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# Pediatric Genetic Counselor Perspective on Serving the Foster Care Population and the Integration of Genetic Information within the Health Passport

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Pediatric Genetic Counselor Perspective on Serving the Foster Care Population and  
the Integration of Genetic Information within the Health Passport

by

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Bachelor of Science  
Florida State University, 2015

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Submitted in Partial Fulfillment of the Requirements

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## **Abstract**

Many states within the foster care system have adopted a document referred to as the health passport, which provides a condensed summary of a child's health history. This passport is intended to remain with the child as he/she moves between placements to improve communication between foster parents, caseworkers, and medical professionals. This exploratory research study examines the foster care system's utility of a child's health passport and opportunities for improvement through an online survey of the pediatric genetic counselor population. First, counselor perspectives on serving foster children were gathered and summarized into themes. Major elements and/or obstacles of counseling the foster care population involved limited information and records, barriers to genetic testing, and psychosocial differences between caretakers. Second, counselors provided input regarding the inclusion of genetic information within the passport. Specifically, topics such as the counselor's interaction with the passport document, prioritization of information to be included, and recommendations for utilization of the passport were addressed. Of the 81 participants who completed the survey, only 11% had previous familiarity with the document, yet 83% expressed that it would be useful in their practice. Participants were asked to rank items in order of importance regarding inclusion in a health passport and the median value was assessed to

determine the order. "Maternal pregnancy history" was reported as the most important item (4.79), followed by "Birth history" (4.46), "Family history" (3.62), "Developmental history" (3.31), "Previous genetic testing" (3.21), and "Patient personal medical history" (1.56). The outcome of this study was to interpret genetic counselors' informational needs and explore how the health passport could address these needs and be incorporated in practice. These results could enhance genetic counselor effectiveness and improve continuity of care for these children.

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# Chapter 1

## Background

### **1.1 History of Foster Care System**

Traditionally, parents facing difficulties with raising their children would seek assistance from outside sources including other family members, charities, or orphanages. From around the 19th century, state policies began interceding to provide support and structure in arranging care for these children. Federal aid arose in the 1930s and helped raise awareness for the need of care. Foster care is a child welfare system that enables the temporary placement of a child in a suitable home due to the inability of the parents to provide appropriate care. Issues of neglect, physical abuse, or parental abandonment and substance abuse account for 70% of court ordered foster care placements (Simms, Dubowitz, & Szilagyi, 2000; Szilagyi, Rosen, Rubin, & Zlotnik, 2015). Over 400,000 children are in foster care within the United States (Cooley & Petren, 2011; Seltzer, Henderson, & Boss, 2015; Szilagyi et al., 2015). The hoped for intention of the foster care system is eventual reunification of the child with the biological parents (Simms et al., 2000). The Child Welfare Reform Act of 1980 reinforces this goal by encouraging reunification of children with the biological family and prevention of out-of-home placements if necessary (Simms et al., 2000). However, stringent interpretation by the states of this policy led to the Adoption and Safe Families Act of 1997. This policy prioritizes the child's

health and safety above reunification goals. From this act, the mindset of foster care changed dramatically to embrace the fact that in some circumstances, reunification with the biological family may not be of the child's best interest and therefore, actions should be made to place the child in appropriate care (Simms et al., 2000; Szilagyi et al., 2015). In these cases, other outcomes such as transition of the foster home into a permanent adoptive home or transfer to kinship care are possible.

Kinship care is the most common placement and differs slightly from the traditional foster care system (Szilagyi et al., 2015). For some children, placement with any blood relatives or those closely tied with the family can serve as caregivers for the child. There are both potential benefits and doubts to the success of this method. It is perceived that keeping a child within care of extended family could provide a sense of familiarity and lessen the trauma of being placed with strangers. Similar cultures and practices are more often maintained within kinship care and sometimes communication and interaction with the parents occurs to improve facilitating possible reunification. Opposition to this structure involves the questioning of whether extended kin or unstable family members are most equipped and capable of caring for these children (Simms et al., 2000; Whenan, Oxlad, & Lushington, 2009). The increased instances of informal arrangements for transfer of children to kinship care may impede proper screening and training of these individuals serving as caregivers.

There are multiple levels of classification for a child within the foster care system. Traditional foster care typically involves children with minimal additional needs other than basic care and nurturing. Medically fragile children are placed in

specific homes where more intensive medical care can be provided (Seltzer et al., 2015). Situations such as a physical disability or complex chronic conditions would categorize a child as medically fragile. Therapeutic or treatment foster care involves children with serious behavioral or mental health issues that require specialized intervention and therapy. These children have often suffered intense trauma and neglect in their past that has greatly affected their mental and emotional well-being (Dorsey et al., 2008). Thorough and accurate analysis of a child upon entering the foster care system is critical in identifying the proper type of placement. Foster care involves multiple integrated relationships to coordinate care. Children are under the management and supervision of a team of individuals that may consist of the foster parents, social workers, lawyers, medical providers, mental health professionals, and other specialists.

## **1.2 Health Disparities for Children in Foster Care**

Foster care children face a unique set of challenges compared to children without a history of out-of-home placement. Unfortunately, neglect and abuse compounded by the trauma of separation from biological parents can highly alter a child's well being. A history of mistreatment is reported for over 70% of children along with substantial exposure to domestic violence (Szilagyi et al., 2015). There is a trend towards a higher prevalence of medical, developmental, and mental health concerns within this group compared to the general US population ("American Academy of Pediatrics. Committee on Early Childhood and Adoption and Dependent Care. Developmental issues for young children in foster care.," 2000; Blythe, Wilkes, & Halcomb, 2014; Lindsay, Chadwick, Landsverk, & Pierce, 1993; Ringeisen,

Casanueva, Urato, & Cross, 2008; Seltzer et al., 2015; Simms et al., 2000; Szilagyi et al., 2015). Often, poor health care and service begins before entrance into foster care and can continue to persist. Studies have shown that hospitalizations increase in frequency and length among foster children versus others with similar environments (Rubin, Alessandrini, Feudtner, Localio, & Hadley, 2004; Seltzer et al., 2015). Special health care needs are more common among foster children and must be appropriately addressed (Lauver, 2008; Ringeisen et al., 2008). These children with special health care needs are described as those at an "increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (Seltzer et al., 2015). Some of these needs include learning disabilities, emotional disturbances, and speech impairments (Ringeisen et al., 2008). This trend could be accounted for by an increased proportion of both environmental and intrinsic, biological factors (Parker & Teasdale, 2016). Extrinsic factors include exposure to poverty, poor prenatal care, violence, and parental mental illness (Simms-Health care needs). Understanding the integration of these multiple factors is helpful in gaining perspective on how these elements affect a child.

A history of out-of-home placement is correlated to this higher incidence of special health care needs (Ringeisen et al., 2008). Research reveals that these health care concerns can consequently impact the child. Having a special care need raises the risk for developmental problems such as cognitive and behavioral delays.

Identification of these concerns early in placement is beneficial to enacting proper

therapies and providing necessary care (Hodges, Landin, Nugent, & Simpson, 2016; Ringeisen et al., 2008). Mental health issues are among the most common of concerns for children removed from the home. Childhood trauma plays a significant role on development and emotional stability. The timing of when a child is placed in foster care impacts proper caregiver attachment and connection. Neglect from biological parents can instill insecurity, mistrust, or avoidance of relating to the foster parents. These children can struggle with establishing appropriate, healthy relationships with others and are at risk for developing mental health conditions like depression (Simms et al., 2000; Whenan et al., 2009).

Specifically, medically fragile children face some of the greatest challenges in receiving care. It is estimated that 5-10% of all foster children are in placement due to medically fragile complications (Seltzer et al., 2015). This arrangement provides alternative care options for children who can no longer be supported by their parents due to a variety of reasons including financial burden and social stress of coping with a child's condition (Seltzer et al., 2015; Simms et al., 2000; Szilagyi et al., 2015). Disparities in health care among children in foster care pose a primary issue. Though medically fragile children may not encompass a majority of the foster care population, they account for a large fraction of medical financial aid to accommodate extensive therapies, equipment, and medications (Seltzer et al., 2015; Szilagyi et al., 2015).

