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A SURVEY OF SPEECH LANGUAGE PATHOLOGISTS' ACADEMIC PREPARATION IN CRANIOFACIAL ANOMALIES

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A thesis submitted to the University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

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Abstract

Craniofacial anomalies occur in 1 of 750 newborns a year with the three main types being cleft lip, cleft palate, and cleft lip and/or cleft palate. There are six main factors that affect craniofacial anomalies that are focused on in this research, including genetics, environmental factors, medications, diet, health risks, and surgical procedures/surgeons. The research found that there is a lot of information on craniofacial anomalies and speech-language pathologists need to learn about as much as possible. The lack of knowledge and academic preparations speech-language pathologists have in craniofacial anomalies has decreased their awareness in the birth defect and has also caused a lack of confidence in their practices to properly treat these patients. In conclusion, there needs to be an improvement in the academic preparation in the CSD undergraduate and graduate programs in craniofacial anomalies.

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CHAPTER ONE

Introduction

Craniofacial anomalies are one of the most common birth defects to occur in babies worldwide. However, many people lack the knowledge of these deformities unless they have known someone with one or personally experienced it themselves. This is the reason the author had a passion for the topic of this thesis. None of the author's family had answers for the reasons of their own cleft palate, just theories and it became a lifelong question. The cleft also caused harsh outcomes throughout their childhood, specifically with chronic ear infections. It was also believed to be genetically passed to the author, since the mother had one also. The author has empathy for other families with histories of craniofacial anomalies, thus the interest for this initial research. Since craniofacial anomalies are also considered hereditary, the author is motivated to decrease the number of birth defects in the future.

The research was first personal, but then became a change the author wanted to make to reform the lives of both the client and speech-language pathologists (SLPs). Each of the subcategories chosen, genetics, environmental factors, medications, diet, health risks, and surgical procedures/surgeons, had a significance to the following theories the author had about their reasonings for the development of their own cleft palate. The research articles found varied from being implemented as recent as the last few years to the previous century. They also target a variety of people besides speech-language pathologists, such as pregnant women, specifically for a healthier lifestyle in order to have healthier offspring. There is a lot of reliable information targeting the best practices to avoid having a child with any craniofacial anomaly as well as creating a plan if the parents were to ever have an offspring with the deformity. The author

wanted to survey significant team members, starting with speech-language pathologists. The first step was to review literature and create survey questions that gave the author an understanding of the knowledge and skills in craniofacial anomalies of the surveyed speech-language pathologists. Each category had key definitions used to form the questions for the survey. Each of the questions asked in the survey, specific to the subcategories, was created from a summary of the key research sections. All research gathered was used to develop the primary hypothesis for this study.

The research emphasized the lack of knowledge and skills speech-language pathologists have in treating craniofacial anomaly clients. The timings of the studies showed the confirmation of the lack of knowledge and skills for SLPs in craniofacial anomalies has very recently received attention. Very few studies have been done, but all have the same results and express a need for a change in the field of speech-language pathology. The results of these studies became the leading aspect on the survey questions created for this study.

Based on the research reviewed prior to the study, the author confirmed that there were several factors that SLPs may not be aware of or in which they may not demonstrate knowledge and skills that are necessary to treat individuals with craniofacial anomalies. There are also concerns in the undergraduate and graduate training programs related to choice of curriculum. Many are aware of the birth defects, but aren't educated properly on preventative measures to avoid craniofacial anomalies during the gestation periods.

Following initial review of the peer-reviewed research, the author decided the first step was to determine the craniofacial knowledge and skills of the speech-language pathologist as a primary treatment team member. The author found it important to include more personal questions, like their years of experience and geographical location, to verify if this is a nation-wide problem or a problem that has always been present but never addressed. The author felt the

need to find the core level of knowledge speech-language pathologists have in this topic. By determining SLPs' current position on the specific subjects related to craniofacial anomalies, the information could help strengthen quality training and increase confidence in treating clients.

The goal of this study is to determine the knowledge and skills of speech-language pathologists who may assess and treat individuals with craniofacial anomalies. The hope is that, with this baseline information, the author's future research in the area of craniofacial anomalies will be directed by understanding the training and knowledge of all craniofacial team members. An additional goal the author has is for there to be an extended awareness of this issue and to improve graduate and undergraduate training in craniofacial anomalies. The author hopes to continue this research at the next level, by being able to improve the education and clinical experiences speech-language pathologists have in craniofacial anomalies. The hope is that this direction will improve therapy for the patients and provide significant results.

The author's goal for this research is to influence others to do research on the topic. The survey was able to not only give craniofacial anomalies more recognition to SLPs, but it was also helpful in finding the amount of training, level of knowledge SLPs had during their training, and the frequency of need for this education and training in their everyday practice.

CHAPTER TWO

Literature Review

The literature review for this thesis addresses possible factors that create craniofacial anomalies in newborns. The purpose of the literature review is to show the complexity of craniofacial anomalies, and thus the strong need for undergraduate and graduate level training in this area. These craniofacial anomalies have an effect on individuals at birth, but they also cause long-term problems to individuals if not identified or resolved. As the Mayo Clinic states in their article from 2018 (Mayo Clinic, 2018), craniofacial anomalies occur during pregnancy when the lip or palate do not form correctly, producing openings in the mouth on the fetus.

The formation of the lips occurs during the seventh week following the palatal shelf closure between the eighth and twelfth week of pregnancy (Jiang, Bush, & Lidral, 2006).

Throughout development of the embryo, the processes of cellular proliferation, differentiation, and apoptosis are regulated by molecular signaling pathways (Mossey et. al, 2009). Each cellular process has its own function; proliferation is the increase of cell numbers, differentiation divides cells into their specialized functions, and apoptosis is the death of unnecessary cells. If any process is interrupted, they can cause healthy cell death and affect the formation of the oral cavity during fetal development (Mikhail & Blagosklonny, 2003). If not treated, the birth defect can cause hearing, speech, dental, and self-esteem problems (Schutte & Murray, 1999). The Christensen study (2004) addresses the cleft causing long-term and psychological effects to the individual and there is also an increased chance for different cancer types, including breast brain, and colon, with children born with any form of craniofacial anomalies (Billie et. al, 2005).

Children with craniofacial anomalies generate many communication interruptions from their

expressive language along with phonetic features in the production of speech (Sreedhenya et. al, 2015). The article has strong evidence of speech and language delays for children left with untreated clefts finding that 68% of children had delayed speech and language abilities. Many of the children received speech services, complicated by the fact that the same problems created academic issues as well. The study also showed how crucial early intervention is for children to reduce the complexity of speech, language, hearing, and swallowing issues as well as improving speech, language, and voice development consistent with their appropriate age level.

The literature review identifies three main types of craniofacial anomalies that tend to be addressed in research. These are cleft lip, cleft palate, and cleft lip and/or palate. Cleft lip occurs when the cellular structures forming the lips don't fully connect and leave a slit through the upper lip. The opening can range from a minor gap to a wide division traveling through the nose. The cut can be unilateral, one side, bilateral, both sides, or full, which means it travels up the nasal septum. Cleft palate is a fault in tissue fusion that creates a gap in the roof of the mouth. Cleft lip and/or palate occurs when the child has a failure of both tissue formation in the hard palate, soft palate, and the lips during pregnancy (Olney Dental Center, 2020). The interruption can cause a cleft starting at the embryonic suture up to the lip or uvula (Kummer, 2017). The craniofacial anomaly the child develops can be either syndromic or nonsyndromic. Syndromic is when the child has another developmental deformity in addition to the craniofacial anomaly, while nonsyndromic only has the craniofacial anomaly developed on the child (Brito et. al, 2012).

The Centers for Disease Control and Prevention (CDC) (2020) has recently stated that causes of the cleft lip and/or palate could possibly be the result of specific genes, environmental factors, health risks, diet issues, intakes of medications, and surgical malfunctions. After the

research analysis was completed, this author decided to focus on the academic training of speech-language pathologists to address many of the diagnostic areas identified in the research.

There are multiple factors that cause craniofacial anomalies and it is also important to discover and promote ways to prevent them as well. Knowing the right diet, essential elements to avoid in the environment, and types of healthy routines to follow could lessen the risks of craniofacial anomalies. Additionally, knowing the correct surgical procedures and possible complications to surgeries on the different cleft phenotypes could be a benefit to having better outcomes for surgeons and improve speech developments (Kosowski et. al, 2012).

Many of the discoveries found in the studies to date would not have been possible without the animal models. In 2013, the Ozturk study used mouse models, specifically Transforming Growth Factor ((Tgf)- $\beta 3$) gene isoforms, which showed eight different genes (Chrng, Foxc2, H19, Kcnj13, Lhx8, Meox2, Shh, and Six3) that caused the development of the cleft palate formation in both $Tgf\beta 3$ -/- mice and humans (Ozturk, 2013). After the Ozturk study was completed, technology tools became more advanced in analyzing the stages after palatogenesis, during the fourteenth through sixteenth weeks of gestation, specifically with the Next Generation Sequencing (NGS) technologies, or RNA-Seq. Another study with $Tgf\beta 3$ models helped researchers investigate the fault in the genetic transfer during the early development of clefts in the embryo (Nah, 2020). This study has helped find the gene routes to fetal development and certain conditions and mechanisms to the formations of the cleft in early stages of pregnancy. The genes found were mostly identified in cleft palates, but distinguished a better understanding of palatogenesis and new techniques for cleft treatment.

Throughout embryonic growth, the Fibroblast Growth Factor (FGF) genes are involved in the proliferation, differentiation, and apoptosis throughout early development (Ornitz, 2001). The

Fibroblast Growth Factor (FGF) regulates cellular processes in the lip and palatal formation through the extracellular matrix (EMC), which directs cellular functions, and epithelial mesenchymal transition (EMT), activating tissue functions to organ maturation (Stanier and Pauws, 2012). Robbins, McGuire, Wehrle-Haller, and Rodgers (1999) found the matrix metalloproteinase (MMP-2), in *Patch* mice, as the proponent in cell migration and causes clefts in fetuses with any deficiencies (Robbins et. al, 1999). Mutations to these genes are known to cause craniofacial development. Another discovery by Kruzynska-Frejtag (2004) found the Periostin protein had created the transcripts to form the palatal fusion in the embryo and presented cell rehabilitation in the EMC and EMT (Kruzynska-Frejtag, 2004). A study in 2010, by Kitase et. al, later clarified that the protein is corrupted during the medial epithelial seam (MES), which is the binding of palatal shelves, and prevents the ability for cells to travel through embryogenesis (Kitase et. al, 2010).

Overall, the animal models showed the highest reactivity in the hard and soft palates with the strongest results. The important objective from these studies was discovering the different ways the palates are structured in each of the palatal shelf regions, known as anterior, medial, and posterior. Both the anterior and posterior are merged through tissue remodeling while the middle is put together through medial extension of the palatal shelves (Chao et. al, 2004; Okano et. al, 2006). The mice models have been a useful guide in acknowledging how certain genes assist in the development of the baby throughout the early stages of pregnancy and what mutations are capable of doing to interrupt the proper growth formations. The models have also been able to easily understand and identify the proper formations of the lip and palates compared to abnormal clefts.

