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The Role of Telehealth Technology in the Remediation of Pediatric

Feeding Disorders

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Report

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Abstract

The Role of Telehealth Technology in the Remediation of Pediatric Feeding Disorders

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Teletherapy, the use of video conferencing technology to deliver therapy services, has the potential to provide ongoing services to children that might not otherwise be able to receive traditional intervention that it essential for them to thrive. Among children who are diagnosed with developmental disorders, as well as those who are typically developing, feeding related concerns are highly prevalent. The current report discusses the nature of feeding disorders in children across the continuum of development and diagnoses, synthesizes the current literature of feeding and non-feeding related intervention programs for children in various settings, and discusses their value for future clinical use and research.

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Introduction

Children with developmental disabilities such as Down syndrome, cleft lip and/or palate, autism spectrum disorder, central nervous system disorders (e.g. cerebral palsy, meningitis, etc.), rare genetic disorders such as Pierre Robin Sequence (PRS), Williams Syndrome, Prader Willi Syndrome, Rett Syndrome, and weak musculature of the face and neck, commonly experience feeding and swallowing disorders (American Speech-Language-Hearing Association, 2014; Cooper-Brown et al., 2008). Feeding disorders affect a broad range of eating activities that may or may not be accompanied by difficulty with swallowing food and liquid. They may be characterized by food behavior, rigid food preferences, less than optimal growth and failure to master self-feeding skills expected for developmental levels.

Due to the complex nature of feeding disorders, the professionals who specialize in child feeding therapy and their facilities are, unfortunately, not readily accessible to the growing number of children presenting with feeding difficulties. However, technology used for video-conferencing has become readily available and a staple in most homes across the country and abroad. Utilizing this technology to provide services has the potential to provide comprehensive care while saving time and money.

Ongoing advances in technology have provided a platform to extend the accessibility of services for children with disabilities across locations, languages and the socioeconomic continuum. Teletherapy, the use of video-conferencing technology to deliver therapy services, is changing the face of healthcare by providing face-to-face interactions among specialists, caregivers, and patients. The current literature has demonstrated success in utilizing teletherapy as a modality for speech-language intervention and for social-behavioral management, while research on feeding therapy remains scarce.

Background

Prevalence/nature of pediatric feeding disorders. The incidence of feeding disorders is estimated to be 25-40% in typically developing children and up to 80% for children with developmental disabilities (Arvedson, 2008). In addition, children with delayed speech and motor milestones have an increased risk for feeding difficulties (Hutchinson, 1999). Treatment of feeding and swallowing disorders found in cases of genetic and developmental disabilities often require a multidisciplinary effort by a team of specialists including, but not limited to, speech-language pathologists, occupational therapists, and medical specialists such as gastroenterologists, cardiologists, geneticists, pediatricians, endocrinologists, psychologists, and nutritionists. Due to the range of professionals who treat children with feeding and swallowing difficulties, there is a broad spectrum of treatment and diagnostic options to be explored (Cooper-Brown et al., 2008).

Feeding-related concerns are among the most common issues in preschool children who are brought to primary health care professionals by parents (Arvedson, 2008). In a 2001 study, 79 preschool-aged children with neurodevelopmental disabilities who presented with suspected feeding disorders were examined. It was found that 56% exhibited gastro-esophageal reflux, 27% presented with oropharyngeal dysphagia, and 18% of the children showed aversive feeding behaviors. These results demonstrate the large scope of feeding difficulties that can occur in infancy and early childhood and strongly suggest the need for individualized, diagnosis-specific treatment for children with feeding disorders (Schwarz et al., 2001). Comparing a child's feeding behavior problem with that of a typically developing child's feeding behavior is crucial in identifying the severity of the feeding problem. Immediately after birth, typically developing babies will feed on breast milk or formula. Within a few weeks, their sucking response should strengthen, as they grow accustomed to and learn how to coordinate the suck-swallow-breathe pattern. After about four to six months, the infants are typically introduced to baby foods. They are able to consume mashed table foods and even small bites of regular, textured food at twelve months, once their dental development progresses (Piazza, 2008).

However, children with feeding difficulties do not progress with food intake in the same way as their typically developing peers. Problematic feeders have poor coordination with the suck-swallow-breathe pattern after birth, and no progression occurs over time. Some children consistently reject breast or bottle feedings, which is especially concerning when continuous and persistent rejection prevents weight gain. Some children with feeding problems feed on the bottle or breast successfully but have an extremely difficult time transitioning to baby, mashed, or table food (Piazza, 2008). The ability to transition from breastmilk or formula to food is important to strengthen oral motor skills and to prepare for chewing solids (Throughton et al., 2001).

