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Jennifer Koval

The University of Toledo

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Implications of an In-Home, Family-Centered Occupational Therapy Approach with a Pediatric Client with Smith-Magenis Syndrome

Jennifer L. Koval

Site Mentor: Julie Pommeranz, MOT, OTR/L
Faculty Mentor: Alexia Metz, Ph.D., OTR/L
Occupational Therapy Doctorate Program
Department of Occupational Therapy
The University of Toledo Health Science Campus
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Abstract

Children with Smith-Magenis Syndrome (SMS) often have increased difficulty with behaviors and self-care skills when compared to same-aged peers. School-based and clinic-based occupational therapy has been found to be effective in bridging the gap in these deficit areas. However, some children do not generalize these skills to the home environment. Parents of children with disabilities experience great deals of stress in their daily routines and often times feel inadequate to carryover therapy recommendations in their already hectic home environment. This case study used an in-home approach to providing occupational therapy services to address morning occupations of daily living. In addition, a family-centered model of practice was used to ensure that the family felt comfortable and capable in carrying out therapy recommendations. Also, the family involvement enhanced therapy through providing helpful observations and a perspective of their own experiences. The Canadian Occupational Performance Measure (COPM) (Law et al., 2005) and the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992) were used to measure progress of the home goals over a 10 week period. Intervention strategies at home, focused on providing ample opportunities to practice increased independence with occupations of daily living, ignoring and preventing negative behaviors while rewarding positive ones, implementing the use of visual schedules, limiting environmental distractions, and providing motivating, structured downtime to improve handwriting skills. The overall results of the case study were significant improvements in occupational performance at home as well as increased competence and decreased stress for the family.
Introduction

Smith-Magenis Syndrome (SMS) is a genetic disorder in which a portion of the seventeenth chromosome is missing, as described by Smith et al. (2006). It is estimated that approximately 1 in 25,000 births result in this disorder. However, with more information revealed about SMS within the past five to ten years it is suspected that some children have gone undiagnosed bringing the prevalence closer to 1 in 15,000. The deletion of this material causes common physical, developmental, and behavioral characteristics. Some common physical characteristics include a flattened mid-face, down-turned mouth, prominent and often rosy cheeks, prominent jaw in older children and adults, dark eyebrows that meet in midline, hypotonia, short fingers and toes, and middle ear problems. Common developmental delays include oral motor dysfunction, speech delay and articulation, sensory integration dysfunction, mild-moderate mental retardation, sleep disturbances, and fine and gross motor control. Finally, common behaviors associated with Smith-magenis syndrome are mouthing of objects and hands, teeth grinding, self-injurious behaviors, attention seeking, sudden mood shifts, decreased attention, prolonged tantrums, impulsivity, and aggressive and destructive behavior.

Despite the negative characteristics associated with Smith-magenis syndrome, children and adults diagnosed are often described as being very affectionate individuals, having appealing personalities, being fun loving and humorous, and having a wonderful memory for names, places, and events.

A recent study investigating characteristics of SMS suggested that as children with SMS grow older their ability to acquire functional occupations of daily living (ODLs) decreases when compared to their typically developing peers. In other words,
typically developing children continue to develop and refine occupations of daily living (ODLs) as they grow, whereas children with SMS may plateau in learning new occupations of daily living (Martin, Wolters, & Smith, 2006).

ODLs such as dressing, teeth brushing, eating, and toilet management are all important occupations to practice and gain independence with during childhood as these occupations allow children to access experiences that enhance their self-identity, and prevent marginalization, and social isolation (Mandich & Roger, 2006). Completing ODLs independently allows children to fit in with their same age peers and be welcomed into friendship webs with more ease. Gaining this independence also allows children to discover their own abilities, problem solve, and develop their own self-identity as individuals. Through doing occupations they are developing physical, cognitive, affective, and social skills (Mandich & Roger, 2006). These skills are important as children grow and begin participating in more challenging occupations throughout their lives. Often times, when an older child is dependent on adults for completion of these ODLs it causes increased strain, stress, and burden on the caretakers involved.

Kellegrew (1998) studied a holistic approach to acquisition of ODLs for children with disabilities in which the frequency of opportunities to attempt ODLs was increased through restructuring the environment and schedule. In two out of three cases, the child’s success improved when given increased attempts and opportunities to learn. Kellegrew concluded that, “The opportunity for daily practice served as the catalyst for skill refinement” (1998, pp. 462).

An article written by Whitney (2009) states that often times the needs and occupations of caregivers and families with children with disabilities are overlooked or
not fully addressed in traditional therapy settings. Therapists offer caregivers and families information about the pediatric client’s needs, but rarely is information offered regarding the needs of the caregivers themselves. This is in part due to restrictions that are placed on the therapists by funding sources. Insurance companies are very strict about the number of sessions that a client receives, where the therapy is to take place, as well as the types of goals that can be addressed during therapy. Therefore, the focus of pediatric occupational therapy in outpatient, inpatient, and school settings is frequently the pediatric client. Therapy goals related to the child’s deficits are addressed in the clinic, hospital, or school. Suggestions are also made to families to implement additional opportunities to practice skills at home that will assist in the achievement of therapy goals. Involving the family in the therapy process is important as previous research has shown that when families are involved then children’s progress is more successful (Kellegrew, 1998). However, implementing these suggestions is often extremely challenging to families as they may be overwhelmed or over burdened with the new demands to carry out therapy at home in addition to an already stressful daily routine. “[The caregiver] must somehow construct habits, routines, and rituals that are engaging, therapeutic, and normalizing, all in addition to [an] already full role in the occupations associated with [caregiving]” (Whitney, 2009, pp. 28).

There has been a recent push for pediatric therapists to encompass the Family Centered Care model of practice (Brown, 2004) by focusing therapy goals and interventions on the needs and desires of the family as a whole and not just the pediatric client. There are three basic principles of Family Centered Care proposed by Rosenbaum et al. (1998). The first is that parents and other family members are the most consistent
people in children’s lives and the most knowledgeable about their own children. Second, families are different and unique. Last, optimal child functioning occurs within a supportive family and community context. Other related attributes proposed to this model include that, “the unit of support and intervention is considered to be the family rather than the individual child; services are provided in ways that are flexible and responsive to family needs, concerns, and priorities; and decision making occurs in a collaborative partnership between parents and professionals reflecting family rather than professional goals” (Brown, 2004, pp. 349). Carrying out these principles during the therapy process has been found to increase parent satisfaction, have positive child and family outcomes, and decrease parental stress (Rosenbaum et al., 1998). So what does this mean to pediatric occupational therapists? First, it means that the best way to conduct therapy is to consider and incorporate the family’s priorities, individual needs, and desires when developing and implementing occupational therapy with the child. Second, it means that we should function in a partnership with parents in a way that both the therapist and the family have equal rights and responsibilities to involve each other in the intervention services. (Darlington & Rodger, 2006)

One important aspect of the Family Centered Care model of practice is that an individual family’s needs and desires cannot and will not always be met through the traditional service model of pediatric care. Although progress with a child may be made in the clinic or school this does not necessarily mean that gains are also being made at home in these same areas. The “homework” and home recommendations that therapists provide for families may not be reasonable or obtainable for the family to carry out for various reasons. “…if [a home intervention program] places demands on the family that
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The parents do not feel they can meet, the program then becomes stressful. The therapist needs to be aware of...the parents' ability to deal with the stress associated with raising a child with special needs” (Humphrey, 1989, pp. 740). In cases like this it would be most beneficial to also provide in home therapy services so that the therapist can collaborate with the family at home to develop a plan of action that the family would be willing and able to carry out without introducing more stress to the family. The goal would be for the therapist to collaborate with the family at home and allow the therapist to gain a better understanding of the environmental factors that are influencing the child’s development such as the family’s routines. Then the parents and therapist can discuss changes that can be tried to help the child make gains in their natural home environment with the help of his or her family. This case study applied the principles of the Family Centered Care model of practice with a pediatric client diagnosed with Smith-Magenis Syndrome and her family.