Genetics

There has been much inquiry in the genetics and the repercussions they cause on craniofacial anomalies. The Institute of Human Genetics in their 2021 study found five new genome regions that disrupt midfacial development associated to cause craniofacial anomalies. Ludwig, from the research team of this study, explains that over 90% of the regions found disrupt the gene activity pattern. The genetic genotypes are important to know for awareness of specific genes that result in the formation of the cleft in the oral cavity. Having familiarity in genetic causes to the cleft lip and/or palate encourages more understanding in genetics and prevents any dangers to pregnant women (Brito et. al, 2012).

There are four different gene categories that are suspicions to craniofacial anomaly formations: (1) genes identified in a particular part of the embryo or time during embryogenesis, (2) genes related to the biological activities involved in the formations, (3) genes found in animals associated with craniofacial anomaly activity, and (4) genes assisting in chemical activity (with drugs or other environmental pollutants) of craniofacial anomalies (Bianchi et. al, 2000). These areas are observed if there is any triggered sensitivity to the craniofacial anomaly being caused specifically by genetics. With these qualities holding accountability, recent studies have been able to identify suspected gene loci, or location, found specifically to affect the formation of craniofacial anomalies. The first one, TGF α , to ever be found was in 1989 by Ardinger. Similar to the role of TGF α , the gene loci, 2p13-p14, also mapped in 6p23 and 2p13, was located through the development of the cleft (Pezzetti et. al, 1998). This led to other identified loci, like 6p24-23 (Scapoli et. al, 2010), 4q21 (Beiraghi et. al, 1994), 19q13 (Stein et. al, 1995), and 13q33 (Radhakrishna et. al, 2006). In similar studies, the researchers discovered the gene *FOXE1* that became the main linked gene-loci for craniofacial anomalies (Letra et al.,

2010; Marazita et al., 2009; Moreno et al., 2009) along with the most consistent to nonsyndromic cleft lip and/or palates being *IRF6* (Zucchero et. al, 2004). As more studies are being executed, there have been many different genes that have been identified to cause formations of the cleft over the years.

A single nucleotide polymorphism (SNP) study was executed in 2017 and it discovered the HYAL2 gene, located in the connective tissue in the heart and hard palate, as the leading gene for the malfunction of palate formations (Sandoiu). The HYAL2 gene also showed links to heart defects that directed to the production of cleft palates. Not long after, Lin-Shiao, from the University of Pennsylvania (2019), detected the p63 protein, known as genome "enhancers," being another cause to craniofacial malformations if disrupted during its processing on the facial structure. He found that the protein allows for the molecules to open or close DNA structures in the chromatin and supports enhancers being expressed to the mRNA. For this reason, the protein synthesis should not be interrupted to support embryogenesis.

Of the well-known defects being examined, 75% are caused by a loci gene (Leslie & Marazita, 2013). It is becoming more common for children to develop craniofacial anomalies if it has been carried in their family. First degree family members with craniofacial anomaly history are thirty-two times more at risk than family members without craniofacial anomaly history (Siversten et. al, 2008). To determine the chances of genetically passing down craniofacial anomalies to an offspring, one can look at lab tests, family/medical history, examinations, severities, and defect phenotypes. The main tests recommended to families are Multiplex Ligation-dependent Probe Amplification (MLPA), Comparative Genomic Hybridization Array (CGH-array), exome sequencing, gene targeting sequencing, and karyotypes (DeVries et. al, 2001). These are important tests to investigate depending on the quantity of family members

with abnormalities, severity, and gender. They can determine if there is a possible recurrence risk that runs in the family through a single-gene disorder, like the *IRF6* gene mutations causing Van der Woude Syndrome (VWS) associated with structural deformities of the mouth. A study in 2007 revealed a rare psychomotor delay, Smith-Magenis Syndrome (SMS), having a cleft palate gene through the CGH-array at only the fourth and fifth weeks of pregnancy (Villenet et. al, 2007). The CDC stated in 2020 that syndromic clefts, specifically, have a 50% chance of being carried on and around 15-30% of the clefts can possibly have an additional malfunction, most likely being velopharyngeal dysfunction. It has been reassured since 2017 by the first study, using sibling population-based measurements, that there is a lower risk of having a second child with the same birth defect (Glinianaia et. al, 2017). Every woman has a 4% risk of having a child with a birth defect (Better Health Channel, 2014), thus, even without any of the known risks, all women are capable of having a child with any type of craniofacial anomaly.

There are many genetic influences to the social environment that are not fully understood. There are four supported impacts that affect an individual's sensitivity to the social environment, such as an individual's response to environmental stress, their sensitivity to beneficial and harmful environments, inherited qualities related to other environments, and inherited tolerance to multiple environments. (Reiss et. al, 2013). However, these factors depend on the qualities the environment brings to certain genotypes. These characteristics show a need for pattern recognition to different gene-environment interactions.

Environmental Factors

There are a number of elements through genetics and the environment that are known to influence embryonic impairments and phenotype manifestations (Merscher et. al, 2001). The

largest environmental risk factors that could increase the risks of craniofacial anomalies are smoking, chemical agents, specifically targeting the wingless/integrated signaling pathway, alcohol, and pharmaceuticals (Shaw et al., 1996; Brent, 2004; DeRoo et al., 2008; Beaty et al., 2016). Smoking during pregnancy has been known to increase the risk of cleft palate formations and low birth weight in newborns (Shi et al., 2008). A study in 2018 showed more maternal exposure to water disinfection by-products can heighten the risks to cleft palates from the chemical disinfectants and organic matter found in the water (Kaufman et. al, 2018). The wingless/integrated signaling pathway is an important pathway that assists in a majority of the cell functions and organ growth in embryogenesis (Komiya & Habas, 2008). With craniofacial anomalies being so common, the pathway has become one of the main biological risks that needs to be the most prevented in avoiding further malformations from certain chemical agents (Hu et al., 2013; Okano et al., 2014). Alcohol has become a weaker risk, but can become proactive if consumed along with an alcohol dehydrogenase genome ADH1C and combined with a reduction in enzyme activity, poor nutrition, stress, and active smoking (Boyles et al, 2010). There have been many studies performed to conclude pharmaceuticals becoming a large threat to the craniofacial anomaly formations. It is difficult to know which medications are the most dangerous to the health of both the fetus and mother, but it seems anti-epileptic drugs (AEDs) have had a large impact (US Food and Drug Administration - FDA, 2011). The case studies have seen older anti-epileptic drugs, such as topiramate, valproate, and phenobarbital, as greater risks to cleft lip during prenatal doses. As a result, there has also been an encouragement of lower doses, specifically less than 200 mg for epileptic users and less than 100 mg from non-epileptic users with topiramate (Janssen Ortho LLC, 2009). The non-epileptic users are usually given drugs for other health problems, like migraines or bipolar disorders.

Some environmental factors are extremely threatening to mothers and fetuses. One of the main issues in the environment today is pregnant women being exposed to cigarette smoking or being an active smoker before and/or during gestation. Around twenty-four studies in 2004 showed a 30% increased threat in cleft lip and/or palate and a 20% increased threat in cleft palate from cigarette exposure (Little et. al, 2004). According to Dr. Jeff Murray at the University of Iowa, the threats of cigarettes to a woman during their pregnancy could be based on the presence of their protein coded gene, glutathione S-transferase theta 1 (GSTT1) status (2007). The main smoking teratogens, fighting against GSTT1 genes, are the chemicals within cigarettes that are interrupting the palatal and maxilla formation throughout the first trimester. The study showed that the oral cavity can form normally without the protein coded gene, but the baby is at a greater risk in being born with a cleft if there is any cigarette smoking chemical that interferes with the fetal development.

With the findings of chemical agents being a dangerous hazard to craniofacial anomalies and other factors that cause the birth defect, there have been a number of recent studies promoting quicker solutions to preventing craniofacial anomalies. The U.S. Environmental Protection Agency has found chemicals that are bioactivity teratogens that cause formations of cleft palates through their ToxCast high-throughput screening (HTS). The high-throughput screenings are used to reveal living cells observed for activity in becoming a chemical hazard. The first study used the high-throughput screenings to separate chemicals as cleft-palate positives and cleft-palate negatives (Wu et. al, 2013). Later on, *in vivo* technology models from the screenings showed 310 chemicals, specifically pesticides, that structure potential molecular origin events leading to cleft palate (Richard et. al, 2016). The studies were able to separate cleft-

palate toxicants and identify further opportunities in finding cleft palate predictions through the chemical screenings.

Many of the chemical agent studies, similarly to genetics, have also been consistent using animal models to find a majority of the discoveries. In 2020, zebrafish models revealed having several chemicals causing craniofacial anomalies (Liu et. al, 2020). Twelve were found, with the three main being BIO, CHIR99021, and WAY-262611, classified as initial inhibitors enforcing interruptions through the wingless/integrated signaling pathways that caused craniofacial anomalies. A study using sulfur mustard (SM), which was a World War I chemical warfare agent along with a treatment used for psoriasis, resolved having an impact on cleft lip and/or palate malformations from exposure to the chemical sulfur warfare (Wormser et. al, 2005). Previous studies have determined the chemical tetrachlorodibenzo-p-dioxin (TCDD) as an agent for cleft palate formations on the Aryl hydrocarbon Receptor (AhR), based on cellular homeostasis and immune stimulations, as a possible pathway triggered by certain teratogens. These past inquiries found the role of guiding the findings of TCDD affecting the palatal cells mediated by the Oct4 transcription factor throughout embryonic development (Tao et. al, 2020).

Despite chemical agents having a large significance on both the mother and the embryo during pregnancy, alcohol consumption does not have as much of an impact. Fetal alcohol spectrum disorder is a disorder from alcohol consumption during pregnancy (Caputo et. al, 2016). Cleft lip and/or palate is notorious for occurring only in 9-18% of newborns with fetal alcohol syndrome (Abel, 1998). Researchers found published articles from 1950 to 2019 by the Cochrane Central Register of Controlled Trials (CENTRAL), the Institute for Scientific Information (ISI), and PubMed (with sparse significance in alcohol consumption inducing craniofacial anomalies), but should still be highly encouraged to stay away from while pregnant

(Yin, J. Li, Y. Li, and Zou, 2019). Since fetal alcohol spectrum disorder is known to mainly affect the brain, a study in Japan concluded that there was no significance to any craniofacial anomalies with alcohol as a factorial, but may have a potential to induce congenital heart defects (CHDs) (Hanaoka et. al, 2018; Boulet et. al, 2006).

Telephone interviews by Shaw and Lammer (1999) established that low consumptions of alcohol showed lower risks of craniofacial anomalies and larger consumptions showed higher risks. Alcohol consumption puts the mother at a greater risk for having an infant with any type of craniofacial anomaly compared to mothers who are nondrinkers, but it also depends how much is consumed at one time. The highest consumption is with binge drinkers, which is five or more drinks per sitting (Gladstone et. al, Koren, 1996). This study has confirmed that the amount consumed per episode is more important than the time and consistency. Even a singular binge event could cause crucial harm in the future. After all the information was finalized, it was proven that binge drinking is the most dangerous to increasing the risk to development of craniofacial anomalies. Smaller portions did not cause as much harm when compared to other environmental factors.