Feeding a child can be one of the most satisfying interactions a caregiver can have with a child. Unfortunately, because feeding problems are a common occurrence among children with developmental disabilities (Palmer & Horn, 1978), parents of children with developmental disabilities instead often experience frustration during feeding. When a caregiver is unable to feed and nourish her child appropriately, she often feels inadequate. Parents of children who have developmental disabilities and medical disorders, often have to make difficult decisions when prioritizing their child's medical and developmental needs (Guerriere et al., 2003).

Adapting and coping with problems in infants and children at any age can be a source of tremendous stress for parents. When parents are ineffective at facilitating feeding for their children, increased feelings of rejection, self-doubt regarding parental capabilities, and an overall increase in stress can occur. Some parents successfully face the strenuous demands made by children with feeding disorders. However, many use unsuccessful coping strategies such as "force feeding." This type of strategy is found to only further induce negative behaviors, such as head turns, coughing, food refusal, or any other avoidant behaviors from the child, which is ultimately counterproductive in reducing the stress of the parent. It is of utmost importance that parents monitor their own emotions to facilitate optimal feeding sessions. The development of coping mechanisms, as opposed to using force-feeding methods, may end a never-ending cycle of negative behavior and stress (Didehbani et al., 2011).

Promise of teletherapy for addressing needs. Video-conferencing technology (i.e. Skype TM, Google Hangouts TM, etc.) emerged for personal recreational use in face-to-face correspondence with family and friends, but soon this powerful tool was introduced into the workplace, due to its communicative effectiveness. This technology has given us the power to communicate visually and audibly from worldwide locations. With the power of the internet and video conferencing technology, we no longer have the

barrier of distance when communicating with clients or associates in the workplace or with distant friends and family. As technology advances and the potential uses for videoconferencing are discovered, the use of this tool grows and expands opportunities for all who utilize it.

In addition to traditional workplace and at-home usage of video conferencing technology, the medical field has swiftly taken notice of its serviceable nature and has been increasingly utilizing this technology. With the medical field taking advantage of this tool to better serve their patients, other health and behavior related fields have experimented with video conferencing technology due to its potential to be a powerful tool for providing individualized and diagnosis-specific therapy services. As a low-cost and accessible option, teletherapy is now a viable source for speech-language, psychological, behavioral and feeding therapies. Historically, teletherapy has been used more regularly in the treatment of acute medical cases. However, recent developments in technology have made teletherapy systems more economical and user-friendly. Due to these improvements, there has been a significant increase in the number of teletherapy programs catering to non-acute cases within the past decade (McCullough, 2001).

Telepractice has been used successfully in other disciplines that provide treatment and trainings, but its use in pediatric care and services has lagged behind. According to the Individuals with Disabilities Education Act (2004), there are strict standards for providing care for children in government funded school-based intervention and homebased early intervention programs. However, due to the lack of resources and

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accessibility, being in compliance with these standards for treatment can be difficult. In sum, to better serve children in need of feeding services, the implementation of videoconferencing as a means of domestic and school-based treatment has the potential to expand the opportunities for quality and consistent rehabilitation for families across the continuum of accessibility (Olsen et al., 2008). In order to implement teletherapy programs within the home and schools, it is critical to have stakeholders' support. Data from the literature on the perspectives and attitudes of stakeholders regarding their experience with teletherapy has a powerful impact on clinical practice and opportunities.

Utilizing Teletherapy to Provide Breastfeeding Consultation

Risk factors for feeding infants with developmental delays. One of the most straightforward, most quantifiable ways to detect a feeding problem is via weight gain. Key indications of a feeding problem that needs treatment are weight loss over a three month period, a decrease in expected rate of growth, or crossing more than two major weight percentiles downward (Piazza, 2008). Children with developmental disorders are more prone to feeding disorders and are at high risk for experiencing such problematic feeding difficulties that can impact growth rate. One of the most crucial periods of growth is during infancy. When growth rate and weight gain are compromised due to problems with feeding, professional intervention is crucial to promote the infant's ability to thrive.

Although not all difficulty with early feeding is a predictor of developmental impairment in the preschool years, a large scale survey study by Motion et al. (2001) predicted that children with persistent feeding difficulties that occur from birth through fifteen months of age would experience significant motor, behavioral, speech and language impairments in early childhood. In addition to feeding difficulty prevalence rates, it was found that infants who presented with persistent feeding difficulties in the first fifteen months were more likely to be born preterm. Infants in this category were also less likely to have been breast-fed after four weeks of age and more likely to use a pacifier. Lastly, infants presenting with feeding difficulties within the first fifteen months

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were more likely to have received assessment by a specialist in a hospital setting (Motion et al., 2001).