Client Background Info

Grace is a seven year old girl who was diagnosed with Smith-Magenis Syndrome at the age of five. She currently lives with her father, mother ("Maria"), and five-year-old, typically developing sister. “Maria” is the primary caregiver of the family and is currently the self-proclaimed home manager, although she is a licensed nurse. Grace was born full term with meconium aspiration causing respiratory distress. She required ventilation for 24 hours and was discharged to home from the PICU after three days. She currently does not take any medications.

Grace has received occupational, physical, and speech therapies since the age of two due to 3-6 month delays in reaching developmental milestones. Standardized testing
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has determined that she has below average performance in the areas of motor
coordination, visual motor coordination, fine motor skills, and visual perception when
compared to her peers. Intelligence test results from 2007 indicated that Grace is
functioning in the mildly impaired range of cognitive abilities. Grace has adjusted well
to her school routine and is currently enrolled in second grade, splitting her time between
a regular education classroom and a special intervention classroom. She continues to
receive school-based and clinic based occupational and speech therapies. In addition,
Grace has been involved with hippotherapy, swimming, piano lessons, and gymnastics.

Grace is currently making adequate progress on her occupational therapy goals in
both the school and at the clinic. Her school-based goals include independently printing
her first and last name, printing the numbers 1-10, and don/doffing her jacket with
fasteners. Her clinical goals include completing connect the dots and simple mazes,
visually tracking a ball, engaging and zipping a zipper, buttoning ½” buttons, sequencing
and writing her last name from memory, and writing numbers 1-10. Although “Maria” is
happy with Grace’s progress at school and in the clinic she is still very concerned about
Grace’s ability to function at home. Grace was not attempting or similarly performing
many of the skills at home that she was making progress with in therapy. In addition,
Grace displays many negative attention seeking behaviors at home (i.e. head banging,
biting, screaming, and temper tantrums) that she does not exhibit in any other setting.
These behaviors are therefore negatively affecting her ability to perform at home. In the
past, “Maria” wanted to seek out services to receive additional assistance at home
however, her insurance did not cover such services, and they were too expensive to pay
for out of pocket. She was thrilled at the opportunity to have an occupational therapy
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A doctorate student came into her home with new and different ideas to help Grace at home. After being informed of the purpose and design of the case study, “Maria” agreed that she and Grace would participate.

**Pre-Intervention Assessment**

The first step in beginning the intervention process at home was to interview “Maria” in order to determine her family’s concerns for Grace at home. The pre-intervention assessment phase began on February 18, 2009. The Canadian Occupational Performance Measure (COPM) (Law et al., 2005) was chosen because of its compatibility with the family centered care model of practice. The COPM uses an interview style process to first identify daily occupations that the interviewee wants to do, needs to do, or is expected to do within the domains of self-care, productivity, and leisure. Next, the interviewee chooses the five most important occupations and rates each one on a scale from 1 (unable to perform/dissatisfied) to 10 (able to perform/satisfied) on their current level of performance and satisfaction with their performance for each occupation. During the interview, “Maria” identified the five most important occupational performance problems for Grace including: (1) Brushing teeth, (2) Being attentive with homework, (3) Handwriting legibility, (4) Dressing, and (5) Zipping/buttoning. The total performance scores are calculated by adding each of the individual performance scores then dividing the sum by the number of problem areas identified. The same process is used to calculate the total satisfaction scores. Grace’s total performance score at the initial evaluation was 3.8 out of 10 while the total satisfaction score was 3.0 out of 10. Other pieces of information that were gained from the interview include that Grace’s behaviors were limiting factors in her ability to make
progress at home; that Grace’s abnormal sleep patterns often cause tiredness during the
day therefore increasing her behaviors; that Grace was often too tired after she got home
from after school therapies to work on homework; and that her decreased ability to attend
to the occupations at home often make her unsuccessful.

In order to gain a fuller understanding of Grace’s self-care capabilities and the
amount of assistance she was receiving at home the Pediatric Evaluation of Disability
Inventory (PEDI) (Haley et al., 1992) was administered. The PEDI is also completed in
an interview style involving a series of checklists. Part I of the assessment looks at the
functional abilities of the child. It asks questions as to whether a child is capable of
completing specific occupations. Part II of the questionnaire investigates how much
assistance the caregiver is actually offering the child when the occupations are
completed. Only the information in the self care domain of the functional skills and
caregiver assistance sections was collected. The PEDI was administered to both “Maria”
and Grace’s classroom teacher to compare the differences between home and school
functioning. The results of “Maria’s” assessment indicated that in the area of the self-
care domain Grace had well below average scores when compared to her same age peers.
Her standard score was below 10, meaning that Grace was functioning more than two
standard deviations below where her same age peers were. At the age of seven years old
Grace should have been able to complete occupations such as preparing a toothbrush,
wiping and blowing her nose, and putting on her pants with fasteners, but she was not. In
addition, the assistance that Grace received from “Maria” at home to complete these self-
care occupations was below average with a standard score of 27.1, which is more than
two standard deviations below average. This means that even the occupations that Grace
was capable of performing she was receiving more assistance from her mother than most children her age do. When comparing “Maria’s” results to the classroom teacher’s response several things were of interest. First, both assessments rated Grace as being capable of completing almost all of the same occupations. However, at school Grace required less assistance from the teacher to complete the same self-care tasks that she completed at home including eating, grooming, and upper and lower body dressing. The question one would then ask is why was there a difference?

The next step in the evaluation phase was to observe an early morning before school routine at Grace’s home. A typical morning routine for Grace was the following:

- 5:00-6:00 am – wake up
- 7:00 am – eat breakfast
- 7:15 am – get dressed
- 7:30 am – brush teeth
- 7:35am – brush hair
- 7:45 am – wait for bus
- 8:00 am – put on coat and shoes
- 8:10 am – get on bus

Several important observations were made during the first visit to Grace’s home. First, Grace was often very distracted by objects in the room and what other people were doing. She would often ask off topic questions throughout the morning routine which would then delay completing the ODL at hand. Second, when Grace refused to do something, “Maria” would attempt to verbally compromise with Grace. This would thereby increase the time it took to complete the ODL and “Maria” often times gave into Grace’s
demands. Third, Grace often stopped completing an ODL when “Maria” gave her younger daughter attention instead of Grace. This sometimes caused Grace to lash out against “Maria” or her sister. Finally, it was easier for “Maria” to do some things for Grace rather than asking Grace to try to do them because it prevented possible tantrums.

Afterwards, observations were discussed with “Maria” and recommendations to begin a behavioral plan as well as some environmental modifications were discussed. “Maria” agreed that these would be helpful to try and asked for more information about the behavioral approach. It was agreed that in home therapy would begin with demonstrating and teaching “Maria” different techniques that she could use and eventually allowing “Maria” to conduct the therapy sessions herself. “Maria” committed to attempting to use the techniques on days when therapy was not being provided and then report her experiences and findings. This method of information exchange proved to be very important throughout the intervention process.

**In-Home Therapy Goals**

Seven goals were developed for Grace at home based upon the results of the evaluation.