The last environmental factor this author will discuss is the increasing risk of craniofacial anomalies relating to pharmaceuticals. There are a number of medications that can have potential effects on interrupting the formations of craniofacial anomalies. In 2001, isotretinoin, which is another form of accutane, a cystic acne medication, showed a slight delay in mice models during palatogenesis (Balducci-Roslindo et. al, 2001). Puhó et. al (2007) observed pregnant women taking oxytetracycline, carbamazepine, thiethylperazine, and phenytoin, which are prescription drugs, discovered a partake in the formations of craniofacial anomalies. Two studies found that individuals who took diazepam (DZ), which is used for anxiety, seizures, and muscle spasms,

had consequently formed craniofacial anomalies when taken during pregnancy (Marinucci et. al, 2009). Anticancer drugs, distinctly cyclophosphamide (CPA), have had sufficient research to show the drugs attack the embryo and cause craniofacial anomalies (Rengasamy; 2017).

The FDA reported that the largest medicated contribution that has been recognized to the increased risk of craniofacial anomalies is topiramate (2011). Another anti-seizure drug, phenytoin, was found to be the most populous pharmaceutical cause of cleft lip (Webster et. al, 2006). In conclusion, there are many studies outlining the risks of pharmaceuticals to craniofacial anomalies with the greatest significance from antiepileptic drugs (AEDs) that affect embryo's during the first trimester of pregnancy and creating cleft lip and/or palates overtime (Laganá et. al, Spina, 2015).

Medications

Medications have shifted to the center of research on craniofacial anomalies. There are various considerations that determine the damage drugs can have on an unborn child during pregnancy: the type of drug, dosage, illness, consistency, individual's response, and fetal stage (Better Health Channel, 2014). Epilepsy is a common disorder and one of the higher risks of a birth defect during pregnancy (Yerby et. al, 2004) and certain doses of these medications could potentially interrupt prenatal development and growth.

Before pregnancy, women should find the appropriate anti-epileptic drug concentrations to intake in order to have a healthy baby and satisfy their needs at the same time. Pennell (2003) justifies that plasma concentration in medications can be dependent on the applicable seizure control to accurately transport medications into the bloodstream (Sabers et. al, 2009). This can become an issue for the climax on the developmental stages of the embryo or fetus with its

demand for normal blood flow, plasma concentrations, and having a nourished pregnancy. Since 2009, it has been noted that topiramate plasma concentrations vary during pregnancy and should be regularly monitored. Knowing the plasma concentrations will allow for the balance of the correct amount of topiramate doses to take during each trimester (Ohman et. al, 2009). An additional study performed in 2008 showed topiramate causing low birth weights in newborns (Hvas et. al, 2000), which may be a significant reason the exposures are so risky and are in need of regular monitoring for all anti-epileptic drugs.

As mentioned before, the largest contributors to embryonic disruptions are anti-seizure drugs, like topamax and phenytoin. These medications extend their needs beyond epilepsy to also treat migraines, psychiatric disorders, and neuropathic pain (Meador et. al, 2008). This could potentially cause more harm to pregnant women, due to the use of these anti-epileptic drugs. The usage during pregnancy may not only pass along epilepsy to the child, but also start cleft formations in the fetus. Women with epilepsy are encouraged to fully discontinue their drugs during pregnancy, but should start anti-epileptic drug therapy since it is dangerous to pause a regular prescription taken for a serious disorder. The anti-epileptic drug therapy is a safer way to control seizures and maintain blood levels (Meador et. al, 2008). Thomson and Battino (2009) clarified through twenty-six different studies that it is not the epilepsy itself that creates peril to women having children with craniofacial anomalies, but the drugs used are the teratogenic agents themselves. The medications become a greater danger by enhancing additional problems from side effects, like nausea and anxiety, they are known to cause. The women will be in need of extra medication to cure other side effects. The more medications taken, the greater the risk.

The FDA has certified to CDC that all the studies recording women with epilepsy taking topamax have shown an increase in craniofacial anomalies when the absorption mostly occurred

before or during the first trimester of pregnancy (2019). Lower doses affect 2.1 of every thousand births while higher doses affect 12.3 of every thousand births. Reports in 2008 showed seventy monotherapy exposures that showed a 4.8% major congenital malformation (MCM) rate that tripled to 11.2% in polytherapy (Hunt et. al, 2008).

Topiramate is also defined as the *Pregnancy Category D* drug, which means fetal risks have been discovered in human studies that can harm the baby. However, the drug has certain exceptions for being taken during pregnancy, like injury or death being a possible outcome with a lack of any type of treatment. The FDA has lowered the topamax average dosage from 200 mg to only 25 mg during the first trimester only if the intake is for epilepsy. In these cases, it is crucial that topiramate intake is not postponed because it could cause further health issues.

The evidence in further reports show that higher doses of anti-epileptic drugs have more extensive risks to craniofacial anomalies than lower dosages, but any dosage becomes a risk. The most appropriate form of treatment to prevent seizures during pregnancy is through anti-epileptic drug monotherapy, one anti-epileptic drug, making sixty percent of patients seizure free (Kwan & Brodie, 2000), and to avoid polytherapy, multiple anti-epileptic drugs at once. Carbamazepine has been known to be the safest anti-epileptic drug during pregnancy and has had proven studies showing no significance in causing craniofacial anomalies (Morrow et. al, 2006). Topamax and lamotrigine, another anti-epileptic drug, showed similar results with varied doses between what the prescriptions are used for during gestation. If used for seizures, women take 200 mg, which increases the risk five times greater for birth defects. For other conditions, the intake is 100 mg, which is a sixty percent increase. Hernendez-Diaz claims topamax doses, for anti-seizure purposes, are the most excessive risks for having a child with any type of craniofacial anomaly.

There still needs to be research implemented to find the most effective regimens to treat seizure disorders.

In addition, many of the recent discoveries have expressed an extensive amount of folate deficiency that can create an absence of fetal or embryo growth support, especially when anti-epileptic drugs are harming these progressions (Meador et. al, 2007). The intake of folic acid supplements has become a further detection that is also a useful type of therapy, besides using anti-epileptic drug monotherapy and is a discovered endorsement to reduce the risks of craniofacial anomalies (Harden et. al, 2009).

One way to decrease the risk of any craniofacial anomalies is through folic acid intakes.

There have been studies with mixed results that showed both positive and uncertain outcomes with the folic acid supplements used in gestational diets. The completed studies have seen more benefits curtailing neural tube defects than craniofacial anomalies. There haven't been many certainties drawn from the studies targeting craniofacial anomalies, however, the higher dosages and intakes, along with the appropriate diet, have seen the best outcomes.

<u>Diet</u>

Another important factor to the prevention of craniofacial anomalies is a regular, healthy diet before and during a mother's pregnancy. A study (2004) organized a questionnaire, distributed to both mothers that had children with craniofacial anomalies and mothers that didn't have children with craniofacial anomalies, asking about their diets during their prenatal and perinatal stages. The results found that the intake of minerals, macronutrients, and vitamins were lower in craniofacial anomaly mothers compared to non-craniofacial anomaly mothers (Krapels et. al). A similar study in 2008 tested Vitamin A, a fat-soluble vitamin, in a maternal diet

resulting in the ninety-fifth percentile of reducing the risks of cleft palates (Johansen et. al). However, a study performed by Yoshida et. al (2020) resulted in identifying multivitamins as having an effect to cause craniofacial anomalies, without the accountability with other drugs or diets, when taken before conception or during the first trimester. There are many healthy habits suggested to maternal women, but the key factors are the health conscious diets that are helpful towards positive neonatal health. This following content provides evidence showing there being a need for further experiments directing women to the best dietary choices.

The fetus' growth and development depends on the mother's health conditions. Since prenatal women are going through multiple body changes, studies have embraced the demanded usage for vitamins, minerals, and proteins. Micronutrients assist the roles of fetal growth, embryogenesis, and health throughout periconception (Cetin et. al, 2010). Micronutrients are vitamins and minerals made of chemical substances that support metabolism and biochemical synthesis in the body (Jariwala & Rath, 2010) and a reduction of any micronutrient substances could bring neonatal injury. It is crucial to have a sufficient diet for an ample metabolism and successful fetal development (Cazzola et. al, 2007).

From the study completed in 2021, Ballestín et. al was able to interpret that micronutrients are a critical necessity for pregnant women. The dietary study in 2022 (Marshall et. al, 2022) emphasizes for pregnant women to "eat better, not more." There is a need for balanced quantities of fruits, vegetables, whole grains, fiber, lower fatty red meat, fish, and oils. This diet should be practiced before conception to begin the habit, since women are not aware they are pregnant during the first couple weeks. Specific nutrients intakes have been detected to prevent birth defects or stillbirth, such as folic acid (Lassi et. al, 2013), vitamin D (Hollis & Wagner, 2017), or carbohydrates (Clapp, 2002). Nonetheless, only eating a singular

micronutrient, such as a banana, will not prevent every possible deficiency from being evaded. The diet will only be supportive if it has a wide selection and is consistent. Studies have established since 2004 that along with intaking micronutrients during gestation, other micronutrient supplements and multivitamins will also improve neonatal health (Botto et. al).

Although micronutrient multivitamins have shown advancement in craniofacial anomaly reduction, studies have shown the intake of both micronutrient and selenium supplements will cause postpartum depression. The expectant mothers reported having no symptoms of depression before or during pregnancy, but reported having symptoms after their child was born (Letourneau et. al, 2020). The intake of selenium was found to induce brain and behavior development, while also becoming a noticeable prenatal factor within the supplement results, but only when it is actively taken during the first trimester and became an extraneous factor during the second and third trimesters (Leung et. al, 2013). A majority of the supplements have the same occurring pattern and needed further research executed for better diets.

There is a crucial need for selenium throughout pregnancy, especially the beginning of the second trimester, in order to fight off any immune deficiencies (Ventura et. al, 2017). Selenium intakes are shown to help dietary needs and the metabolism, but it has side effects that can cause stress, social or mental issues, and other health conditions that could potentially harm the newborn (Leahy-Warren et. al, 2011). The selenium intakes are still beneficial, but higher doses could trigger depressive disorders during post-perinatal periods to the mother (Leung et. al, 2013).

A further way to continue having an approved diet during pregnancy is macronutrient domination. Similarly to micronutrients, macronutrients also provide energy that is an imperative supply for a proper developing fetus. The study by Krapels et. al (2004) supports both

micronutrients and macronutrients being an active part of a pregnant woman's diet in order to limit craniofacial anomalies. Unhealthy habits, including diets high in sugar, lack the proper nutrients and vitamins that are needed and can potentially lead to several birth defects or other health conditions, like diabetes (Pflipsen & Zenchecko, 2017). Having a balance of both micronutrient and macronutrient diets is required for the pertinent amount of energy needed to reproduce a healthy baby (Savarino et. al, 2021). Pediatric leaders should encourage the most resourceful balanced diets using both types of nutrients.