Addressing needs for feeding infants through teletherapy. Video-conferencing technology has been shown to be useful in consulting with new mothers, who are experiencing problems with breastfeeding their infants. As modern mothers are more commonly taking their infant-related questions to the Internet, whether it be on a search engine, forum, or social media site, they are becoming increasingly more comfortable with using the latest forms of technology, such as video-conferencing, to receive counsel from family members, friends and professionals (Macnab et al., 2012). Research and professional practice has indicated that video-conferencing technology has a place in the field of lactation support for mothers and their infants. Costs and inconvenience of travelling with a small infant to a private practice or hospital are some of the largest barriers for mothers in need of assistance with feedings.

While there can be monetary challenges to this form of therapy, the costs of technology are decreasing and mothers' familiarity with video-conferencing tools make this form of consultation viable and accessible across the continuum of mothers experiencing difficulties with nursing (Macnab et al., 2012). A prime example of the successful use of telehealth technologies for lactation consultation is evident in its use by the Tele-Lactation Pilot Project (TLPP), one of 13 community-based breastfeeding projects implemented in Indiana in 2013 funded by the Centers for Disease Control and Prevention. The TLPP explored the feasibility of using videoconferencing technology to

provide breastfeeding support and education to women of low socioeconomic backgrounds by a centrally located International Board Certified Lactation Consultant (IBCLC). The videoconferencing sessions were held during the women's regularly scheduled prenatal and postnatal visits at the community health center. During the 9month project, the TLPP served 35 mothers total. Overall, 134 visits (30-45 minutes each) were provided. After the TLPP was concluded, interviews with key participants revealed that their attitudes about videoconferencing sessions suggest that they were easy to implement, allowed the IBCLC to provide services to a wider client base, and gave women the opportunity to receive support that they would not have received otherwise. In addition, anecdotal comments from the women suggested that it increased their confidence and decreased their anxieties about caring for their infant (Friesen et al., 2015). Similarly to the success teletherapy demonstrated in the role of facilitating feeding in infants, the use of teleconferencing technology has been suggested to be effective in the medical setting with older children and their parents.

Utilizing Teletherapy to Provide Medical-Based Feeding Services

A 2008 pilot study performed by the Feeding Disorders Program at the Children's Hospital in Richmond, Virginia demonstrated the efficacy of utilizing teletherapy for feeding interventions and offers potential for the continued success of teletherapy for this purpose. The Feeding Disorders Program houses a multidisciplinary team of feeding specialists who provide treatment for children who exhibit mild, moderate and severe feeding disorders. Due to the program's specialization, families of children with feeding disorders outside of the Richmond area, travel great distances to seek out their professional care (Children's Hospital of Richmond at VCU, 2014). In order to provide cost-effective services from the Feeding Disorders Program to families in remote locations, both in the United States and abroad, the Children's Hospital of Richmond began developing a pilot teletherapy program (Clawson et al., 2008). The pilot teletherapy feeding program was implemented for 15 pediatric participants with complex feeding disorders, ranging in age from 8 months to 10 years (80% under the age of 5). All participants lived in remote areas in the United States and in England. The children, their families and the feeding specialist team at the Children's Hospital of Richmond worked collaboratively, using video-conferencing technology to deliver feeding interventions. The participating families and children attended teletherapy sessions at their nearest collaborating hospital or university. Outcomes of the pilot teletherapy intervention, derived from family responses on a survey following the program, demonstrated that families of the participating children were highly satisfied with the care their child received. Moreover, the children exhibited less reliance on present feeding tubes and

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more nutritional intake after the 26 month treatment period (Clawson et al., 2008). The following were goals for the pilot feeding teletherapy study:

Goal 1: Offer a resource to community-based physicians to provide necessary care after local resources have been exhausted.

Goal 2: Provide sufficient information to recommend the next steps in the child's feeding treatment, whether community-based or center-based.

Goal 3: Minimize costs for families.

Goal 4: Maximize generalization and effective medical follow up in the patient's home community.

Goal 5: Ensure that the treatment team is comfortable with the availability of adequate clinical information and the technology of teleconferencing.

Goal 6: Ensure that families are adequately informed about what to expect from the teleconference, both the format of the conference and the range of possible outcomes resulting from the teleconference.

Goal 7: Maximize the efficiency and effectiveness of treatment teams at both sites of the teleconference.

Goal 8: Have adequate information on the basis of a teleconference consultation to justify authorization by the insurer of the next steps of care needed. Goal 9: Enable the child to receive effective treatment for feeding disorders as soon as possible.

(Clawson et al., 2008, p.214)

Much like the intended goals of the Clawson et al. (2008) pilot feeding program, teletherapy utilized in the home and school environments embodies comparable goals and demonstrates similar success for children who are not acute, and require consistent longterm treatment.

