for 4 weeks from November to December of 2018. The survey consisted of 38 questions that were a combination of multiple choice, Likert-scale, and free response styles (see Appendix B). The first part of the survey asked respondents about the frequency they see patients who are in foster care, who attends the appointments, common referral reasons, and resources they utilize. Further questions collected information about differences in genetic counseling session content between those involving a child in foster care compared to a more traditional setting, involvement with state assigned case workers, and opinions on how we can best serve this population of pediatric patients as a profession moving forward. The final part of the survey collected basic demographic information including gender, years of experience as a genetic counselor, and geographic region.
Procedures

A recruitment notice was distributed to genetic counselors via the NSGC listserv in November 2018 to approximately 4,000 members with a reminder email was sent out 3 weeks after the initial notice. Based on Professional Status Survey data from the NSGC, 23% of members identify as practicing in a pediatric specialty (National Society of Genetic Counselors, 2018). If recipients were interested in participating, they were directed to the start of an anonymous online survey.

Participants were excluded if they did not meet eligibility criteria and redirected out of the survey using branch logic developed by the Qualtrics software. Participation in the survey was completely voluntary and responses were kept anonymous. Upon survey completion, participants were given the chance to enter their email address into a separate, unlinked raffle for the chance to win one of three $50.00 Amazon.com gift cards.

Data Analysis

Data analysis conducted using SPSS (v) included descriptive statistics, frequency information, and correlation analysis using SPSS software. Thematic analysis was utilized to analyze the free response answers. Basic demographic data from participants was used to comment on the samples representation of the profession as a whole.
RESULTS

Respondent Demographics

A total of 135 participants started the online survey. Ten participants did not meet eligibility criteria or failed to complete more than 75% of the questions. The remaining 125 participants’ responses were included in analysis.

The majority of respondents were female (91.2%, n=114), with less than 5 years of experience as a genetic counselor in a pediatric specialty (72.6%, n=114). All six National Society of Genetic Counselors (NSGC) geographical regions were represented. This demographic data is shown in Table 1.

<table>
<thead>
<tr>
<th>Gender</th>
<th>(n=114)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>7.0%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>91.2%</td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1.8%</td>
<td></td>
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</tbody>
</table>

<table>
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<tr>
<th>Total Years Experience</th>
<th>(n= 114)</th>
<th></th>
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<tbody>
<tr>
<td>4 or less</td>
<td>67.5%</td>
<td></td>
</tr>
<tr>
<td>5 to 9</td>
<td>19.3%</td>
<td></td>
</tr>
<tr>
<td>10 or more</td>
<td>13.2%</td>
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<table>
<thead>
<tr>
<th>Years Experience as Pediatric Genetic Counselor</th>
<th>(n=113)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4 or less</td>
<td>72.6%</td>
<td></td>
</tr>
<tr>
<td>5 to 9</td>
<td>19.3%</td>
<td></td>
</tr>
<tr>
<td>10 or more</td>
<td>13.2%</td>
<td></td>
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<table>
<thead>
<tr>
<th>NSGC Region</th>
<th>(n=114)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1 (CT,MA,ME,NH,RI,VT,CN Maritime Provinces)</td>
<td>7.0%</td>
<td></td>
</tr>
<tr>
<td>Region 2 (DC,DE,MD,NJ,PA,VA,WV,PR,VI,Quebec)</td>
<td>14.9%</td>
<td></td>
</tr>
<tr>
<td>Region 3 (AL,FL,GA,KY,LA,MS,NC,SC,TN)</td>
<td>15.8%</td>
<td></td>
</tr>
<tr>
<td>Region 4 (AR,IA,IL,IN,KS,MI,MN,MO,ND,NE,OH,OK,SD,WI,Ontario)</td>
<td>38.6%</td>
<td></td>
</tr>
<tr>
<td>Region 5 (AZ,CO,MT,NM,TX,UT,WY,Alberta, Manitoba, Sask.)</td>
<td>12.3%</td>
<td></td>
</tr>
<tr>
<td>Region 6 (AK,CA,HJ,ID,NV,OR,WA,British Columbia, Yukon)</td>
<td>11.4%</td>
<td></td>
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Table 1: Respondent Demographics
Characterizing Genetic Counselor Interactions with the Foster Care Population

Nearly 70% of respondents reported they see a patient in foster care at least one time per month (see Figure 1). For analysis purposes, the respondents that answered “Very Often (at least 1 time per week)” and “Frequently (2-3 time per month)” were combined into one group labeled “Frequently”. Similarly, respondents that answered “Rarely (a few times per year, but less than once a month)” and “Very Rarely (at least one time in the past)” were combined into one group labeled “Rarely”.

