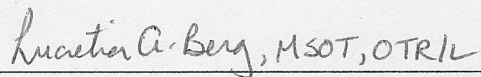


Beyond the physical outcomes: An investigation into the experience of a pediatric mCIMT camp

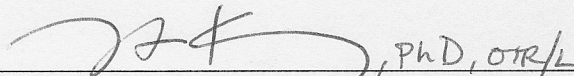
Elizabeth Andrews, Maria Miller, and Ashley Satter

University of Puget Sound

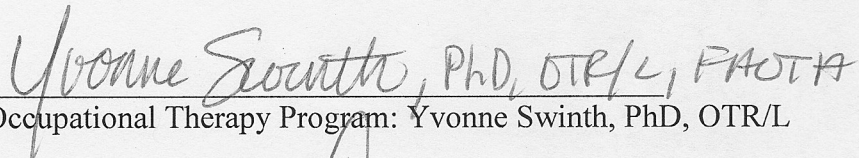
This research, submitted by Elizabeth Andrews, Maria Miller, and Ashley Satter, has been approved and accepted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy from the University of Puget Sound.



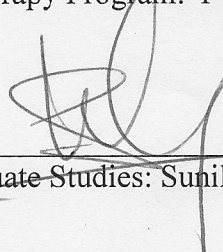
Committee Chairperson: Lucretia Berg, MSOT, OTR/L



Reader: Tatiana Kaminsky, PhD, OTR/L



Director, Occupational Therapy Program: Yvonne Swinth, PhD, OTR/L



Dean of Graduate Studies: Sunil Kukreja, PhD

Abstract

Objective: Modified constraint induced movement therapy (mCIMT) is a technique for treating children with unilateral neurological motor impairments by constraining a child's unaffected upper extremity to force the use of the affected upper extremity. Outcomes from mCIMT camp participation reported in the literature tend to be heavily overrepresented by quantitative measures. When included, qualitative information was anecdotal and lacked the depth and rigor necessary to recognize psychosocial changes as a meaningful camp outcome. The purpose of this study was to investigate the experience of a mCIMT camp, as reported by parents and children who participated in a mCIMT camp.

Method: In order to gather empirical qualitative information regarding the mCIMT camp experience, two focus groups were held with camp participants: one with 4 children and one with 5 parents.

Results: The four themes that emerged to describe the experience were relationships, fun, empowerment, and frustrations. The relationships and fun experienced during camp created a social context in which therapeutic activities occurred, which facilitated the development of empowerment. Frustrations tended to be logistical and were not deterrents to pursuing future camp opportunities.

Conclusion: The results from this qualitative study validated the importance of gathering data on any psychosocial changes attained during camp in addition to the typical quantitative changes. Suggestions provided by both the care providers and child participants may assist occupational therapists in the development of a more consistent, family-friendly mCIMT camp.

Beyond the physical outcomes: An investigation into the experience of a pediatric mCIMT camp

Constraint Induced Movement Therapy (CIMT) is a therapy technique involving constraining a participant's unaffected upper limb in order to force the use of the impaired limb (Gilmore, Ziviani, Sakzewski, Shields, & Boyd, 2010). CIMT is thought to work by influencing cortical reorganization and re-mapping the impaired limb, which loses cortical representation through learned non-use (Charles & Gordon, 2005; Gillot, Holder-Walls, Kurtz, & Varley, 2003). Learned non-use refers to when individuals with hemiparesis choose not to use their impaired limbs during activities because it is difficult and they often experience failure (Nascimento, Gloria, & Habib, 2009; Stearns, Burtner, Keenan, Qualls, & Phillips, 2009). By forcing use of the impaired limb, CIMT both activates the impaired muscles and increases the cortical representation of the impaired limb (Nascimento et al., 2009).

CIMT has repeatedly been shown to be effective in treating adults with stroke and hastening their return to functional activities (Gillot et al., 2003), and has more recently been adapted for use with children with unilateral upper extremity impairment (Eliasson, Bonnier, & Krumlind-Sundholm, 2003). However, pediatric CIMT lacks a consistent protocol and standard outcome measures (Sheehan, 2012). Pediatric CIMT has been increasingly delivered as a group treatment and often described in the literature as a camp (Eliasson, Boyd, Shaw, Krumlind-Sundholm, & Ponten, 2009; Gilmore et al., 2010). A CIMT camp is any therapy that involves two or more children simultaneously and utilizes functional tasks. A variety of outcome measures have been utilized to evaluate the effectiveness of pediatric CIMT camps. Of these measures, only a few have been qualitative in nature (Hoare & Carey, 2007; Sheehan, 2012), and to date only one study has explored the child's experience of the camp (Gilmore et al., 2010). While the quantitative outcome measures focusing on performance skills and body functions are

irreplaceable for documenting improvement, researchers have noted that participants tend to emphasize how important the experience of the CIMT treatment was in causing long-term changes (DeLuca, Echols, Law, & Ramey, 2006; Eliasson et al., 2003; Stearns et al., 2009). Understanding the experience of the children and parents participating in CIMT may help researchers identify which parts of the camp were perceived as positive or negative. This will aid in developing a more consistent treatment protocol that minimizes the negatives and maximizes the positives, which will increase the likelihood of full participation in therapy.

Currently, protocols for CIMT, both individually and in a camp setting, differ in type of constraint, duration of constraint use, type of activity, and intensity of activity (Charles & Gordon, 2005). Some studies have seen success with as little as 1.5 hours of therapy per day (Rostami & Malamiri, 2012) while others have administered as many as 6 hours per day (de Brito Brandaõ, Gordon, & Mancini, 2012). Regardless of the amount of direct intervention, CIMT treatment is compatible with traditional occupational therapy goals. The desired outcome of occupational therapy is to increase independence in occupational performance, and CIMT accomplishes this through facilitating increased use of the affected limb (Reidy et al., 2012).

The recognized importance of evidence-based practice combined with the specificity of client needs makes qualitative data about CIMT an important missing link in determining how to best implement a CIMT camp. While quantitative data are useful in expressing the efficacy of a particular CIMT treatment protocol, qualitative data are useful in communicating the experience of participating in that treatment. If this experience can be accurately captured, it will provide occupational therapists with specific feedback that could be used in planning for future camps and in establishing an effective and more standardized treatment protocol (Gilmore et al., 2010).

Background

Hemiplegia and hemiparesis are neurological conditions that affect 1 in every 1,000 children (Cerebral Palsy Source, 2005; Willis, Morello, Davie, Rice, & Bennett, 2002). These conditions can be caused by trauma, cerebrovascular accident (CVA), tumor, or other cortical injuries to one hemisphere of the brain and can occur pre-natally, peri-natally, or post-natally. A child with hemiplegia or hemiparesis will present with a unilateral functional impairment (CHASA, 2013a). From an early age, motor and sensory deficits will significantly affect the child's ability to engage in play and perform his or her daily self-care activities (Charles & Gordon, 2005; Rostami & Malamiri, 2012). The severity of the functional impairment varies from person to person and the term used to describe the impairment depends on the individual's function. Hemiplegia is defined as "paralysis of one side of the body" (CHASA, 2013b) and children with hemiplegia will present with no movement in their affected limb. Hemiparesis is defined as "slight paralysis or weakness of one side of the body" (CHASA, 2013b), and children with hemiparesis will present with some movement of their affected limb. CIMT is a treatment for hemiparesis in which a person's non-affected upper extremity (UE) is restrained to force the volitional use of the affected extremity (DeLuca, Echols, & Ramey, 2007). Many studies of CIMT use the term hemiplegia to describe their participants; however, this is an inaccurate description of their impairment. Since volitional movement is a requirement for CIMT, the term hemiparesis will be used throughout this paper.