Utilizing Teletherapy in the School and Home Environments

Challenges to provide consistency of care. Children with developmental disabilities, who are between birth and early childhood, typically receive services domestically, through early intervention services or in a clinical setting exclusively or in combination. It can be a challenge to provide consistent and quality treatment for individuals who are in need of feeding intervention services in rural or remote areas. In these cases, challenges for both parents and interventionists can include travel distance, weather conditions and the shortage of qualified pediatric early interventionists (Olsen et al., 2008).

Early intervention programs or therapy provided at school are government-funded and an accessible option for children with developmental disabilities. However, flaws in these types of services can hinder a child's progress in their therapy goals (McCullough, 2001). Since parent involvement is an essential component of their child's success in therapy, it is crucial that parents are knowledgeable and up-to-date on the skills their child is working on and their progress in therapy. However, traditional governmentally funded face-to-face services provided in the home or at school are susceptible to having a low rate of parental involvement, in both early childhood and in school-based therapy, and a lack of facilitating newly acquired skills at home ((McCullough, 2001).

Utilizing teletherapy to increase parent participation. Video conferencing technology has the potential to increase parent-involvement in the therapy process in its use during school-based therapy sessions. During these sessions, parents have the ability

to utilize video conferencing technology in order to observe their child receiving therapy during school. This allows the parent to view the techniques the clinician is using, their child's progression, and the ability to ask the clinician questions. This opportunity for parent observation and participation has the potential to increase the progression of their child toward their therapy goals (McCullough, 2001). Furthermore, in addition to utilizing teletherapy to allow parents to "televisit" their child during school-based therapy, video conferencing technology also allows clinicians to virtually visit clients and their parents in their most natural environment at home. Since the clinician and parent must work together to facilitate the therapy session for the child, the outcome is highly parent-involved which translates to parent confidence in working on learned skills at home with their child. This carry-over of new and previously acquired skills is crucial for further development and progression (McCullough, 2001).

The success of such therapy program can be exemplified in research by McCullough (2001), in which a small sample of children attending both private and public preschools received in-school and at-home language therapy using videoconferencing technology. Three of the children were diagnosed with Down syndrome, and one child was diagnosed with Cornelia de Lang syndrome, a rare genetic developmental disorder. It should be noted that children with genetic disorders, are particularly susceptible to feeding disorders.

The three children who attended private preschool 3 days a week received one teletherapy session at school and at home per week. The one child attending mainstream public preschool five days a week received one teletherapy session in the home per week. Parents and therapists were given a survey created by the researcher at three points during the study- pretrial, trial, and post-trial to measure attitudes toward the tele-based therapy program. Pretrial results indicated that parents had concerns operating the videoconferencing technology, were "camera shy," and expressed concerns about privacy and time constraints. Trial results most notably indicated that therapists rated visual quality lower than parents, audio quality was ranked less than video for both, but still within the "good range." Post-trial data, on average, suggested that parents rated observing interactions between the child and the therapists via teletherapy as very useful, and being observed by the therapist at home to be very useful. In addition, therapists also had equal views of observing parent and child, and the ability for parents to observe by means of teletherapy. On average, parents rated their child's improvement on receptive and expressive language to be "greatly improved," and therapists rated in agreement with parent perspectives (McCullough, 2001).

McCullough (2001) suggests that teletherapy is a viable and effective treatment method for speech and language intervention of preschool-aged children in which parents gained a greater understanding of their child's language development through the opportunity to observe their child receiving therapy at school and gained confidence in fostering their child's language development from immediate, but not invasive, feedback from the clinician. The speech-language pathologist was able to observe the child in the most natural setting without interrupting the family dynamic and was able to give more frequent support without traveling to the home. Lastly, parents did not have to attend costly and time consuming parent-training seminars.

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During the therapy period, the researchers recorded anecdotal evidence that further supports the integration of teletherapy in preschools and at home. For example, families reported more fathers stayed home to attend the session, improving the interdisciplinary dynamic and potential for carry-over of skills. Additionally, sessions were enjoyable for the children, and they performed in a natural and spontaneous way (McCullough, 2001).

Addressing feeding disorders for children on the autism spectrum through teletherapy. Some individuals with developmental disorders have a greater likelihood of developing a feeding and/or swallowing disorder, such as those diagnosed with autism spectrum disorder (ASD). The diagnosis and classification of feeding disorders in children with ASD can be challenging due to the unique characteristics of each individual case in which delays and hypersensitivities manifest themselves. It is suggested that if severe feeding problems or atypical feeding behaviors are causing failure to thrive in infancy, there is an impetus for professional evaluation for underlying ASD. Research suggests that feeding disorders in children with ASD can be related to vulnerabilities in biology that can cause sensory, cognitive and/or emotional deficits in combination with atypical attachment and learned behaviors (Keen, 2008).