Figure 1: Frequency of cases involving a patient in foster care (n=125)

Nearly all of the respondents (94.2%, n=125) report that foster parents frequently or always accompany the patient to their appointment. Only 0.8% report that they are frequently or always accompanied by a biological parent, 8.9% another biological relative, and 16.8% a caseworker. The majority (76.0%) of respondents reported that there are aspects of their structure or approach to their counseling when the patient is in foster care that are different from when the patient is in the care of their biological parents. Similarly, 56.8% of respondents report there are aspects that are different when the patient is in kinship care of an extended
biological relatives versus a traditional foster care setting (n=125). *Table 2* summarizes this data.

<table>
<thead>
<tr>
<th>Patient in foster care vs. the care of their biological parent</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>76.0%</td>
</tr>
<tr>
<td>No</td>
<td>24.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient is in foster care vs. kinship care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>56.8%</td>
</tr>
<tr>
<td>No</td>
<td>43.2%</td>
</tr>
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</table>

*Table 2*: Differences in Genetic Counseling Session Approach or Structure (n=125).

Participants were asked if there were differences in the structure or content of their genetic counseling sessions based on whether the child was in the care of an unrelated foster parent or a non-parent relative.

The majority of respondents (70.4%, n=125) felt that the referral reasons for patients in foster care were similar to their non-foster care pediatric patients. When asked to select common reasons for genetics referral for their patients in foster care, developmental delay, intellectual disability / autism spectrum disorders, and congenital anomalies/birth defects were selected most commonly, as outlined in *Table 3*. Nearly 20%, (n=125) of respondent’s felt the proportions of referral reasons differed from their non-foster care patients. Thirteen of the 20 who further explained how they felt the referrals were different, commented that the proportion of referrals for prenatal exposures and ruling out non-accidental trauma was elevated in the foster care cohort compared to their other patients. Six out of those 20 respondents felt there was an increased incidence of developmental delay/ autism spectrum disorder / behavioral related referrals than the general clinic population.
We further asked participants to describe in their own words how their typical genetic counseling sessions differed when a patient was in foster care. Compared to a session where the patient is in the care of biological parents, genetic counselors reported when the patient is in foster care they may tailor their initial contracting to acknowledge that the foster parent might not have all the answers to the questions they will ask, and will generally ask more open-ended questions and less targeted ones when gathering history information. Regarding content of the visit, genetic counselors reported they may gather a less detailed family history, spend less time discussing the potential impact of testing on other biological relatives, and address specific test limitations that may arise due to possible lack of samples from biological relatives. They also discussed the importance of being especially sensitive to the child’s awareness of the situation, and the specific psychosocial concerns that may need to be addressed. When a child is in kinship care of an extended biological relative, respondents reported they might place more weight on the potential implications of testing on other family members, and are more

<table>
<thead>
<tr>
<th>a. Most Common Referral Reasons</th>
<th>Percent (n=125)</th>
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<tbody>
<tr>
<td>Developmental Delay</td>
<td>92.6%</td>
</tr>
<tr>
<td>Intellectual Disability / Autism</td>
<td>86.1%</td>
</tr>
<tr>
<td>Congenital Anomalies / Birth Defects</td>
<td>53.3%</td>
</tr>
<tr>
<td>Seizures / Epilepsy</td>
<td>20.5%</td>
</tr>
</tbody>
</table>

| b. “Are referral reasons for foster care and non-foster care patients similar?” |
|---------------------------------|----------------|
| Similar                         | 70.4%          |
| Different                       | 19.2%          |
| Not sure                        | 10.4%          |

Table 3: Common referral reasons among foster care patients (n=125). (A) Participants were asked to select the most common reasons for genetics referral for patients in foster care. Note percentages do not sum to 100% because participants were allowed to select multiple responses. The top 4 answers are shown. (B) Participants were asked if the referral reasons for foster care and non-foster care patients are similar in proportions.
cognizant of how family dynamics may impact the visit. One respondent commented that these situations can be challenging, saying,

“[m]any times with a related caregiver, blame is expressed from that caregiver toward one or both biological parents and this has to be avoided during the session so as not to upset the child. Additionally, these extended relatives also have their own narratives about what is going on with the child and these can be difficult to overcome.”

Other participants echoed this theme, mentioning that “family dynamics play a much larger role” and that “sessions can be more emotional, as the caregiver... may have strong opinions on the biological parents.”

Factors that Shape Those Interactions

Respondents were also asked to comment about the level of impact specific factors had on a genetic counseling session where the patient was in foster care. Over 50% of respondents ranked access to history information as a factor that had “high impact”. Over 50% of respondents ranked family history, discontinuity of care, status of the placement, the patient’s past experiences, and complex family dynamics as having “some impact” (n=125). See Figure 2.

![Impact on Genetic Counseling Sessions](chart)

**Figure 2**: Level of impact factors have on genetic counseling encounter (n=125)
Participants were asked to further elaborate on how the factors they ranked as "high impact" affected their counseling visits. Unsurprisingly, many respondents commented about the challenges of working with limited history information, mentioning the challenges providing correct risk assessments and enabling appropriate testing decisions. One participant wrote, "[f]amily history information is vital to risk assessment and differential diagnosis; incomplete family histories can significantly increase the uncertainty factor," while another stated that, "[n]ot having access to history information can hinder our ability to decide upon the most appropriate genetic testing to order."