1. Grace will brush her teeth at home with Mom present using a visual schedule and maximal verbal prompts 3/5 attempts.
2. Grace will remain on task while completing academic related occupations for 10+ minutes with no more than 4 verbal cues and 4 physical cues 75% of attempts.
3. Grace will remain in a 1” given space when copying letters 75% of attempts.
4. Grace will legibly write her first and last name with appropriate spacing between letters 75% of attempts.

5. Using a visual schedule Grace will get dressed for school requesting minimal physical assistance for upper body dressing 3/5 mornings.

6. Using a visual schedule Grace will get dressed for school needing minimal physical assistance and no more than 4 verbal prompts for lower body dressing 3/5 mornings.

7. Grace will independently engage and zip her coat after one verbal prompt to stabilize the left side of the zipper 4/5 attempts.

Intervention

Beginning on February 23, 2009 Grace received ten, one hour in-home occupational therapy interventions within a six week period, while her usual school and clinical therapy schedules were maintained. Intervention strategies at home, focused on providing ample opportunities for Grace to practice increased independence with occupations of daily living, ignoring and preventing negative behaviors while rewarding positive ones, implementing the use of visual schedules, limiting environmental distractions, and providing motivating, structured downtime to improve handwriting skills.

Providing Opportunities for ODLs

“Maria” identified several areas of occupation that Grace was struggling with at home, but was making gains within the clinic. After initial observation in the home, it was brought to “Maria’s” attention that Grace may become more successful with these ODLs in the home if more opportunity was given for her to practice them. This
The recommendation was based off of Kellegrew’s (1997) article, previously mentioned, as well as the Acquisitional model of practice (Royeen & Duncan, 1999). The Acquisitional model of practice is based on the belief that therapy focuses on learning specific skills that a child will need to be successful in his or her environment. The therapist focuses on reinforcing skills and behaviors that will be helpful for the child to use to learn a specific occupation. One way this is accomplished is by repeating an occupation over and over in order to refine and shape the skills needed to be successful with the occupation. Therefore, by providing extra opportunities for Grace to practice ODLs and teaching her the skills she needs to complete them she should become more independent in completing her ODLs.

In the past, “Maria” had attempted to have Grace perform an occupation such as getting dressed in the morning. However, over the years “Maria” and Grace have unknowingly grown accustomed to “Maria” dressing Grace because it was easier and faster. Therefore, Grace had decreased opportunities to attempt to dress herself making it less likely that she would learn to dress independently. Therefore, one of the first therapy interventions that was implemented was to increase opportunities for Grace to be successful with independently completing portions of her morning routine including upper and lower body dressing, teeth brushing, and zipping her coat.

To make this transition easier for Grace, “Maria” observed the first few therapy sessions at the home then “Maria” gradually took on the responsibility herself. This allowed “Maria” to see what Grace was capable of, give input from her own experiences, as well as learn new techniques to assist Grace in being independent.
Some of the home modifications that were made included allotting extra time in the morning routine, setting up the materials that Grace needed to be successful, and breaking down the occupations into smaller steps to increase Grace’s success.

Ignoring Negative and Rewarding Positive Behavior

As mentioned earlier, Grace had various negative behaviors that were limiting her ability to function independently. Several things were learned from observation in the home. First, when Grace did not want to do something she would either ask questions to change the topic or “shut down” by not talking or responding towards what was being asked of her. Second, if she was made to do something she did not want to do she would often react with self-injurious behaviors or lash out at her sister or mother. In all of the above situations, Grace had learned to manipulate her environment so that she either avoided doing something she did not want to do, prolonged the time before doing something she did not want to do, or received more assistance than she actually needed with the occupation she was asked to do. With all three of these outcomes she was receiving a reward even though she had not completed the occupation asked of her.

The Acquisitional model of practice (Royeen & Duncan, 1999) also is based upon a behavioral approach to increase desired behaviors and decrease undesired behaviors. Functional skills are learned through reinforcement within the environment to provide feedback throughout the therapy process. Positive reinforcement is used to encourage a child to continue to react in a desired way while negative reinforcement is used to extinguish an undesired reaction.
Modifications that were made included increasing the amount of verbal encouragement and praise given to Grace when she was on task, ignoring Grace’s questions and attempts to change the conversation until after she had completed the occupation asked of her, using hand-over-hand techniques to help Grace complete a task when she was refusing, using a reward system for brushing teeth, ignoring tantrums, and providing Mom information about tantrums and how to keep Grace safe during the tantrums.

Implementing each of these modifications was a learning process for both Grace’s Mom as well as the occupational therapy doctorate student. Every child reacts differently to various reward systems and types of rewards. Therefore, it was a collaborative process to find a balance between the amount of reinforcement, frequency of reinforcement, and type of reinforcement that worked for the family and only reinforced the behaviors that were desired for Grace to repeat. Grace reacted very well to verbal encouragement as a reward. Most children with Smith-Magenis syndrome are attention seeking. Therefore, Grace loved to do something correctly and then be praised for it. “Maria” learned through this process that it was important for her to give Grace more positive feedback even for the smallest success when she was attempting new or challenging occupations. Another fairly effective approach was ignoring Grace’s off task behaviors and questions. In the past she had learned that if she did something wrong on purpose she would receive attention from “Maria” through comments like, “Are you being silly?” or “Grace, do you need me to help you?” Receiving this attention even though it was meant to be negative was rewarding for Grace. Therefore, when “Maria” began to ignore these behaviors and only acknowledge Grace’s “good” behaviors then Grace became more likely to remain on
task so that she could receive the attention she was craving. In both of these situations the environmental modifications were easy for “Maria” to incorporate into their daily routine. She gained experience with these techniques through observation as well as practice. It has now become an integral part of their daily routines.

Another modification that was made included using hand-over-hand assistance when Grace was refusing to do something. Initially when Grace refused to do something, such as don her shirt, “Maria” would attempt to negotiate with Grace and would prolong the time it took to actually put on the shirt. This meant that Grace was getting out of doing something that she didn’t want to do. Instead “Maria” was instructed to repeat the command that she wanted Grace to do, “Grace put on your shirt” then gently guide Grace’s arm into the shirt. Often times Grace would then complete the occupation on her own and then “Maria” would praise her for putting her shirt on. This decreased the time it took to get dressed and decreased the chance of having a tantrum because Grace was successful and received praise. It also made it more likely that the next time Grace attempted that occupation she would be more successful.

A reward chart was also implemented with Grace for her most challenging morning occupation, brushing teeth. (See appendix A for a description of a detailed occupational synthesis that describes Grace’s occupational performance during brushing teeth.) Grace refused to brush her teeth at home although she would attempt it in both the clinic and classroom settings. It was thought that this occupation needed more reinforcement then simply verbal praise. However, the initial reward system of two stars then a prize did not provide enough immediate reinforcement for Grace. Next, a one to one reinforcement schedule was trialed meaning that every time Grace attempted to brush
her teeth at home she would receive a small prize. This reinforcement schedule was intended to eventually be faded to a more variable schedule. Grace was successful with the schedule when the occupational therapy doctorate student was assisting her with brushing her teeth and “Maria” was present. However, whenever “Maria” attempted to assist Grace with brushing her teeth, even with the OT student present, Grace would shutdown and begin a full blown self-injurious tantrum. After much discussion, “Maria’s” wishes were respected and it was decided that “Maria” would no longer take part in the brushing teeth occupation at home. Instead home therapy focused on Grace becoming independent with this occupation without “Maria’s” assistance.

