

December 2016

Examining the Lived Experience of Caregivers Learning a Home Program from a Pediatric Occupational Therapist

Michelle Finet

University of Wisconsin-Milwaukee

Follow this and additional works at: <https://dc.uwm.edu/etd>



Part of the [Adult and Continuing Education and Teaching Commons](#), [Occupational Therapy Commons](#), and the [Other Education Commons](#)

Recommended Citation

Finet, Michelle, "Examining the Lived Experience of Caregivers Learning a Home Program from a Pediatric Occupational Therapist" (2016). *Theses and Dissertations*. 1363.
<https://dc.uwm.edu/etd/1363>

This Dissertation is brought to you for free and open access by UWM Digital Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of UWM Digital Commons. For more information, please contact open-access@uwm.edu.

EXAMINING THE LIVED EXPERIENCES
OF CAREGIVERS LEARNING A HOME PROGRAM
FROM A PEDIATRIC OCCUPATIONAL THERAPIST

by

Michelle Finet

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
in Urban Education

at

University of Wisconsin – Milwaukee

December 2016

ABSTRACT

EXAMINING THE LIVED EXPERIENCES OF CAREGIVERS LEARNING A HOME PROGRAM FROM A PEDIATRIC OCCUPATIONAL THERAPIST

by

Michelle Finet

University of Wisconsin – Milwaukee, 2016
Under the Supervision of Professor Barbara J. Daley

The purpose of this study was to examine the lived experiences of family caregivers as they learned a home program from an occupational therapist for their child. Gaining information from the caregiver on experiences with patient education may enable therapists to develop an understanding of the needs of caregivers during the educational process that occurs when a therapist is giving the caregiver a home program. Meeting the learning needs of the caregivers may possibly reduce the amount of overall therapy needed by the child. This phenomenological approach sought to answer the following research questions: (a) what are the lived experiences of caregivers of children with special needs when learning about delivery of an occupational therapy home program for their child from the occupational therapist, (b) how did the caregiver learn the home program, and (c) what helped or hindered the caregiver in learning the home program from the therapist. These research questions were answered by purposefully sampling nine caregivers of children with cerebral palsy who had experienced learning a home program for their child from an occupational therapist. Two interviews were conducted with each caregiver along with completion of Critical Incident Questionnaires and a diary. Findings indicated that caregivers experienced a range of negative emotions including guilt, being misunderstood and feeling criticized. The caregivers felt communication was key. It helped

when the therapist was patient, compassionate and made the caregiver feel heard. It hindered learning when the therapist was defensive or said things which contributed to the caregiver having negative feelings. Caregivers wanted the therapist to explain why they were being asked to do certain activities within the home program. They wanted information, resources and more time learning how to do what will help the child. Lastly, caregivers wanted the relationship with the therapist to be a partnership.

Therapists could benefit from receiving education on teaching/learning theories such as andragogy, experiential and transformational learning. The therapist would then be better prepared to incorporate teaching approaches and would be better prepared to enter the teaching and learning environment of the therapy session and work with their clients.

© Copyright by Michelle Finet, 2016
All Rights Reserved

I dedicate this dissertation to

Alexander James Finet

You are the light of my life. Thank you for being so patient with me through all my numerous times of saying that I had work to do. You are the most important person in my life and always will be. I love you to infinity times infinity kiddo...

TABLE OF CONTENTS

	PAGE
List of Tables	ix
List of Abbreviations	x
Acknowledgements.....	xi
Chapter One: Introduction	1
Need for Research.....	4
Research Questions.....	7
Purpose of the Research.....	8
Significance of the Research.....	14
Summary	19
Operational Definitions.....	20
Chapter Two: Literature Review	22
A Brief History of Occupational Therapy	22
Paradigms of OT	22
The Client Therapist Relationship	25
Family-Centered Care.....	28
The Impact of a Child's Disability on a Family	32
Client Education.....	34
Other Fields of Literature.....	37
Home Programs for Children with Cerebral Palsy	41
Factors Which May Influence the Caregiver's Experience	43
Stressors	43