Carmichael et. al (2012) claimed that neural tube defects and craniofacial anomalies can most likely be reduced if intaking a Food Guide Pyramid and/or a Mediterranean diet, while a western diet induces birth defects (Vujkovik et. al, 2007). An intake of a number of nutrients from fruits and vegetables has shown progression in reducing the risks of craniofacial anomalies (Kraples et. al, 2004). Most of the diets consist of leafy greens, meat, and dairy, but studies have shown mixed results to folic acid reducing the risks of craniofacial anomalies.

Folic acid is Vitamin B in vegetables, citrus, beans, and whole grains (Wilcox, 2007). It provides various functions to the body: repairs DNA and genetic material, reproduces red blood cells, and prevents neural tube defects and other disabilities, like autism or arthritis. Having a lack of folic acid could cause health issues, most commonly anemia, and can also boost weakness, fatigue, and paleness (Felman, 2020). The studies done by the Hungarian Congenital Anomaly Registry in 2004 show results of increasing the folic acid dosage to 6 mg would reduce the risks of cleft palates by 74% (Czeizel). Another study performed in 1995 (Shaw et. al) found that actively taking folic acid during the first trimester of gestation (8-14 weeks) will be more preventative to the formation of craniofacial anomalies. However, later studies have shown there being no significance in folic acid on reducing orofacial clefts (Ray et. al, 2003). A similar study

by Little (2008) supports there being no significance to folic acid helping the reduction to craniofacial anomalies and only in neural tube defects.

The National Institute of Health Sciences (NIEHS) showed research for pregnant women and having a folate diet, and intaking at least 0.4 mg of folic supplementations a day, will reduce the baby's risk of having a craniofacial anomaly by one third – Wilcox says these findings created more benefits to help make a healthier diet and environment for pregnant women (2007). It also helped researchers realize that there are possible resolutions for not just neural tube defects, but also craniofacial anomalies. Most of the studies done have seen the most success using folic acid multivitamins. One resulted in having a 60% reduction in cleft palates (Werler et al., 1999), 40% in cleft palates and cleft lip and/or palates (Loffredo et al., 2001), and cleft lip and/or palates by 50% (Itikala et al., 2001). More studies were implemented using grain products and showed a significant effect on neural tube defects, but not for craniofacial anomalies (Ray et al., 2003), and a similar study the same year used wheat flour showing no great significance either (Castilla, 2003).

The Medical Research Council (MRC) has evidence from their study expressing that folic acid supplements have become a preventative segment to neural tube defects and reduces their child's risk by 72% (Lancet, 1991). The study also shows how effective the higher doses of folic acid are compared to other vitamins taken during pregnancy, but contradictory to the other studies, didn't find any significant reductions for craniofacial anomalies (Czeizel et al. 2004). Therefore, there needs to be more research done to certify if the vitamin is a useful dietary habit for both the expectant mother and child.

Health Risks

A complimentary topic that is not frequently recognized is the health risks craniofacial anomalies can potentially cause to children during their growth and development. According to JAMA Pediatrics, cleft palates have greater risks for autism, intellectual disability, anxiety, epilepsy, musculoskeletal disorders, and cerebral palsy. Cleft lip and/or palates have been shown to have more risks associated with cerebral palsy and intellectual disabilities (Cowden, 2016). There have been multiple studies performed that found chronic ear problems, specifically conductive hearing loss (CHL) or eustachian tube dysfunctions (ETD) resulting from long-term effects of craniofacial anomalies (Imbery et. al, 2017). Ann Kummer explains other long-term effects, like dental and nasal issues. The dental malformations can cause a smaller oral cavity and dental intrusions on speech productions. The nasal issues form a smaller septum and cause irregular breathing and resonance to speech (2017). These clefts can provoke a child's poor psychosocial status, physical health, and quality of life (Wehby & Cassell, 2010), which may remain from infancy into adulthood (Kapp-Simon & McGuire, 1997).

Craniofacial anomalies have also provided children with learning disabilities, which lead to oral language issues and poor processing and reading skills (Eedan & Stringer, 2020). An additional study showed thirty-six month olds having "at risk/delayed" – expressive language showing faulted success in their education and communicating in social environments at a young age (Neiman & Savage, 1997). For this reason, there is high advocacy for children to repeat grades in order to communicate at an age-appropriate level (Broder et. al, 1998). A study by Stock et. al (2018) encouraged sufficient training and knowledge in teachers to improve their preparation for children with craniofacial anomalies. After the studies observed behavioral

activities of children born with a craniofacial anomaly, it was concluded that there is a lack of studies or observations done with children younger than six years old.

Craniofacial anomalies are also known to cause other long-term issues, like facial disfigurement, hearing loss, speech, and language disorders that need both clinical and surgical attention (Trainor & Richtsmeier, 2015). Kummer (2017) also shares neurological malfunctions formed from craniofacial anomalies, which can affect language delays and cognitive performances. Parents, in some instances, can be in denial and refuse to believe their children need more assistance in schools, therapy, or at home. Avoiding care for a child at a younger age is a leading cause of their learning, physical, and mental problems as they grow older (Broder et. al, 1998).

Another way of increasing risks for craniofacial anomalies in the fetus is through exposure to rubella disease. Rubella is a viral infection spread through saliva when a person sneezes, coughs, or talks (O'Neil, 2014). Rubella is contagious all throughout the illness and the following two weeks after the disease. The symptoms are similar to the flu, including joint pain, fever, and swollen lymph nodes. Rubella became one of the first viruses that was investigated for the birth defect possibilities from environmental exposure, as well as being classified as a teratogen, a malformation in the embryo. If exposure occurs, there is a 90% chance that the unborn child will be affected by rubella disease during the first trimester, which can be very dangerous during gestation. When pregnant women catch rubella during the first few months of gestation and while passing through the placenta, they have Congenital Rubella Syndrome (CRS) (Bouthry et. al, 2014). Congenital rubella syndrome can also cause cardiac, sensorineural, ocular, and auditory malfunctions; or even the possibility of a miscarriage.

Researchers have also used animal models for studies on how the rubella virus impacts cell activity. The results showed that rubella shortens the life cycles of cells and boosts the chances of premature cell death (O'Neil, 2014). Congenital Rubella Syndrome has presented the development of birth defects, such as deafness and heart development, impaired vision, and damages to the central nervous system. Many conditions serve as a role in the severity of congenital rubella syndrome by the transfer of antibodies in the fetus, by an increase in immune responses, and by the embryo's sensitivity to teratogens during pregnancy. It has been known for decades that the best way to prevent a person from catching rubella is by vaccinations. The US Centers for Disease Control and Prevention recorded 57,686 cases in 1969 falling rapidly to only nine cases in 2004, attributed to the success of the vaccinations.

Not only do craniofacial anomalies cause stress and fear to children, but the stress and fear carry over to the parent, usually during periconception. The parents usually experience a variety of emotions: denial, guilt, confusion, and depression (Rey-Bellet & Hohlfeld, 2004). The birth defect affects the relationship of the family after birth as well. Studies have expressed a need for evaluations before and after cleft surgeries for psychiatric and psychological support (De Sousa et. al, 2009). The following studies have provided insightful information to people to see how difficult the first year is for both the parents and the child, whether it is care adjustments, bottle feeding, or social interactions (Grollemund et. al, 2020). There have been frequent concerns on a child's behavior when dealing with social withdrawals, especially during the first year of a child's life (Re et. al, 2018). These studies have brought considerations in monitoring the health of both the child and mother a regular routine.

Most of the mental health and self-esteem difficulties occurred from the outcomes of surgical repairs. The improvements depend on training, expertise, and the overall knowledge of

the surgeons and their team. Veau classifications, or LAHSHAL code, are useful resources for determining the cleft diagnosis of the most proper surgical techniques to use for the best results (Kriens, 1989). The LAHSHAL coding is used to identify the severity of the cleft an individual has, such as unilateral or bilateral clefts. Surgical care is indicated by three factors: (1) velopharyngeal insufficiency (VPI), when the soft palate and throat do not work together, (2) midface hypoplasia, when the upper jaw and other facial structures are smaller than the rest of their face, and (3) palatal fistula, is the opening of the oral and nasal cavities (Phua, 2008; Mars & Houston, 1990).

Timing of surgery also creates impacts on the life outcomes of a child (Rohrich, 2000). The primary surgical plan should be to target speech advancements and is encouraged to have the procedure completed by six months of age (Peck et. al, 2021). Earlier palatal repairs, specifically by thirteen months of age, have shown to improve their speech skills, since it's prior to their talking stages (Klintö et. al, 2014). A Klintö study (2022) found similar results presenting no significant differences with the palatal closure stages, but could cause negative speech performances in a child if the surgery was completed after twenty-five months of age. There was small progress if the last palatal procedure was before thirteen months, but the latest time an individual should get their last primary palatal surgery done is at twenty-four months. Speech development accelerates with closure of the hard palate (Peterson-Falzone, 1996) and maxillary growth advances with delayed closure (Friede, 2007). Some procedures are done at a later date because of other health issues, which could be helpful to the patient with more severe circumstances (Willadsen et. al, 2017).

Improved facial appearances is another goal for the surgeries performed. The surgeries are a way to boost a person's self-esteem and social delivery (Wildgoose et. al, 2013). Cleft lip

and/or palate patients begin to have behavioral problems because of their self-conciousness, depression, anxiety, and social challenges (Hunt et. al, 2005). A patient's self-perception also depends on the success and positive impacts of the surgeries. The study reassures patients having more satisfaction after the second facial surgery (Sinko et. al, 2005). The Mayo Clinic (2022) claims different clefts are best identified through an ultrasound, however, cleft lips are easier to diagnose over a cleft palate after thirteen weeks of pregnancy. There are a number of different types of procedures, but there is still uncertainty as to which ones have the most impact on patients. Self-perception becomes an immense part of someone's self-esteem when dealing with craniofacial anomalies forming their psychosocial viewpoint (Strauss et. al, 1988).

Surgical Procedures/Surgeons

Children born with craniofacial anomalies can expect several medical interventions during their first eighteen years of life (Supit & Prasetyono, 2008). The most progressive treatment from the surgical teams relies on identifying normal/abnormal anatomy, diagnostic evaluations, postoperative care, surgical procedure practices, team collaborations, and surgery experience (Kosowski, 2012). Kummer explains, one of the goals surgeons have is avoiding velopharyngeal insufficiency. Even with surgeons going to maximum protections to avoid velopharyngeal insufficiency, patients will most likely have the dysfunction after surgical repairs, resulting from poor velar movements (Bardach, 1995). This risk brings more chances of having speech or resonance disorders in the future. Leow stated in 2008 that since the recently advanced maxillary operations, the main focus has been to work on the normal speech of the patient to keep them on track with their peers. The past few decades have brought improvements for the orderly anatomy of the cleft and have created more successful surgeries with enhanced postoperative results.