Due to the underlying increased risk for health and psychiatric concerns, foster children account for some of the greatest costs and utilization of health care services (Simms et al., 2000). Despite the importance of addressing the multiple

health concerns that can present, foster children still face obstacles in obtaining an adequate level of care. The intricate system of checks and balances between caseworkers and foster parents can delay timing and consent of appropriate services. Neglect of health care can stem from various sources involving both the foster care and medical system (Simms et al., 2000). Both increasing caseloads for social workers and lack of foster parent knowledge on health conditions can contribute to a child's needs remaining unaddressed. Foster parents are often relied on to discern the timing and type of care for children without adequate understanding or consent to properly fulfill this role. Comprehensive health assessments are mandated by most states within 30 to 60 days of a child's placement in a foster home (Simms et al., 2000). Beyond this initial assessment, appropriate referrals for further evaluations are sometimes missed. Additionally, physician care can be limited due to frequent placement transfer of children into different foster homes. Physician training may not particularly address identifying some of the specific concerns or signs of poor care and abuse for foster children (Simms et al., 2000; Szilagyi et al., 2015). The complicated nature and variability of health care within the welfare system makes it difficult to establish and coordinate a standard of care. Incomplete health care information at the time of a placement transfer creates uncertainty in the accuracy of a child's health history. This transient nature causes discontinuity in health management (Simms et al., 2000; Szilagyi et al., 2015). Efforts have been made by several organizations, including the American Academy of Pediatrics, to regulate care and establish guidelines for management of this high-risk population. The Fostering Connections to Success and Increasing

Adoption Act of 2008 mandated the practice of a medical home for children to continue care under the same physicians despite placement changes. This concept has been previously encouraged by organizations such as the American Academy of Pediatrics and thought to maximize health services for children (Rubin et al., 2004; Schneiderman, Smith, & Palinkas, 2012). However, research has not clearly determined whether use of the medical home is being fully adopted (Seltzer et al., 2015). A key concept in accomplishing this goal is the creation of an individualized health care plan and the proper implementation and communication of that plan among all associated foster care and health professionals (Simms et al., 2000).

### **1.3 Foster Parent Challenges**

Foster parents or caregivers are given a unique responsibility with its own set of both rewards and challenges when caring for foster children. It is the mindset that placement of a child within a home is to be temporary and the caregivers receive a time-limited amount of interaction with a child. During these shortened periods, however, caregivers still play a role investing in the child's medical, emotional, and physical needs. The common behavioral and mental instability of foster children can pose stress on caregivers. Adding complex medical issues for a child can greatly alter family dynamics and place additional burden on care compared to children with fewer health care needs (Seltzer et al., 2015).

The complex nature of medically fragile children gives foster parents increased responsibilities. Studies suggest that these parents struggle with feelings of inadequacy in caring for complex medical needs (Brown & Rodger, 2009; Whenan et al., 2009). Frequently, they receive limited or missing medical information and



are not properly equipped on how to confidently approach the health care system. A common reflection is that parents do not feel fully prepared for the realistic expectations and greater obligations required of them as caregivers (Cooley & Petren, 2011; Lauver, 2008; Seltzer et al., 2015). Foster parents sometimes are not aware of a child's condition before placement and may not feel willing to take on such responsibility (Brown & Rodger, 2009). The caregiver's role can be portrayed as a gatekeeper by playing an extensive role in medical management. These tasks involve scheduling and attending appointments, transporting children, and enacting possible at home instructions from physicians for continued care (Schneiderman et al., 2012). Most states have adopted the intention that training is to be completed by caregivers before placement of a child in the home (Dorsey et al., 2008). However, loose interpretation of these training requirements can lead to wide variation in structure (Lauver, 2008). More specific training beyond the general level is helpful in improving the abilities of these foster parents (Cooley & Petren, 2011; Schneiderman et al., 2012). Caregivers are in need of practical assistance, resources, and emotional support to encourage positive relationship with the welfare system and medical professionals (Blythe et al., 2014). Training is critical for providing caregivers with the appropriate tools and skills they will need to adequately care for these children. Empowering parents with the proper skills can positively impact their authority in navigating a child's medical care.

#### **1.4 Genetic Testing in Foster Care Setting**

The realm of genetic testing and pediatrics can be a difficult area to navigate. Though testing of children is commonplace, appropriate considerations should be

made before pursuing testing. The American Academy of Pediatrics released a policy statement in 2013 addressing some of the ethical concerns involving testing of children ("Ethical and policy issues in genetic testing and screening of children,," 2013). Ultimately, decisions regarding testing or screening should be made in the best interest of the child (Holaday, 2010; Parker & Teasdale, 2016; Phadke & Gowda, 2013). It is encouraged that consultation and access to testing be achieved through a genetic counselor. According to the National Society of Genetic Counselors, genetic counseling is described as the "process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (National Society of Genetic Counselors, n.d.). This process involves several foundational aspects of family and medical history interpretation, communication of disease etiology including possible testing and management strategies, and counseling on adaptation to the susceptibility or diagnosis of a condition. The skills acquired during training equip genetic counselors to serve patients in a variety of capacities and work closely with a team of medical professionals to provide quality health care.

Main indications for testing of children revolve around the clinical utility of the information. Appropriate counseling on the benefits and limitations of genetic testing should be clearly conveyed with parents before making a decision ("Ethical issues with genetic testing in pediatrics,," 2001; Parker & Teasdale, 2016).

Diagnostic testing for symptoms of a genetic disease present in a child are well supported yet should be properly consented by the parents and obtain child assent if possible ("Ethical and policy issues in genetic testing and screening of children,,"

2013; Phadke & Gowda, 2013). Predictive testing of asymptomatic children raises ethical hesitation in some cases (Holaday, 2010). Children at risk for childhood conditions are generally recommended for testing as opposed to predictive testing for adult-onset conditions. If there are no applicable interventions that should be performed at the time of testing, it is highly encouraged that testing is deferred until the child reaches adulthood and can autonomously make that decision (“Ethical issues with genetic testing in pediatrics,” 2001). This complex nature of pediatric testing highlights the influential role genetic counselors play in managing proper genetic evaluation.

Despite the common drawback of limited family history, foster children should not be withheld from the benefits genetic testing can offer. Utilizing genetics to investigate prenatal teratogen exposures or unique physical symptoms holds value in managing care for a child (Parker & Teasdale, 2016; Phadke & Gowda, 2013; Rauch, 1990). Though genetic testing may not always offer a diagnosis, this powerful tool can provide valuable information for foster children with limited family history. Therefore, researching methods to improve genetic counseling for this population could uncover voids in a child's medical information.

### **1.5 Utilization of Health Passport**

Numerous studies have shown the risks of improper health care for foster children due to inconsistency and transient placement changes (DiGiuseppe & Christakis, 2003). From addressing the challenges and shortcomings in care for foster children, several efforts have been made to improve service. One initiative has been the introduction of a health passport within multiple states (Chisolm, Scribano,

Purnell, & Kelleher, 2009; Lindsay et al., 1993). This document is intended to be a concise record of significant medical history and remain with the child's file between placements. The goal is to create a more coordinated system of communication and continuity of care. Such a system could have numerous benefits including improved health care and a reduction in emergency visits (Seltzer et al., 2015). Gaps in information and the switching of medical providers during placement changes can hinder consistency and maintenance of healthcare (Szilagyi et al., 2015). The proper utilization of the passport can help optimize care for foster children. Summarizing health information into a brief and concise format enables easier access and usefulness for physicians, social workers, and foster parents (Chisolm et al., 2009).

Additional considerations still need to be made concerning full benefit of the passport. Maximum potential will require a commitment from all involved parties in order to maintain proper updates and keep information relevant. Utilization of an electronic database for the passport is often desired and can provide an efficient method of maintaining and sharing information (DiGiuseppe & Christakis, 2003; Szilagyi et al., 2015). However, factors such as accessibility, time, and resources can set limitations on the feasibility of this format. Incomplete data within the passport is a common issue, but despite this limitation, even minimal information can be valuable to physicians who have no previous records (Chisolm et al., 2009). Foster parents should be encouraged to engage in the child's medical care by bringing the health passport to all medical visits if available (Lindsay et al., 1993; Simms et al., 2000). Coordinated training for caseworkers, medical providers, and caregivers are

needed to promote consistency and establish guidelines for the use and expectations of the passport.

Overall, this passport presents promise of improving care for foster children by addressing the prevalent issues of knowledge gaps and discontinuity in conveying a child's health history between placements. If used properly, the passport can prove to be a valuable tool for managing a child's case and facilitating communication between multiple healthcare providers. Investigating the incorporation of genetic information into the passport can contribute additional utility by raising awareness on the impact that genetic counseling services can have on investigating possible genetic diagnoses for a child. The absence of research involving benefits of including genetic information within the passport shows that this is an area that has not been previously addressed. By accessing genetic counselor perspectives, new insight could be gathered on the need for this valuable information within the passport.

### **1.6 Value of Study**

Previous literature has shown the disparity in health care among foster children and the need for improvement. The transient nature of the foster care system increases the risk for a break in continuity of care as children often transfer to different medical providers between placements. Genetic counseling is one specific area where foster children present challenges for receiving care. Limited family and medical information can leave gaps in knowledge concerning a child's full history. Therefore, this study aims to unfold an area that has not been previously researched. By targeting pediatric genetic counselors that have experience working

with this population, their responses will be the most appropriate for investigating this area of research. Counselor perspectives on their informational needs will yield suggestions for improving genetic counseling of foster children. Additionally, the utility of the foster care health passport regarding its provision of genetic information will be explored.