	PAGE
Support.....	44
Background of the Caregiver	45
Cultural and racial-ethnic background of the caregiver.....	46
Being a Caregiver	51
Level of Willingness	51
Additional Factors.....	52
Factors Which Influence Caregiver's of Children with Cerebral Palsy	52
Theories of Learning and Teaching	54
Summary	62
Chapter Three: Methodology	64
Framework of the Study.....	64
Research Questions.....	67
Researcher Reflexivity.....	67
Study Design.....	69
Participants.....	71
Data Collection Procedures.....	73
Data Analysis	76
Trustworthiness and Quality Control.....	77
Summary	79
Chapter Four: Results	81
Participants.....	81
Findings	84

	PAGE
Feelings of Caregivers: A Parent's Hurt.....	84
Importance of Communication: Tell Me More.....	92
Helping or Hindering the Learning Process: Thinking Outside the Box.....	99
Summary	103
Chapter Five: Discussion	105
The Feelings of the Caregivers	105
The Importance of Communication	112
The Helping or Hindering of the Learning Process	116
Limitations of the Study.....	119
Implications for Future Research.....	119
Implications for the Preparation of Occupational Therapists	120
Summary	122
References	124
Appendix A: Recruitment Letters.....	149
Appendix B: Common Characteristics of Children with Cerebral Palsy Table	151
Appendix C: Critical Incident Guides.....	158
Appendix D: Diary Questions.....	161
Appendix E: Interview Guides.....	163
Curriculum Vitae	167

LIST OF TABLES

	PAGE
Table 1: Demographic Information for Participants of Study	82
Table 2: Common Characteristics of Children with Cerebral Palsy	152

LIST OF ABBREVIATIONS

ACOTE	Accreditation Council for Occupational Therapy Education
ADL	Activity of Daily Living
AJOT	American Journal of Occupational Therapy
AOTA	American Occupational Therapy Association
FCC	Family-Centered Care
LRE	Least Restrictive Environment
IADL	Instrumental Activity of Daily Living
IDEA	Individuals with Disabilities Education Act
NICU	Neonatal Intensive Care Unit
OPC	Occupational Performance Coaching
OT	Occupational Therapy or Occupational Therapist
OTA	Occupational Therapy Assistant
OTHP	Occupational Therapy Home Program
PAR	Participatory Action Research

ACKNOWLEDGEMENTS

This has been a long journey, longer than expected when I started it. Along the way there have been many people who have impacted my life and without whom I could not have made it to the end. First off, a thank you is necessary to my advisor, Dr. Barbara Daley. You were patient, caring, and thoughtful and always pushed me to do my best. I appreciate you more than you could know. I want to say thank you to my committee who came together to make this research what it is today and helped throughout the process to allow it to finally reach the end. I would like to say thank you to all the educators who had a part of my doctoral journey and worked to instill in me the knowledge that I know will help me far into my future. I would also like to say a fond thank you to Dr. Larry Martin, who was the best educator I've ever had and will always hold a dear place in my memory.

A thank you also goes out to all of my participants. I could not have completed this without your willingness to open your lives and share them with me. I hope this research and experience helped you as I know it helped me.

I also would like to acknowledge and thank the colleagues who supported me along the way as I worked and studied all at the same time. I could not have done this without your moments of understanding and support. Dr. Joyce Engel who was a best friend at the University of Wisconsin-Milwaukee when I was a professor there and who wasn't afraid to give a hug when it was needed. A thank you to all my new colleagues at A. T. Still University who have been understanding and supportive. In particular, Dr. Mary Greer who has been a wonderful new friend and who has commiserated with me over all the struggles in the last push to the end. Dr. Rachel Diamant who always had words of encouragement. And Dr. Gupta, who is never afraid to question me, help me grow and gave me the time I needed to bring this all together.

Last, but certainly not least, I would like to thank my friends and family. A big thank you goes out to my best friends Mara, Matt, Jon and Aaron. You listened when I felt like it was an impossible task to undertake and you reminded me of my strengths. A thank you to my puppies, as anyone who truly knows me knows I couldn't have done this without their cuddles. A thank you to my dad who always helped in unexpected ways. A huge thank you to my mom who was my editor, my food maker, my puppy feeder and who has always been my biggest supporter and cheerleader since the day I was born. And the biggest thank you goes to my son, Alex. Alex, you gave me the freedom to chase my dreams and always understood when 'Mom has to work'. You are the reason I push myself to be better...because I want you to be proud. I love you so much. Thank you for being the best son a mother could ask for.