Components of CIMT. CIMT is a treatment technique that utilizes functional tasks to improve the motor function of the affected UE. CIMT involves structured intervention provided by a therapist, employing repetitive practice and shaping techniques to encourage volitional movement of the affected UE (DeLuca et al., 2007; Gordon, Charles, & Wolf, 2005).

Repetitive practice involves performing a series of functional activities for a predetermined amount of time. Functional activities include entire tasks such as wrapping presents and practicing handwriting (Winstein et al., 2003). Shaping is a technique of CIMT in which a larger task goal is accomplished through breaking an activity into many small steps and practicing each step until successful (DeLuca et al., 2006). For example, a client may initially be rewarded for minimal movement toward a target, but as the client progresses, expectations increase to include longer duration and more controlled movements. The therapist may initially physically guide the client through movements to ensure early success (DeLuca et al., 2006). Shaping might also involve increasing the demands of the task or the speed at which the task is performed. In repetitive practice and shaping, specific and direct feedback is given to the client after each successive trial (Charles & Gordon, 2005; DeLuca et al., 2007; Winstein et al., 2003).

Theory. CIMT was first applied experimentally as neurorehabilitation with monkeys with learned non-use. Learned non-use is the conditioned suppression of movement, and takes place after an injury to the central nervous system (Taub, 2012). In studies with monkeys, somatic sensation was surgically removed by severing all sensory roots of spinal nerves to one limb, which resulted in non-use of the deafferented limb, despite intact motor function (Taub, 2012). The use of the deafferented limb was successfully induced using two different methods, each utilizing a punishment and reward system. One method was training the animal to use the extremity with the use of electric shock or food as punishment or reward. The other method, constraint of the non-affected limb, was effective as well, and caused the animal to use the deafferented extremity extensively to avoid non-use and therefore the punishment of being rendered helpless (Taub, 2012). Both methods produced long lasting effects, but only the constraint method was ethically transferable to use with humans.

Theoretically, the success of the CIMT treatment of experimental unilateral deafferentation leading to learned non-use in monkeys should transfer to CIMT treatment of humans with CVA because both instances present with conditioned suppression of movement (Taub, 2012). In learned non-use, people with hemiparesis opt not to use the impaired limb during activities because it is difficult and they often experience failure (Nascimento et al., 2009; Stearns et al., 2009). Treatment of learned non-use involves restoring the dysfunctional motor pathway. With CIMT, the patient is forced to use the affected extremity to overcome learned non-use.

Multiple studies have reported evidence supporting the claim that CIMT is an effective treatment for adults who have experienced a CVA (Gillot et al., 2003; Taub, Pidikiti, DeLuca, & Crago, 1996). A CVA may unilaterally affect an upper extremity, leaving the patient with a seemingly permanent loss of function, but often incomplete paralysis on the affected side. Evidence has shown that adults with CVA who participated in CIMT experienced significant improvements with activities of daily living (ADL) and the changes were maintained 2 years later, suggesting permanent improvement. No such change was reported in control groups (Taub et al., 1996). CIMT “produced very large improvements in the patients’ ability to use the more affected arm, just as in the case of the deafferented monkeys” (Taub, 2012, p. 161). Evidence supporting the effectiveness of CIMT at overcoming these phenomena can also be seen in physical changes within the brain (Johnston, 2009).

Physical changes in the brain following CIMT include anatomical adaptations, cortical reorganization, and increased neuronal activation of the affected sensory-motor pathways of the affected limb. Evidence of these cortical changes can be seen within minutes of applying a constraint (Johnston, 2009) and have been documented using functional magnetic resonance

imaging (fMRI) scans. Yun-Hee, Ji-Won, Myoung-Hwan, Sung-Ho, and Lee (2004) demonstrated functional physical changes in the brain following CIMT treatment using fMRI, as well as behavioral quality of movement changes using traditional motor assessments. The fact that intervention focusing on facilitation of movement resulted in physical changes in the brain supports the notion that functional improvements occur through a continually adapting neural feedback loop. This feedback loop is present from birth and demonstrates that just as neural pathways influence movement, movement can also influence neural pathways (Taub, 2012).

Theoretically, CIMT should work better with children than with adults. The enhanced plasticity mechanisms present in the developing nervous system allow it to be influenced more strongly by experience and the environment than the adult brain (Charles & Gordon, 2005; DeLuca, 2002; Johnston, 2009). Whereas learned non-use is the conditioned suppression of movement of a limb that was fully functional, developmental disregard occurs in children who are born with hemiparesis and thus have never used the limb normally. As a result of developmental disregard, these children never develop the motor pathways necessary to use the affected extremity (DeLuca, 2002).

Pediatric treatments of hemiparesis. Many children with hemiparesis learn to compensate for the affected extremity by performing tasks one-handed, rather than incorporating the affected side, thus increasing the effects of developmental disregard (Dickerson & Brown, 2007). Some therapy treatments for pediatric hemiparesis aim to improve motor function in the affected limb by developing the motor pathways using the developmental disregard theory. The most common approach is neurodevelopmental treatment (NDT), which is based on the assumption that children must experience normal movement in order to develop adequate motor pathways (DeLuca, 2002). Through the use of facilitation, a therapist helps the child move in

typical movement patterns through functional, goal-directed movement, which will hypothetically strengthen the motor pathway and improve normal motor function (DeLuca, 2002). Another treatment option involves injection of botulinum toxin A into the high tone muscle groups to decrease spasticity and encourage more controlled movements of the weaker muscle groups (Eliasson et al., 2009). Splinting, casting, and forced use are different from CIMT because they don't include structured intervention, but have also been used to treat hemiparesis (Gordon et al., 2005).

CIMT is the latest in a collection of treatments based on the developmental disregard theory to improve motor function in the affected limb. Despite evidence supporting the use of CIMT with children with hemiparesis, there is a lack of consistency regarding type of constraint, duration of constraint use, intervention duration, and outcome measures (Huang, Fetters, Hale, & McBride, 2009; Sheehan, 2012). Casting has been used as the constraint in several studies to date (DeLuca et al., 2006; Taub, Ramey, DeLuca, & Echols, 2004; Willis et al., 2002) although other studies have used fabric mitts or slings (Gordon et al., 2005; Wallen, Ziviani, Herbert, & Evans, 2008). The duration of time spent constrained has ranged from 1 to 24 hours per day. Eleven of the 21 studies reviewed by Huang et al. (2009) constrained the participants' unaffected extremities for at least 10 hours per day. In these studies, skilled intervention duration ranged from as little as 1 hour per week to as many as 7 hours per day. Specific inclusion criteria regarding the minimum active movement requirements in pediatric CIMT studies were not reported in all articles. The articles that were found that reported minimum active movement requirements specified 20 degrees of wrist extension and 10 degrees of finger extension, from a position of full flexion; although, the reason for these movement criteria was not specified (de Brito Brandaõ et al., 2012; Gordon et al., 2005; Rostami & Malamiri, 2012; Stearns et al., 2009).

The typical CIMT protocol involves constraint of the lesser-affected or unaffected limb and 3 or more hours per day of therapy, while a modified CIMT (mCIMT) protocol involves less than 3 hours per day of therapy (Aarts et al., 2012). Some, but not all mCIMT treatments require additional time in the constraint outside of therapy, but again, there is no consistent protocol (Aarts et al., 2012; Case-Smith, DeLuca, Stevenson, & Ramey, 2012). Furthermore, there was inconsistency in the literature regarding the use of the term mCIMT when describing protocols (Gilmore et al., 2010). A recent publication outlining guidelines for pediatric constraint programs reviewed current literature and found that most studies utilize a mCIMT protocol, even if the protocol was referred to as CIMT (Eliasson et al., 2014). Since mCIMT appears to be the more accurate term to describe current pediatric protocols, the remainder of the current study will use the term mCIMT.

mCIMT camps. Recently, pediatric mCIMT has been increasingly delivered in a camp or group setting as opposed to during individual therapy sessions. A group setting makes mCIMT more feasible than individual mCIMT treatment. mCIMT is expensive, time-consuming, and labor intensive for therapists, participants, and families (Wu, Hung, Tseng, & Huang, 2013). Insurance companies are hesitant to reimburse for a treatment that is so intensive without strong evidence supporting its efficacy (Gordon et al., 2005). Recent studies evaluating the feasibility of group mCIMT concluded that delivering mCIMT in a group decreases cost to families and third-party payers, and decreases demands on therapists, while maintaining the positive outcomes seen in individual mCIMT treatments (Gordon et al., 2005; Wu et al., 2013).