## Chapter 2

### Pediatric Genetic Counselor Perspective on Serving the Foster Care Population and the Integration of Genetic Information Within the Health Passport

#### **2.1 Abstract**

Many states within the foster care system have adopted a document referred to as the health passport, which provides a condensed summary of a child's health history. This passport is intended to remain with the child as he/she moves between placements to improve communication between foster parents, caseworkers, and medical professionals. This exploratory research study examines the foster care system's utility of a child's health passport and opportunities for improvement through an online survey of the pediatric genetic counselor population. First, counselor perspectives on serving foster children were gathered and summarized into themes. Major elements and/or obstacles of counseling the foster care population involved limited information and records, barriers to genetic testing, and psychosocial differences between caretakers. Second, counselors provided input regarding the inclusion of genetic information within the passport. Specifically, topics such as the counselor's interaction with the passport document, prioritization of information to be included, and recommendations for utilization of the passport were addressed. Of the 81 participants who completed the survey, only 11% had previous familiarity with the document, yet 83% expressed that it would be useful

in their practice. Participants were asked to rank items in order of importance regarding inclusion in a health passport and the median value was assessed to determine the order. "Maternal pregnancy history" was reported as the most important item (4.79), followed by "Birth history" (4.46), "Family history" (3.62), "Developmental history" (3.31), "Previous genetic testing" (3.21), and "Patient personal medical history" (1.56). The outcome of this study was to interpret genetic counselors' informational needs and explore how the health passport could address these needs and be incorporated in practice. These results could enhance genetic counselor effectiveness and improve continuity of care for these children.

## **2.2 Introduction**

Traditionally, parents facing difficulties with raising their children would seek assistance from outside sources including other family members, charities, or orphanages. From around the 19th century, state policies began interceding to provide support and structure in arranging care for these children. Foster care is a child welfare system that enables the temporary placement of a child in a suitable home due to the inability of the parents to provide appropriate care. Issues of neglect, physical abuse, or parental abandonment and substance abuse account for 70% of court ordered foster care placements (Simms, Dubowitz, & Szilagyi, 2000; Szilagyi, Rosen, Rubin, & Zlotnik, 2015). Over 400,000 children are in foster care within the United States (Cooley & Petren, 2011; Seltzer, Henderson, & Boss, 2015; Szilagyi et al., 2015). Foster care involves multiple integrated relationships to coordinate care. Children are under the management and supervision of a team of



individuals that may consist of the foster parents, social workers, lawyers, medical providers, mental health professionals, and other specialists.

Foster care children face a unique set of challenges compared to children without a history of out-of-home placement. Special health care needs are more common among foster children and must be appropriately addressed (Lauver, 2008; Ringeisen et al., 2008). These children with special health care needs are described as those at an "increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (Seltzer et al., 2015). Some of these needs involve learning disabilities, emotional disturbances, and speech impairments (Ringeisen et al., 2008). This trend could be accounted for by an increased proportion of both environmental and intrinsic, biological factors (Parker & Teasdale, 2016). Extrinsic factors include exposure to poverty, poor prenatal care, violence, and parental mental illness (Simms-Health care needs). Understanding the integration of these multiple factors is helpful in gaining perspective on how these elements affect a child. Having a special care need raises the risk for developmental problems such as cognitive and behavioral delays. Identification of these concerns early in placement is beneficial to enacting proper therapies and providing necessary care (Hodges, Landin, Nugent, & Simpson, 2016; Ringeisen et al., 2008).

Due to the underlying increased risk for health and psychiatric concerns, foster children account for some of the greatest costs and utilization of health care services (Simms et al., 2000). Despite the importance of addressing the multiple

health concerns that can present, foster children still face obstacles in obtaining an adequate level of care. Specifically, medically fragile children face some of the greatest challenges in receiving care. It is estimated that 5-10% of all foster children are in placement due to medically fragile complications (Seltzer et al., 2015).

Disparities in health care pose a primary issue. Though medically fragile children may not encompass a majority of the foster care population, they account for a large fraction of medical financial aid to accommodate extensive therapies, equipment, and medications (Seltzer et al., 2015; Szilagyi et al., 2015).

Neglect of health care can stem from various sources involving both the foster care and medical system (Simms et al., 2000). Both increasing caseloads for social workers and lack of foster parent knowledge on health conditions can contribute to a child's needs remaining unaddressed. Additionally, physician care can be limited due to frequent placements of children into different foster homes (Simms et al., 2000; Szilagyi et al., 2015). The complicated nature and variability of health care within the welfare system makes it difficult to establish and coordinate a standard of care. Incomplete health care information at the time of a placement transfer creates uncertainty in the accuracy of a child's health history. This transient nature causes discontinuity in health management (Simms et al., 2000; Szilagyi et al., 2015). Efforts have been made by several organizations, including the American Academy of Pediatrics, to regulate care and establish guidelines for management of this high-risk population. The Fostering Connections to Success and Increasing Adoption Act of 2008 mandated the practice of a medical home for children to continue care under the same physicians despite placement changes. A key concept

in accomplishing this goal is the creation of an individualized health care plan and the proper implementation and communication of that plan among all associated foster care and health professionals (Simms et al., 2000).

The realm of genetic testing and pediatrics can be a difficult area to navigate and appropriate considerations should be made before pursuing testing. The American Academy of Pediatrics released a policy statement in 2013 addressing some of the ethical concerns involving testing of children (“Ethical and policy issues in genetic testing and screening of children,” 2013). Ultimately, decisions regarding testing or screening should be made in the best interest of the child (Holaday, 2010; Parker & Teasdale, 2016; Phadke & Gowda, 2013). It is encouraged that consultation and access to testing be achieved through a genetic counselor. Diagnostic testing for symptoms of a genetic disease present in a child are well supported yet should be properly consented by the parents and obtain child assent if possible (“Ethical and policy issues in genetic testing and screening of children,” 2013; Phadke & Gowda, 2013). This complex nature of pediatric testing highlights the influential role genetic counselors play in managing proper genetic evaluation. Despite the common drawback of limited family history, foster children should not be withheld from the benefits genetic testing can offer. Utilizing genetics to investigate prenatal teratogen exposures or unique physical symptoms holds value in managing care for a child (Parker & Teasdale, 2016; Phadke & Gowda, 2013; Rauch, 1990). Though genetic testing may not always offer a diagnosis, this powerful tool can provide valuable information for foster children with limited family history. Therefore, researching

methods to improve genetic counseling for this population could uncover voids in a child's medical information.

Numerous studies have shown the risks of improper health care for foster children due to inconsistency and transient placement changes (DiGiuseppe & Christakis, 2003). From addressing the challenges and shortcomings in care for foster children, several efforts have been made to improve service. One initiative has been the introduction of a health passport within multiple states (Chisolm, Scribano, Purnell, & Kelleher, 2009; Lindsay et al., 1993). This document is intended to be a concise record of significant medical history and remain with the child's file between placements. The goal is to create a more coordinated system of communication and continuity of care. Such a system could have numerous benefits including improved health care and a reduction in emergency room visits (Seltzer et al., 2015). Gaps in information and the switching of medical providers during placement changes can hinder consistency and maintenance of healthcare (Szilagyi et al., 2015). Summarizing health information into a brief and concise format enables easier access and usefulness for physicians, social workers, and foster parents (Chisolm et al., 2009). Foster parents should be encouraged to engage in the child's medical care by bringing the health passport to all medical visits if available (Lindsay et al., 1993; Simms et al., 2000). The proper utilization of the passport can contribute great potential in managing care for foster children and maximum potential will require a commitment from all involved parties.

Overall, this passport presents promise of improving care for foster children by addressing the prevalent issues of knowledge gaps and discontinuity in

conveying a child's health history between placements. Investigating the incorporation of genetic information into the passport can contribute additional utility by raising awareness on the impact that genetic counseling services can have on investigating possible genetic diagnoses for a child. The absence of research involving benefits of including genetic information within the passport shows that this is an area that has not been previously addressed. By accessing genetic counselor perspectives, new insight could be gathered on the need for this valuable information within the passport.

### **2.3 Materials and Methods**

#### *Participant Population and Survey Distribution*

An email invitation (Appendix A) was distributed to full member genetic counselors via the National Society of Genetic Counselors (NSGC) online listserv in October 2016. A reminder email was sent 4 weeks later. Participants were required to be a certified or board-eligible genetic counselor currently practicing in pediatrics and having counseled at least one case involving foster care children within the past 12 months. Participants were excluded if they were not a pediatric genetic counselor or had not counseled at least one session involving foster children within the past year. Eligibility was determined at the start of the study through a series of selected questions. If participants did not meet criteria, they were excluded and directed out of the survey using branch logic developed by SurveyMonkey. Participation was voluntary and responses were kept completely anonymous. Approval for the study was obtained from the University of South Carolina Institutional Review Board.