Children with ASD who present with complex and severe feeding difficulties most likely require a dynamic and multidisciplinary intervention (Keen, 2008). The prevalence of feeding problems in children with ASD often occurs due to detail-oriented characteristics, perseveration, impulsive behaviors, and aversion to new experiences, food intolerance, sensory deficits and difficulties with compliance. Feeding disorders in children with ASD can be categorized as both behavioral and sensory-based feeding disorders. Behavioral feeding disorders are categorized by aversive feeding behaviors such as refusal, gagging, choking and food expulsion without a medical reason. In contrast, sensory-based feeding disorders are categorized by aversions to certain textures of food (Schawrz, 2003).

The treatment of children with ASD requires long-term and intensive care, and support for parents contending with these significant mealtime challenges. The literature states that providing services to children with ASD in their natural home environments with parents as the main initiators of therapy demonstrates the most success for global development. However, to reach the child's therapy goals, supervision is often required from a trained specialist to effectively initiate therapy.

As expected, availability of professional care needed to meet the long-term and intense requirements that are necessary for a child with ASD is lacking. The use of videoconferencing technology has the potential to fill the gap between the professional care that is accessible to families of children with ASD and the regular, long-term, intense care which they require to make significant improvements (Baharav & Reiser, 2010). A 2010 pilot study compared two clinical models of therapy to promote positive behavior and communicative interaction for children with ASD: 1) traditional face-to-face therapy and 2) traditional face-to-face therapy combined with teletherapy home-based sessions. Two children, ages 4 and 5 years old, clinically diagnosed with ASD, participated in the study with their respective parents. The study consisted of two 6-week treatment periods, the first being a control period wherein both participants received traditional therapy twice weekly. Following the control period, they were treated once weekly with traditional therapy and once weekly with teletherapy sessions in their homes for the second 6-week experimental period. During teletherapy sessions, the clinician shared lesson plans with the child's parents as well as provided them with cues to implement therapy strategies in their home (Baharav & Reiser, 2010). By comparing the children in the experimental and control conditions, it was determined, that the participants made similar gains in social, behavioral and communicative skills, using the combined teletherapy and traditional therapy model, as they did with the traditional therapy model. Other findings included increased parent confidence in engaging their children in therapeutically meaningful interactions and an overall sense of ability to assist their children's development. Furthermore, parent questionnaires indicated overall positive experiences with the use of the technology and the teletherapy process (Baharav & Reiser, 2010).

Although the Baharav and Reiser (2010) study focuses its efforts on utilizing teletherapy as a means for social and behavioral communication skills, the success of parent-mediated therapy should be highly noted as valuable information when comparing traditional therapy to home-based teletherapy for children with developmental disabilities, especially those with ASD. Not only did the children make similar global gains in communication, but the parent's confidence levels in their ability to make meaningful change in their child's life. Unlike traditional therapy where the clinician is typically the initiator and mediator of all intervention, teletherapy provides a much different dynamic where parents' participation is critical to facilitate therapy and has demonstrated to increase their confidence in the carry-over of skills learned in therapy which is critical for success in all speech, language, and feeding goals. The literature has established that one of the most promising aspects of teletherapy is its ability to facilitate parent involvement. Similarly to the ability of teletherapy to reach parents so that they might have a larger impact on their child's care, teletherapy also provides a way to facilitate communication between professionals and treatment teams both domestically and abroad.

Utilizing Teletherapy to Provide Feeding Services to Underserved Populations

Children and adults, in remote underserved regions around the world, often carry the burden of developmental disorders and structural abnormalities of the head and neck. Environmental factors such as limited access to health care, lack of nutrition, and behavior related risk factors increase the prevalence of these serious disorders. Unfortunately, these locations offer minimal or no opportunities for subspecialty care (i.e. speech-language pathology, otolaryngology, audiology, etc.) (Groom et al., 2011). To illustrate the immense need for subspecialty care in these developing areas, research has suggested that in 2004, for every 100,000 people in the continent of Africa, there were .11 otolaryngologists. In the United States, there were 3.1 otolaryngologists for every 100,000 people (Fagan & Jacobs, 2009). For over ten years, professionals have considered using teletherapy to remedy the lack of subspecialty medical services. In 1997, the World Health Organization (WHO) Director General Dr Hiroshi Nakajima, stated, "Developing an adequate and affordable telecommunication infrastructure can help to close the gap among the haves and the have-nots in health care." (Groom et al., 2011, p. 1252). Since he made that statement, immense progress has been made in telecommunication and video-conferencing technologies. However, while large strides are being made in technological advancement, the utilization of teletherapy for humanitarian relief is still lagging behind. As research continues to investigate the varying uses for teletherapy, its potential as a modality for treating underserved domestic and remote locations remains to be seen (Groom et al., 2011).