Unfortunately, group mCIMT treatment also lacks an established protocol. Type of constraints used across various camps included splints, gloves, and slings (Aarts et al., 2012; Gilmore et al., 2010; Wu et al., 2013). Camps have ranged in duration from 9 days (Eliasson et

al., 2009) to 8 weeks (Aarts et al., 2012), with daily intervention ranging from 2.5 hours per day (Wu et al., 2013) to 7 hours per day (Eliasson et al., 2009). High-intensity training may lead to frustration in children (Nascimento et al., 2009) and treatment over 4 hours per day is not supported by current insurance and service delivery models (Cope, Forst, Bibis, & Liu, 2008). Since these group studies resulted in positive outcomes despite the varied protocols, a potential next step for researchers would be to develop the most feasible and efficacious, child- and family-friendly protocol.

Outcomes of mCIMT. In addition to a lack of consistency between camp protocols, the current body of research is heavily overrepresented by quantitative outcome measures that fail to capture the meaning of the participants' perceived improvements (Sheehan, 2012). Only two of the five mCIMT group studies found specifically included qualitative data (Gilmore et al., 2010; Knis-Matthews et al., 2011). The remaining three articles mentioned qualitative data, but did not systematically analyze themes and experiences (Eliasson et al., 2009; Gordon et al., 2005; Wu et al., 2013). This is concerning because delivering mCIMT in a group setting appears to increase the efficacy of the treatment beyond quantitative outcomes specific to upper extremity movement and use. Studies of group mCIMT treatment protocols reported that parents and therapists observed that participants had higher self-esteem and increased motivation to participate in difficult activities compared to before the camp (Aarts et al., 2012; Dickerson & Brown, 2007; Eliasson et al., 2009; Knis-Matthews et al., 2011; Wu et al., 2013). Participants also reported these benefits, and emphasized the importance of social support (Gilmore et al., 2010). Participants showed improvements in performance because they could model their actions after their peers, and they were more willing to persist in difficult or frustrating activities (Eliasson et al., 2009). Furthermore, participants indicated that they felt a sense of belonging, and appreciated

seeing other children with similar motor deficits (Aarts et al., 2012; Eliasson et al., 2009; Gilmore et al., 2010; Knis-Matthews et al., 2011). These social benefits typically are not reported in individual treatments, yet they are often indicated by participants and family members as the most dramatic, long-lasting, and important improvements from group treatment (Eliasson et al., 2009; Gilmore et al., 2010; Knis-Matthews et al., 2011).

These psychosocial benefits are in line with the domain of occupational therapy, as outlined in the Occupational Therapy Practice Framework (American Occupational Therapy Association [AOTA], 2014). Social participation is one of the areas of occupation that occupational therapists consider when providing treatment (AOTA, 2014), and treatment in a group setting provides more opportunities to engage in social participation. Occupational therapists work to improve physical client factors, like strength and endurance, but they also work to improve mental factors, including experience of self and awareness of one's identity and body (AOTA, 2014). In a group setting, mCIMT has the potential to simultaneously target both physical and mental client factors, and occupational therapists are uniquely trained to facilitate these improvements.

Quantitative outcome measures are overrepresented in the current literature, and any qualitative measures that have been included tend to only be a paragraph dedicated to psychosocial changes. These qualitative anecdotes lack the depth and rigorous analysis necessary to recognize psychosocial changes as a meaningful camp outcome. Since social and emotional improvements are commonly seen in mCIMT group treatments, but are not measured using predetermined and reliable outcome measures, the current study aimed to collect qualitative information from camp participants and parents. This information may aid in the development of future consistent protocols, as well as provide information regarding the psychosocial outcomes

of group mCIMT. Therefore, the purpose of this study was to investigate the experience of a mCIMT camp, as reported by parents and children who participated in a mCIMT camp.

Method

Design

This qualitative research study utilized a phenomenological approach to investigate the experience of children who participated in a mCIMT camp and that of their parents. For the purposes of this study, a mCIMT camp is a program that treats children with a neurological unilateral UE motor impairment, and lasts no more than 3 hours per treatment day for a duration of at least 3 weeks. At least 1 treatment day per week must be with the group in the camp setting. According to Luborsky and Lysack (2006), phenomenological research is used to gain insight into the meaning of an individual's personal experience. Using this approach, children were asked to describe their experience in the mCIMT camp, and parents were asked to reflect on their experience and the changes they observed in their children during and following the mCIMT camp, including physical, behavioral, emotional, and psychosocial changes. The researchers then assigned further meaning and derived common themes from the participants' discussions (Luborsky & Lysack, 2006). In order to gather data, the researchers conducted a series of focus groups.

According to Stewart, Shamdasani, and Rook (2007), there are several characteristics that differentiate a focus group from other qualitative interview methods. A focus group allows for topic-specific research. In a focus group, it is possible to "gather qualitative data from individuals who have experienced some 'particular concrete situation,' which serves as the focus of the interview" (Stewart et al., 2007, p. 9). In this study, the concrete situation that tied the participants together was the experience of a mCIMT camp. Discussion among the group

members elicited a more in-depth response than individual interviewing methods would. Moreover, the physical presence of each participant in the focus group created a dynamic that could not have been emulated through less interactive methods (Stewart et al., 2007). Based on these criteria, the researchers concluded that a focus group was the most appropriate qualitative method for gathering information from the target populations. Focus groups with 4 to 6 people are common because they are convenient for the researchers and comfortable for the participants (Krueger & Casey, 2000).

Trustworthiness. The researchers carefully embedded techniques into their focus group data collection methods that enhanced trustworthiness. Each researcher completed the data coding process individually before the data were analyzed as a group, resulting in triangulation of investigators. Triangulation of data sources occurred through comparison of the results of the children's focus group to the results of the parent's focus group (Krefting, 1991). Member checking occurred with parents and children after the focus group themes were identified. Peer checking occurred with an experienced qualitative researcher during data analysis (Krefting, 1991).

Each researcher volunteered as a student buddy at a 2013 mCIMT camp. This experience provided the researchers with a context to assist in understanding the topics that were discussed in the focus groups. However, this introduced a potential bias. The researchers completed reflexive bracketing by journaling about expectations and assumptions before, during, and after the focus group to minimize bias (Ahern, 1999). Researchers journaled independently, and discussed reflections as a group.

Participants

Children met the inclusion criteria for this study if they were between 5 and 12 years of age and attended at least one mCIMT camp in King, Pierce, or Thurston counties in Washington state in 2012 or 2013. Parents were eligible for this study if their children met these criteria. Four children, aged 6 to 8 years, and 5 parents participated in the focus groups (see Table 1). These children all attended at least one mCIMT camp at the same facility during 2012 or 2013. Three of the children attended the same camp in 2012, which consisted of 3 hours per day at camp and 3 hours per day at home for 5 days per week for 3 weeks. Three of the children attended the same camp in 2013, which consisted of 3 hours at camp 1 day per week, and 3 hours per day at home for 4 days per week, for 3 weeks (see Table 1). In both of these camps, the children were paired with an occupational therapy student from the University of Puget Sound.