Finally, the behavioral aspect of the Acquisitional model was used to address Grace’s tantrums and “Maria’s” reaction to them. Initially when Grace lashed out at someone or began self-injurious behavior “Maria” would send her to time out. When in time out Grace would become more violent towards herself and in turn “Maria” would continue to talk to her and tell her to stop. “Maria” reported that after Grace would calm down from her tantrums she would need about five minutes to re-center herself and then Grace would voluntarily reenter the room in a calm state. Literature from Murray-Slutsky & Paris (2005) that addressed the behavioral approaches to tantrums was provided for “Maria”. Pieces of the literature were reviewed in collaboration including the importance of “Maria” intervening before a tantrum begins; remaining calm, not yelling, talking, or making eye contact with Grace when she was in a tantrum; techniques to teach Grace to help her calm herself such as counting or taking deep breaths; making sure that Grace is in a safe area; and preventing Grace from injuring herself or others in a non-reinforcing manner. It was also addressed that Grace should retry the occupation
that first caused the tantrum so that Grace did not learn that she could avoid occupations she didn’t want to do simply by tantruming. This was difficult information for “Maria” to incorporate into their daily routines as it took an extreme amount of time and effort, and it was emotionally and physically stressful for “Maria” to carryout. This is because Grace’s tantrums initially got worse because she was no longer receiving the attention that she was used to while tantruming and she was mad at “Maria” and physically lashed out at her more. Due to the emotional and physical distress that was caused to the family, “Maria” decided that she would not attempt to restrain Grace from her self-injurious behaviors during her tantrums. However, “Maria” did begin to intervene before a tantrum began, remained calm, placed Grace in a safe area, and did not make any sort of contact with Grace until she was calm.

Implementing Visual Schedules

Children with Smith-Magenis syndrome have more success throughout their days when in a set routine with visual prompts (Haas-Givler, 1994). The visual prompting helps the child to recognize what is coming next so that the transition is easier for them to complete. Various visual schedules were implemented with Grace to help establish a definite routine to her morning, help her learn the steps she needed to complete her morning occupations, and become independent through the use of the visual schedules with her morning occupations. Three visual schedules were introduced to Grace including one for getting dressed (see Appendix B), one for brushing teeth, and one for putting on her coat and book bag. Grace quickly learned to use the schedules although she needed some reminders not to remove the picture until she had completed that step. This modification was simple for “Maria” to
incorporate into their morning routine as she could simply hand Grace her visual schedule and then Grace would follow the steps needing minimal supervision and verbal prompting to refer to the schedule when off task.

Limiting Environmental Distractions

Another modification suggested to “Maria” is to limit the amount of distractions in Grace’s environment while completing her morning routines. Grace exhibits attention deficits and difficulty staying on task in all environments. It is more likely that Grace will become distracted and forget what she is doing with increased objects and people in the room. Limiting the environmental distractions was somewhat difficult to enforce because Grace completed all of her morning occupations at the kitchen table with her Mom and younger sister present. Grace’s sister was often the biggest distraction as she demanded some of “Maria’s” attention at the same time that Grace wanted “Maria’s” full attention. Therefore, Grace was less successful with her morning occupations when “Maria” was providing Grace’s sister with attention or praise. Other distractions in the environment included random objects on the table or countertop that Grace would pick up and begin to play with as well as “Maria” packing lunches while Grace was getting dressed. “Maria” did her best to keep the kitchen area free of distracting objects and had Grace’s sister get dressed at a different time or in a different room when possible, although at times this was challenging.

Providing Motivating Structured Downtime for Handwriting

The last modification that was attempted in the home environment was to provide fun engaging times that Grace could practice her handwriting skills. “Maria” reported that often times Grace was too tired at night to complete her homework assignments and
she often refused to do her work when “Maria” asked her to do it at home. Most mornings after completing her regular morning occupations there was approximately 20 minutes of downtime in which “Maria”, Grace, and Grace’s sister sat and waited for the bus to come. This unstructured downtime became problematic on certain days as Grace was more likely to lash out at her sister at this time. It was recommended that this downtime would be utilized by introducing fun handwriting exercises that would focus on improving Grace’s letter formation and legibility, goals that were carried over from her school and clinic services. The handwriting program Callirobics© (Laufer, 2006) was introduced to Grace at home.

The Callirobics© program is being used by many occupational therapists to provide a multisensory approach to teaching handwriting skills as reported by Woodward and Swinth (2002). In addition, an occupational therapist and mother of a child with Smith-Magenis Syndrome recommended the program in a recent newsletter to other parents to assist with handwriting skills in their children with SMS (Hetherington, 2006). Despite the apparent successful results, no formal research has been conducted to address Callirobics’© effects on handwriting performance. The program is designed to incorporate various sensory modalities incorporating the visual, auditory, and tactile systems while learning handwriting strokes. The workbook that was used with Grace incorporated both upper and lower case letters. The letters that were first introduced included letters that were included in her name. Each worksheet incorporated tracing the letter with her finger, then tracing rows of the letter with the pencil, fading the prompt on each line until the last line she was copying the letter independently (See Appendix D). Throughout the tracing and copying process a silly song incorporating words, which start
with that letter, was played in the background. The rhythm of the music was intended to assist Grace in finding a rhythm in her writing. There were two categories of music; music for straight lined letters and music for curved lined letters. “The first group consists of straight lines and angles. They are intended to increase persistence, determination, and the ability to concentrate. The music accompanying the exercises is up beat and has a very clear tempo. The second group of exercises consists of curved and rounded strokes. These are intended to achieve inner balance, relaxation and fluidity of thought. Here, the music accompanying the exercises is calmer, relaxed and, most important, slower.” (Laufer, 2008). This program was highly motivating for Grace as she loved listening to the music while she worked.

Post-Intervention Evaluation

The post-intervention assessment was completed on April 13, 2009, results are as follows. The Canadian Occupational Performance Measure was used to re-evaluate the five areas originally identified by “Maria” as occupational performance problems for Grace at home. Individual performance and satisfaction scores can be found in Table 1. Overall results indicated a performance score of 5.8 out of 10 and a satisfaction score of 6.6 out of 10. These findings indicate a 2-point increase with Graces overall performance scores and a 3.6 increase in satisfaction with her performance. According to the COPM an increase of 2 points in each category is a significant difference. Therefore, according to “Maria’s” response Grace had made significant gains at home in the five occupational performance areas that she struggled with at time of initial evaluation.

Results of the Pediatric Evaluation of Disability Inventory suggested that there were no differences in the functional skills, self care domain with a normative standard
score of below 10 which is more than 4 standard deviations below age level. This score was identical to the pre-intervention results. However, the post-intervention score for caregiver assistance in the self-care domain was a standard score of 32.8. This was an increase of 5.7 points, placing Grace’s need for assistance within 2 standard deviations of the norm. These results still place Grace at a below average performance level. 90% of children achieve complete independence in the self-care domain between the ages of 5.0 and 7.0. These results indicate that throughout the ten week intervention period Grace did not gain the ability to perform new occupations. However, Grace did begin to complete occupations more independently at home then she was previously doing.

The goals that were addressed with Grace at home were sub-occupations of larger occupations. For example, Grace’s goal of lower extremity dressing focused on her ability to put a pair of pants on with an elastic waist. This is a sub-occupation of the larger occupation of putting on pants including a fastener such as a zipper and snap. The occupations were broken down into smaller sub-occupations and were consistent with the Acquisitional model theory that first one needs to gain skills needed for the occupation before the entire occupation can be mastered.