The range of head and neck abnormalities and disorders is wide-ranging in underdeveloped countries, due to environmental factors that have an adverse effect on overall health and wellness. If untreated, one of the prevalent developmental disorders that has profound effects on children, adolescents and adults is cleft lip and/or palate (CL/P). Cleft lip and/or palate are congenital craniofacial abnormalities wherein a child is born with an opening in the lip, the palate or both. These openings have significant effects on speech production, feeding and often on hearing ability. CL/P can often be observed during preterm ultrasounds, however, medically underserved mothers are less likely to have access to these important screenings. If a CL/P is not observed during ultrasounds before the time of birth, signs of the cleft lip will be observed at birth. Cleft palate, if not observed at the time of birth examination, will be evident during feedings. A child with cleft palate does not have sufficient closure between the mouth and the nose, causing food or liquid to come out through the nose. Furthermore, children with cleft palate have problems with speech and hearing as a result of their craniofacial abnormalities. Children with a cleft palate often need multiple surgeries over time to close the opening in the palate that causes feeding, speech and hearing problems (American Speech-Language-Hearing Association, 2014).

It is widely accepted across the world medical community that a multidisciplinary approach is necessary for the remediation of cleft palate. Surgery alone is not enough; pre and postoperative care are necessary for optimal recovery. However, developing countries lack the number of trained professionals to provide long-term care for those with cleft palate. These trained professionals who are involved with the treatment of cleft palate can include maxillofacial surgeons, oral surgeons, reconstructive surgeons, speechlanguage pathologists, audiologists and dentists. With the assistance of videoconferencing technology and the expanding availability of wireless internet, essential treatment for patients with cleft palate in remote developing locations has the potential to become more accessible (Furr et al., 2011).

A 2011 study by Furr et al. investigated the use of teletherapy to provide preoperative and postoperative speech-language therapy for patients with cleft palate in Peru. The patients ranged in age from 4 to 24 years of age and participated in 15-25 minutes of tele-based speech-language therapy sessions with the assistance of a remote healthcare assistant who coordinated appointments and aided in setting up the equipment. It was observed that the participating patients embraced the use of video-conferencing technology and those who attended multiple teletherapy sessions showed great improvement in speech intelligibility and nasality. Due to the high degree of enthusiasm and progress that patients with cleft palate made during speech-language teletherapy sessions, the authors predicted that the participants' improvements would be closely equivalent to that of face-to-face traditional therapy (Furr et al., 2011). Furthermore, the same rate of success could be applied to preoperative and postoperative consultation in other disciplines, namely, feeding therapy.

Cleft lip and cleft palate have a broad range of severity which affects the amount of feeding and swallowing therapy needed. For an infant with an isolated cleft lip, feeding problems are minimal. For an infant with cleft palate, and multiple other anomalies, feeding therapy is crucial. However, regardless of the severity of the cleft lip and/or palate, strategies to optimize growth and development are vital (Cooper-Brown et al., 2008).

Through humanitarian mission surgical team efforts and growing local surgeon accessibility in developing countries, patients with cleft lip and palate have the opportunity to correct the craniofacial abnormalities that they were born with. However, in cases of CL/P, surgery is just the beginning of recovering speech, hearing and feeding skills. A multidisciplinary team of subspecialists is essential to advances in recovery and ultimately quality of life (Furr et al., 2011). Through the utilization of wireless internet connectivity and video-conferencing technology, professionals have the opportunity to provide care to pediatric special populations in need of cost-effective and accessible longterm treatment.

Stakeholder Support for the Use of Teletherapy

In further support for teletherapy as a means of speech, language, and feeding therapy, a more recent study by Lincoln et al. (2014) investigated stakeholders'(i.e. teachers, principals, and speech-language pathologists) views on the feasibility and acceptability of a pilot speech pathology teletherapy program for children attending a rural school in New South Wales, Australia. The Come N See (Royal Far West, 2013) therapy program was implemented that addressed both speech and language goals. Stakeholders concurred in their belief that the CNS program was a highly acceptable service delivery model, and all reported improvements to children's communication skills. Parents who attended their child's teletherapy sessions reported they had also gained skills in supporting their child's communication.