### *Instrumentation*

A three-part questionnaire comprised of original questions was developed and created using an online survey generator, SurveyMonkey. Consent for participation was included on the first page (Appendix B). Both quantitative and qualitative questions were utilized and answer formats included multiple choice, Likert scale, ranking, and free response.

After eligibility was determined, the first section of the questionnaire assessed participants' experiences with counseling the foster care population. Logistical information, such as average age of patients, referral sources and indications, and records was gathered. Participants were then given the opportunity to discuss their perspectives regarding unique and challenging aspects of counseling this population. These particular questions were written in a free response format, allowing participants to share personal thoughts.

The second section focused on the health passport and a brief, original description was provided. Genetic counselor utilization and interaction with the passport in their practice was gathered. Specifically, participants were also asked to comment on the usefulness and concerns regarding the passport. A targeted series of questions measured the level of importance for individual topic areas to be included in the passport via a Likert scale. Participants were then asked to rank the same topic categories in order of importance. This section also allowed responses on whether the passport was most appropriate for including genetic counseling information and additional suggestions for improving genetic counselor care for foster children.

The remaining questions pertained to demographics, including years of clinical experience, certification, geographic location, gender, age, and ethnicity. Responses to these questions were voluntary and used only to gather insight regarding population characteristics. A full list of questions can be found in Appendix C. Additionally, a table representing response rate for each question is included in Appendix D.

### *Data Analysis*

Descriptive statistics were utilized for both quantitative and qualitative questions. Analysis of quantitative data was specifically performed using Statistical Package for the Social Sciences 23.0 (SPSS) and Excel 2011. Questions involving a Likert scale were assessed on a scale of 0-4, with 0 representing highly unlikely/highly unimportant and 4 representing highly likely/highly important, depending on the context of the question. Frequencies were calculated for all questions, including mean and standard deviation calculations when necessary to provide additional analysis. Means and standard deviations were reported as suggested in the APA Publication Manual. Qualitative data was assessed via themes identified by the principal investigator. The most frequent 2-3 themes were reported for each question and reviewed by committee members.

## **2.4 Results**

### *Participant Demographics*

A total of 96 counselors initiated the questionnaire and 14 participants did not meet eligibility criteria and were therefore routed out of the survey. One participant was excluded based on failure to complete at least 80% of the

questionnaire. The remaining 81 participants met all criteria and responses were incorporated for analysis.

A majority of participants were female (98.5%), of Caucasian ethnicity (95.3%), and between the ages of 20-29 (57.6%). One participant indicated that they worked in Canada. Of the 63 participants who reported working in the United States, location was categorized into regions based on state: Region 1 (25.4%), Region 2 (15.9%), Region 3 (27.0%), Region 4 (11.1%), and Region 5 (20.6%). A complete representation of patient demographics is provided in Table 2.1.

#### *Foster Care Population Perspectives*

Regarding the number of cases involving foster care children participants have counseled in the past 12 months, 44% reported 1-5 cases, 23% reported 6-10 cases, and 33% reported counseling over 10 cases. Of these cases, 38% reported the typical age of patients as 0-2 years, 48% reported 3-5 years, and 13% reported ages of 6-12 years (Figure 2.1). The two most common referral sources reported were pediatricians (48.8%) and healthcare specialists (25.6%). Examples of other sources provided from participants included caseworkers, court orders, and NICU follow-up (Figure 2.2). Of the referral reasons listed, developmental delay was the most common reason reported (65.9%), with birth defects (7.3%), autism (2.4%), and metabolic disorders (1.2%) following in order of frequency. Other reasons provided included evaluation for Fetal Alcohol Syndrome and ruling out abuse versus a skeletal dysplasia, such as osteogenesis imperfecta. This information is summarized in Figure 2.3. 72.0% of participants responded that they did typically receive medical records on children in foster care prior to a session in addition to other



types of information, such as primary care physician notes or referral form notes, and electronic medical records if the child has been previously cared for at the same institution. Foster parents are reported to typically accompany the foster child to a genetic counseling session by 69.5% of participants, with caseworkers reported at 1.2% and both foster parents and caseworker reported at 22.0%.

When participants were asked to describe unique elements of counseling children in foster care, several themes emerged. Of the 72 responses to this question, 42 commented on the occurrence of limited or missing history for a patient, including family, medical, and pregnancy history.

*"Limited records and unknown family history...Occasionally there may be some knowledge of a sibling or parent with intellectual disability but more specific information and pertinent details about half sibs or full sibs is not known."*

*"Little to no information on prenatal history, birth history, family history, and early developmental history. Medical history knowledge typically begins at age child entered foster care. Discussion about biological family is limited, and young children may not be aware of their birth family."*

Aspects regarding genetic testing and consent was the second most common theme identified in 20 responses. Within this topic, specific issues such as achieving proper consent, release of results, and barriers to interpretation were mentioned.

*"Consenting for genetic testing is very unique and challenging as the genetic testing itself may produce important health information for the biological parents, who typically are not there for the session."*

*"Consenting for genetic testing also needs to be obtained from the foster care agency, which can be logistically challenging. Inability to test parents for sequence variants can be a barrier to variant interpretation."*

A third theme involved the discussion of recurrence risk and how it differs in the context of the foster care population. Since the foster parents are not biologically related to the foster child, this topic is typically approached differently for this setting with *"less focus on recurrence risk."*

Similar themes previously addressed as a unique element were also considered among some of the greatest obstacles or difficulties in a genetic counseling session involving children in foster care. A total of 34 out of 71 participants classified limited or unknown information regarding family, medical, and/or pregnancy history as the greatest obstacle in a genetic counseling session. *"Lack of knowledge regarding health history prior to entering care, including family history....For example, many children I've seen are symptomatic by the time they enter foster care, and we can not get an accurate age of onset for symptoms."* Another theme described by 15 participants centered on genetic testing aspects-including appropriate consent, obtaining parental samples for additional testing, and result interpretation.

*"Lack of ability to meet, assess, and/or test biological parents is often a challenge to teasing out what is familial versus unique to the patient."*

*"Often these patients did not receive the same testing because the physician I worked with was uneasy about proceeding with testing unbeknownst to the bio parents. He was concerned about the ethical considerations if the children*

*rejoined their bio parent households at some point with genetic information that could impact the bio parents in some way (recurrence risks, etc.)."*

The third major theme regarded continuity of care and issues with communicating information and/or results with the proper parties and was identified by 10 participants.

*"Communication of results and ensuring that those follow the children regardless of whose care they are in. I often find that we have to re-educate every time a child returns because they are with a new family/caregiver."*

*"The constant transition of the children between caretakers. If there is a known diagnosis we can counsel the current caretakers about a condition then the child may be moved to 3-4 different homes in the next 1-2 years so that information is not passed along."*

Counseling dynamic differences for cases involving foster parents were also addressed by participants. Of the 63 responses, 20 expressed a perceived difference in the emotional attachment or investment in the child's care and genetic counseling session. Comments ranged on both ends of the spectrum, with some foster parents appearing less invested while others did not greatly differ from typical counseling sessions due to intentions in long-term care for the child.

*"I find that foster parents are more willing to do any genetic testing or other test that we recommend. I believe it stems from two different but related causes: that they are eager to get any help possible for these often medically fragile children they have been charged to take care of and that they have no skin in the game so to speak. They do not have any of the parental or societal guilt that they may*

*have caused the child's condition or any of the other many psychosocial issues biological parents face in our appointments"*

*"It depends on whether they have a long-term relationship with the child and seem invested in the information we are providing, or if they are just a temporary stop before the child moves on to the next placement. Some foster parents seem very interested in the evaluation, our findings and how they will benefit the child, while for others it just seems like they are ticking off boxes in bringing the child for this and other medical appointments."*

*"It seems that foster parents seem...realistic about the child's potential medical course. While they are invested in the child's care and health, they may be less likely to go through the stages of grief."*

An additional theme addressed the issue of informational gaps and its affect on the counseling agenda. Participants reflected on their experience interacting with foster parents as historians and how that can be addressed during a session.

*"Foster parents often feel 'inadequate' when they cannot recall a lot of the needed information."*

*"It is important to be sensitive when the foster parents apologize for not knowing all of the health and family history. Some foster parents will get overwhelmed and feel unhelpful when it is not their fault that they are not provided much information about the child."*

Overall, 62 out of 63 participants thought foster parents were more accepting of a genetic diagnosis (75.6%), with only one who selected that parents were less accepting. Participants were then given the opportunity to explain their reasoning.

For the 61 counselors who expounded on their selection, 23 remarked on the difference in biological relationship and absence of "parental guilt" that biological parents might express.