“Maria” reported that she has observed marked improvement with Grace’s self-care performance at home. “Maria” stated, “I was never sold before on the benefits of intensive therapy, but after seeing the results from the last ten weeks I am looking for ways that I can continue services for Grace at home.” When asked what some of the specific details that she liked and disliked about receiving in-home family centered occupational therapy, “Maria” replied that there was nothing that she disliked about it, but rather many things that she did like including having an extra set of eyes to assess the
situation, being provided with new information to teach Grace at home, and receiving assistance with establishing and maintaining a routine that worked for Grace and the family. “Maria” also stated that she is experiencing less stress in her own life. This is because Grace is exhibiting less tantrums at home and Grace is needing less of “Maria’s” assistance when completing morning ODLs.

Grace’s progress with each of her in home occupational therapy goals are as follows:

1. Grace will brush her teeth at home with Mom present using a visual schedule and maximal verbal prompts 3/5 attempts.

   This goal was met. Grace was successfully brushing her teeth by following a visual schedule with a third party present. She required maximal verbal prompts to attend to the task and complete each step after beginning the step. “Maria” was able to remain in the room; however, Grace would not attempt teeth brushing if “Maria” was providing the prompting. Future recommendations would be to continue this occupation daily and gradually fade the prompts. In addition, it was recommended that oral motor desensitization was initiated to increase Grace’s ability to tolerate the toothbrush in her mouth.

2. Grace will remain on task while completing academic related occupations for 10+ minutes with no more than 4 verbal cues and 4 physical cues 75% of attempts.

   This goal was partially met. With the use of the Callirobics © program, Grace was able to attend to handwriting worksheets for 10-15 minutes at a time. This is attributed to the highly motivating aspect of the combination of music and handwriting during the task. In order to complete the worksheet, Grace often required more than 4 verbal cues.
It was recommended that this goal would continue to be addressed at home. Since music is highly motivating for Grace it was recommended that music be played in the background while completing all homework assignments. In addition, “Maria” ordered a compression vest for at home use to help Grace with organization and attention skills. This was recommended due to successful use of the compression vest in the classroom environment. Finally, it was recommended that Grace complete her homework in the morning as she is more alert and attentive then in the evening.

3. Grace will remain in a 1” given space when copying letters 75% of attempts.

This goal was partially met. Grace is remaining within a given space 66% of letters written while using the Callirobics © program. However, Grace often wrote larger than the given space with difficult to form letters, such as letters with diagonals. Therefore the accuracy of this goal was decreased. When Grace was copying letters that she was familiar with she was remaining within the given space at least 75% of attempts. See Appendix C for a pre-intervention classroom writing sample and Appendix D for a post-intervention Callirobics © writing sample. It is recommended that Grace continue to practice letter formation as well as sizing and alignment when writing words.

4. Grace will legibly write her first and last name with appropriate spacing between letters 75% of attempts.

This goal was partially met. Grace is legibly writing her full name with 42% accuracy due to lack of spacing between letters of her name. The overlap of the letters causes it to be messy and difficult to read at times. However, she is
making gains in this area and does better with initial verbal prompts to use spacing before beginning to write her name.

5. Using a visual schedule Grace will get dressed for school requesting minimal physical assistance for upper body dressing 3/5 mornings.

   This goal was met. Grace is able to dress and undress her upper body independently at home. She uses the visual schedule to remain on task although she has memorized the steps. She requires occasional physical assistance to remove her arm from long sleeved shirts when she is stuck. On rare occasions Grace requires minimal verbal prompting, when she is purposefully being silly, to turn her shirt around or place a tank top on before her t-shirt. Recommendations are to introduce shirts that have buttons and zippers to increase Grace’s ability to dress herself.

6. Using a visual schedule Grace will get dressed for school needing minimal physical assistance and no more than 4 verbal prompts for lower body dressing 3/5 mornings.

   This goal was met. Grace is able to complete lower body dressing and undressing independently. She uses the visual schedule to sequence her steps and remain on task although she has the steps memorized. Grace frequently needs the most assistance with donning her socks as the frequently become twisted. Recommendations would be to introduce pants that include zippers and snaps as currently Grace only wears elastic waist bands.

7. Grace will independently engage and zip her coat after one verbal prompt to stabilize the left side of the zipper 4/5 attempts.
This goal was met. Grace is completely independent with engaging and zipping her coat independently at home. Recommendations include introducing other articles of clothing that have different zippers to explore if Grace is able to generalize this skill to unfamiliar articles of clothing.

Overall, Grace made great gains in her goals during the ten weeks of in-home occupational therapy. Although, Grace is still not functioning at an age appropriate level, she is making steady progress as evidenced by her progress in these sub-occupations during the short 10 week time period. It is likely that she will eventually master independence with the overall occupations, if she continues to receive services and opportunities to practice them. It is recommended that the PEDI is re-administered after a six month time period to measure and document Grace’s long term progress.

Recommendations to Family

General recommendations given for Grace and her family, for the purposes of continued skill obtainment and increased independence of ODLs, included the following:

- Investigate in home therapy options to continue services in the home in order to continue intensive treatment at home, school, and clinic as many gains were seen during this time and to prevent regression at home

- Re-administer the PEDI after a six month time period to measure Grace’s continued progress

- Use of a compression vest during school work and handwriting tasks at home to increase attention and focus

- Continue to provide opportunities for independence in order to develop and refine self-care skills at home
• Continue the use of visual schedules with difficult occupations in order to increase independence by decreasing verbal cues required for sequencing, decreasing distractions, and redirecting attention to the task.

• Initiate Oral Motor therapy for desensitization of the oral cavity to facilitate independence with teeth brushing occupation

• Continue to use behavioral strategies and interventions to reward and increase on task behaviors and ignore and extinguish off task behaviors, self-injurious behaviors and tantrums

• Continue to limit environmental distractions in order to increase attention to the occupation at hand

• Play music softly in background when completing homework assignments to provide motivation to complete work, facilitate attention, and increase legibility

• Complete school work in the morning rather than at night so that work is being completed at times when Grace is alert and willing to work instead of when she is tired after school or evening therapy sessions.

• Seek out support groups, respite services, or counseling as needed to provide additional support to family during times of high stress and transitional periods

Two Week Follow-Up

A two week follow-up was scheduled after the post-intervention re-assessment. The follow-up was completed on April 27, 2009. No formal assessments were used at this time, however, “Maria” provided a verbal update on Grace’s progress. She stated that Grace was still more independent then when in-home therapy initially began, but she currently was requiring more prompting than two weeks ago when therapy ended.
“Maria” did say that Grace was ill during the previous week and kept home from school for several days. This interrupted Grace’s morning routine and so “Maria” attributed the extra prompting needed to getting back into her routine. She felt confident that Grace would begin to need less prompting as time went on. Also, “Maria” reported that Grace would be receiving in-home assistance from an Applied Behavior Analysis program over the summer that will continue to focus on some of her morning routine occupations of daily living.

Discussion

Results of the pre- post-test comparison suggest that the interventions and education, focusing on self-selected goals that were implemented with Grace and her family were successful in improving her overall independence with her morning occupations of daily living. Not only were goals obtained, and independence with ODLs improved, but also family dynamics changed. “Maria” reported a decrease in stress since assistance was provided at home and Grace had obtained more independence with her morning routine. Stress, anxiety, and depression are three psychosocial factors that are prevalent in families with children diagnosed with Smith-Magenis syndrome (Kozachek, Foster, Kanotra, Stern, Elsea, 2008). Alleviating this stress is instrumental in empowering caregivers to incorporate intervention strategies into daily routines.