Thank you to all the people acknowledged here and to the many more who were with me along the way. I fully know I could not have accomplished this without your help and support and I thank you from the bottom of my heart.

Chapter One: Introduction

Occupational therapy is the field that treats people with disabilities or illnesses through the use of activities which are meaningful to them and often involves some level of education for the person. Occupational therapy (OT) began as a field in 1917 and throughout history it has undergone many changes in its viewpoints on the most effective manner of working with clients. The field currently focuses on treating clients from what is termed a client-centered point of view. This involves a change in the dynamics of the client-therapist relationship from how it has been known to exist in the past. This is especially true in pediatric occupational therapy as federal legislation makes it mandatory to involve clients and their families in the decision making process of the therapy process. Therefore, as client-centered services have become more and more a part of everyday treatment delivery, involving the family of the client has become essential. This has taken pediatric occupational therapy practice from being not only a client-centered practice but to a broader more holistic service approach called family-centered practice which focuses on the family as a whole rather than on only the child's needs (Begun, 1996). The importance of caregiver-child interactions is well recognized by multiple fields. In a pediatric setting, this involvement of the family is imperative as the child relies on his/her caregiver for a variety of functions.

It is true that including families in the therapy process with children is not only best practice, but it is also mandatory under federal legislation (Bazyk & Case-Smith, 2010). In 1975, Congress enacted the *Education for All Handicapped Children Act* (also, known as EHA or Public Law 94-142) as a method of helping meet the needs of children with disabilities to receive the services they needed in the school system. In the times before this act was passed it was commonly accepted in society for children with disabilities to be institutionalized in group

homes. In 1967, records showed that almost 200,000 persons with disabilities were living in state institutions (U.S. Department of Education, 2007). In these settings persons with disabilities were taken care of by providing them with the basic needs to live without any concern regarding their education or improvement. As programs and services such as early intervention and Head Start were implemented under pressures from advocacy associations and parents of children with disabilities, federal laws began to be implemented to provide the support needed. It was in this social environment that Public Law 94-142 (PL 94-142) was ratified. It was meant to address the more than one million children unable to receive services from the educational system due to their disabilities and the additional children who had only limited access (U.S. Department of Education OSEP, n.d.). The four stated purposes of PL 94-142 were as follows:

- to assure that all children with disabilities have available to them...a free appropriate public education which emphasizes special education and related services designed to meet their unique needs
- to assure that the rights of children with disabilities and their parents...are protected
- to assist States and localities to provide for the education of all children with disabilities
- to assess and assure the effectiveness of efforts to educate all children with disabilities

The act served to mandate how children with disabilities should be served in the school system to allow them to receive an education comparable to a child without disabilities. The original act was amended in 1983 (PL 98-199), 1986 (PL 99-457), and 1990 (PL 101-476), at which time a

change of name occurred to change it to the *Individuals with Disabilities Education Act*. It was further amended in 1992 (PL 102-119), and 1997 (PL 105-17) to include providing services and programs to children with disabilities from birth through school and to allow for the transition services from the school setting to leading an adult life (U.S. Department of Education, OSEP, n.d.). The law was re-authorized in 2004 and is now commonly referred to currently as IDEA 2004.

Another important change that occurred in the 1997 amendments, besides strengthening the role of parents and looking at the services provided, was the concept of least restrictive environment (LRE). The idea of LRE is that children should be educated in an environment with children without disabilities whenever possible; they should also be able to have the same access to services, programs and educational opportunities. Under IDEA 2004, children with disabilities should be given additional services such as therapy or school aides to allow them to be in the least restrictive environment possible. These changes have lead to what is termed mainstreaming and/or inclusion of children of disabilities into regular education classrooms. The difference between the two is that mainstreaming involves the child with disabilities being in the regular classroom all day, whereas inclusion usually refers to the child with disabilities being in a regular education classroom for only a part of the day (which may be during nonacademic times). As IDEA 2004 provides for therapy services in as natural an environment as possible, services have moved into classrooms and homes rather than clinics or therapy rooms as often as possible.