*"Many parents who have a child with a genetic disorder feel like it's their 'fault'.*

*Having no biological relationship removes that psychosocial barrier to accepting a genetic diagnosis."*

*"There is less personal/familial assumption of guilt with a genetic diagnosis with a foster parent-the emotional ties to possible passing on a genetic condition is removed."*

Interestingly, 8 participants shared that they did not perceive a significant difference in foster parent acceptance of a diagnosis compared to other families. *"My limited experience suggests the foster parents are very invested in these kids, similar to another parent, and their acceptance of a diagnosis is not different."*

#### *Health Passport Utilization*

A portion of the questionnaire pertained to the health passport document and its utilization. Only 11.0% of participants reported familiarity with the existence of a health passport prior to survey participation and 7.3% reported ever seeing a health passport for a child. However, 83% expressed that a health passport would be useful in their practice. Three themes emerged when participants were asked to elaborate on their thoughts. A total of 21 out of 54 responses pertained to the benefit of a health passport to improve continuity of care and reduce the amount of missing or unknown information.

*"Having all of this information in one location for a child would make the session and evaluation a lot easier and more meaningful. It's a lot easier to consider differential diagnoses when you have all of the medical history readily available and don't have a lot of gaps."*

*"It is very useful for the continuity of care and communication between different specialists and primary care, especially if the child is being passed between major healthcare systems."*

A second theme was identified in 4 participants who highlighted the effect of a health passport to improve testing strategies and decrease the occurrence of duplicate testing for a patient. *"This would provide so much valuable information for directing testing and providing interpretation of results!"* Lastly, several responses mentioned concerns that could affect the usefulness of the passport.

*"If all parties are clear on what type and amount of information should be included...it could help with clarifying who should be included in communications about the child."*

*"If it contained accurate information about family history, previous specialists and their notes, could be very useful."*

Regarding the format of the passport, 61.0% reported a preference for electronic and 23.2% reported paper format. Participants were asked their likelihood for participation in updating a child's health passport given a section regarding genetic information as included. A Likert scale ranking 1-4, with 1 being "highly unlikely" and 4 being "highly likely", was used and a mean of 3.54 with standard deviation of 0.68 was reported. Concerns regarding genetic counselor use

of a health passport were investigated, revealing several themes. Out of 56 total responses, 19 reflected no concerns over genetic counselor involvement with the health passport. 13 participants mentioned comments regarding the accuracy and completeness of information within the passport.

*"...it is easy for incorrect information and/or diagnoses can be perpetuated without basis if too much weight is put on the passport rather than trying to obtain a history with definite knowns and unknowns."*

*"My main concern would be accuracy of the information included and the source of that information."*

Additionally, 12 responses involved aspects of training, logistics, and the time involved in reviewing and updating a health passport. *"Who is going to be responsible to making updates and making sure that all of the providers get this updated information?"*

A set of questions assessed genetic counselor views on the importance of specific topics within the health passport; means and standard deviation was reported. This question was rated on a 1-4 Likert scale for six different areas, with 1 representing "highly unimportant" and 4 being "highly important". For the 69 genetic counselors that answered these questions, the mean was 3.62 and standard deviation of 0.77 for "Family history". "Patient personal medical history" had a mean of 3.72 with a standard deviation of 0.81. The mean for "Previous genetic testing" was 3.65 and standard deviation of 0.82. "Birth history" had a reported mean of 3.57 and 0.83 standard deviation. A mean of 3.71 with standard deviation of 0.77 was reported for "Developmental history". The mean was 3.49 with standard deviation

of 0.84 regarding "Maternal pregnancy history". Participants were then asked to rank the items in order of importance regarding inclusion in a health passport and the median value was assessed to determine the order. "Maternal pregnancy history" was reported as the most important item (4.79), followed by "Birth history" (4.46), "Family history" (3.62), "Developmental history" (3.31), "Previous genetic testing" (3.21), and "Patient personal medical history" (1.56). These results are summarized in Figure 2.4. Additional suggestions for other areas to be considered for inclusion in the health passport were gathered. 17 out of 41 responses mentioned information on the patient's social history. Previous imaging studies were suggested by 9 participants. Examples included results from MRI, CT, and X-ray scans. Additionally, 4 responses desired a list of previous specialists and treating providers to be included.

When asked whether a health passport is the most appropriate place to include information regarding a genetic counseling session for children in foster care, 54.9% responded yes, while 25.6% thought it was not most appropriate. Comments regarding thoughts of where this information should be located centered on a major theme. A total of 10 out of 17 responses similarly mentioned that genetic counseling session information should be located in the child's medical record and cautioned about the need for privacy and a more restricted control of access to the information.

*"I believe it should be noted on the passport that it has occurred but the actual records should be separate and produced only for those requesting."*



*"This should be in their medical record. Genetic testing should not be available for everyone to see. There should be some level of privacy for the sake of the child."*

Finally, participants were given the opportunity to share open-ended suggestions for improving genetic counselor care for children in foster care. Of the 33 responses, 9 involved discussion of clear and consistent documentation of records, including session details, results, and follow-up recommendations.

*"Documentation is important as verbal communication to the foster family may not be passed on as easily. I think documentation should be present in the passport, medical records, and with the pediatrician."*

*"Having access to records and making sure that the records/recommendations from my evaluation/session are available to the patient as they get older is very important."*

Additionally, 7 participants highlighted communication and continuity of care as important for improving genetic counseling services.

*"I think continuity of the information is important -- making sure that accurate information travels with the child for the benefit of the child's care now and for the child's future benefit when he/she is old enough to understand and take responsibility for knowing and making decisions based on their own personal medical and genetic information."*

*"It helps to have a good working relationship with the case workers, social workers, and foster parents of medically fragile children..."*

The last identified theme was regarding the consenting process and helping improve efficiency and clarity in obtaining proper consent.

*"How can we get bio parents in for counseling to receive proper informed consent? Maybe to have training for the medical staff/nurses at the foster agencies who are arranging this on our behalf. Otherwise, we are often telling foster parents to come back when/if they have parental rights."*

The emerging themes were varied in addressing a different aspect of care and management of a genetic counseling session. Other comments introduced areas such as improved education on state laws and regulations regarding foster care, specialized training for counselors to address unique psychosocial concerns, and increased access of genetic counselors to the foster care community.

## **2.5 Discussion**

The foster care population is one that has not been heavily researched in the context of genetic counseling. Though a majority of participants responded having only counseled 5 or fewer cases involving foster children, it was encouraging that 27% have counseled over 10 cases. Capturing this range in experience is helpful for gathering varying perspectives and opinions. The majority of the patient population was referred for developmental delay or other reasons. The most common reasons listed included evaluation of fetal alcohol syndrome and ruling out abuse versus a genetic syndrome, such as in the case of osteogenesis imperfecta. These responses reveal some of the differing characteristics of foster care counseling and the added complexity of uncertain social history. Additionally, who is receiving the genetic counseling information is unique as mostly foster parents are accompanying the

child to the appointment and receiving the information. The transient nature of foster care can be challenging when the foster parents present during one appointment may not be the same ones who continue to care for the child long term. This factor should be considered when evaluating how genetic counselors can best communicate and interact with these patients and their caretakers. All of these considerations lead to the importance of this research, as previous studies have yet to specifically address foster care in the realm of genetic counseling.

Interestingly, the themes that emerged as unique elements and greatest obstacles to counseling the foster care population illuminate some of the major components of the genetic counseling practice. According to the National Society of Genetic Counselor's website, counselors participate in communicating "how family and medical histories may impact the chance of disease occurrence or recurrence" (National Society of Genetic Counselors). Lack of information pertaining to history-whether family, medical, or developmental-provides a large gap in complete care and understanding of a patient's case. Though recurrence risk may typically be addressed in a genetic counseling session, participants shared how they address this topic differently in these cases due to the social situations and difference of biological relationships. This also affects a counselor's ability to adequately perform other essential tasks such as education on "how inherited diseases and conditions might affect them or their families." Obtaining a medical history and pedigree are skills emphasized during a genetic counselor's training and ones that are integral to a session. As one participant stated, *"one of our biggest and best tools is the pedigree."* The uncertainties faced in the foster care population regarding accurate history are

a challenge that counselors must navigate during a session. A third component of a counselor's scope of practice is determining "which genetic tests may or may not be right for [patients], and what those tests may or may not tell." Decisions regarding the most efficient and informative testing strategies are commonly encountered during a session. Not only are challenges present regarding proper consent and approval for genetic testing of a child in foster care, but the interpretation of results can also be difficult in the absence of follow-up studies and parental testing. One participant remarked on this dilemma and its effects. *"So often with genetic test results, we are not making clear diagnoses with clear prognoses or predictions of what the future will hold. This is one of the most psychosocially challenging aspects of counseling for children in foster care..."* Identifying these various shortcomings is useful in focusing areas for improvement and how to reduce these disparities.

Through investigation of genetic counselor perspectives on counseling this population, continuity of care specifically emerged as a topic of concern and a major obstacle to the session. The complicated structure and involvement multiple individuals in a foster child's care can impact communication of information. As a participant explained, *"often foster parents are unaware of a child's medical history and previous testing/counseling, requiring each session to either lack direction or be a time to catch the foster family up on the case."* These barriers in fluid communication of information among caretakers and healthcare professionals are noteworthy and warrant change. Despite the social complexity, this population still needs to be served with a high standard of care.