Along the same vein as their free-response answers in previous questions, many respondents agreed that incomplete history information may make it difficult to determine the ‘best’ or most appropriate testing” (66.4%, n=125) and that it “can lead to a fair amount of uncertainty about the genetic contribution to a child’s health or developmental concerns versus an environmental component” (83.2%, n=125).

Many participants also commented that the person attending the appointment with the child often influences their access to accurate history information. Several participants commented that since the adult attending the appointment often recounts the family and medical history, their knowledge and perspective has a large impact on their session. Several commented that caregivers without complete history information can limit what they know about the patient, and one participant even commented that they worry about potential inaccuracies or biases that may be introduced, commenting that:

"Many patients in the foster care system come with foster parents, state wards, etc. who either have no information about family history or limited information that sometimes seems to have a bias against it... I have often wondered if the history information provided
is truly accurate or if some if it is embellished due to resentment or anger against the bio parents."

In addition to its impact on the information that’s available, participants commented that the adult attending the appointment also has an impact on what is discussed or what testing is performed. One respondent wrote,

"How much education provided for long term impact depends on who is in the room and who will be caring for the child long term...When it comes to testing decisions, the status of the people in the room impacts how much their opinion impacts facilitation of decision making."

Because of the often transient nature of a foster care placement, the effects of discontinuity of care was a final recurring theme among free response answers. It seems as though discontinuity of care due to the transient nature of some foster care placements may contribute to the lack of history information reported. Several respondents commented that re-establishing care was challenging each time the child moves to a new foster family, since past history information is often incomplete or of uncertain accuracy.

One genetic counselor stated, “every foster family basically has to start from scratch to establish care. We see lots of individuals who were lost to follow-up in some way, shape, or form.” Others echoed this idea, that in cases where “there is incomplete information and the child has been under the care of multiple foster parents, it is difficult to understand what work up has already been done and how much the current foster parent understands of the child’s full health history.” Another mentioned this discontinuity “can make it difficult to track down appropriate or needed records” and that with “significant uncertainty about whether evaluations have been done, what results were, whether the information is accurate, etc., [can make] it difficult to trust the information provided.”
Over 80% of participants (82.4%, n=125) reported they were not aware of any outside foster care-specific resources genetic counselors could provide families as additional support. No statistically significant correlation was observed when compared to the frequency in which they see patients in foster care.

While the majority of patients come to their appointment in the care of their foster parents, in many situations, the conversations surrounding a child’s genetic evaluation seem to also need to include the state. Over 80% of respondents say they have spoken with a child protective services employee or state assigned caseworker regarding a patient's genetic evaluation (n=125). Over 60% of respondents said that they discuss implications of genetic test results with the caseworker and they will contact the caseworker to obtain legal consent for testing “most of the time” (n=125). Over half (62.7%, n=125) of this study's participants said they would contact the caseworker regarding family studies, or when genetic test results have implications to biological family members' health or reproductive risks at least half the time.

When asked in free response format to describe how they would proceed in a scenario where they just received positive genetic testing results for a patient who is in state custody that have implications on the patient's biological relatives, there was a clear lack of consistency between responses. About half (52.6%, n=97) wrote they would start by discussing the situation with the patient’s state-assigned caseworker. One respondent wrote, “this happens a lot; it really is up to the case worker/state to make sure the biological family gets the information and we are the facilitators of that process.” Others reiterated similar processes and commented on associated frustrations. One genetic counselor writes “[g]enerally the caseworker is able to tell me whom I can speak with... This process takes a long time as it is usually hard to get a hold of the caseworker.” Another mentioned, “I have tried, and I don’t really know of any protocols in place. I usually reach out to the caseworker, and try to get that person to reach the family. Honestly this
has always been ineffective for me." Other major scenarios that arose were using a letter to communicate results to biological relatives directly or to give to the foster parent to pass along, and many stressed the need to document the specific implications and their efforts in the child’s medical record. Over 20% of the free-text responses (20/97) specifically cite their lack of knowledge about any specific protocols for such a situation, with one respondent elaborating that, “we had to bring legal into our clinic because there were no protocols in place.”

**Best Serving this Population in the Future**

Finally, participants were asked about their exposure to the foster care system while attending their genetic counseling program. Less than half felt that their GC program provided information on the foster care system (41.6%, n=125), or discussed working with this unique population (45.9%, n=125) However, 50.4% (n=125) of participants agreed that their program provided experiences or opportunities that included working with this pediatric cohort. Participant responses were analyzed further to look for differences based on years of genetic counseling experience to see if there were noticeable differences in opinions based when they attended graduate school, but no statistically significant correlation was observed.