Dental-facial growth, facial appearance, hearing, speech, breathing, quality of life, and patient satisfaction are taken into accountability when analyzing cleft treatments (Mossey et. al, 2003; Asher-Mcdade, 1992). All of the categories are equally important during post-surgical procedures in order to determine other potential extensive procedures. Early surgical procedures, with the cleft lip repair being between three to six months of age and cleft palate being before twelve months of age, has shown stronger speech outcomes (Adeyemo, 2009). With close cleft team collaborations and cooperations, there is a better chance of successful surgical outcomes and low complication rates (Abdurrazaq et. al, 2013).

Despite the high possibilities of having velopharyngeal insufficiency, speech has become a big focus for craniofacial anomaly surgery goals. A study performed in 2015 showed how noticeable the untreated clefts were in the speech skills and vocalizations in children (Sreedhanya et. al, 2015). If untreated, the inadequate valving of the velopharyngeal port interferes with the laryngeal valving patterns and lowers intraoral pressure (Mayo et. al, 1998). Closure of the velopharyngeal port becomes more difficult when intraoral pressure grows, which are the requirements for speech production.

The age of the child generates different goals for each of the surgeries. From one week to three months, the surgeries focus on combining the cleft and lip together while giving symmetry to the nose. This procedure is called nasoalveolar molding and is performed by an orthodontist or maxillo-facial surgeon. At three to six months, surgical repairs address the separation of the lip. During nine to eighteen months of aging, reconstruction of the roof of the mouth is done, so the patient is able to eat, drink, and speak normally. At five to seven years, surgery addresses the palatal expansion (Swanson, 2022). As the patients grow older, there are many other surgeries that are also used to repair other parts of the facial structures, like the jaw, nasal airways, or

dental arch, depending on the severity and circumstances. Not everyone needs multiple surgeries or facial structures reconstructed, but these are all possibilities.

Katzel et. al (2009) found that Furlow palatoplasty and Bardach intravelar palatoplasty, which are both different techniques to reconstruct muscle flaps on the palate, and are the most frequently used surgical techniques. Even with these limited techniques, there are still a variety of other clefts that have a chance of needing other procedures done depending on their necessary needs. To find the appropriate surgeries, serverities, and exact locations of the cleft, the surgeons usually use the Tessier Classification System (Kummer, 2017). The surgical teams use a 0-14 scale, with the midline as 0, and can identify the exact location and length of the cleft. This has become a useful tool in finding the most successful treatments for patients.

Understanding the preoperative, perioperative, and postoperative practices are crucial to prepare for successful surgeries. Preoperative variables have to do with the type of surgeon, quality of equipment, timing of diagnosis, and patient's cleft severities. Perioperative practices focus on the techniques, surgical team, and possible complications. The actions taken after surgery, postoperative, are also important in preventing any future errors, damage, or more possible surgeries (Agrawal, 2009). The Cleft Width Ratio (CWR, 2021) is a scale used for the cleft's severities and measures the ability of the palate to be lengthened through surgery. This device along with the nasal ram pressure (N-RamP) (Bunton et. al, 2014), to measure velopharyngeal port size, proved to be resourceful measures that have helped with many surgical studies in helping a patient's future (Auslander et. al, 2021).

New and improved surgical techniques allow surgeons to reduce the number of procedures needed, however, a craniofacial team of multiple members allows for the most comprehensive care for patients. The team collaboration holds a lot of responsibilities: support from practices,

positive practice environments, mentorship and learning, and leadership (Schmitz et. al, 2017). Collaboration has helped cleft lip and/or palate teams internationally (Hlongwa & Rispel, 2021). Every person born with cleft lip and/or palate needs to have an interprofessional team until adulthood consisting of orthodontists, pediatricians, maxillo-facial and plastic surgeons, nurses, social workers, psychologists, audiologists, and SLPs (Sánchez-Ruiz et. al, 1999).

The most fundamental part of treatment for cleft lip and/or palate is not looking for the best surgical technique, but looking for the best tactics to achieve the most successful rehabilitation to avoid any problems as the child reaches adulthood (Posnick & Kinard, 2020). It is also important to provide care for both the child and the parents dealing with the difficult process. Psychosocial health is a large portion of the family environment that associates with their self-esteem (Gussy & Kilpatrick, 2006), adjustment (Berger & Dalton, 2011), and self-perception (Millard & Richman, 2001). Many patients go through teasing and bullying that can affect their mental health and relationships. It is necessary to rearrange the way patients become aware of their conditions and how others perceive it as well.

Overall, each of the subcategories, genetics, environmental factors, medications, diet, health risks, and surgical procedures/surgeons,mentioned have contributed in their own ways to the effects and outcomes of craniofacial anomalies. After all the research was reviewed, it was concluded that there is a scarcity of evaluations on the children, as factors such as information about their surgeries, the patient's socioeconomic status (SES), types of craniofacial cleft teams, and special care (Kapp-Simon, 2004). Each factor needs to have more research conducted for a better understanding and awareness on how common the birth defects can be. Cleft palates are the fourth most common birth defect and affect 1 in every 750 newborns in the United States (Upstate Otolaryngology and Communication, 2019). It is important to identify the preventive

aspects since the lip, spinal cord, and palate are the first parts of the body to form on the fetus and can be easily interrupted during the first stages of pregnancy (Felman, 2020).

An unsolved problem that has come up during the research is the lack of knowledge and confidence Speech Language Pathologists (SLPs) have on working with patients with craniofacial anomalies. Many SLPs are familiar with the birth defect, but know little about treatment and best practices that should be performed. Interviews were conducted asking SLPs about their experiences with craniofacial anomalies and their feedback explained that they accepted the chance to work with the patients, but they started to have doubts over time when trying to find the appropriate treatment (Alighieri, Bettens et. al, 2021). The craniofacial teams, containing surgeons, SLPs, and orthodontists, have become less experienced in working with craniofacial anomaly patients. According to the American Speech-Language-Hearing Association (ASHA), an SLP is supposed to uphold the responsibility to administer services giving their craniofacial anomaly patients the best treatment possible. However, this is challenging to do when having little experience with a collaborative cleft palate team and limited training in craniofacial anomalies. The Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or other Craniofacial Differences from the American Cleft Palate Association (ACPA, 2018) explains that parents should be given updated, accurate information on normal speech language development, cleft impact on speech, and the best tactics to strengthen their child's speech. This information should not only be automatically provided to parents, but expertised by SLPs during clinical visits.

A majority of SLPs have different opinions on how to treat patients with different types of craniofacial anomalies. Most SLPs were taught differently and have different intervention goals, depending on age and level of language development (Kummer, 2008). The work in the field is

always changing. The older therapy for velopharyngeal swallowing functions used to start at 3.6 to 4.0 years of age (Shprintzen & Golding-Kushner, 1989) and now the therapy has started at 3.0 years of age (Kummer, 2014). Dr. Baigorri and Dr. Crowley (2022) grew to realize that SLPs during their training in Guatemala would treat craniofacial anomaly patients with "nonspeech oral motor exercises" and not for errors in cleft palate speech. This therapy would consist of sucking through straws, tongue exercises, massaging faces, blowing through horns, and so many more activities, but none improved speech development (Leaders Project, 2022). There is also a lack of resources available in the speech-pathology field. Parents give a lot of their trust to clinicians who in return should be able to provide their family with quality treatment and knowledge of possible outcomes. SLPs have diverse opinions in craniofacial anomaly training and some of the practices are not evidence-based, making therapy difficult for SLPs to follow (Hardin-Jones et. al, 2019).

Recent studies have confirmed graduate programs removing and/or not requiring courses in craniofacial anomalies (Mills & Hardin-Jones, 2018). Craniofacial anomalies need to be addressed in education and clinical training to adequately prepare expecting parents when having the potential of delivering a newborn with a craniofacial anomaly as well as identifying its familiar characteristics. The entire field and academic training is already more opinion based (Mills et. al, 2018), meaning the knowledge and experience take part in a large role to different answers in treatment for clinical practices. SLPs and the rest of their team need to become better qualified in working with these types of patients. Undergraduate and graduate programs should have better preparation for SLPs' training in early childhood craniofacial anomalies throughout their early practice experience. Moreover, there needs to be training on craniofacial anomalies for each member of the cleft teams. Since teachers have been required to expertise their

knowledge on these conditions for certain circumstances in their classrooms, SLPs should be as well, especially since it is a part of their specialty. This type of training and clinical education is not an easy process and will possibly be a permanent part of this field, especially with how common craniofacial anomalies are. Despite the advancements, more research needs to be done to continue to strive for better answers and enhance treatments and practices to address the craniofacial anomalies.

CHAPTER THREE

Methodology

Purpose of this Research:

The purpose of this research project was to determine the knowledge and skills of speech language pathologists, with a Certificate of Clinical Competence, CCC-SLP, and find their core confidence in craniofacial anomaly training. The individuals were able to rate their knowledge on each subcategory, found in the research, that defined the impact and significance on craniofacial anomalies. The study presents the educational preparation the CCC-SLP individuals were given on craniofacial anomalies during their undergraduate school levels, graduate school levels, and early practice experience.

Subjects:

The author attempted to contact 100 CCC-SLPs, with at least five years of clinical experience, in five different regions of the United States: Southeast, Northeast, Southwest, Midwest, and West. The CCC-SLP participants completed a thirteen question survey, approved by the IRB, asking them to rate their knowledge and confidence in treating patients in craniofacial anomalies. The participants were recruited by word of mouth, social media networks, and text messages, if the author had a personal relationship. After agreeing to participate, the CCC-SLPs would contribute their email addresses for the author to use in order to send all of the information for proper completion.

The participants were asked to give consent, by verifying if they held a certificate of clinical competence as a speech-language pathologist. The only other personal question that was

asked in the survey was to share their geographic location in their current practice setting and years of practice. Every CCC-SLP was given privacy by being anonymous throughout the full survey participation. There was no payment or reward given to the participants for completing the survey. Each participant had the right to withdraw at any point during the survey and could skip any question without penalty.

Survey Questions and Knowledge:

The CCC-SLP participants completed a thirteen question Qualtrics survey, approved by the IRB, asking them to rate their knowledge and confidence in treating patients in craniofacial anomalies. The Qualtrics survey had easy online access and could be taken on any electronic device. The Qualtrics survey was sent individually to each participant through email along with the cover letters, with IRB approval. The survey consisted of thirteen questions and was able to be completed in twenty minutes or less. The answers related to the six subcategories: genetics, environmental factors, medications, diet, health risks, and surgical procedures/surgeons. Each question associated with the subcategories provided their meanings of each topic and how it impacted the formation of craniofacial anomalies. They were asked about their craniofacial education and preparation in their undergraduate and graduate programs. The speech-language pathologists rated their knowledge on each subcategory, along with their key definitions, with the following choices: no knowledge, minimal knowledge, moderate knowledge, and extensive knowledge. At the completion of the survey, there was an opportunity to write additional comments that the participants felt the need to include in order to improve the accuracy of the survey.

Data Collection:

The data was collected and analyzed based on central tendencies of their knowledge level on craniofacial anomalies for each question. After contacting speech-language pathologists from the five regions of the United States, the author obtained fifty-nine responses during the survey period. The goal of this survey was to analyze speech-language pathologists' knowledge and abilities in treating their patients with craniofacial anomalies as well as with the resulting complications.