One of the goals of this study is to evaluate improvement of genetic counseling for foster children via utilization of the health passport. The lack of familiarity of the health passport expressed by participants reveals the need for improved education of this resource. Of note is the fact that 82.9% of counselors, however, responded that a passport would be useful for their practice. This expresses a perceived potential for utilizing this document as part of a patient's care. In regards to how this document could be useful, improving continuity of care was the most stated reason, addressing one of the main obstacles previously discussed. By exploring methods of adapting the passport and integrating it into genetic counseling sessions, these concerns can hopefully be addressed.

Determining the type of content desired within the health passport is valuable for creating an effective document. Participants identified maternal pregnancy history as the most important information to be included in a passport. Understanding maternal health and exposures during pregnancy is essential information in evaluating environmental effects that could impact a child's development. Participants specifically listed these types of situations, such as in fetal alcohol syndrome, as a common reason for referral. The ability to rule out environmental factors on a differential diagnosis can help guide directions for genetic testing. Without this information, there can be uncertainty over the influence of environment versus an underlying genetic cause for a child's symptoms.

Aside from the topic areas provided to participants in the survey, social history was most mentioned as an additional area of interest. Though this information may not directly pertain to a child's medical condition, understanding

social history can be helpful, especially in the context of foster care. Regarding social history, one participant shared that *"it is important to know if the child was in several foster homes because their home environment is going to affect their development."*

Understanding a patient's background and history of caretakers is helpful in knowing who information has been communicated to previously and who has been involved in the child's care up to that point. Participant suggestions for improvement of genetic counseling for this population also highlighted documentation as a priority. Specifically, ensuring that not only are necessary records accessible, but also that pertinent information regarding genetic counseling is recorded and appropriately conveyed. Providing the opportunity for this information to be recorded and kept in a health passport aims to address continuity of care by promoting communication of information. From this research, a more targeted approach can be utilized to advance the health passport by incorporating desired information and helping improve genetic counseling effectiveness.

As an exploratory study that investigated a new area of research, there were limitations to the design. Providing a method of explaining the health passport to participants was a challenge, as there was not a universal structure among foster care systems. Therefore, providing an original description could have introduced bias and affected interpretation as opposed to a standard definition. Another recommendation would be obtaining a larger number of participants that would allow results to be more reflective of the participant population. The differences and lack of uniformity between foster care systems among states is another factor that could not be controlled for this study. Each state has individual regulations and

protocols for the implementation of foster care services. The health passport has currently not been adopted by all states and therefore is still gaining awareness. With these circumstances, it is difficult to establish results that could be implemented by any foster system.

With limited research on genetic counseling for the foster care population, there is the potential for future direction and expansion of this study. Ultimately, the foster care population is influenced by interaction with many different specialties that all play a role in a child's care. Through enhancing the health passport, genetic counselors can receive more accurate information that is crucial to their genetic evaluation and providing the highest quality of care. The health care needs and disparities for these children reveal the necessity for enacting change. One opportunity for future research is surveying the foster parent population for their understanding and thoughts on the health passport. As multiple individuals contribute to the success of the health passport's implementation, accessing foster parents can provide insight on how to improve care for foster children from this perspective. Additionally, performing paired studies that compare both counselor and foster parent use of the passport can help assess improvement in continuity of care. To enhance education on genetic counseling as it relates to the foster care community, a focus on foster parent perspectives could be approached. Aspects such as foster parent education and understanding of a genetic counseling session and retrospective evaluation of how that information is interpreted and shared could be gathered. Results would benefit genetic counselors in their discussions to help communicate most efficiently with this population. With the narrow research

that has previously been conducted, continued exploration would further illuminate the needs within the foster care system and methods for improvement. Though genetic counseling may play one specific role in the grand scheme of a foster child's care, equipping genetic counselors and families with the proper tools and materials, such as a health passport, can influence change and raise their quality of care.

## **2.6 Conclusions**

This study is the first of its kind to explore the integration of genetic counseling and the foster care community in the context of the health passport document. The intention of this document for creating a brief overview of a child's medical care can be utilized in the genetic counseling field. Pediatric genetic counselors were surveyed for their perspectives on the differences and challenges in working with this population. Additionally, they were given the opportunity to assess the types of information contained within the health passport in terms of importance and efficacy for their practice. Participants were given several opportunities to share personal opinions and experiences through free response questions. This research was then analyzed to gain understanding of participant views and informational needs in regards to using the health passport.

Results of this study revealed several major themes. The disparity regarding access and reliability of historical information for a patient was a commonly addressed issue and concern unique to the foster care population. The ethical and legal restrictions pertaining to genetic testing of foster children is another area that genetic counselors must navigate as part of their services. The multiple professionals and caretakers involved in a foster child's medical care are an



additional concern that can negatively impact continuity of care. This observation was reflected in our participant group as influencing their ability to adequately assess and direct a patient's case.

Focusing on the health passport is one area of potential for improving genetic counseling practice. The ability to capture valuable information within this document for counselors to access can help provide more complete information on a patient's history that is often lacking. Through this research, genetic counselors were given the opportunity to share the specific kind of information desired to help direct the design of this document to meet their needs. This kind of research, though limited, is beneficial in providing direction and guidance for implementing practical change through effective adoption of the health passport by foster care systems. Though foster care patients may introduce different challenges for a genetic counseling session, it is important to investigate ways that these services can be improved to benefit the patient. One participant expressed a foundational value that highlights the importance of being an advocate as a healthcare professional.

*"I think it's just as important that we advocate as fiercely for children in foster care as any child. Sometimes these children don't have a lot of people in their corner...and it's easy to let things drop when you don't have a parent or advocate pushing you."*

Adopting this mentality is essential for establishing a high quality of care for the foster care population. By improving and increasing awareness of the health passport, genetic counselors can contribute to alleviating the disparities for foster children and provide more effective services.

Table 2.1 Demographic Information of Research Participants

| <b>Demographic</b>                                       | <b>n</b> | <b>%</b> |
|--|----------|----------|
| <b>Sex</b>   |          |          |
| Male   | 1        | 1.5      |
| Female   | 64       | 98.5     |
| <b>Age</b>   |          |          |
| 20-29  | 38       | 57.6     |
| 30-39  | 21       | 31.8     |
| 40-49  | 1        | 1.5      |
| 50+  | 6        | 9.1      |
| <b>Region</b>  |          |          |
| Northeast  | 16       | 25.4     |
| Southeast  | 10       | 15.9     |
| Midwest  | 17       | 27.0     |
| Southwest  | 7        | 11.1     |
| West   | 13       | 20.6     |
| <b>Ethnicity</b>   |          |          |
| Caucasian  | 61       | 95.3     |
| Other  | 3        | 4.7      |
| <b>Certification</b>                                     |          |          |
| Board-eligible   | 5        | 7.6      |
| ABGC certified   | 61       | 92.4     |
| <b>Years experience as pediatric counselor</b>           |          |          |
| <1   | 10       | 15.1     |
| 1-4  | 39       | 59.1     |
| 5-9  | 8        | 12.1     |
| 10-14  | 5        | 7.6      |
| 15+  | 4        | 6.1      |
| <b>Cases involving foster children in past 12 months</b> |          |          |
| 1-5 cases  | 36       | 44.5     |
| 6-10 cases   | 18       | 22.2     |
| >10 cases  | 27       | 33.3     |

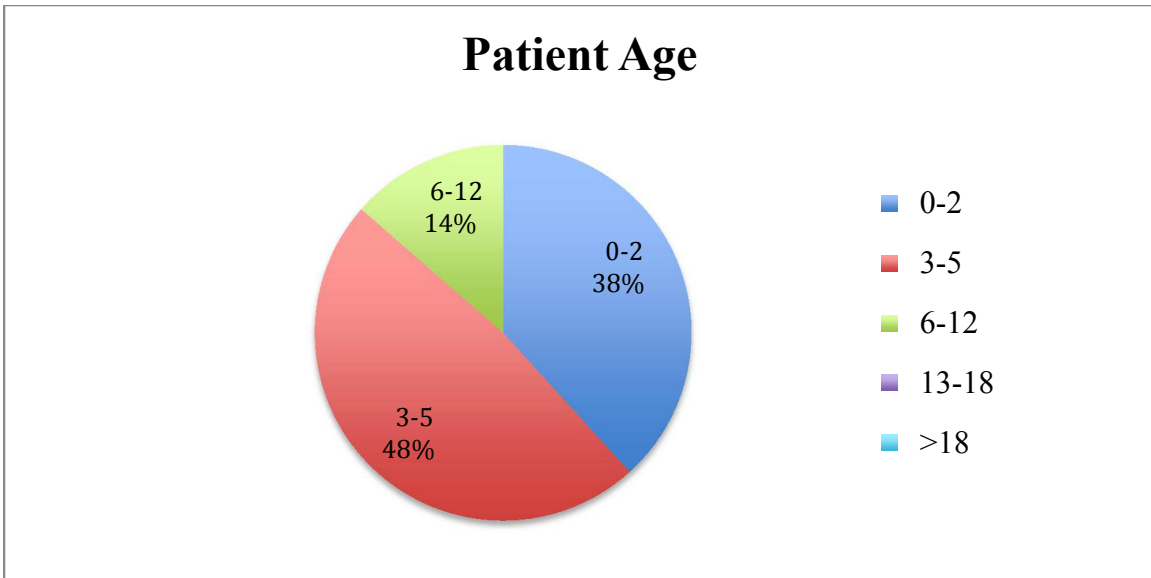


Figure 2.1 Average ages of foster care patients counseled by participants.