Participants were asked to comment on what would be helpful, or has been helpful in the past, to better prepare to serve the foster care cohort. The most common theme was access to informational resources or opportunities to better their understanding specifically on the foster care system itself, and legal aspects that are pertinent to health care of these patients. Other themes included on-the-job experience with working with this population, and access or knowledge of resources for both families and health care providers that are specific to this population.

When asked how genetic counselors as a whole can better serve this population in the future, many comments focused on education: better educate ourselves on our state’s child
welfare systems and what resources are out there, educate caseworkers and foster families on genetics as a part of a child’s healthcare evaluation, and implement pieces of more formal instruction or awareness of the unique aspects of working with this population in genetic counseling training programs. Other common answers were improving clarity around institutional level protocols, striving towards better access and coverage of genetic evaluations through state insurance coverage, being aware of unique psychosocial implications of this population, and using documentation in medial records and written letters to better communicate with families and other medical providers. Multiple other responses say that we should continue to strive to provide the best care possible despite any challenges or obstacles, just like our profession strives to do for any other patient. One participant summed it up best, stating that genetic counselors “are more comfortable with the unknown, the uncomfortable, or things not being very black and white. Thus we are uniquely positioned to help.”
DISCUSSION

Study Limitations

This research has some inherent limitations that should be considered when interpreting and applying its findings. Study participants were recruited through the National Society of Genetic Counselors (NSGC) email listserv, thereby excluding any genetic counselors that are not NSGC members. In the National Society of Genetic Counselors 2018 Professional Status Survey, 581 genetic counselors (23% of respondents) identified as working in a pediatric specialty. The 125 participants in this research is only a proportion of the field as a whole, and is likely not representative of all genetic counselors. The number of participants may have been limited due to the eligibility criteria of having been involved in at least one case involving a patient in foster care. It’s possible many pediatric genetic counselors have not encountered such a case and therefore were ineligible to participate.

While genetic counselors of all NSGC geographical regions were represented in this study, the proportions of respondents in each region are not representative of the proportions from the latest NSGC Professional Status Survey. Region 2 was underrepresented (15% compared to 22% of NSGC 2018 Professional Status Survey respondents). Region 6 was also underrepresented in this research compared to Professional Status Survey (PSS) data, with just over 11% of participants from this region compared to 19% of PSS respondents. Region 3 and 4 were overrepresented with 15% and 39% of survey participants from this region respectively, compared to 12% and 28% respectively from PSS data (National Society of Genetic Counselors, 2018).
The sample population may also have been affected by ascertainment bias; genetic counselors with particularly strong opinions or experiences with the foster care population may have been more likely to participate. Additionally, a significant number of participants responded “neither agree nor disagree”, or “unsure” if they were listed as choices, which may have skewed data and limited statistical power. Another limitation of this research is that data was gathered at a national level, the foster care system and clinic protocols vary very much by state and by institution. The differences between the foster care systems among different states is a factor that was not controlled for in this research. Each participant responded with their experiences and perceptions of the in the state they practice. As with any survey-based research, questions may have been interpreted differently among participants and all data is self-reported by the respondent.

Practice Implications

The foster care population has not been extensively researched in the context of genetic counseling. However, if 6% of children in the United States will be involved in foster care at some point in their life, it is reasonable to expect genetic counselors to encounter this cohort not infrequently (American Academy of Pediatrics, 2000; Turney & Wildeman, 2016). Indeed, over 40% of respondents in this study reported seeing a patient in this cohort at least 2 times per month. This frequency appears to be higher than reported in related research in the past, where the majority of counselors reported seeing 5 or fewer cases involving the foster care population, but this may in part be derived by our study recruitment parameters that stated participants had to have seen at least one patient in foster care in order to participate (Douglas, 2017). If genetic counselors are involved in the health care of many of these children, research on this topic could prove instrumental in identifying shortcomings or specific challenges that exist and enabling more equitable care to be enacted through meaningful change.
The majority of counselors reported these patients are commonly referred for developmental delay or intellectual disability / autism spectrum disorders. The majority also reported referral reasons are similar to their general clinic population, but some participants commented on the increased proportion of fetal alcohol syndrome evaluations as well as ruling out non-accidental trauma from abuse vs. a genetic condition such as osteogeneis imperfecta in the foster care cohort. This is congruent to findings of a related research study, which outlines similar common reasons for referral (Douglas, 2017). The reportedly increased incidence of maternal exposure and non-accidental trauma evaluations in this population also point to how the sometimes complex or uncertain social history of many foster children may intersect with a genetics evaluation, since many children in foster care are placed in state custody due to neglect, abuse, and/or parental substance abuse (Szilagyi et al., 2015; US Department of Health and Human Services & Administration on Children Youth and Families, 2013). Others who felt referral reasons were different than their non-foster care patients reported they felt the proportions of developmental delay, autism spectrum disorder, and behavior-related referrals were more prevalent among their patients in foster care. These cited differences are not surprising, as it has been reported that the proportions of children with developmental delays and Autism Spectrum Disorder are significantly higher in children within the foster care system than those who are not (Cidav et al., 2018; Drillien et al., 1988; Leslie et al., 2005).