As evidenced by this case study, the Family Centered Model of Practice has great potential to be incorporated into pediatric occupational therapy practice. Pediatric occupational therapy intervention that focuses solely on the child may set the child up for failure. As evidenced earlier, the child is part of a larger group: the family. The majority of a child’s life is spent within the family group and this is where learning occurs most
frequently. It is the family’s responsibility to care for the child and provide intervention
for the child when at home and in community settings, as this will increase success in
therapy goals. Unfortunately, not all caregivers have the knowledge, time, or energy to
juggle this responsibility along with their already stressful routines. As professionals we
need to advocate for our pediatric clients by reaching out to families and caregivers,
providing them with information, answering their questions, collaborating with them on
stress-free intervention strategies, and ensuring that ample opportunities for both the
caregiver and the pediatric client are provided for success. This means that as a
profession we need to be available move out of the clinics, schools, and hospitals to work
with families in their natural environments. Home visits and community outings are
central to the Family Centered Model because they allow the occupational therapist to
gain a better understanding of how environmental factors are affecting the family’s
performance and in turn to provide intervention that can be generalized to the family’s
daily life.

The results of this case study are in strong support of the Family Centered Model
of Practice used in-home in conjunction with the Acquisitional Model. However, further
investigation of the use of this model should be conducted as it is not yet widely used in
the field, although it is widely accepted. Occupational therapists have a great opportunity
to assist families in making occupational gains in the home environment, modifying the
home environment to support child and family needs, and partnering with families to
empower caregivers in their own homes. Unfortunately, in reality this will never occur
until third party payers recognize the importance of these services and allow these
services to be paid for. Therefore, future research investigating the Family Centered
Model’s efficacy is important as it can provide concrete evidence that the success rate of in-home family centered practice is worth the funding. The primary limitation in applying the knowledge resulting from this report to broad clinical practice is in its single case design. Future research can help to generalize the successful results with larger populations of children with Smith-Magenis Syndrome, as well as children with other diagnoses. Furthermore, this was a case study intended to enhance the knowledge and practice skills of the student therapist and as such did not include an experimental design controlling for factors such as the possibility that the increase in the amount of time spent in therapy during the week accounted for gaining skills at home regardless of the setting. In other words, perhaps gains at home would be made if the time spent in occupational therapy at the clinic increased. This however is unlikely as “Maria” was not receiving the one-on-one training from the school or clinic based therapy that she was when at home. It is also unlikely because even with the therapy that Grace was receiving in the clinic and school settings she was not carrying over any of the skills to the home environment prior to initiating in-home therapy.

In summary, this case study used a unique approach to utilizing the Family Centered Practice and Acquisitional Model by focusing on the needs of the family and the environmental factors within the home in an effort to increase the occupational performance of the pediatric client with a rare genetic disorder; Smith-Magenis Syndrome. SMS provides caregivers and families with unique challenges due to the nature and severity of behaviors that are exhibited in the home. In every day practice, occupational therapists have limited time to attempt to provide such families with resources and information to assist them with difficulties at home. However through the
completion of this case study, collaborative, in-home therapy interventions were effective in increasing one pediatric client’s independence with morning occupations of daily living based upon the results of two standardized assessments. Occupational therapists have the unique ability to analyze current occupational performance and environmental factors in order to make recommendations and changes that will improve future occupational performance. It is the recommendation of this case study that therapists begin to work more closely with families in their home environments in order to help children with disabilities make gains in home as well as in schools and clinics.
Acknowledgements

The completion of this case study project would not have been made possible without the help and encouragement of several organizations and individuals. I would first like to thank Toledo Hearing and Speech Center and Waterville Elementary School for providing me with a rich learning experience this semester with hands-on training. I would also like to thank my site mentor Julie Pommeranz and faculty mentor Alexia Metz for their time, guidance, support, and wisdom throughout completion of my capstone. Also, my warmest thanks to “Maria” and Grace for their participation in the study and their openness and willingness to allow me into their home. Another huge thank you to Laura Laufer for provision of her Callirobics © program to use as a part of my intervention process. Finally, I would like to thank my husband Jason, my classmates, family, and friends for their constant encouragement, support, and patience throughout my graduate school experience.
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Appendix A
Occupational Synthesis “Brushing Teeth”

Occupational Form

Grace’s daily morning routine is always completed in the downstairs kitchen area at the kitchen table. It is a large circular wooden table that seats four to six people. The half bathroom that is used for the morning brushing teeth routine is directly across the hallway. The bathroom is approximately 6’ x 4’ and contains a typical toilet and tall standing sink. The height of the sink is equivalent to Grace’s chest. It is just low enough that Grace is capable of reaching both of the turn handled knobs for hot and cold water. It is also low enough that Grace is able to lean over the rim of the sink and spit toothpaste, mouthwash or water into it. Grace’s standard children’s toothbrush, non-fluoride toothpaste, and children’s mouthwash with attached cup are left out on the sink’s rim at all times for easy access and storage. While standing in the bathroom the activities and noise from the kitchen area can clearly be heard. This typically consists of the crumpling of bags and opening and closing of cabinets while lunches are being packed as well as muffled talking between Grace’s mom and sister. A visual schedule consisting of five picture cards Velcroed and laminated onto a paper strip with an “all done” folder stapled to the back of the strip and positioned on the sink rim. The five picture cards included “open lid”, “toothpaste on brush”, “brush teeth”, “rinse mouth”, and “spit in sink”. The occupational synthesis was videotaped with the permission of “Maria” and Grace.

Occupational Synthesis

After collaborating with “Maria”, it was decided that Grace would begin with the last two steps of the brushing teeth routine; “rinse mouth” and “spit in sink”. These two
steps were the only steps that Grace was periodically attempting with “Maria” at home. Therefore, it was decided to begin with these familiar steps and introduce the visual schedule. By doing this the occupation would be graded down until using the visual schedule became familiar. These two steps were meaningful for Grace as she enjoyed the flavor of the bubblegum mouthwash and she thought that it was fun to get to spit in the sink. Prior to going into the bathroom a social story was read with Grace at the kitchen table to reinforce the importance of brushing teeth. Grace was able to recite and answer questions about the main point of the story that the toothpaste cleans our teeth so we don’t get cavities and that we need to brush our teeth at home everyday. Grace expressed that she did not want any cavities because she previously had several teeth pulled due to cavities. Therefore, it appeared that this occupation was meaningful as Grace knew she needed to brush her teeth so that she did not get cavities.