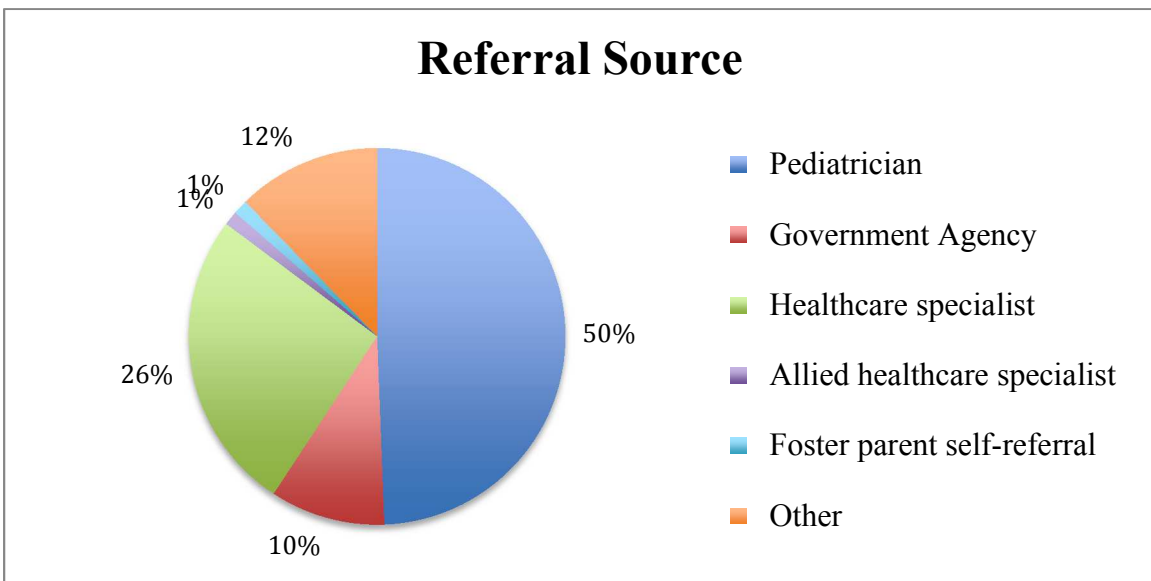


Figure 2.2 Most common referral sources reported for foster care patients.

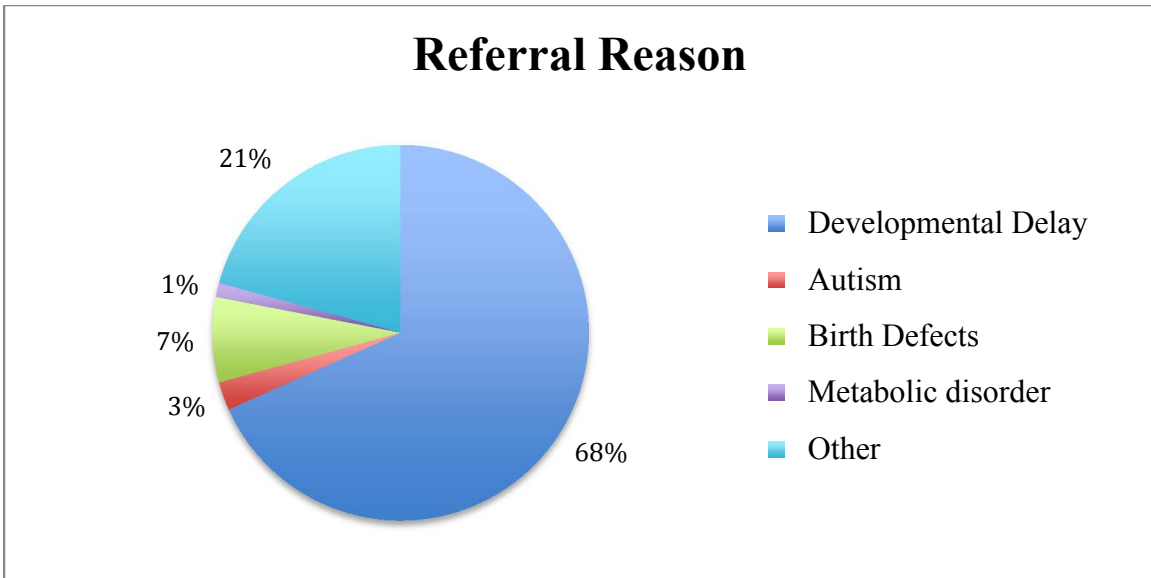


Figure 2.3 Most common reasons for referral of foster children to genetic counseling.

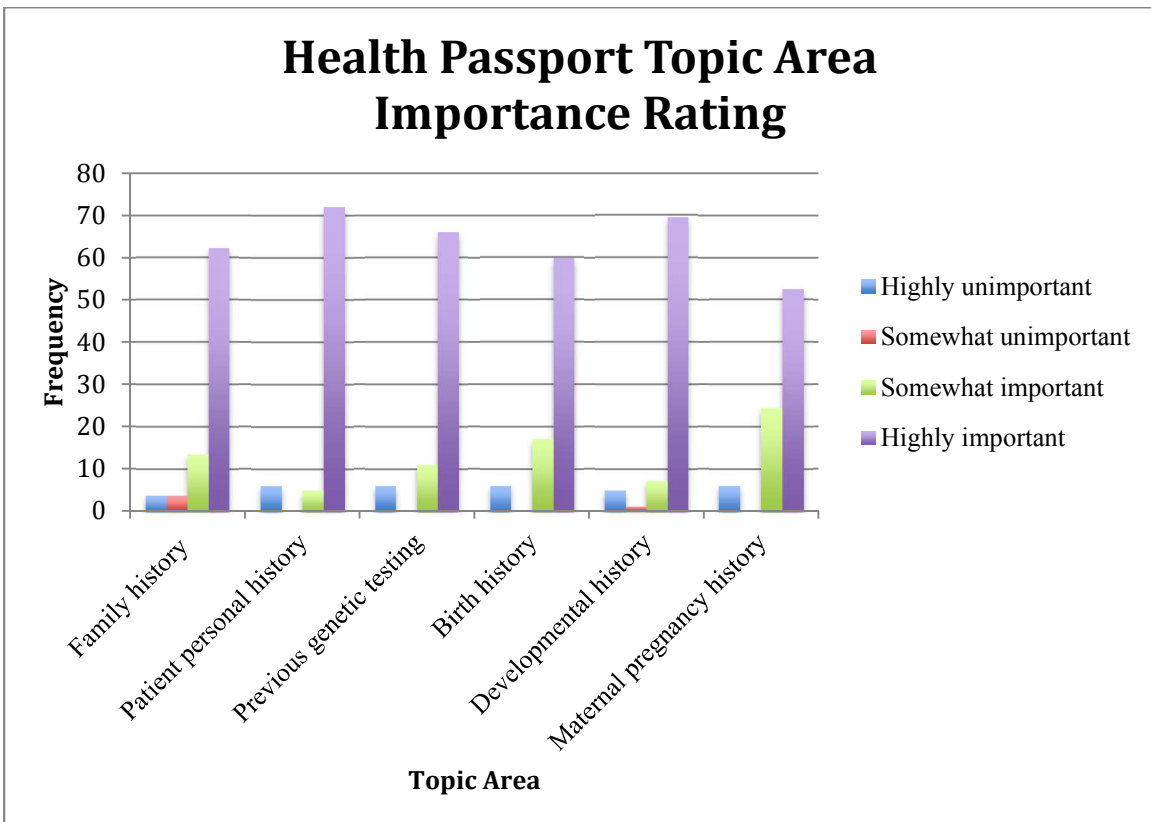


Figure 2.4 Participant ranking of various category topics for inclusion within the health passport based on a 1-4 Likert scale.