Procedures

The researchers submitted their project to both the University of Puget Sound's Institutional Review Board and the University Enrichment Committee. Researchers were aware of one qualifying mCIMT camp directed by a professor in the Occupational Therapy department at the University of Puget Sound. The professor was given 25 flyers to distribute to camp participants. The researchers then utilized snowball sampling by asking the professor to identify additional camps. Three additional programs were identified, and 25 flyers were sent with an informative letter to each facility. The flyer instructed interested parents of camp participants to contact the researchers via email. Five parents contacted the researchers. Researchers responded to parents with a pre-drafted email containing pertinent details regarding the study, including study design, inclusion criteria, expected time commitment, and purpose of the study. All parents and their children met the inclusion criteria, and had attended a camp directed by the professor.

A reminder email was sent 1 week before the scheduled focus group, and one researcher made reminder phone calls 2 days before the scheduled focus groups.

Focus groups took place at the University of Puget Sound. Each parent participating in the focus group signed an informed consent form before the focus group commenced. All parents of children participating in the children's focus group also signed an informed consent form for their children, and children provided verbal assent to participate in the focus group. Verbal assent was documented using a checklist to verify the assent had been obtained. All focus group participants were reminded that they could choose not to answer any specific questions or withdraw at any point during the focus group. The parent's focus group lasted 90 minutes, and the children's focus group lasted 60 minutes. All focus groups were audio-recorded and transcribed with pseudonyms and stripped of any other identifying information, such as the names of therapists.

Both focus groups had a lead moderator, a co-moderator, and a note taker. The lead moderator was responsible for leading the focus group and asking follow-up questions. The co-moderator was responsible for keeping track of time and contributed follow-up questions as necessary. The note taker was responsible for recording observations regarding group dynamic and nonverbal communication during the focus groups (Krueger & Casey, 2000). These positions remained constant across both focus groups to increase internal validity. Rehearsal focus groups were conducted with occupational therapy students from the University of Puget Sound. Through this pilot focus group, the researchers became familiar with their roles and received feedback regarding their performances (see Appendices A and B for focus group questions).

The moderators used a funnel approach to structure the focus groups. Morgan (1997) described a funnel approach as one utilizing a progression from broad questions to more specific questions over the course of the interview. This design facilitated development of deeper reflection as the focus group progressed. For the current study, the researchers utilized the funnel approach in order to ensure that focus group participants described their experiences without being led by the researchers. This initial self-interpretation was critical because it allowed the participants to develop a deeper understanding of their experience, a key component of the phenomenological approach (Luborsky & Lysack, 2006). Having a less structured beginning to the focus group provided the opportunity for participants to remember and process their experience while the group progressed towards a more meaningful free discussion.

Data analysis

A professional transcriptionist was hired to transcribe verbatim the content of the focus groups. Once the transcripts were received, the researchers cleared the data of all identifying information.

Conventional content analysis. Conventional content analysis was utilized in this study. Using conventional content analysis, researchers established codes and themes from the data, rather than applying preconceived categories. This approach was appropriate for the current study because the purpose of the study was to investigate a shared experience, and there was limited research describing the experience (Hsieh & Shannon, 2005).

Individual analysis. To begin the data analysis process, each researcher completed individual analysis of the transcripts. Researchers listened to the audio files of the focus groups a minimum of two times. Once the transcripts were received, the researchers read the transcripts in their entirety one time without making notes. Next, the researchers read the transcripts in their

entirety while making reflective notes in the margins (Peacock & Paul-Ward, 2006). Finally, the researchers again read the transcripts in their entirety while highlighting key words and phrases that reflected the key elements of the discussion (Hsieh & Shannon, 2005).

The researchers then cut out excerpts of the transcripts containing key words and phrases, and grouped similar excerpts together into common codes (Hsieh & Shannon, 2005). The coding process was repeated twice, with a minimum of 3 days in between each coding session. After the coding process had been completed twice, each researcher met with an experienced qualitative researcher for peer checking (Krefting, 1991). Once codes had been established, the researchers sorted the codes into common themes.

Group Analysis. After individual analysis had been completed, the researchers came together as a group to compare codes and themes. Differing codes and themes were reconciled through discussion to reach agreement regarding labels (Peacock & Paul-Ward, 2006). In addition, the researchers compared the themes identified between the two focus groups. Upon completion of data analysis, each participant was contacted for member checking of the themes identified by the researchers.

Results

Four themes emerged from the data that captured the experience of the mCIMT camp. These themes were relationships, fun, empowerment, and frustrations. Each theme had subthemes, as described below. Both the parents and the children spoke to these themes, although the parents' descriptions tended to be more insightful than their children's descriptions. Information regarding the experience of the mCIMT camp was consistent within and across both focus groups.

Relationships

The most pervasive theme identified in the data was the development of relationships. The relationships were seen by both parents and children as paramount to the camp experience. As one parent described, “Relationships are what cause learning to happen. And without a relationship, learning doesn’t happen.” All focus group participants acknowledged that the camp experience influenced the development of relationships, including between the children at the camp, the student buddies, and the parents.

Children like me. The relationship between the children at the camp was the most frequently mentioned relationship. All of the parents indicated that his or her child was the only child with hemiplegia at his or her school, and the camp experience taught each child that there were other children like them. This bond between the children created an environment that fostered feelings of trust and acceptance, which encouraged them to attempt new activities without fear of judgment. When asked what they remembered about their friends at camp, the first thing one child mentioned was that they were all wearing a constraint. All the children nodded in agreement. One parent described how being around children with a similar disability was motivating to her son. “So it is just motivation to see there are other people going through the same thing as me, and oh, they are kids too, and they are my same age.” This environment and the resulting motivation could not have occurred during individual mCIMT therapy. The bonds built between the children are unique to mCIMT delivered in a group setting.

Another parent described how being around children with a similar disability provided “peer pressure in a good way.” The parents discussed how their children were influenced by seeing other children like them succeed with tasks that were challenging or intimidating. Parents

mentioned that the environment was not competitive, but instead that the children pushed each other to attempt activities they wouldn't have otherwise tried.

Children and their student buddies. The children described their student buddies as being helpful when an activity was challenging. Parents also recognized that the relationship between the children and the student buddies were helpful. One parent stated, "they would have a student helping them one-on-one, which seemed like the best therapy you could get." Furthermore, the student buddies were seen as young and fun, and perceived to be friends rather than authority figures. This differentiated the child-buddy relationship from the traditional child-therapist relationship. Parents recognized that their children were motivated to please their student buddies, and therefore persisted in more challenging activities.

Children and their parents. The relationship between children and their parents changed as they went through the camp. As children realized their abilities, they attempted activities they had previously relied on their parents to do. As parents witnessed their children's initiative, they became more willing to let their children experiment with using their affected arm. One parent summarized this when she said:

Another huge thing, which freaked me out, was, "Mom, come outside." I come outside and he actually had climbed up in the tree. Oh, get down. But that was something he could not do. So I was like, "Sit there." Got to get the camera. But just to know that he could actually do that, and he is outside and he is shooting a basketball, and he is holding onto it with both hands instead of just trying to do everything with his right.

This shift in the dynamic of the parent-child relationship is integral to the experience of empowerment.

Parents like me. The camp also provided an opportunity for parents to build relationships with other parents who also had children with hemiparesis. They expressed that in traditional therapy, they often did not feel they could approach other parents. In the camp setting,

parents were more comfortable discussing their personal experiences from therapy with each other. One parent stated, “when we go to [traditional therapy] we can’t ask anybody what’s going on with them . . . so in the camp it was definitely much more open and everyone can talk about their therapy, their successes, and their challenges.” This relationship between parents was clearly seen as a benefit of the camp, and parents expressed a desire to further their networking resources in future camps.