An additionally unique aspect of this cohort is that a biologically unrelated guardian, usually a foster parent and sometimes a state assigned caseworker, often accompanies them to the appointment and is therefore supplying and receiving the pertinent healthcare information. This is likely a major factor in what drives some of the challenges and differences reported in a genetic counselor’s approach to patient in foster care compared to a patient in the care of their biological family. Given that the agendas of pediatric genetic counseling sessions revolve closely
around information about the biological family history and medical history of the child, sessions with children in foster care may be difficult to conduct the same as in a more traditional setting. This was illustrated with the results of this research. Among participant responses, some psychosocial based themes emerged, such as genetic counselors conscious of the child’s awareness and sensitivity to the situation, and navigating complex family dynamics. Other more structural or content-based themes included genetic counselors tailoring their intake questions to be more open ended to account for the potential lack of known history information, spending less time discussing the potential impacts regarding recurrence risk or other biological relatives, and spending more time discussing the specific limitations applicable to the situation without trio or cascade testing. These likely all stem from the often-limited involvement of biological family members in the child’s care.

Participants reported history information most frequently as having a significant impact on a genetic counseling session involving a child in state custody. Previous studies have hypothesized that limited history information coupled with complex confidentiality issues and social situations can lead to a fair amount of uncertainty about the genetic contribution to a child’s health or developmental concerns and may leave a large gap in comprehensive care and overall understanding of the patient’s case (Douglas, 2017; Parker & Teasdale, 2016). Part of a genetic counselor’s scope of practice is determining which genetic testing options may or may not be appropriate for their patient. This appears to be challenging in a situation involving a patient in foster care: 66.4% of respondents agreed that incomplete history information may make it difficult to determine the ‘best’ or most appropriate testing” and 83.2% agreed that it can “can lead to a fair amount of uncertainty about the genetic contribution to a child’s health or developmental concerns versus an environmental component” (n=125). This points to the need for efforts geared towards increasing the continuity of care and access to history
information to help genetics professionals determine appropriate testing options and provide comprehensive care to their patients in foster care.

This study is the first of its kind to examine the interactions between genetic counselors and child protective service personnel such as a caseworker. Over 80% of respondents reported they have spoken with a child protective service employee regarding a patient’s evaluation, often for genetic testing consent purposes, to discuss implications of a genetic test result, or regarding family studies (n=125). It seems the collaborative interactions between genetic counselors and caseworkers could prove imperative in the utility of a patient’s genetics evaluation. While most, but not all, respondents report they would start by contacting the child’s caseworker if they received positive genetic test results for a pediatric patient in state custody with implications on the patients biological relatives, responses varied greatly between participants. Almost all genetic counselors report they are unaware of any protocol for a situation such as this to outline their duty’s to inform biological relatives to an appropriate level. Creating conclusive best practices for such a situation could help streamline care for the patient and their family, as well as help genetic counselors fulfill their responsibilities in a more standardized way.

It seems in general, genetic counselors feel as though they could benefit from further education and knowledge about resources that are specific to their local foster care system. Over half of participants report their genetic counseling program did not provide any information on the foster care system or discuss working with this unique population in clinical setting, but did provide opportunities to work with this cohort through clinical rotations. Additionally, the majority (82.4%) of participants were not aware of any foster care specific resources they could provide to families. Respondents frequently reported that having some formal education about how the system works, the different roles of the different people
involved, and legal implications applicable to health care would be helpful in helping genetic
counselors better serve this pediatric cohort. This could be implemented at the level of genetic
counseling training programs through case study examples, or a panel of foster parents or
caseworkers. This would not be without challenges and caveats, as genetic counseling
programs need to consistently adapt to the many changes that accompany the growing field.
Since foster care systems operate at a state-level, it may be difficult to disseminate useful
information when many students may end up practicing in a different state than they trained in.
While education through training programs is not the only way genetic counselors can better
their understanding of working with this cohort, it may be one place we can improve
awareness and knowledge. Education through employment institutions may be another avenue
to raise awareness and supply genetic counselors with useful state-specific knowledge and
tools to help them better serve the needs of their pediatric patients.

Research Recommendations

The limited existing research on genetic counseling and the foster care population leaves
room for potential future explorations to expand on this study. The health care experiences of
the foster care population involve their interactions with the multiple individuals responsible
for their care. Just as this study examined the interactions genetic counselors have with this
cohort, there is potential for other health care providers to voice their perspectives and
experiences in future research. The disparities and unique health care needs that are present in
this pediatric population reveal the need for change. By examining the perspectives and
interactions of health care providers that play a role in these children's care, we can take steps
to improve the quality, continuity, and access to health care they receive.