In individual interviews, stakeholders described factors that promoted or threatened the acceptability of the program. Results indicated that stakeholders attributed most of the success of the program to its accessibility for all families. Their confidence in technology increased over the course of the study, despite some troubleshooting. In addition, stakeholders believed that the children responded positively and were motivated by the use of technology in the sessions, and believed that children's privacy was upheld due to other children thinking they were getting to do some work on the computer during their session time (Lincoln et al., 2014).

In terms of negative feedback, school staff and parents believed that it was difficult to collaborate with other teachers, parents, and therapy facilitators, and to find a quiet space to treat students due to the school environment. They suggested that because the SLP was not present at the school, these partnerships were most difficult to make, and it was the therapy facilitator that had a pivotal role on the team in coordinating partnerships between the SLP and the stakeholders (Lincoln et al., 2014).

Mair and Whitten (2000) provided a systematic review of patient satisfaction with telemedicine to the field. The systematic review consisted of clinical trials that explored patient satisfaction that included consultation from a clinical healthcare provider and a patient using real time video conferencing. All clinical studies were used regardless of sample size or methodology because of the scarcity of information on this topic. Outcomes measured included patient overall satisfaction with teletherapy overall, and their willingness to utilize this modality of therapy again in the future. Results from the systematic review suggest that patients found teletherapy to be acceptable, and noted advantages such as increased accessibility of professionals, reduced travel and waiting times, however, results also yielded some overall feelings of unease about using this method as a mode of communication between healthcare providers and patients.

Conclusions

Due to the high prevalence of speech, language, and feeding disorders in infants and children with developmental disorders, access to services from the time of birth currently a challenge, yet necessary for those affected to thrive. Previous literature provides grounds for the successful implementation of teletherapy practice within the scope of speech-language pathologists and has highlighted the immense need for feeding therapy services around the world. Furthermore, previous literature critically confirms stakeholder's positive attitudes toward the use of video-conferencing technology to access therapy resources otherwise unavailable to them.

Although the literature is limited, the knowledge base for the use of teletherapy as a means of speech-language therapy is substantially larger than the published research on the use of teletherapy for feeding therapy in infants and children. Because the field of speech-language therapy's scope of practice continues to grow to include specialties such as feeding therapy, it is in the best interest of children worldwide to have access to clinicians with special skills.

Future Directions and Considerations

Continued research on the use of teletherapy is of the utmost importance in all areas of the field of speech-language pathology in order to understand the isolated limitations of teletherapy. With this knowledge, clinicians will have more confidence in making a decision to provide services via telecommunication while adhering to national and state ethical standards and codes of conduct. Furthermore, current research is critical in order to secure and advocate for reimbursement for teletherapy services, as only a portion of treatments and assessments are covered by some insurances today. As the power of technology increases daily, the research of teletherapy must reflect the most current status of video-conferencing technology in order to advocate for the use and reimbursement of this type of service provision effectively.

Due the highly heterogeneous nature of treating children with feeding and swallowing disorders, a randomized control trial of the efficacy of the treatment is unlikely to be feasible. However, further empirical evidence for success is not out of reach. A synthesis and analysis of qualitative data from a structured interview from clinicians who practice using teletherapy to treat feeding and swallowing disorders in infants and children illustrating their success and challenges would be highly useful in order to understand the nature of the current status of using this service model for these populations. Furthermore, analysis of related variables such as patient and clinician demographics, and familiarity with the technology required to use teletherapy would provide additional correlational evidence.

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ASHA (2016) states that clinicians who practice teletherapy must be specially trained in order to properly provide effective services. Conclusions from a qualitative study, such as the one proposed before, have the potential to serve as a foundation to create treatments, assessments, and technology that address the successes and challenges that clinicians are currently recognizing in their teletherapy practice. As the potential of technology and the field of teletherapy grows and becomes more recognized, the need for modified treatment and assessment tools and techniques will also increase. Provided the continuation of research within the areas of infant and child feeding and swallowing disorders, and the efficacy of teletherapy, the future of the field's ability to address the needs of families who present with barriers in receiving traditional services suggests to be positive.

References

Arvedson, J. C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*,

14(2), 118–127. doi:10.1002/ddrr.17 PMID:18646015

Baharav, E., & Reiser, C. (2010). Using Telepractice in Parent Training in Early Autism. *Telemedicine Journal and e-Health*, *16*(6), 727–731. doi:10.1089/tmj.2010.0029

PMID:20583950

Clawson, B., Selden, M., Lacks, M., Deaton, A. V., Hall, B., & Bach, R. (2008).