## Chapter 3

### Conclusions

This study is the first of its kind to explore the integration of genetic counseling and the foster care community in the context of the health passport document. The intention of this document for creating a brief overview of a child's medical care can be utilized in the genetic counseling field. Pediatric genetic counselors were surveyed for their perspectives on the differences and challenges in working with this population. Additionally, they were given the opportunity to assess the types of information contained within the health passport in terms of importance and efficacy for their practice. Participants were given several opportunities to share personal opinions and experiences through free response questions. This research was then analyzed to gain understanding of participant views and informational needs in regards to using the health passport.

Results of this study revealed several major themes. The disparity regarding access and reliability of historical information for a patient was a commonly addressed issue and concern unique to the foster care population. The ethical and legal restrictions pertaining to genetic testing of foster children is another area that genetic counselors must navigate as part of their services. The multiple professionals and caretakers involved in a foster child's medical care are an additional concern that can negatively impact continuity of care. This observation

was reflected in our participant group as influencing their ability to adequately assess and direct a patient's case.

Focusing on the health passport is one area of potential for improving genetic counseling practice. The ability to capture valuable information within this document for counselors to access can help provide more complete information on a patient's history that is often lacking. Through this research, genetic counselors were given the opportunity to share the specific kind of information desired to help direct the design of this document to meet their needs. This kind of research, though limited, is beneficial in providing direction and guidance for implementing practical change through effective adoption of the health passport by foster care systems. Though foster care patients may introduce different challenges for a genetic counseling session, it is important to investigate ways that these services can be improved to benefit the patient. One participant expressed a foundational value that highlights the importance of being an advocate as a healthcare professional.

*"I think it's just as important that we advocate as fiercely for children in foster care as any child. Sometimes these children don't have a lot of people in their corner...and it's easy to let things drop when you don't have a parent or advocate pushing you."*

Adopting this mentality is essential for establishing a high quality of care for the foster care population. By improving and increasing awareness of the health passport, genetic counselors can contribute to alleviating the disparities for foster children and provide more effective services. The health passport is one tool that when designed and implemented properly, holds the potential for impacting not

only a genetic counselor's practice, but a team of healthcare professionals involved in a foster child's care.

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## Appendix A

### Email Invitation to Participate in Research Study

*Subject:* Pediatric genetic counselor survey on foster care perspectives and counselor informational needs

Hello,

I am seeking pediatric genetic counselors that have counseled at least one patient from the foster care system within the past 12 months. You are invited to participate in a graduate thesis questionnaire addressing pediatric genetic counselor needs and perspectives on serving the foster care population. Additionally, it will explore the utility of integrating genetic information within a foster care system's health passport: a document intended to summarize a child's relevant health history. This questionnaire attempts to ascertain your views on the challenges in serving foster care children and gather suggestions for improvement in care. Your responses will provide great benefit not only to the field of genetic counseling, but could influence changes in foster care policy and medical documentation.

Your participation is voluntary, and if interested, please follow this link to complete a brief questionnaire. By completing the questionnaire, you are consenting that you have read and understood this information.

Thank you for your time and consideration.

Angela Douglas, BS  
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## Appendix B.

### Letter to Participants

Dear Potential Participant:

You are invited to participate in a graduate research study focusing on the utilization of genetic information and history within the foster care medical passport. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates the perspectives of pediatric genetic counselors when counseling patients in foster care and the integration of genetic information within a child's passport document. Participation involves completing a brief 5-10 minute online survey.

This survey attempts to ascertain your views on the challenges in serving the foster care population and suggestions for improvement in care. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. Demographic information is sought only to gather description of the participants. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

Your participation in this research is voluntary. By completing the survey, you are consenting that you have read and understood this information. At any time, you may withdraw from the study by not completing the survey.

Thank you for your time and participation in this survey. Your responses may help improve care and genetic counseling services for the foster care population. If you have any questions regarding this research, you may contact either me or my faculty adviser, Richard Ferrante, PhD., using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

Kind regards,

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## Appendix C

### Study Questionnaire

1. Are you a pediatric genetic counselor?

Yes

No

#### **Foster Care Perspectives**

2. What is number of cases involving foster care children you have counseled in the past year?

How many cases involving foster care children have you counseled in the past 12 months?

0 cases

1-5 cases

6-10 cases

>10 cases

3. For these cases, what age group do they typically fit into?

0-2 years

3-5 years

6-12 years

13-18 years

4. What is the most common referral source for these children?

Pediatrician

Family Practice Physician

Government Agency (i.e. social worker)

Healthcare Specialist (i.e. developmental pediatrics, neurology, psychiatry)

Allied Healthcare Specialist (i.e. audiology, psychology)

Foster parent self-referral

Other (please specify)

5. What is the most common reason for referral?

Developmental delay

Autism

Birth defect(s)

Hearing loss

Metabolic disorder

Other (please specify)

6. Do you typically receive medical records/summary on children in foster care before a session?

Yes

No

7. Please provide what other information, if any, you typically receive for these children.

8. Who typically accompanies the foster child to the genetic counseling session?

Foster parent(s)

Caseworker

Both

Other (please specify)

9. What are some of the unique elements of counseling children in foster care?

10. What would you describe to be the greatest obstacle or difficulty in a genetic counseling session involving children in foster care?

11. How does the counseling dynamic differ from other cases when interacting with foster parents?

12. Do you think foster parents are more accepting or less accepting of a genetic diagnosis?

More accepting

Less accepting

13. Please explain.

### **Health Passport**

Please read the following description:

The foster care health passport is a documented summary of relevant medical and health history for a foster child. The intention is to facilitate communication and continuity of care by sharing information among foster parents, caseworkers, and medical providers. The passport is designed to accompany children to medical appointments and remain updated.

14. Before this questionnaire, were you familiar with the existence of a health passport for foster children?

Yes

No

15. Have you ever seen a foster care health passport for a child?

Yes

No

16. If yes, why?

To review child's previous medical history

Update document with information from genetic counseling session

Both

Other (please specify)

17. Do you think that a health passport for children in foster care would be useful in your practice?

Yes

No

18. Please elaborate on reasons for your previously selected choice.

19. In what format would you prefer to access a health passport?

Electronic

Paper copy

20. Please describe and elaborate.

21. What are your concerns regarding use of a health passport by genetic counselors?

22. How likely are you to update a child's health passport if a section on genetic information was included?

1 - Highly unlikely

2 - Somewhat unlikely

3 - Somewhat likely

4 - Highly likely

23-28. Please select how important you think each area is for inclusion within a health passport.

1-Highly unimportant

2-Somewhat unimportant

3-Somewhat important

4-Highly important

Areas

Family history

Patient personal medical history

Previous genetic testing

Birth history

Developmental history



### Maternal pregnancy history

29. Are there any other areas not included in this questionnaire that you think should be included in a health passport?

30. Due to logistic limitations of space allotted within a health passport, please rank the following areas in order from most important to least important regarding inclusion within a health passport, with 1 being the most important area.

- Family history
- Patient personal medical history
- Previous genetic testing
- Birth history
- Developmental history
- Maternal pregnancy history

### **Implications**

31. Is a health passport the most appropriate place to include information pertaining to a genetic counseling session for children in foster care?

- Yes
- No

32. If no, please provide where you think this information should be included and why.

33. What suggestions do you have for improving genetic counselor care for foster children?

### **Demographic Info**

34. How many years have you been working as a clinical pediatric genetic counselor?

- <1 year
- 1-4 years
- 5-9 years
- 10-14 years
- 15+ years

35. Are you a certified genetic counselor?

- Yes
- No
- Board eligible

36. In which country do you work?

- United States
- Canada

37. Which province/state/territory?

38. Gender:

Male

Female

Choose not to answer

39. Age

20-29 years

30-39 years

40-49 years

50+ years

Choose not to answer

40. Ethnicity

Caucasian

African American

Hispanic

Native American

Asian/Pacific Islander

Other (please specify)

Choose not to answer

## Appendix D

### Questionnaire Response Frequencies

| Question | n  |
|----------|----|
| 1        | 81 |
| 2        | 81 |
| 3        | 81 |
| 4        | 81 |
| 5        | 80 |
| 6        | 80 |
| 7        | 16 |
| 8        | 78 |
| 9        | 72 |
| 10       | 71 |
| 11       | 63 |
| 12       | 63 |
| 13       | 61 |
| 14       | 69 |
| 15       | 67 |
| 16       | 7  |
| 17       | 69 |
| 18       | 54 |
| 19       | 69 |
| 20       | 47 |

| Question | n  |
|----------|----|
| 21       | 56 |
| 22       | 69 |
| 23       | 68 |
| 24       | 68 |
| 25       | 68 |
| 26       | 68 |
| 27       | 68 |
| 28       | 68 |
| 29       | 41 |
| 30       | 66 |
| 31       | 66 |
| 32       | 17 |
| 33       | 33 |
| 34       | 66 |
| 35       | 66 |
| 36       | 66 |
| 37       | 64 |
| 38       | 66 |
| 39       | 66 |
| 40       | 66 |