Another opportunity for future research is gathering the perspectives and experiences
of foster parents with genetics professionals, or the health care system as a whole. Accessing
this population may help provide further insight into how to improve access, continuity, and quality of health care for these children. Studies of foster parent understanding and comprehension of genetic counseling sessions, and how the information they receive is interpreted and shared with others could also be explored. Results could be beneficial in helping genetic counselors communicate most effectively with foster families.

This study could not control for differences in foster care systems between states. Future studies hoping to draw conclusions on how we can enact change or establish strategies for best practice could examine in more detail the perspectives of providers and families on a statewide, instead of on a national scale.
CONCLUSION

This research is among the first of its kind to explore the crossroads of genetic counselors and the foster care community. The intention of this research was to better understand the perspectives of pediatric genetic counselors that work with children in the foster care system in order to gather insight on ways the genetics field can better serve this pediatric population and their families.

This research is congruent with the small amount of existing data outlining some of the challenges and unique aspects of caring for this population. The challenges described by participants show how the unique aspects of working with this pediatric cohort may complicate their traditional scope of practice. Specifically, results highlight how discontinuity and incomplete history information may be major obstacles in providing comprehensive genetic evaluations in children in foster care and reveal the necessity of more standardized protocols and education for genetic counselors in addition to the potential increased need for resources for foster families. The specific legal complexities related to the genetic testing of children in the foster care system in addition to the social complexities often reported within this population are other areas genetic counselors must navigate. The perspectives of the genetic counselors that participated in this research underline the potential need for better education for healthcare providers on the legal aspects of the foster care system that pertain to healthcare and increased awareness of the specific psychosocial issues that may need to be addressed. Identifying areas where improvement can be implemented in the future may prove instrumental in streamlining processes for both genetic counselors and patients and their
families, in addition to improving equity and reducing the healthcare disparities faced by this population.
REFERENCES


Douglas, A. R. (2017). *Pediatric Genetic Counselor Perspective on Serving the Foster Care Population and the Integration of Genetic Information within the Health Passport.* University of South Carolina.


Subject: Student Research: Pediatric Genetic Counseling in a Foster Care Setting

Dear NSGC member,

My name is Talia Flamos and I am a second-year genetic counseling student at Brandeis University. You are invited to participate in my Master’s thesis research project centered around pediatric genetic counseling and the U.S. foster care population.

All American Board of Genetic Counseling (ABGC) board-certified or board-eligible genetic counselors are eligible to participate if they:

• have provided genetic counseling to pediatric patients in the United States within the last 5 years, and
• have counseled at least one pediatric patient in the foster care system (state custody) at the time of their appointment

The aim of my research is to improve our understanding of the process and impact of genetic counseling within the foster care system. I hope to gather your perspectives and explore your experiences in hopes to gain insight on potential ways we can better serve the foster care population in our unique area of health care.

Participation involves completing a brief 10-15 minute anonymous online survey. Your participation is voluntary and may be discontinued at any time. Your responses will be collected anonymously and stored securely. Upon completion of the survey, you can choose to enter a raffle drawing for the chance to win one of three $50 Amazon gift cards.

You can access the survey by clicking the link below:
https://brandeis.qualtrics.com/jfe/form/SV_1ZhLDyO763B5zut

If you have any questions about this research you may contact me (tflamos@brandeis.edu) or my faculty advisor, Cassandra Buck (cbuck@brandeis.edu).

This research has been approved by Brandeis University Institutional Review Board. For any questions about your rights as a research subject, please contact the Brandeis University Human Research Protection Program by phone (781-736-8133) or email (irb@brandeis.edu).

Thank you for your consideration!

Sincerely,

Talia Flamos
Genetic Counseling Graduate Student
Brandeis University
tflamos@brandeis.edu

Cassandra Buck
Advisor for Genetic Counseling Research
Brandeis University
cbuck@brandeis.edu
APPENDIX B: STUDY INSTRUMENT

Q1 Welcome! You have been invited to take part in my Master's thesis exploring pediatric genetic counseling encounters with the United States foster care population.

Eligibility
You are invited to participate in this survey if:
- You are an American Board of Genetic Counseling (ABGC) board-certified or board-eligible genetic counselor
- You have provided genetic counseling services to pediatric patients in the United States within the last 5 years
- You have counseled at least one pediatric patient in the foster care system at the time of their appointment

Length
- The survey will take approximately 10-15 minutes to complete.

Confidentiality
- No personally identifying information will be collected as part of this research project.
- All survey responses will remain anonymous.

Compensation
- At the end of the survey, you will have the option to enter a raffle to win one of three $50 Amazon.com gift cards.
- If you choose to enter the raffle, you will be redirected to a separate page to enter your email address. This information will not be linked to your survey responses.

Risks & Alternatives to Participation
- Thinking about serving the foster care population may evoke complex emotions about a difficult case, a loved one, or related circumstance.
- Your participation is completely voluntary.
- You are welcome to skip any of the survey questions and or exit the survey at any time.