Complex Pediatric Feeding Disorders: Using Teleconferencing Technology to Improve

Access to a Treatment Program. Pediatric Nursing, 34(3), 213–216. PMID:18649810

Cleft Lip and Cleft Palate. (n.d.). Retrieved Aug 30, 2014, from

http://www.asha.org/public/speech/ disorders/CleftLip/

Cooper-Brown, L., Copeland, S., Dailey, S., Downey, D., Petersen, M., Stimson, C., &

Van Dyke, D. C. (2008). Feeding and swallowing dysfunction in genetic syndromes.

Developmental Disabilities Research Reviews, 14(2), 147–157. doi:10.1002/ddrr.19

PMID:18646013

Didehbani, N., Kelly, K., Austin, L., & Wiechmann, A. (2011). Role of Parental Stress on Pediatric Feeding Disorders. *Children's Health Care*, *40*(2), 85–100.

doi:10.1080/02739615.2011.564557

Fagan, J. J., & Jacobs, M. (2009). Survey of ENT services in Africa: need for a comprehensive intervention. *Global Health Action*, *2*, 10.3402/gha.v2i0.1932.

http://doi.org/10.3402/gha.v2i0.1932

Feeding and Swallowing Disorders (Dysphagia) in Children. Retrieved June 7, 2014, from http://www.asha.org/ public/speech/swallowing/feeding-and-swallowing-disordersin-children/

Feil, E. G., Baggett, K., Davis, B., Sheeber, L., Landry, S., Cart, J., & Buzhardt, J. (2008). Expanding the Reach of Preventive Interventions: Development of an Internetbased Training for Parents of Infants. *Child Maltreatment*, *13*(4), 334–346. http://doi.org/10.1177/1077559508322446

Friesen, C. A., Hormuth, L. J., Petersen, D., & Babbitt, T. (2015). Using

Videoconferencing Technology to Provide Breastfeeding Support to Low-Income Women Connecting Hospital-Based Lactation Consultants with Clients Receiving Care at a Community Health Center. *Journal of Human Lactation*, *31*(4), 595-599.

Furr, M., Larkin, E., Blakeley, R., Albert, T., Tsugawa, L., & Weber, S. (2011).

Extending Multidisciplinary Management of Cleft Palate to the Developing World.

Journal of Oral and Maxillofacial Surgery, 69(1), 237-241-237-241. Groom, K.,

Ramsey, M., & Saunders, J. (2011). Telehealth and Humanitarian Assistance in

Otolaryngology. Otolaryngologic Clinics of North America, 44(6), 1251–1258.

doi:10.1016/j.otc.2011.08.002 PMID:22032479

Guerriere, D. N., McKeever, P., & Llewellyn-Thomas, H. et al. (2003). Mothers' decisions about gastrostomy tube insertion in children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, *45*(7), 470–476. doi:10.1111/j.1469-8749.2003.tb00942.x PMID:12828401

Hutchinson, H. (1999). Feeding problems in young children: Report of three cases and review of the literature. *Journal of human nutrition and dietetics*, *12*(4), 337-343.

Keen, D. V. (2008). Childhood autism, feeding problems and failure to thrive in early infancy. *European Child & Adolescent Psychiatry*, *17*(4), 209–216. doi:10.1007/s00787-007-0655-7 PMID:17876499

Macnab, I., Rojjanasrirat, W., & Sanders, A. (2012). Breastfeeding and Telehealth. *Journal of Human Lactation*, 28(4), 446–449. doi:10.1177/0890334412460512 PMID:23087193

Mair, F., & Whitten, P. (2000). Systematic review of studies of patient satisfaction with telemedicine. *Bmj*, *320*(7248), 1517-1520.

McCullough, A. (2001). Viability and effectiveness of teletherapy for pre-school children with special needs. *International Journal of Language & Communication Disorders*, *36*(S1), 321-326.

Olsen, S., Fiechtl, B., & Rule, S. (2012). An Evaluation of Virtual Home Visits in Early Intervention: Feasibility of "Virtual Intervention". *The Volta Review*, *112*(3), 267–281.

Palmer, S., & Horn, S. (1978). Feeding problems in children. *Pediatric nutrition in developmental disorders/edited by Sushma Palmer and Shirley Ekvall.*

"Royal Far West - Caring for Country Kids." *Royal Far West - caring for country kids*. Web. 15 Nov. 2015. <<u>http://www.royalfarwest.org.au/</u>>

Schwarz, S. M. (2003). Feeding disorders in children with developmental disabilities. *Infants & Young Children*, *16*(4), 317-330.

Schwarz, S. M., Corredor, J., Fisher-Medina, J., Cohen, J., & Rabinowitz, S. (2001).
Diagnosis and Treatment of Feeding Disorders in Children With Developmental
Disabilities. *Pediatrics*, 108(3), 671–676. doi:10.1542/peds.108.3.671 PMID:11533334