The overall data that was collected had a variety of answers from the fifty-nine participants. The survey was used to compare the data to the results recorded in previous studies, which were found in the research that tested the speech-language pathologist's knowledge levels on craniofacial anomalies. After completion, most of the participants would contact the author to notify completion, which cued the author to analyze the data individually.

The author was able to observe each participants' answers in depth, including duration, date, and any additional comments. The overall results were gathered from the recorded responses by the Qualtrics survey and visually averaged on a bar graph. The results included the minimum, maximum, mean, standard deviation, and full count of the total responses. The author focused on the full count of the total responses out of all of the different forms of responses used from the survey. The counts were also shown in percentages that averaged the participants' responses individually by each answer choice on every question. The written choices had each response listed out that the participants distributed. The collected data, ordered by each question, was presented in graphs with the average results from each participant and seen in figures 1-11.

CHAPTER FOUR

Results

Curriculum in the undergraduate and graduate level for Communication Sciences and Disorders programs has continually been improved over the years. The author's focus was that craniofacial anomalies may have become a topic that SLPs are less familiar with, if programs must make decisions about what courses to include in their curriculum. Various Communication Sciences and Disorders programs (speech-language pathology and audiology) in the United States may approach their curriculum plans in different ways with different course emphasis. If programs do not include a course in craniofacial anomalies, preparation and assessment for treatment may be limited, affecting knowledge and skills on the enrolled SLPs and audiologists. This author located eighty articles related to source, treatment, and effects of craniofacial anomalies. From the foundation of research, the author created the questions for this survey research.

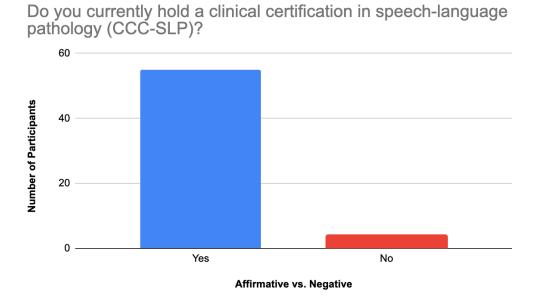
Each of the following questions will be displayed including the survey data collected from the respondents. Key words including – genetics, diet, drugs, medications, surgical procedures/surgeons, and environmental factors were used in the literature review as well as in the question development. The survey questions were tested on five individuals prior to sending the survey to volunteer participants, following IRB approval from the University of Mississippi. The research led to results such as the lack of knowledge CCC-SLPs have in craniofacial anomalies.

The survey consisted of thirteen questions (See Appendix B for survey questions). The following will discuss the questions asked, results, and comments from the fifty-nine SLPs, who

completed the survey between September 2022 and October 2022. This chapter will conclude the summary of the results and overall analysis to each of the questions.

The first question of the survey was the research's consent form for the subjects (Figure 1). The first question asked if the SLP participant currently held a Certificate of Clinical Competence (CCC) in speech-language pathology. If the subject chose yes, the participant could continue to complete the survey. If the subject chose no, then the survey would end and the subject would no longer participate. Fifty-eight of the fifty-nine subjects gave consent to participate in the study.

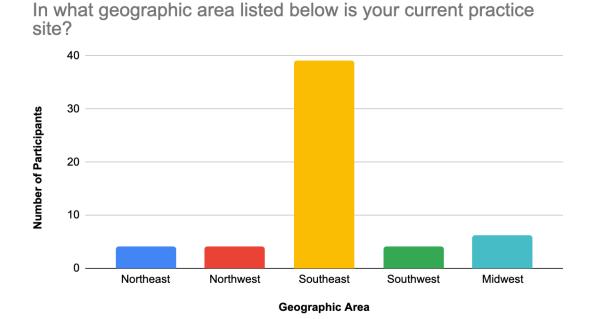
Figure 1. Consent given by the subjects (n=58/59), claiming they hold clinical certification.



The second question asked the geographical area each of the subjects' practice is in throughout the United States with the choices of Northeast, Northwest, Southeast, Southwest, and Midwest (Figure 2). Fifty-seven of the subjects provided an answer to this question. Four of

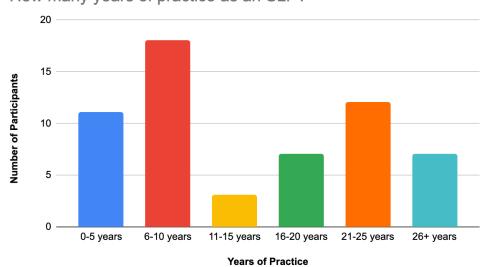
the subjects reported currently practicing in the Northeast, four from the Northwest, thirty-eight from the Southeast, four from the Southwest, and six from the Midwest.

Figure 2. The geographical area in which the participants are located.



The third question asked the SLPs to self-report their years of practice (Figure 3). The answer selections the subjects could choose from were: 0-5 years, 6-10 years. 11-15 years, 16-20 years, 21-25 years, and 26+ years. The question had fifty-eight respondents and showed ten having 0-5 years, eighteen for 6-10 years, three for 11-15 years, seven for 16-20 years, twelve for 21-25 years, and seven for 26+ years of experience.

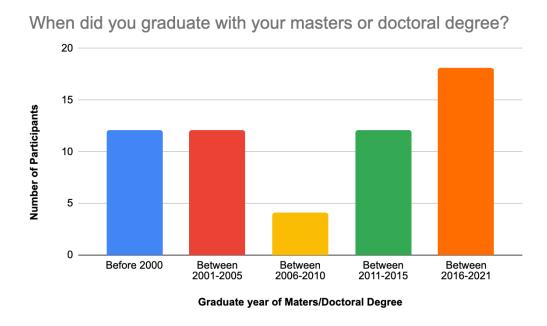
Figure 3. Years of experience each of the SLPs have in the field.



How many years of practice as an SLP?

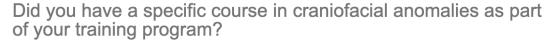
The fourth question asked how many years ago the SLP individuals graduated with their masters or doctoral degree (Figure 4). The answers given to choose from were: before 2000, between 2001-2005, between 2006-2010, between 2011-2015, and between 2016-2021. The results showed fifty-eight answers split, with twelve before 2000, twelve between 2001-2005, four between 2006-2010, twelve from 2011-2015, and seventeen between 2016-2021.

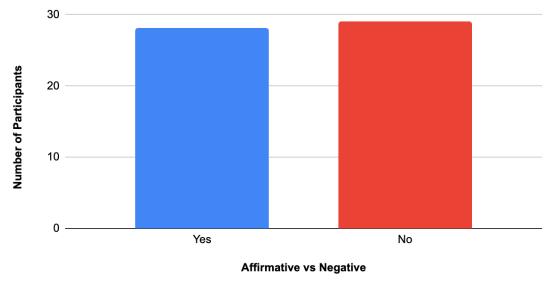
Figure 4. The years each SLP individual graduated with their masters or doctorate degree.



Question five asked if the SLP subjects had a specific course in craniofacial anomalies as part of their training program (Figure 5). The subject could either answer yes or no to the question. Of the fifty-seven subjects, twenty-seven of the subjects answered yes to having a specific course in their training program, twenty-nine of the subjects answered no. This question was followed by the sixth, instructing the subjects to name the specific course they had during their training programs, if they answered yes to the previous question. The answer used the text entry option for the subjects to record their specific course. The subjects had a variety of answers including – "CSD 624" – Craniofacial and Resonance Disorders, "Craniofacial Anomalies in Children," and "Craniofacial."

Figure 5. Number of SLPs that had a specific course in craniofacial anomalies as part of their training program.

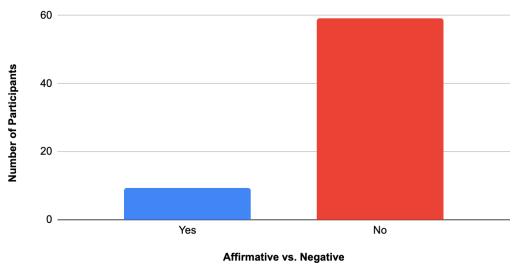




The seventh question on the survey asked the subjects if they were currently working with a patient with a craniofacial anomaly (Figure 6). The subjects would answer yes if they have a patient and would answer no if they did not have one. The fifty-eight answers showed nine of the subjects answered yes and forty-eight answered no to currently working with a patient with a craniofacial anomaly. The overall research defined craniofacial anomalies as occurring during pregnancy when the lip or palate do not form correctly, producing openings in the mouth on the fetus.

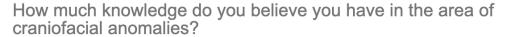
Figure 6. Number of SLPs working with a patient with a craniofacial anomaly.

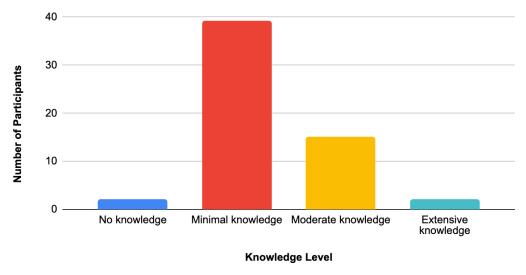




The eighth question asked the subjects how much knowledge they had in the area of craniofacial anomalies (Figure 7). The fifty-eight answers showed two of the subjects answered having no knowledge, thirty-nine had minimal knowledge, fourteen had moderate knowledge, and two had extensive knowledge.

Figure 7. Knowledge level of SLPs in the area of craniofacial anomalies.

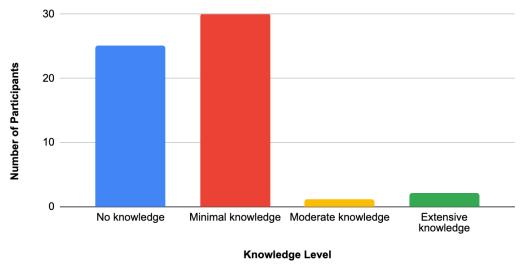




The ninth question on the survey asked the subjects to rate their knowledge level regarding genetics and its impact on the formation of craniofacial anomalies through gene loci, specifically $TGF\alpha$, IRF6, and HYAL2, which are discovered genes found in the formation of clefts, on an individual with craniofacial anomalies (Figure 8). The question had fifty-eight answers split with twenty-five reported having no knowledge, twenty-nine had minimal knowledge, one had moderate knowledge, and two had extensive knowledge.

Figure 8. The knowledge level of the SLP individuals on genetics.

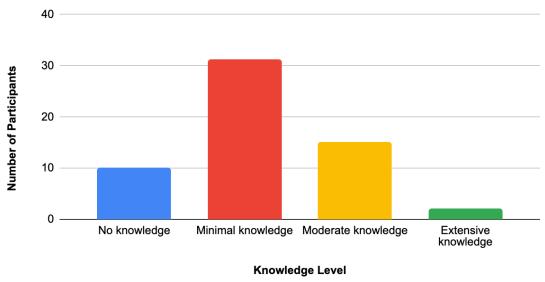




The tenth question asked the subjects to rate their knowledge level regarding environmental factors and the effects of alcohol, smoking, pharmaceuticals, and chemical agents on causing craniofacial anomalies to form through the formations of the lip and/or palate (Figure 9). The fifty-eight results showed ten subjects having no knowledge, thirty had minimal knowledge, fifteen had moderate knowledge, and two had extensive knowledge.