If you have any comments or questions about this research project, please contact the student researcher Talia Flamos (tflamos@brandeis.edu) for the faculty advisor, Cassie Buck (cbuck@brandeis.edu).

For any questions about your rights as a research subject or concerns regarding this research, please contact the Brandeis University Human Research Protection Program by phone (781-736-8133) or email (irb@brandeis.edu).

Do you agree to participate in this survey?

☐ Yes, I agree

☐ No, I do not agree

Skip To: End of Survey Q1 = No, I do not agree
Q2 Are you a board certified genetic counselor?

- Yes
- No, but I am board eligible
- No

*Skip To: End of Survey Q2 = No*

Q3 Do you currently work in a clinical setting seeing pediatric patients in the U.S., or have you within the past 5 years?

- Yes
- No

*Skip To: End of Survey If Q3 = No*

Q4 Have you ever counseled a pediatric patient that was in the U.S. foster care system at the time of their appointment?

- Yes
- No

*Skip To: End of Survey If Q4 = No*
Q5 Which choice best describes how often you counsel a patient currently in foster care (state custody)?

- Very often (at least 1 time per week)
- Frequently (2-3 times per month)
- Occasionally (about 1 time per month)
- Rarely (a few times per year, but less than 1 time per month)
- Very rarely (at least one time in the past)

Q6 When counseling a patient in foster care, how often is the patient accompanied by the following people:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Almost always or Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>foster parent(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>biological parent(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>other biological relative(s) (not a parent)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>state caseworker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q7 Select up to 3 of the most common referral reasons you receive for a pediatric patient in foster care.

☐ Developmental delay

☐ Intellectual disability or Autism Spectrum Disorders

☐ Seizures / Epilepsy

☐ Congenital Anomalies or Birth Defects

☐ Hearing Loss

☐ Single Gene Disorders (diagnosed or suspected)

☐ Metabolic Disorder

☐ Other ____________________________________________________

Q8 Do you feel these referral reasons for children in state custody are similar in proportion to the ones received for children who are not?

☐ Yes, I feel they are similar

☐ No, they I feel they are different

☐ I'm not sure

Display This Question (Q9): If Q8= No, they I feel they are different

Q9 In what ways do you feel like the referral reasons differ amongst the foster care population?

________________________________________________________________
Q10 For cases involving a child in foster care, how often do you address the specific social history during the session?

- Never
- Sometimes
- About half the time
- Most of the time
- Always

Q11 How comfortable do you feel navigating the sometimes complex social histories and family dynamics that can co-occur in sessions involving a patient in state custody?

- Extremely uncomfortable
- Somewhat uncomfortable
- Somewhat comfortable
- Extremely comfortable

Q12 Are you familiar with any specific foster care resources you could provide families as an additional support?

- Yes
- No

Display This Question: If Q12 = Yes

Q13 How frequently do you offer these resources to patients?

- Never
- Sometimes
- About half the time
- Most of the time
- Always
Q14 When your patient is in foster care, how often do you have access to records containing each piece of information below before you see them in clinic?

<table>
<thead>
<tr>
<th>Information</th>
<th>Infrequently (&lt; 50% of the time)</th>
<th>Sometimes (~50% of the time)</th>
<th>Frequently (&gt; 50% of the time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Prenatal and/or birth history</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Medical history</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Previous genetic testing</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Developmental history</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Social history</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Correct details about the current custody status of the child</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Q15 For a patient in foster care, how often is the history information you receive prior to their appointment accurate and up to date?

- ○ Never
- ○ Sometimes
- ○ About half the time
- ○ Most of the time
- ○ Always
Q16 In cases where the history information is incomplete, please rank your agreement with the following statement:

This makes it more difficult to determine the “best” or most appropriate testing to pursue.

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q17 In cases where the history information is incomplete, please rank your agreement with the following statement:

This can lead to a fair amount of uncertainty about the genetic contribution to a child’s health or developmental concerns versus an environmental component.

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q18 In cases where the history information is incomplete, please rank your agreement with the following statement:

This can make it challenging to determine who the correct person is to give permission for genetic testing and/or who should receive any results.

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree
Q19 Please rate the impact of the following factors on your counseling sessions that involve a patient in foster care:

<table>
<thead>
<tr>
<th>Factor</th>
<th>No impact</th>
<th>Some impact</th>
<th>Significant impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history information (or lack thereof)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complex family dynamics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance coverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discontinuity of medical care or services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who attends the appointment with the child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to history information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient's past experiences or traumas</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Status of the foster placement (long term/short term/adoption pending / kindship care)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster caregiver opinion</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Display This Question: If Q19 = Significant impact

Q20 You mentioned the following factors as having a "high impact" on counseling sessions: {Q19/SelectedChoicesForAnswer/3}
Please use this space to elaborate a bit more on the positive/negative impact each factor may have in your session.

________________________________________________________________
Q21 The next few questions are designed to gather information about different scenarios that might arise when counseling patients that are in state custody.