Fun

All of the parents and children used the word fun to describe the camp experience. One child described, “I thought it would be fun because I would get to play games and have fun with my friends. And I thought it would be fun.” Specifically, the parents discussed how their children perceived camp as play, but traditional therapy was perceived as work. “One of the difficult things for her is therapy is too much like work, but camp was a lot more like play because there is [sic] games and prizes and other kids.”

Variety. Parents and children both indicated that variety of camp activities and themes was part of what made camp a fun experience. At these particular mCIMT camps, each week had a different theme, such as pirates or superheroes, and the camp environment and activities were designed around that theme. Some activities were the same each week, but presented in a different way based on the theme. One parent emphasized that “the variation of what was done is key.” Another parent stated that her daughter was “more willing to participate if it was something new.” The weekly themes created a changing context in which to experience the activities, which made the activities appear new and fun instead of repetitive and like work.

Prizes. At these particular camps, the children picked a prize out of a treasure chest at the end of the day. The children repeatedly mentioned how fun it was to pick a prize. They saw the

prize as a reward for their hard work. One child said, “after you were done using your bad hand a lot to make it really work, you got to get into this treasure chest where you could get a bunch of stuff.” The tangible reward was memorable and fun for the children, and may have motivated them to persist during more challenging activities.

Social interactions. The relationships described in the previous section also helped make the camp experience fun. The camp activities themselves were fun, but the experience was more fun because it occurred in a social context. One parent tried to recreate the activities at home but did not feel fully successful, in part because she could not provide the interactions with peers and student buddies. She stated, “once you pull out the fun factor of being in an environment with other kids and having your student buddy -- to bring it back home to the usual environment -- again, it went from fun to work.” The relationships built at camp were critical in creating a fun environment where children were willing to participate in challenging therapeutic activities.

Empowerment

All parents expressed that the camp experience was empowering for them and their children. Although the children did not explicitly mention this theme, several of their comments indicated that they experienced empowerment. Parents discussed the result of empowerment through three interconnected experiences: affirmation, confidence, and independence.

Affirmation. The initial step in the children developing feelings of empowerment was recognizing their improvement and receiving encouraging feedback during camp. Children experienced intrinsic positive feedback by realizing gains in their abilities. For example, when asked to describe a difficult frisbee activity, one child said, “when you threw it, it was fun to see how far it went and then it was fun to see each day how much you improved.” Parents confirmed that their children were beginning to recognize their success. As one parent said about her

daughter, “I think it was really helpful for her to be able to realize that she really can do things with her right hand. Things I don’t think she necessarily knew she could do before.”

Children also received positive feedback and encouragement from their peers, their student buddies, and their parents. This feedback significantly contributed to the development of the relationships discussed in the previous section. As one parent described, “at camp, everybody was cheering when you did just the smallest thing. And that immediate feedback and positive reinforcement. That’s got to be there.” Specifically, parents mentioned that they made an effort to praise their children for accomplishments at home. Student buddies were described as personal cheerleaders who increased the children’s self-confidence through praise and encouragement. The children also mentioned cheering for each other during challenging activities. The positive feedback from others validated to the children that their hard work during camp was paying off. The children’s recognition of their improvements paired with affirmation from others led to increased confidence in their abilities.

Confidence. As the children became more aware of their improvements, they became more confident in their physical abilities. Parents witnessed their children taking pride in their accomplishments. One parent described a shift in her daughter’s attitude from uncertain to confident. After camp, she recalled her daughter saying, “I can do this. I can do this now.” She went on to say, “And that was really cool, because she would want to show you.” The children’s eagerness to call attention to their accomplishments signifies an increase in their confidence.

In addition to noticing increased confidence in physical abilities, parents also described an increase in their children’s psychosocial confidence. One parent described how her son “was more open about his disability...and then a lot more confident to talk about it.” For example, two parents stated that after the camp their children asked to bring their orthotics to show and tell at

school. During the focus group, the children also demonstrated this increased psychosocial confidence. When asked what they would tell their friends about camp, one child said, “I would tell my friend, this is meant for kids that have one hand that works better than the other and then they could know a little bit more about the camp.” All children answered this question in a similar way. These examples demonstrate that the children were not only taking ownership of their disability, but also recognizing the opportunity to educate their peers. As the children’s physical and psychosocial confidence increased, they gradually became more independent. All the parents agreed that their children “learned that confidence from the camp.”

Independence. As the children gained confidence, they began to take risks by attempting tasks they did not think they could do before. During a drawing activity in the focus group, one child described his drawing by saying, “So that’s me throwing a frisbee and she wants to help me but I said no don’t help me.” Additionally, all parents provided personal anecdotes of seeing their children succeed in using their affected arm in daily routines, such as climbing trees, playing basketball, tying shoes, and putting on a belt. As children started taking these risks, parents realized how much they had been holding their children back. One parent reflected, “I really felt the camp gave them that motivation and gave it to us too, and really opened our eyes up to allow our children to do more than what we expected of them.” As a result, parents began to give their children the opportunity to attempt to complete challenging tasks independently. This shift in the relationship between the children and their parents was a key component of the camp experience, and greatly contributed to the resulting empowerment. One parent summarized:

So just to know that he could do that, and that gave me confidence in, OK, I can let go a little bit. Because I protect him so much -- don’t do that. Don’t climb over here. You are going to fall -- and allowed me to, OK, my son can do this -- I

mean, like step back. So I think that kind of gave him confidence, and then let mom let go. He is a boy. He can grow up a little bit more.

Thus, the interaction among affirmation, confidence, and independence resulted in an experience of empowerment. Through the camp experience, children took ownership of their disability and recognized their potential to continue improving. The camp helped parents and children realize that in order to reach this potential, they needed to have the opportunity to experience success and failure in a variety of contexts, not just in therapy. For example, when the children were asked why they wanted to go back to camp, most of them stated that they wanted the opportunity to help other children who were new to the camp. For two of the children, this expanded to a desire to become a therapist later in life. As one child said, "I want to be an OT when I grow up ... because I know what the kids are feeling because I've had it before." This long-term perspective was also discussed by parents. According to one parent:

The experience definitely helped to show her what she could do, and showed me what she could do ... It is something that has to be -- not so much a lifestyle, but just a constant reminder of using that and it is possible - just keep trying.

Frustrations

Parts of the camp experience were identified as frustrating for parents and children. The only frustration identified by the children was the constraint. They described the constraint as hot, sweaty, and uncomfortable. Children suggested that the camp would be improved if they did not have to wear the constraint. Parents confirmed that they thought their children would prefer to attend camp without wearing the constraint, but didn't suggest removing the constraint as an improvement to the camp. However, parents identified additional frustrations that influenced their experience of the camp.

Several frustrations regarding the logistics of camp were discussed. The most frequently acknowledged frustrations were related to time. The camps attended by these participants

included a maximum of 3 hours per day at camp with the other children. Parents expressed that this was challenging to manage with their work schedules. These camps also required 3 hours per day of therapy activities at home, and parents found it difficult to find the time to dedicate to these activities and to maintain their children's motivation for so long. Parents indicated that more time at camp during the day would improve the camp experience for them and their children. Although time during the day was not directly expressed as a frustration for the children, they too indicated a preference for more hours per day at camp.

The 2012 camp consisted of 3 hours per day at the camp and 3 hours per day at home for 5 days per week. The 2013 camp consisted of 3 hours at the camp 1 day per week, and 3 hours per day at home for the remainder of the week. Parents of children who attended both camps indicated that they saw a greater improvement in their children during the 2012 camp. They also experienced frustration during the 2013 camp because they didn't have the same daily support that they did during the 2012 camp. Even though the parents spent the same amount of time doing therapy at home, the 2013 camp was more frustrating because the children were less willing to participate at home. One mother said, "as long as we started out at the camp, [my daughter] was on board." All parents expressed a preference for a camp that meets 5 days per week because they valued the immersion experience this would provide their children. Children also stated that they would like to attend camp more days per week so they could spend more time with their friends and have more opportunities for fun.