Figure 9. The knowledge level of SLP individuals on environmental factors.

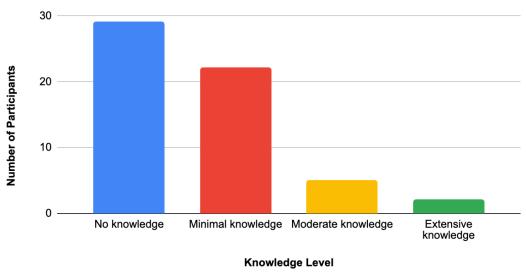




The eleventh question asked the subjects to rate their knowledge level regarding medications and the influence anti-epileptic drug usage has on pregnant women when the consumption occurs during the first trimester of pregnancy in forming craniofacial anomalies (Figure 10). The fifty-eight answers provided twenty-nine reported having no knowledge, twenty-two had minimal knowledge, four had moderate knowledge, and two had extensive knowledge.

Figure 10. The knowledge level of SLP individuals on medications.

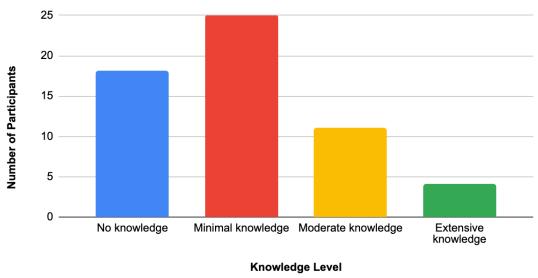




The twelfth question asked the subjects to rate their knowledge level regarding diet and the effect of eating habits and intakes of folic acid and/or multivitamins have with pregnant women and their fetuses (Figure 11). The fifty-eight results showed seventeen reported having no knowledge, twenty-five had minimal knowledge, eleven had moderate knowledge, and four had extensive knowledge.

Figure 11. The knowledge level of SLP individuals on diet.

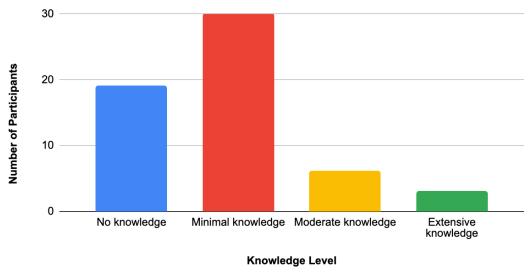




The thirteenth question asked the subjects to rate their knowledge level regarding health risks and health issues pregnant women have before gestation that could bring harm to the future offspring with craniofacial anomalies without the appropriate treatment and/or therapy (Figure 12). The question had fifty-eight answers containing eighteen with no knowledge, thirty with minimal knowledge, six with moderate knowledge, and three with extensive knowledge.

Figure 12. The knowledge level of SLP individuals on health risks.





The first formal research question was answered with question five of the survey. The survey showed that twenty-nine of the fifty-seven subjects did not have a course in craniofacial anomalies as a part of their training program. It also leads to survey question eight in identifying how training affected their current knowledge and skills in craniofacial anomalies. The responses consisted of two with no knowledge, thirty-nine with minimal knowledge, fifteen with moderate knowledge, and two with extensive knowledge. The first formal research question provides information that there is not enough academic preparation for SLPs to have the useful experience they need to perform successful therapy on patients. A majority of the other subjects would most likely have chosen having "extensive knowledge" if they were given the training and specific courses they needed to become more confident in their knowledge on craniofacial anomalies.

The second formal research question was analyzed through survey questions eight through thirteen. The results showed the subjects mostly answering either having "minimal knowledge" or "no knowledge" on each of the questions. Fewer subjects would answer having

"minimal knowledge" over "no knowledge" when rating their knowledge on the subcategories genetics, environmental factors, diet, and health risks. Only two subjects answered having extensive knowledge to each of the questions. The eleventh and twelfth questions in the survey were able to distinguish the most knowledge and the least amount of knowledge SLPs have in craniofacial anomalies, diet holding the most and medications having the least. The results showed that even having craniofacial anomaly training through their education, it's still not enough insight for SLPs to be familiarized with the topic.

Questions eight through thirteen had mixed results. A majority answered having "minimal knowledge" or "no knowledge," but the questions had different quantities to each answer, meaning, some SLP subjects were more knowledgeable on other subcategories. Their familiarity was not extensive, but it changed on every question. Therefore, the SLPs' knowledge might not be at a professional level, but it was higher in other subjects, which presents a good starting route for the improved education.

The third formal research question was answered through all of the questions from the survey. With the subjects answering a variety of the questions with "minimal knowledge" on the different topics, it expresses the need for more courses at the undergraduate and graduate level for more educational training in the field of craniofacial anomalies. The role of the SLP is to provide a better life for an individual that needs any type of help in their specialty. Having a lack of knowledge on a topic that is a part of their therapy and a type of patient they see is a huge issue. Not only should SLPs have confidence in their work, but the patients and families should be assured when going to their clinical therapy sessions.

CHAPTER FIVE

Discussion and Summary

Relevance of Current Research

Research studies have shown SLPs may have limited training and knowledge in assessment and treatment on individuals with craniofacial anomalies (Bedwinek et. al, 2010). This can create a lack of confidence in their ability to evaluate and treat individuals with craniofacial anomalies. SLPs, who were interviewed in one study, admitted to being self-conscious when finding the best practice for patients with craniofacial anomalies (Alighieri et. al, 2021). The purpose of this survey was to analyze the knowledge and skills in the SLPs' training in craniofacial anomalies during undergraduate school, graduate school, and early practice experience. The reported results from this study show the need for improved academic and clinical training in craniofacial anomalies.

The survey had certain questions that were essential in determining possible reasons for limited knowledge and training to work with individuals with craniofacial anomalies. The second question asked the geographical region of each of the subjects, to determine if the academic training was equivalent around the nation. It appears that the amount and quality of the academic education and clinical training is similar in all regions. Question three asked for the years of practice, which was important in establishing whether the academic training has improved over the years. A majority of the subjects had six to ten years of experience, confirming that most of the SLPs were newer to the field with less academic and clinical training in craniofacial anomalies over the more recent years. The fifth survey question asked if the SLPs had a specific course in craniofacial anomalies as part of their graduate program to assess if courses about

craniofacial anomalies were still a viable part of the curriculum. More than half answered that they did not have a specific course, which shows the academic and clinical training limitations for SLPs with clients who have craniofacial anomalies. Some factors that could affect the answers to these results are the participants' consistency in continuing their education in craniofacial anomalies or how recent their academic and clinical training occurred. The course could have also been called something else, like low-incidence disorders, that the participant was more familiar with, besides the terms used in the survey. Similar craniofacial content could have been included in courses addressing low incidence disorders or voice science disorders.

Implications

The information provided from in study indicates that SLPs would have improved knowledge and skills on craniofacial anomalies with more academic and clinical preparation throughout their training in undergraduate and graduate school. The survey results revealed that SLPs are not given the academic preparation needed to fulfill the needs of patients with craniofacial anomalies. This study was able to analyze where relevant topics in craniofacial anomalies become difficult. Most of the topics that were discussed in the surveys confirmed SLPs having little knowledge about craniofacial anomalies. Lack of academic and clinical training, or a reduction in the academic or clinical training in craniofacial anomalies will create great risk to patients demonstrating this diagnosis.

Proper preparation will bring more awareness to the craniofacial disorders assessment and diagnosis as well as treatment for individuals with this diagnosis. Improved quantity and quality of this training will encourage a sustained approach to dealing with these patients, both pediatric and adults over time. These changes could potentially improve identification,

assessment, and treatment of patients with craniofacial anomalies as well as improving the confidence, knowledge, and education of the treating SLPs.

Limitations and Future Directions

This study used a survey to target SLPs around the country to rate their knowledge and determine their academic preparation in the area of craniofacial anomalies. The survey reported SLPs having limited knowledge and training in their individual undergraduate and graduate levels. The data from the results confirmed there is a need to resolve this issue since craniofacial anomalies is a recognized treatment area for SLPs. Some limitations that occurred in the survey were duration and effort. For instance, one subject took 00:43 seconds to complete the survey while another subject took 12:50 minutes. Therefore, some subjects took more time to finish the survey, which could have affected their answer choices. Another limitation was giving subjects the power to rate their own knowledge on the different sub-topics related to craniofacial anomalies. The subjects could have their own perception of knowledge levels that may be different from others, which could affect their answers as well.

Future studies could ascertain where and how in the undergraduate and graduate curriculum, academic, and clinical training could be improved. Accredited graduate programs as well as graduate programs could be evaluated in different regions of the country. Medical and educational sites across the country could be studied to determine the number and type of craniofacial anomalies that seem to be prevalent in the individual locations. In specific geographic locations, the types of diagnoses, and treatments could be analyzed to determine sufficiency of training and education for the training SLPs. It could also help determine if the

lack of knowledge is the same in other diagnoses and an improvement in other topics. The study could also extend to other professionals to compare their lack of knowledge to SLPs.

In conclusion, this study affirms that SLPs have a lack of academic knowledge and clinical training in craniofacial anomalies. If the specific training courses continue to be removed from the curriculum it will affect the knowledge and training in craniofacial anomalies of graduating SLPs. More research needs to be conducted to include review of CSD curriculum plans to ascertain the level, quality, and intensity of introduction to craniofacial anomalies for SLPs. Discussing this with further clinicians and academic professionals could encourage consistency of curriculum expectations across all CSD programs.

Improving the knowledge and clinical training could make significant differences in the lives of so many individuals with this diagnosis. The progression of quality care for craniofacial anomaly patients is important and can be done by improving the academic impact for SLPs in their training programs. An improvement of training will not only help the academic preparations of SLPs, but it will also be able to bring more awareness to craniofacial anomalies in the CSD programs. More SLPs will be inspired to learn more about craniofacial anomalies and hopefully expertise it in the future. Having more experts in the field will provide more teaching opportunities in this topic and bring the needed awareness to undergraduate programs, graduate programs, and the general population. It is important in bringing the knowledge to all professionals and specialists, especially on the cleft teams, and deliver solid, repetitive collaborations to satisfy the patient's needs and give them a better life. If it is recognized now, then there can be a big difference for both the patients and the SLP clinicians in the future. There is an immediate need to improve the quantity and quality of training in craniofacial anomalies for undergraduate and graduate SLP students.

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Appendix A (IRB Approval Letter)

PI:

This is to inform you that your application to conduct research with human participants, "A Survey of Speech Language Pathologists' Academic Preparation in Craniofacial Anomalies" (Protocol #23x-032), has been determined as Exempt under 45 CFR 46.101(b)(#2). You may proceed with your research.

Please remember that all of The University of Mississippi's human participant research activities, regardless of whether the research is subject to federal regulations, must be guided by the ethical principles in The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.