After reviewing the importance of teeth brushing, Grace was told by the occupational therapy student (OTS) that it was time to brush her teeth. She willingly walked into the bathroom and immediately picked up her toothbrush. The OTS picked the visual schedule up off of the sink and showed Grace the schedule. Grace read each one. Then the OTS took off the first 3 steps and said, “Grace today we are only going to do rinse mouth and spit in sink. Are you ready?” Grace enthusiastically nodded her head. The OTS asked Grace, “What’s next?” she looked at the schedule and said, “spit.” The OTS said, “Not yet. What’s first?” and pointed to the correct picture. Then Grace motioned to her mouth and said, “What that guys is doing.” The OTS said, “Rinse mouth” Grace then asked, “All done?” and attempted to take the picture off the schedule but the OTS put it back on the schedule and answered, “Not yet. Get your mouth wash.”
Grace then independently picked up the mouthwash off the sink and took the lid off but dropped the lid in the sink because she was still holding her toothbrush. The OTS reminded Grace that she could put her toothbrush down because she didn’t need it anymore. Grace followed instructions then picked the mouthwash up off the sink, and left the lid in the sink, and asked the OT student for help because she realized that she got some mouthwash on her shirt. Grace set the mouthwash back down and the OTS helped her wipe it off. Then Grace asked, “Did I throw up?” The OTS assured her that she did not throw up. Grace responded, “Oh” then she picked up the mouthwash again, saw that her toothbrush fell in the sink and picked that up. She then began to move the mouthwash towards her mouth as though she was going to put some in her mouth but then hesitated and looked at the OTS with a nervous uncertain look for several seconds. The OTS asked Grace, “What are you supposed to be doing?” Grace asked, “Huh?” The question was rephrased and Grace did not respond. The OTS gave two choices “Are we brushing our teeth or rinsing our mouth?” Grace smiled and said, “brushing our teeth” and waited for a reaction from the OTS. Instead the OTS shook her head no and said, “try again…we are rinsing our mouth. Put it in your mouth and swish it around.” Grace lifted the bottle above her head so the OTS said, “One, two, three, go!” and guided it towards Grace’s mouth. Grace reacted by turning around and playing with the toilet paper roll. The OTS said, “Grace we are almost finished.” Grace responded by leaning against the wall, laying her head on the sink, and then leaning over with her arms hanging as though she was going to touch her toes. This behavior continued for approximately 1 minute. The OTS then stated, “Grace you can do it yourself or I can help”. Grace did not respond so the OTS took Grace’s finger and placed it in the mouthwash then touched it to
Grace’s mouth. The OTS immediately praised Grace for a good job of using the mouthwash. Grace put the picture in the all done pocket then read the next card. She spit in the sink. The OTS then placed a star on Grace’s prize chart, but Grace did not smile or seem excited about the star. The OTS reminded her that she needed one more star and then she could pick out a prize from the prize bag.

*Observations from Occupational Performance*

Several important factors were observed from this original occupational performance. Grace appeared to be unmotivated to complete any portion of the teeth brushing routine. Even with this familiar and enjoyable occupation of using mouthwash, Grace refused to complete the steps that she was normally independent with. Some of the behaviors she displayed with the intention of delaying her occupational performance included putting the picture in the all done folder before completing it, starring blankly at the OTS when asked to put the mouthwash in her mouth, responding with an incorrect answer when asked what she was supposed to be doing, changing the topic by asking if she threw up when mouthwash got on her shirt, turning around, and putting her head down on the sink. From this observation, it was determined that more motivation and encouragement throughout the occupational performance may be required. In addition, the star chart that was created for Grace did not appear to be motivating enough as she did not appear to associate that two stars equaled a prize. Therefore, it was assumed that a more immediate reward system may be needed.

*Changes made in the Planned Occupation*

It was expected that Grace would willingly and independently participate in the planned occupation of completing the last two steps of the teeth brushing schedule. This
is because in the past she has displayed the ability to do so. However, when she delayed and refused to perform the occupation several changes to the planned occupation occurred. First, unwanted behaviors were ignored; this ensured that these behaviors were not being reinforced through attention. For instance, when Grace laid her head on the sink and turned around the OTS did not look at or acknowledge what Grace was doing because Grace was seeking negative attention. Instead, the OTS with flat affect provided verbal and visual redirection via the visual schedule. It wasn’t until after Grace completed a step that she was praised and affirmed and therefore only her desired behaviors were reinforced. In addition, the OTS used hand-over-hand assistance to assist Grace in using the mouthwash when she no longer showed any attempt in using it herself. This change was made because Grace was asked to do something and to allow her to not do it at all would be reinforcing her undesired behavior. Therefore, by dipping her finger in the mouthwash and touching it to her lips she was still successfully using the mouthwash and was able to receive praise for doing so. The OTS did not attempt to pour the mouthwash into Grace’s mouth because she could have choked on the liquid or it could have poured down the front of Grace onto the bathroom floor.

*Changes for Resynthesis of Brushing Teeth Occupation*

Several changes were made when re-synthesizing this occupation during the next visit. The first major change was that the visual schedule would only be used as a whole in future attempts. This was decided for several reasons. First, by allowing Grace to only complete the last two sub-occupations in the initial occupational synthesis it showed Grace that she did not need to complete some of the steps and would still be rewarded. Initially this technique was intended to make Grace more successful with the use of the
visual schedule as it eliminated sub-occupations. However, this plan was unsuccessful and that was not the message that Grace’s Mom and the OTS wanted Grace to learn. However, if Grace began to attempt all of the sub-occupations it would become more of a routine for her and less behaviors were expected when she came to the sub-occupations that she did not want to perform. In addition, Grace’s Mom and the OTS collaborated and decided that the mouth washing sub-occupation was less important than the teeth brushing sub-occupation. This meant that if Grace would complete the teeth brushing sub-occupation and not the mouth washing sub-occupation substantial gains would be made in her occupational performance. Therefore, in future attempts Grace was given the option of using her mouth wash or wiping her mouth for sub-occupation four. This allowed Grace to gain some control over the situation and helped her to become more successful overall.

The second major change was that the occupation was made to be more motivating and reinforcing for Grace. This was accomplished through presenting her with a musical toothbrush with her favorite Disney© character on it. The toothbrush was exciting because she was able to listen to the music while she brushed her teeth but it also provided vibrations to her mouth that assisted with some of the oral sensitivities that she was experiencing. Also, the prize chart was decreased to a one-to-one reinforcement schedule meaning that every time Grace successfully completed her tooth brushing routine that she would be allowed to choose a prize. Before beginning the tooth brushing session Grace would get to look through the prize bag and choose what she wanted to try to earn. The item was then placed on the sink side so that she could see it while she was brushing her teeth as extra motivation. This reinforcement schedule was intended to later
be faded to a more variable schedule, but initially was used to increase motivation to increase occupational performance. Finally, the occupation was made to be more motivating by including more nonverbal praise throughout the occupation when Grace was on task such as thumbs up signs, high-fives, and silly faces.

_Adaptations and Compensations_

Overall, two main adaptations were made by Grace throughout the ten week period while working towards independence with the teeth brushing occupation. The first was that Grace learned the sub-occupations that she was required to perform in order to be successful with teeth brushing. When asked, she was able to recite the steps from memory prior to beginning the occupation. The second adaptation is that Grace learned how to successfully organize the occupation by checking the visual schedule. When Grace became distracted or forgot which sub-occupation came next she referred to her visual schedule independently or with minimal verbal prompting. The main compensation already mentioned was that Grace used the visual schedule while brushing her teeth to assist her on staying on task. Another compensation was that she did not brush all of the teeth in her mouth due to oral sensitivities. Therefore, it was recommended to Grace’s mom that oral motor desensitization therapy would be performed with Grace to decrease some of her sensitivities so that she would eventually be able to thoroughly brush her teeth.
Appendix B
Visual Schedule for Getting Dressed
Appendix C
Writing sample pre-intervention
Copied from a model
Appendix D
Writing Sample Post intervention
Callirobics© Worksheet
Table 1
*COPM Performance and Satisfaction scores at Pre- and Post-intervention*

<table>
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<th>Occupational Performance Problems</th>
<th>Pre-intervention Performance</th>
<th>Post-intervention Performance</th>
<th>Pre-intervention Satisfaction</th>
<th>Post-intervention Satisfaction</th>
</tr>
</thead>
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<td>5</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Attention to Homework</td>
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<td>4</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Handwriting</td>
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<td>6</td>
<td>3</td>
<td>7</td>
</tr>
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<td>Dressing</td>
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<td>7</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Zipping</td>
<td>5</td>
<td>7</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>
Fine Motor Control and Handwriting

Jennifer Koval, B.A., OTD/S
April 22, 2009
Objectives

After the presentation participants will be able to:

- Identify at least 4 areas that affect fine motor control
- Define at least 4 in hand manipulation skills affecting fine motor control
- Recognize mature pencil grasps
- Implement short activities in the classroom to improve fine motor control
- Understand the difference between writing and drawing letters
What is Fine Motor Control?