Another common logistical frustration was related to communication. Parents expressed a desire to network with other parents to share ideas and strategies for completing camp activities at home. One parent explained:

I think that having a parent opportunity for conversation and such would be very helpful. That way, we could chat and say, "This is what I am doing, what are you

doing?” for these home things ... there are some things that you are doing that are awesome that I might not know about and I am not thinking about. So I think having, I don't know, even just a short debrief for the parents either once a week, or some sort of communication forum, even by email, might help us, as parents, to just say, “This is what I am experiencing.”

This led to a discussion about all the ways parents could help each other through the camp process, including carpooling, sharing ideas and challenges, and how to motivate their children.

The *parents like me* relationship was valued as an important part of the camp experience for parents, but they clearly identified a need for further networking resources.

An additional frustration about the camp experience was the lack of communication between the parents and the therapists. At the end of each day, parents were debriefed by student buddies about the day. Parents appreciated the involvement of the student buddies, but would have preferred to check-in with the supervising therapist at the end of every day. Parents felt excluded from the therapy process because they were receiving information about the camp primarily from student buddies instead of the supervising therapist. This experience of exclusion was described by one parent, who stated, “internally [the camp] was fantastic, but we were kind of on the outside and I think that extra communication piece would have helped us.” Parents suggested including additional volunteers to perform clerical duties to allow the supervising therapist to check in with parents at the end of the day.

All of the children who participated in this study also attended a 1 day mini-camp several months after the conclusion of the 2013 camp. Parents found this experience beneficial not only for the therapy, but also for the friendships built during camp. Parents voiced a desire to attend regular mini-camps throughout the year.

Despite the frustrations, parents felt the camp experience was worthwhile. They recommended that parents considering mCIMT camp persist through initial frustrations because

the benefits outweighed the challenges. As one parent summarized, “It shouldn’t be that difficult to do something this wonderful, and that is a frustration.”

Discussion

The purpose of this study was to investigate the experience of a mCIMT camp, as reported by parents and children who participated in a mCIMT camp. mCIMT is increasingly being delivered in a group setting, which provides the potential for both psychosocial and physical improvements (Aarts et al., 2012; Eliasson et al., 2009; Wu et al., 2013). However, current literature over represents quantitative outcome measures and neglects the qualitative experience of group treatment. This study addressed the qualitative outcomes of a mCIMT camp.

The parents indicated that the camp experience resulted in gains that were beyond what their children had accomplished in traditional therapy. The camp experience offered a context and environment that could not exist in traditional therapy. AOTA defines context and environment as “a variety of interrelated conditions that are within and surrounding the client” (2014). The camp provided a fun experience that exposed the children to others who were facing similar challenges. This social context fostered a feeling of camaraderie that empowered the children to take ownership of their disability and engage in activities that were once perceived to be impossible. The description of this social experience is consistent with previous literature, which suggested that group therapy was fun and motivating because it occurred with other people (Eliasson et al., 2009; Gilmore et al., 2010; Knis-Matthews et al., 2011; Wu et al., 2013).

While the themes of relationships and fun have been documented (Eliasson et al., 2009; Gilmore et al., 2010; Knis-Matthews et al., 2011; Wu et al., 2013), the theme of empowerment has not been addressed in previous literature. This may be because previous mCIMT research primarily focused on quantitative outcome measures. When included, qualitative observations

appeared to be afterthoughts intended to document psychosocial changes witnessed by the researchers. However, these reports lacked the rigorous analysis necessary to uncover the experience of empowerment. The current study documented clear changes in psychosocial client factors. AOTA's Occupational Therapy Practice Framework includes beliefs as an important client factor (2014). The camp experience led to a change in the children's beliefs because they felt more empowered after camp. This documented change in client factors supports the observations suggested by previous literature (Dickerson & Brown 2007; Eliasson et al., 2003; Eliasson et al., 2009; Gilmore et al., 2010; Stearns et al., 2009; Wu et al., 2013), and indicates that qualitative outcome measures are critical in understanding the full impact of a mCIMT camp.

Although the camp experience of empowerment was not addressed in previous occupational therapy literature, the empowerment process described by the parents is consistent with literature outlining empowerment theory. Cattaneo and Chapman (2010) described empowerment as a process that relies on self-efficacy, knowledge, and competence, which is similar to this study's empowerment theme with the subthemes of affirmation, confidence, and independence. Furthermore, Cattaneo and Chapman (2010) explained that the social context permeates through all of these components and helps link them together.

Cattaneo and Chapman (2010) described self-efficacy as "the individual's beliefs about his or her abilities" and the "recognition of the power and capabilities that individuals already possess" (p. 652). This is consistent with the current study's experience of affirmation, which highlights the positive feedback and recognition of the children's improvements and accomplishments. Knowledge was defined as the ability to develop a course of action in order to achieve goals (Cattaneo & Chapman, 2010). This course of action usually revolves around an

understanding of power dynamics. This is consistent with the current study's experience of confidence, in which children took ownership of their disability and used their newfound determination to advocate for themselves. Competence was defined as developing the skills necessary to complete a given task (Cattaneo & Chapman, 2010). Successes and failures are critical in teaching an individual how they can succeed in a given task. This is consistent with the current study's experience of independence, in which children capitalized on the opportunity to attempt challenging tasks without help.

One aspect of camp that has been neglected by previous studies is the experience of the parents. A review of the literature did not reveal any studies that included analysis of the experience of the parent beyond their perceptions of their child's experience. The current study found that the experience of the parents was an important aspect of the camp. Specifically, the psychosocial changes that parents experienced resulted in a shift in the dynamic between the child and the parent. This shift contributed to the increase in the child's independence. The children were more willing to attempt challenging tasks, and parents were more willing to allow their children to experience successes and failures. Independence was a critical part of the child's experience of empowerment, and without the parent's realization of the child's abilities, empowerment may not have occurred.

Parents also voiced frustrations regarding the logistics of the camp, but these frustrations were not serious enough to deter them from pursuing future camp opportunities. They also expressed a desire for increased networking opportunities with other parents. Previous literature did not consider the importance of the experience of the parents, and as a result failed to recognize how the camps affected them and their children.

Implications for Occupational Therapy

The current study expands the body of literature to include the qualitative components of group treatment. Specifically, mCIMT camps provide intensive treatment in a social context, and have been shown to result in both physical and psychosocial changes (Aarts et al., 2012; Eliasson et al., 2009; Wu et al., 2013). As such, future camp directors should consider the psychosocial components of camp when establishing a protocol. The participants of the current study suggested that their ideal camp protocol would be a full day camp that meets 5 days per week and includes opportunities for parent networking. They also expressed a desire to have regular follow-up sessions to maintain physical changes and friendships.

Based on the suggestions of parents and children, the researchers propose a mCIMT camp experience that emulates typical camp formats. This camp could meet 5 full days per week to make camp easier to manage with typical parent work schedules. The camp would involve 3 hours per day of mCIMT with student buddies and occupational therapists. The remaining time would be spent doing typical camp activities without the constraint. During these hours, the occupational therapists would not be present, and thus parents would not be charged for therapy for the full day. However, student buddies would remain for the full day to further the development of this relationship. Camp activities during these hours would require the use of both hands to encourage carryover of gains made during the mCIMT portion of camp. As the children age, this model could be expanded to include an overnight component as well.

The researchers believe that the psychosocial benefits of group treatment revealed in this study are not specific to mCIMT. As such, therapists should consider implementing group treatment in a camp setting for children with a variety of therapy needs. By providing treatment in a fun and motivating way with a group of children with similar diagnoses, therapists can

create a social context that may amplify the outcomes of the therapy. Previous literature has supported this delivery model. Briery and Rabian (1999) documented the psychosocial outcomes of children who attended camps designed for children with asthma, diabetes, or spina bifida. Following camp, these children had more positive attitudes towards their illness and decreased anxiety (Briery & Rabian, 1999). Since psychosocial benefits appear to be common across many specialized camp programs, occupational therapists should consider developing camp programs for their clients.