Q22 Are there differences in the way you might approach or structure a genetic counseling session when the patient is in the care of an unrelated foster parent compared to when the patient is in the care of their biological parents?

- Yes
- No

Display This Question: If Q22 = Yes

Q23 Please describe any differences in how you do/might structure or approach a genetic counseling session when the patient is in the care of an unrelated foster parent instead of their biological parents.

________________________________________________________________

Q24 Are there differences in the way you might approach or structure a genetic counseling session when the patient is in the care of a biological extended relative (kinship care) compared to when a patient is in the care of an unrelated foster parent?

- Yes
- No

Display This Question:If Q24 = Yes

Q25 Please describe any differences in how you might structure or approach a genetic counseling session when the patient is in the care of a biological extended relative (kinship care) compared to a session where the patient is in the care of unrelated foster/adoptive parents.

________________________________________________________________

Q26 Suppose you've just received positive genetic testing results for a patient who is in state custody that have implications on the patient's biological relatives. How have you handled a situation such as this in the past, as far as disseminating the results and passing along information about the implications on family and/or need for follow-up testing. Do you have, or know of, any specific protocols that need to be followed? If you haven't experienced this particular situation, how might you resolve the disseminating of the familial implications of the results?

________________________________________________________________
Q27 In your experience, has the genetic evaluation of a child effected their transition from foster care to adoption in any way?

- Yes
- No

(Display This Question: If Q27 = Yes)

Q28 Please describe a time that a genetics evaluation effected a patient in foster care's adoption process?

________________________________________________________________

Q29 Have you ever spoken to a child protective services employee or state assigned caseworker regarding a patient's genetic evaluation?

- Yes
- No

(Display This Question: If Q29 = Yes)

Q30 Please select the choice that best describes how often each of the following genetic counselor - child protective service personnel contact occurs concerning a patient in state custody.

<table>
<thead>
<tr>
<th>Option</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>I educate the caseworker about general genetics concepts</td>
<td>▼ Rarely ... Most of the time</td>
</tr>
<tr>
<td>I educate the caseworker about the nature or utility of genetic counseling or testing</td>
<td>▼ Rarely ... Most of the time</td>
</tr>
<tr>
<td>I discuss the implications of genetic test results of the patient with the caseworker</td>
<td>▼ Rarely... Most of the time</td>
</tr>
<tr>
<td>I ask the caseworker about contacting biological family members if needed for further family studies for my patient</td>
<td>▼ Rarely... Most of the time</td>
</tr>
<tr>
<td>I ask the caseworker about contacting other biological family members if genetic test results have implications about their health / reproductive risks</td>
<td>▼ Rarely ... Most of the time</td>
</tr>
<tr>
<td>I contact the caseworker to sign off or consent to genetic testing for a patient, or to ensure the foster caregiver has the legal right to do so.</td>
<td>▼ Rarely ... Most of the time</td>
</tr>
</tbody>
</table>
Q31 The following few questions pertain to your training and how genetic counselors as a field can serve this unique pediatric population in the future.

Q32 Please rate your agreement for the following statements:

<table>
<thead>
<tr>
<th>Statements</th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My genetic counseling program provided some information on the foster care system</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My genetic counseling program discussed working with this unique population</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My genetic counseling program provided experiences or opportunities that included working with children who are not in the custody of their biological parents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt/feel prepared to work with foster care patients upon graduation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q33 What would be helpful, or what has been helpful, to better prepare to serve this unique pediatric cohort?

________________________________________________________________

Q34 How do you feel genetic counselors as a profession can better serve this cohort of pediatric patients?

________________________________________________________________

Q35 Gender:

☐ Male

☐ Female

☐ Non-Binary

☐ I prefer not to answer

Q36 How many years have you been a practicing genetic counselor in any setting?

☐ Less than 1 year

☐ 1-4 years

☐ 5-9 years

☐ 10-14 years

☐ 15+ years
Q37 How many years have you been a genetic counselor in a setting where you saw a primarily pediatric patient population?

- Less than 1 year
- 1-4 years
- 5-9 years
- 10-14 years
- 15+ years

Q38 What region do you practice in?

- NSGC Region 1 (CT,MA,ME,NH,RI,VT,CN Maritime Provinces)
- NSGC Region 2 (DC,DE,MD,NJ,NY,PA,VA,WV,PR,VI,Quebec)
- NSGC Region 3 (AL,FL,GA,KY,LA,MS,NC,SC,TN)
- NSGC Region 4 (AR,IA,IL,IN,KS,MI,MN,MO,ND,NE,OH,OK,SD,WI,Ontario)
- NSGC Region 5 (AZ,CO,MT,NM,TX,UT,WY,Alberta, Manitoba, Sask.)
- NSGC Region 6 (AK,CA,HI,ID,NV,OR,WA,British Columbia, Yukon)
- Outside of U.S. and Canada