- Coordination of small muscle movements occurring in the hand and fingers usually in coordination with the eyes.

- This is sometimes also referred to as dexterity.
A study conducted by McHale and Cermak (1992) found that 31-60% of a child’s school day consists of fine motor skills. Of the time focusing on fine motor skills 85% of the time were pencil and paper tasks. Therefore, children are spending ¼ to ½ of their day with pencil and paper writing tasks.

Poor fine motor skills affects handwriting by: decreasing legibility, decreasing speed and fluency of movements, increasing time to complete assignments when compared to peers, increased difficulty with taking notes and studying from them later, decreased ability to learn grammar, and increasing writing avoidance or participation in class.
What affects Fine Motor Control?

- Proximal stability and control
- Upper Extremity and Hand Strength
- In Hand Manipulation skills
- Pencil Grasp
- Motor Planning
- Sensory Processing
- Visual Motor Skills
- Visual Perceptual Skills
- Bilateral Integration

…..Just to name a few. Today we will be focusing on the 1st 4 highlighted in green.
Let's first talk about the components of good seating.....This provides proximal support for the student. Without proximal support then precise distal control is nearly impossible. (Imagine yourself on a balance board) When a student's body is supported properly it helps to keep the child's core muscles from fatiguing as quickly. This allows a student to complete handwriting tasks such as journaling and test taking for longer periods of time. Providing a chair and desk that is the correct size for a student is creating an environment that will give the student an optimal start. If the desk is too high or low for a student then arm positioning is not optimal. This may cause handwriting to be sloppy due to fatigue from holding their arm up too high or simply because their paper is not in direct line of sight and so may be difficult to see what they are writing. Positioning the arm at approx 30 allows the thumb and finger movements necessary for writing to occur best in this position. Often times it is evident that a student's desk or chair may not be the correct size when they are sitting on their feet, swinging their feet, or leaning/standing up when writing. *Foot stools-phone books.
Without the support of individual hand arches then the hand is floppy and soft. The hand arches are important to provide support so that fingers can make controlled movements.

Developing the muscles of the hand are important for multiple reasons. Children with weak muscles may have difficulty holding and maintaining a proper pencil grasp, they may not be able to make the small precise movements necessary to make writing/prewriting strokes, and they may not have the endurance needed to complete writing assignments. Often times children try to compensate for having weak UE and hand muscles. Sometimes this can be in the form of writing with their whole hand or arm versus using their fingers, holding the pencil very tightly, pushing down hard when writing, or using an immature pencil grasp. All of these compensations are bad because they can increase the chances of fatigue.

Upper body strengthening ideas-wall push ups, chair push ups, animal walks, doing class work or playing games in prone, rearranging desks and chairs in classroom, carrying crate of library books,

Extrinsic Activities-play with playdough/clay and roll it in the palms of the hand, use rubber stamps, animal walks on hands, pinch pieces of clay inbetween the thumb and each finger, crumple pieces of paper on table top using one hand

Intrinsic Activities- use clothespins, pick up small objects (marble) in between each finger’s web space, translation with a marble, marble or straw tug o war, hide small objects in clay, make paper chain links, tear pieces of paper, rotate ball in one hand, peel off backs of stickers, make paper clip chains, use tweezers, play with tops

Hand arch activities-use rubber band around fingers and stretch them out, shuffle a deck of cards, hold a coin with all fingertips, cutting with a knife, use a hole punch, crumple pieces of paper with one hand then see how small you can make it, balance a lid using finger tips, shake dice in hands,
Most develop these skills between ages 3-6

Our hands are designed to have a power side and a precision side. The power side of our hand allows support to the precision side while completing fine motor tasks. The power side is made up of the pinky and ring fingers. Often times while writing these two fingers are curled under into the palm of our hand. The precision side is made up of the thumb, pointer, and middle fingers. These digits provide the ability to make small dynamic precise movements while holding our writing utensils. If students are trying to use all fingers to hold a writing utensil try having them hold onto a small object in their power side such as a broken piece of crayon.

Finger isolation is the ability to move each finger independently from the rest. A good way to practice this is by pretending to play the piano as well as singing a song such as “Where is thumbkin?” Finger isolation allows each finger to move the writing utensil in different directions without eliciting the movement of the entire hand/arm.

Finger opposition means that you touch the thumb to each one of the finger pads in both a forward and backward direction. Maintaining opposition is important for holding and maintaining proper pencil grips. Opposition allows for an open web space to rest the pencil in.

Translation means the ability to move objects from the palm to the fingers and then from the fingers to the palm without the use of the other hand.

Rotation comes in two forms first simple which means that you have the ability to pick up an item and turn it the correct way to hold it 180 degrees. Complex rotation is the ability to rotate an object in one hand 360 degrees.

Finally shift is the ability to move an object up an down.

Refer to handout for ideas on how to facilitate some of these in hand manipulation skills.
There are 3 categories of grasps

- Immature Grasps
- Transitional Grasps
- Mature Grasps
All of these movement comes from the upper extremity. The forearm is not resting on the table/desk. Rarely observed after the age of 4 yrs old.

Not pictured: index finger pointing down pencil toward paper
Decrease with age but still continue into age 6. Typically transitional grasps rely on mostly hand movements and some finger movements. The forearm is resting in the table/desk.
Transitional Grasps

Four Fingers Grasp
Increased use with age. With mature grasps movement comes mainly from the fingers and some from the hand (when larger movements are required)

Mention the third type that is acceptable but not widely taught with pencil held between 2 & 3rd digit and supported by thumb underneath
Classroom Implementation

- What is one strategy or activity that you could incorporate into your daily classroom routine to help improve fine motor control affecting handwriting?
Handwriting is a motor skill. In motor learning theory there are 3 stages of learning a new motor skill. The first is cognitive...this is when we are learning how to do something—we are able to do it but we have to think about how to do it as we are doing it often slowing our time down. The next stage is the transitional stage. This is when we are beginning to remember how to do parts of it without thinking about how but we are not fully confident in our ability, some parts of the motor skill are still challenging and require thought while completing it. Finally, we reach an autonomic stage in which the motor skill has been completely learned and is ingrained into our systems. We no longer have to think about what we are doing it simply comes natural.

To give an example of this process think about when you first learned to drive a car. In the beginning you had to think about everything (where to place your hands on the wheel, what your speed was, which hand to use to turn on the blinker, etc) [this was the cognitive stage]. Then as time went on you began to think less about these things but occasionally you would need to remind yourself to do them (maybe you got confused which side was the blinker and which side was the windshield washer) [this is transitional]. Finally you reached a place were you are now. You are able to listen to music or talk to others in the car while driving because driving is no longer something new for you, you can focus your attention on other skills.

Reaching autonomic stages of motor skills takes a lot of practice to obtain. Handwriting itself does not become a functional skill until it reaches an autonomic stage. Students should not need to think about how they are writing rather they should be thinking about what they are writing and what the teacher is talking about.
Handwriting Exercise

- Write your first and last name using the symbols in the key.
How long did it take you to write your name the second time? This is what some of our students feel like every time that they are writing. This is why it is important to practice handwriting and letter formation frequently so that writing can become an automatic process. Enabling students to not have to think about how to form the letters of the alphabet when they are writing can allow them to focus on spelling, holding their pencil correctly and allows them additional writing time that will automatically develop their strength and endurance in their hands. So it’s an all around win-win situation.
Questions

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References