Future camp directors should also strive to include qualitative data in their documentation. Physical quantitative measures alone do not represent the complete outcome of the camp, therefore occupational therapists need to document any psychosocial changes they witness during the camp. Occupational therapists could also assess qualitative changes through interviews with parents before and after camp, and at follow-up camp sessions. The camp has the potential to simultaneously target both physical and psychosocial client factors, but without qualitative documentation, the psychosocial changes are at risk of being dismissed as a camp outcome.

Limitations

The participants in this study all attended the same camps. This homogeneity of participants may impact the generalizability of the findings. Additionally, all three of the researchers were student buddies during the 2013 camp, which may have influenced their interpretations of participant responses. It is important to note, however, that the researchers took reasonable measures to prevent any biases from tainting the data, including peer and member checking, reflexive bracketing, and triangulation of investigators. A final limitation of this study was the lapse in time between the end of the camps and the focus groups. The focus groups were

held 6 months after the 2013 camp and 18 months after the 2012 camp. Although the adults seemed to remember their experiences rather explicitly, the children may have had a difficult time recalling more specific details of the camp, including the feelings associated with the camp experience. Furthermore, the children's memories of camp may have been influenced by hearing the responses of other children.

Future Research

Future research studies should continue to build the body of literature regarding the development of mCIMT programs. This includes development of a standardized protocol that is family-centered while still maintaining the intensive treatment necessary for mCIMT. Furthermore, future studies should investigate the use of qualitative outcome measures that are reliable and feasible to administer for a camp. As a profession, occupational therapy would benefit from a randomized controlled trial with a large sample size that utilizes a family-centered protocol and includes both quantitative and qualitative outcome measures.

Additional research should also be conducted regarding the long-term effects of empowering young children with disabilities. Doubt and McColl (2003) interviewed teenagers with physical disabilities about their satisfaction with their integration into academic and community settings. The results indicated that barriers limiting integration included physical limitations, inaccessibility of extra-curricular activities, and exclusion by themselves and peers (Doubt & McColl, 2003). Longitudinal research should be conducted to explore whether the empowerment resulting from programs like mCIMT camps in young children persists into adolescence, which may decrease barriers that limit integration.

Conclusion

The current study documented the experience of four families who participated in a mCIMT camp. The participants emphasized that the fun environment and the relationships built during camp created a social context that facilitated the experience of empowerment. Since previous literature has neglected qualitative information, the findings of this study were previously undocumented. The 2008 Occupational Therapy Practice Framework outlined that empowerment is a “key feature in health and participation” (AOTA, 2008, p. 666). However, empowerment is a construct that can only be represented by qualitative data. As the profession of occupational therapy strives to be science-driven and evidence-based, it is imperative that researchers establish the value of qualitative data. The current study did establish the value of qualitative data regarding the experience of mCIMT camps. These findings can be used to design a mCIMT camp protocol that maximizes both physical and psychosocial outcomes, enabling the children to surpass previous expectations and thrive in the experience of childhood.

References

- Aarts, P. A., van Hartingsveldt, M., Anderson, P. G., van den Tillaar, I., van der Burg, J., & Geurts, A. C. (2012). The pirate group intervention protocol: Description and a case report of a modified constraint-induced movement therapy combined with bimanual training for young children with unilateral spastic cerebral palsy. *Occupational Therapy International, 19*, 76-87.
- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9*, 407-411.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy, 62*, 625-683.
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy, 68* (Suppl. 1), S1-S48.
- Briery, B. G., & Rabian, B. (1999). Psychosocial changes associated with participation in a pediatric summer camp. *Journal of Pediatric Psychology, 24*, 183-190.
- Case-Smith, J., DeLuca, S. C., Stevenson, R., & Ramey, S. L. (2012). Multicenter randomized controlled trial of pediatric constraint-induced movement therapy: 6-month follow-up. *American Journal of Occupational Therapy, 66*, 15-23.
- Cattaneo, L. B., & Chapman, A. R. (2010). The process of empowerment: A model for use in research and practice. *American Psychologist, 65*, 646-659.
- Cerebral Palsy Source. (2005). *Hemiplegia and cerebral palsy*. Retrieved from http://www.cerebralpalsysource.com/Types_of_CP/hemiplegia_cp/index.html

Charles, J., & Gordon, A. M. (2005). A critical review of constraint-induced movement therapy and forced use in children with hemiplegia. *Neural Plasticity, 12*, 245-261.

CHASA. (2013a). *Hemiplegia*. Retrieved from <http://www.chasa.org/medical/hemiplegia/>

CHASA. (2013b). *Hemiplegia, Hemiparesis, Hemiplegic Cerebral Palsy – What’s the difference?*

Retrieved from <http://www.chasa.org/hemiplegia-hemiparesis-hemiplegic-cerebral-palsy-whats-difference/>

Cope, S. M., Forst, H. C., Bibis, D., & Liu, X.-C. (2008). Modified constraint-induced movement therapy for a 12-month-old child with hemiplegia: A case report. *American Journal of Occupational Therapy, 62*, 430–437.

de Brito Brandaõ, M., Gordon, A. M., & Mancini, M. C. (2012). Functional impact of constraint therapy and bimanual training in children with cerebral palsy: A randomized controlled trial. *American Journal of Occupational Therapy, 66*, 672–681.

DeLuca, S. C. (2002). *Intensive movement therapy with casting for children with hemiparetic cerebral palsy: A randomized controlled crossover trial* (Unpublished doctoral dissertation). University of Alabama in Birmingham: Birmingham, AL.

DeLuca, S. C., Echols, K., Law, C. R., & Ramey, S. L. (2006). Intensive pediatric constraint-induced therapy for children with cerebral palsy: Randomized, controlled, crossover trial. *Journal of Child Neurology, 21*, 931-938.

DeLuca, S. C., Echols, K., & Ramey, S. L. (2007). *ACQUIREc therapy: A training manual for effective application of pediatric constraint-induced movement therapy*. Hillsborough, NC: MindNurture.

- Dickerson, A. E., & Brown, L. E. (2007). Pediatric constraint-induced movement therapy in a young child with minimal active arm movement. *American Journal of Occupational Therapy, 61*, 563–573.
- Doubt, L., & McColl, M. A. (2003). A secondary guy: Physically disabled teenagers in secondary schools. *Canadian Journal of Occupational Therapy, 70*, 139-151.
- Eliasson, A., Bonnier, B., & Krumlinde-Sundholm, L. (2003). Clinical experience of constraint induced movement therapy in adolescents with hemiplegic cerebral palsy - A day camp [Letter to the editor]. *Developmental Medicine and Child Neurology, 45*, 357-360.
- Eliasson, A., Boyd, R., Shaw, K., Krumlinde-Sundholm, L., & Ponten, E. (2009). Feasibility of a day-camp model of modified constraint-induced movement therapy with and without botulinum toxin A injection for children with hemiplegia. *Physical and Occupational Therapy in Pediatrics, 29*, 311-332.
- Eliasson, A. C., Krumlinde-Sundholm, L., Gordon, A. M., Feys, H., Klingels, K., Aarts, P. B. M., ... Hoare, B. (2014). Guideline for future research in constraint-induced movement therapy for children with unilateral cerebral palsy: An expert consensus. *Developmental Medicine & Child Neurology, 56*, 125-137.
- Gillot, A. J., Holder-Walls, A., Kurtz, J. R., & Varley, N. C. (2003). Perceptions and experiences of two survivors of stroke who participated in constraint-induced movement therapy home programs. *American Journal of Occupational Therapy, 57*, 168-176.
- Gilmore, R., Ziviani, J., Sakzewski, L., Shields, N., & Boyd, R. (2010). A balancing act: Children's experience of modified constraint-induced movement therapy. *Developmental Neurorehabilitation, 13*, 88-94.