It is especially important for you to keep these points in mind:

- You must protect the rights and welfare of human research participants.
- Certain changes to your approved protocol must be reviewed and approved before initiating those changes. These changes include the addition of a vulnerable subject group (children, persons with disabilities, and prisoners), as well as the addition of research materials, such as the addition of surveys or interview questions and test articles, the addition of the use of deception, or any changes to subject confidentiality. Personnel amendments for exempt protocols are no longer required. Instead, PIs are responsible for keeping an up to date record of all active personnel and for ensuring that personnel have completed the necessary training to be on their protocol.
- You must report promptly to the IRB any injuries or other unanticipated problems involving risks to participants or others.
- If research is to be conducted during class, the PI must email the instructor and ask if they wish to see the protocol materials (surveys, interview questions, etc) prior to research beginning.

If you have any questions, please feel free to contact the IRB at irb@olemiss.edu.

Appendix B (Survey)

A Survey of Speech-Language Pathologists' Academic Preparation in Craniofacial Anomalies

- 1. Do you currently hold a clinical certification in speech-language pathology (CCC-SLP)?
 - a. Yes
 - b. No

[If you do not hold a current CCC or are retired, then do not continue with the questionnaire.

Confirmation of current CCC confirms you are 18 years or older.]

- 2. In what geographic area listed below is your current practice site?
 - a. Northeast (CT, ME, MA, NH, NJ, NY, PA, RI, VT, MD, DE)
 - b. Northwest (AK, CA, HI, ID, MT, NV, OR, UT, WA, WY, CO, PR)
 - c. Southeast (AL, AR, SC, TN, WV, VA, GA, NC, MS, FL, KY, LA)
 - d. Southwest (AZ, NM, TX, OK)
 - e. Midwest (IN, ND, SD, IL, OH, MI, IA, MN, WI, MO, KS, NE)
- 3. How many years of practice as an SLP?
 - a. 0-5 years
 - b. 6-10 years
 - c. 11-15 years
 - d. 16-20 years
 - e. 21-25 years
 - f. 26 + years
- 4. When did you graduate with your masters or doctoral degree?

a. Before 2000 b. Between 2000-2005 Between 2006-2010 d. Between 2011-2015 e. Between 2016-2021 5. Did you have a specific course in craniofacial anomalies as part of your training program? a. Yes b. No 6. If you had a specific course in craniofacial anomalies, what was the name of your course? Include a narrative box. 7. Are you currently working with a patient with a craniofacial anomaly? a. Yes b. No 8. How much knowledge do you believe you have in the area of craniofacial anomalies? a. No knowledge b. Minimal knowledge c. Moderate knowledge d. Extensive knowledge 9. Rate your knowledge level regarding genetics and its impact on the formation of craniofacial anomalies through gene loci, specifically TGFα, IRF6, and HYAL2, which are discovered genes found in the formation of clefts, on an individual with craniofacial

anomalies.

- a. No knowledge
- b. Minimal knowledge
- c. Moderate knowledge
- d. Extensive knowledge
- 10. Rate your knowledge level regarding environmental factors and the effects of alcohol, smoking, pharmaceuticals, and chemical agents on causing craniofacial anomalies to form through the formations of the lip and/or palate.
 - a. No knowledge
 - b. Minimal knowledge
 - c. Moderate knowledge
 - d. Extensive knowledge
- 11. Rate your knowledge level regarding medications and the influence anti-epileptic drug usage has on a pregnant woman when the consumption occurs during the first trimester of pregnancy in forming craniofacial anomalies.
 - a. No knowledge
 - b. Minimal knowledge
 - c. Moderate knowledge
 - d. Extensive knowledge
- 12. Rate your knowledge level regarding diet and the effect of appropriate eating habits and intakes of folic acid and/or multivitamins have on a pregnant woman and their future offspring with potentially forming craniofacial anomalies.
 - a. No knowledge
 - b. Minimal knowledge

- c. Moderate knowledge
- d. Extensive knowledge
- 13. Rate your knowledge level regarding health risks and the health issues pregnant women have before gestation and the health outcomes that could become a harm to the future offspring with craniofacial anomalies without the appropriate treatment and/or therapy.
 - a. No knowledge
 - b. Minimal knowledge
 - c. Moderate knowledge
 - d. Extensive knowledge

Appendix C (Geographic Regions)



Appendix D (Figures 1-12)

Figure 1. Consent given by the subjects (n=55/59), claiming they hold clinical certification.

Do you currently hold a clinical certification in speech-language pathology (CCC-SLP)?

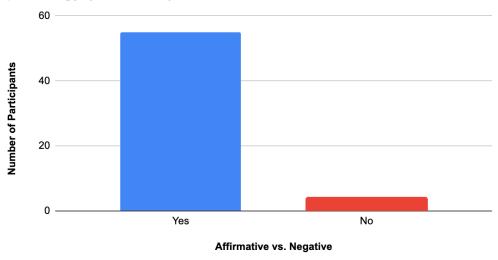


Figure 2. The geographical area in which the participants are located.

In what geographic area listed below is your current practice site?

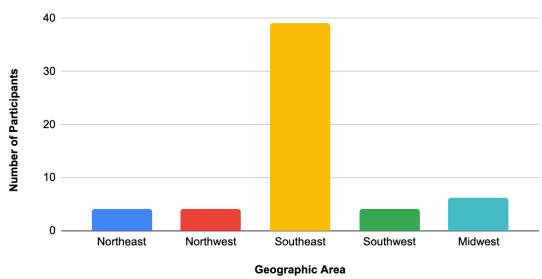


Figure 3. Years of experience each of the SLPs have in the field.

0-5 years

How many years of practice as an SLP? 15 Number of Participants 10 5 6-10 years 21-25 years

11-15 years

16-20 years

Years of Practice

26+ years

Figure 4. The years each SLP individual graduated with their masters or doctorate degree.

When did you graduate with your masters or doctoral degree? 20 15 **Number of Participants** 10 5 0 Between 2001-2005 Between 2006-2010 Between 2011-2015 Between 2016-2021 Before 2000 **Graduate year of Maters/Doctoral Degree**

Figure 5. Number of SLPs that had a specific course in craniofacial anomalies as part of their training program.

Did you have a specific course in craniofacial anomalies as part of your training program?

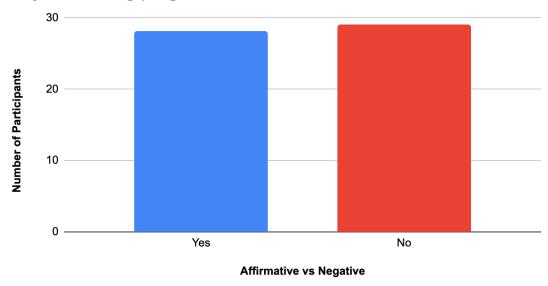


Figure 6. Number of SLPs working with a patient with a craniofacial anomaly.

Are you currently working with a patient with a craniofacial anomaly?

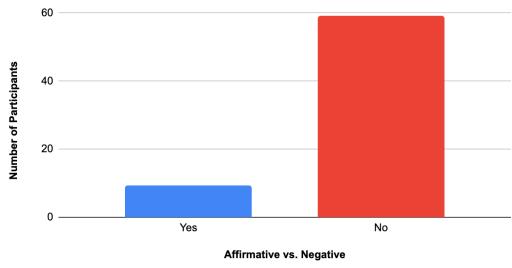


Figure 7. Knowledge level of SLPs in the area of craniofacial anomalies.

How much knowledge do you believe you have in the area of craniofacial anomalies?

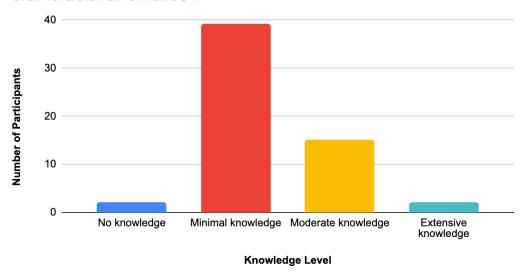


Figure 8. The knowledge level of the SLP individuals on genetics.

Rate your knowledge level regarding genetics and its impact on the formation of craniofacial anomalies through gene loci

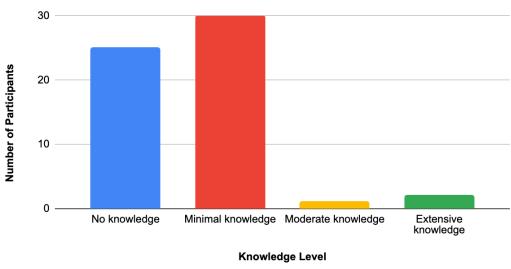


Figure 9. The knowledge level of SLP individuals on environmental factors.

Rate your knowledge level regarding environmental factors and the effects of alcohol, smoking, pharmaceuticals, and chemical

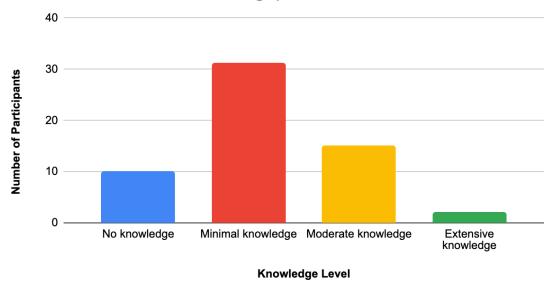


Figure 10. The knowledge level of SLP individuals on medications.

Rate your knowledge level regarding medications and the influence anti-epileptic drug usage has on a pregnant woman

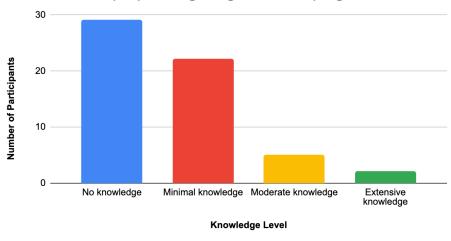


Figure 11. The knowledge level of SLP individuals on diet.

Rate your knowledge level regarding diet and the effect of appropriate eating habits and intakes of folic acid and/or multi

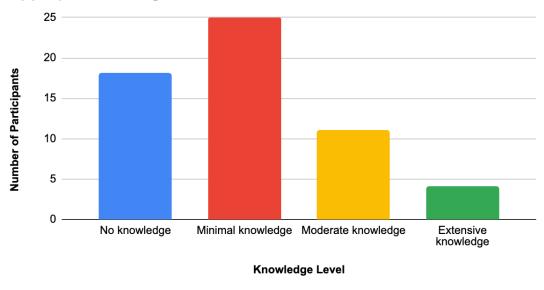
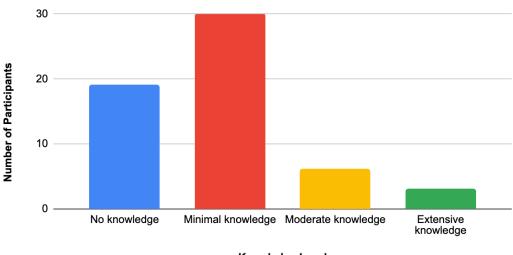


Figure 12. The knowledge level of SLP individuals on health risks.

Rate your knowledge level regarding health risks and the health issues pregnant women have before gestation and the



Knowledge Level