- Gordon, A. M., Charles, J., & Wolf, S. L. (2005). Methods of constraint-induced movement therapy for children with hemiplegic cerebral palsy: Development of a child-friendly intervention for improving upper-extremity function. *Archives of Physical Medicine and Rehabilitation, 86*, 837-844.
- Hoare, B., & Carey, L. (2007). Constraint induced movement therapy in the treatment of the upper limb in children with hemiplegic cerebral palsy: A Cochrane systematic review. *Clinical Rehabilitation, 21*, 675-685.
- Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277-1288.
- Huang, H., Fethers, L., Hale, J., & McBride, A. (2009). Bound for success: A systematic review of constraint-induced movement therapy in children with cerebral palsy supports improved arm and hand use. *Physical Therapy, 89*, 1126-1141.
- Johnston, M. V. (2009). Plasticity in the developing brain: Implications for rehabilitation. *Developmental Disabilities Research Reviews, 15*, 94-101.
- Knis-Mathews, L., Falarano, M., Baum, D., Manganiello, J., Patel, S., & Winters, L. (2011). Parents' experiences with services and treatment for their children diagnosed with cerebral palsy. *Physical & Occupational Therapy in Pediatrics, 31*, 263-274.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*, 214-222.
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research*. Thousand Oaks, CA: Sage Publications.

- Luborsky, M. R., & Lysack, C. (2006). Overview of qualitative research. In G. Kielhofner (Ed.), *Research in occupational therapy* (pp. 326-340). Philadelphia, PA: F. A. Davis Company.
- Morgan, D. L. (1997). *Focus groups as qualitative research*. Newbury Park, CA: Sage Publications.
- Nascimento, L. R., Gloria, A. E., & Habib, E. S. (2009). Effects of constraint-induced movement therapy as a rehabilitation strategy for the affected upper limb of children with hemiparesis: Systematic review of the literature. *Revista Brasileira de Fisioterapia*, *13*(2), 97-102.
- Peacock, N., & Paul-Ward, A. (2006). Contemporary tools for managing and analyzing qualitative data. In G. Kielhofner (Ed.), *Research in occupational therapy* (pp. 358-371). Philadelphia, PA: F. A. Davis Company.
- Reidy, T. G., Naber, E., Viguers, E., Allison, K., Brady, K., Carney, J., ... Pidcock, F. (2012). Outcomes of a clinic-based pediatric constraint-induced movement therapy program. *Physical and Occupational Therapy in Pediatrics*, *32*, 355-367.
- Rostami, H. R., & Malamiri, R. A. (2012). Effect of treatment environment on modified constraint-induced movement therapy results in children with spastic hemiplegic cerebral palsy: A randomized controlled trial. *Disability & Rehabilitation*, *34*, 40-44.
- Sheehan, A. (2012). *Measuring outcomes for pediatric mCIMT: A systematic review* (Unpublished master's thesis). University of Puget Sound, Tacoma, WA.
- Stearns, G. E., Burtner, P., Keenan, K. M., Qualls, C., & Phillips, J. (2009). Effects of constraint-induced movement therapy on hand skills and muscle recruitment of children with spastic hemiplegic cerebral palsy. *NeuroRehabilitation*, *24*, 95-108.

- Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2007). *Focus groups: Theory and practice*. Thousand Oaks, CA: Sage Publications.
- Taub, E. (2012). The behavior-analytic origins of constraint induced movement therapy: An example of behavioral neurorehabilitation. *The Behavior Analyst* 35, 155-178.
- Taub, E., Pidikiti, R. D., DeLuca, S. C., & Crago, J. E. (1996). Effects of motor restriction of an unimpaired upper extremity and training on improving functional tasks and altering brain behaviors. In J. F. Toole & D. C. Good (Eds.), *Imaging in neurologic rehabilitation* (Vol. 9, pp. 133-154). New York, NY: Demos Vermande.
- Taub, E., Ramey, S. L., DeLuca, S., & Echols, K. (2004). Efficacy of constraint-induced movement therapy for children with asymmetric motor impairment. *Pediatrics*, 113, 305-312.
- Wallen, M., Ziviani, J., Herbert, R., & Evans, R. (2008). Modified constraint-induced therapy for children with hemiplegic cerebral palsy: A feasibility study. *Developmental Neurorehabilitation*, 11, 124-133.
- Willis, J. K., Morello, A., Davie, A., Rice, J. C., & Bennett, J. T. (2002). Forced use treatment of childhood hemiparesis. *Pediatrics*, 110, 94-106.
- Winstein, C. J., Miller, J. P., Blanton, S., Taub, E., Uswatte, G., Morris, D., ... Wolf, S. (2003). Methods for a multisite randomized trial to investigate the effect of constraint-induced movement therapy in improving upper extremity function among adults recovering from a cerebrovascular stroke. *Neurorehabilitation and Neural Repair*, 17, 137-152.
- Wu, W., Hung, J., Tseng, C., & Huang, Y. (2013). Group constraint-induced movement therapy for children with hemiplegic cerebral palsy: A pilot study. *American Journal of Occupational Therapy*, 67, 201-208.

Yun-Hee, K., Ji-Won, P., Myoung-Hwan, K., Sung-Ho, J., & Lee, P. K.W. (2004). Plastic changes of motor network after constraint-induced movement therapy. *Yonsei Medical Journal*, 45, 241-246.

Appendix A

Guiding questions for parent's focus group

- Tell us your name, your child's name, and what camps your child attended.
- Tell us how you heard about the camp and what led to the decision to attend the camp?
- Before starting camp, what did you hope your child would accomplish during the camp?
- After the first day of camp, what were your initial impressions of the camp?
- What do you think were your child's initial impressions?
- Did your impressions change as the camp progressed?
- What kinds of things did your child say about camp?
- Did you notice any changes in your child during the camp?
- What was the best part of the camp?
- What was the worst thing about the camp?
- How would you change the CIMT camp?
- What do you think your child would change about the camp?
- If you had a chance to give advice to the parent of a child attending a CIMT camp, what would you tell them?
- Overall, how would you describe the experience of the CIMT camp?
- Is there anything else you think is important for us to know?

Appendix B

Guiding questions for children's focus group

- Tell us your name and how old you are. How many CIMT camps you've been to?
- Practice brainstorming: words about pizza
 - Brainstorming involved writing words and ideas the children had about a certain topic up on a whiteboard. The first question was about pizza to familiarize the children with the process and to model how to bring up both positives and negatives.
- What do you remember about camp?
- What words can you come up with to describe camp?
- What was the best part about CIMT camp?
- What was the worst part about CIMT camp?
- Do you want to go back to CIMT camp?
- How would you change CIMT camp?
- If your best friend asked you about CIMT camp, what would you tell them?
- Is there anything else you want to tell us about camp?

Table 1

Demographics of Focus Group Participants

Child	Age (years)	Gender	Number of parents participating in adult focus group	Camp attended	
				2012	2013
1	8	M	1 (mother)	X	
2	6	F	1 (mother)	X	X
3	7	F	2 (mother and father)		X
4	7	M	1 (mother)	X	X

Acknowledgements

We would like to thank our participants for their time and insightful participation in our focus groups. This project would not have been possible without the support of our committee chair Lucretia Berg, MSOT, OTR/L and our committee reader Tatiana Kaminsky, PhD, OTR/L. We would also like to thank George Tomlin, PhD, OTR/L and Anne Birge James, PhD, OTR/L for their guidance in writing our project proposal. This study was partially funded by the University of Puget Sound University Enrichment Committee.