This shift to the home environment allows for not only natural environments to be the setting for therapy sessions, but also for more full involvement of the family caregivers. Although the law applied primarily to pre-school age children for the home environment and

school aged children for the school environment, its effects can be seen throughout the pediatric rehabilitative field. Family-centered services are considered best practice whether the child is younger and being seen in the home or older and being seen in the clinic/classroom. Therapists involve families to varying degrees in the therapy session, as well as, in goal-setting and carryover of services. The family has many experiences interacting with the therapist who is working with their child, one of which is the experience of being educated by the child's therapist on what types of activities and exercises should be done with the child when the therapist is absent. The focus of this study was to describe what the primary family caregiver experiences when being educated on how to deliver a home program for his/her child with special needs. This study sought to gain information on how therapists can best provide services for families by uncovering the caregivers' perspective of how learning from the therapist occurs. It sought a more in-depth comprehension of what families experienced in the educational process and what the family needed the therapist to do to allow them to be able to learn from the therapist in a more effective manner. This comprehension can provide information that will allow for the possibility of better training and preparation of therapists prior to their working with family caregivers in pediatric practice.

Need for the Research

In working with the families of children with disabilities, time is a valuable commodity. Often the therapist is with the child only one hour per week. This is not viewed by therapists to be enough time to effect real change. It is more likely that positive changes will occur if the child with special needs is able to practice the needed skills throughout the week in between therapy sessions. Therefore, it is imperative that the therapist use the hour of time to educate the family caregiver on what he/she can do for his/her child when the therapist is not present. This

allows for the interventions to be more effective and to maximize the potential for the child to develop the needed skills as quickly as possible. Occupational therapy home programs (OTHP) allow for the repetition and practice of activities and exercises defined by motor learning and motor control theories. Practicing these programs in the natural environment is key to success (Jaffe, Humphry & Case-Smith, 2010).

Pediatric practice success is dependent upon having the primary caregiver play an active role in the child's treatment. The caregiver experiencing this educational process is learning from the therapist through the teaching of self-management techniques. This empowers the caregiver to make decisions regarding his/her child's development and allows the caregiver to take the proper action necessary to help his/her child with special needs. The importance of involving the parent is a given and family-centered care recognizes the significance that family members play in the child's life. It is generally understood that children need a caregiver to provide shelter, food, and other necessities of life the most important of which is love. It is partially through the caregiver that a child learns his/her values, responsibilities, social and cultural norms, and how to set goals. Caregiver-child interactions are important enough that they are considered to be essential to child development. In researching attachment theories it has been shown that disruptions in the child-parent relationship contribute to future difficulties in many areas of a child's life and are a predictor of psychopathology (Berlin & Cassidy, 2001; Cassidy, 1999; Green & Goldwyn, 2002; Olson & Esdaile, 2000). The effects of the caregiver on the child interactions during play have also been well documented. For example, it has been shown that children participated in higher developmental play more frequently and for longer periods of time when interacting with a caregiver than when playing by themselves (Belsky, Goode & Most, 1980; Bornstein, Haynes, O'Reilly, & Painter, 1996; Bornstein, Haynes, Pascual,

Painter & Galperin, 1999; Daunhauer, Coster, Tickle-Degnen & Cermak, 2007; Fiese, 1990; Slade, 1987). Research has additionally shown statistically significant relationships between parent interaction and the rate of development of children over the years, with higher levels of parent interaction being correlated with a better rate of development (Brooks-Gunn & Lewis, 1984; Mahoney, Bryce, Fewell, Spiker & Wheeden, 1998). All of this research helps support the common assumption held by therapists that involving the caregiver in therapy facilitates progress of the child. Therefore, the important role of caregiver-child interactions must be considered when treating the child client. The family-centered approach values this role.

It has been established that OTHP provided in the natural environment and provided by the child's caregivers are key elements to moving the child forward in his/her development. One would assume that OTHP are always followed through by those to whom the OTHP are given. This, however, would be a faulty assumption. A study by Rone-Adams, Stern and Walker (2004) which examined compliance with home programs by caregivers of children with disabilities found that sixty-six percent of caregivers reported some level of non-compliance with the home program. They also found the level of compliance to be significantly and negatively correlated with the amount of stress the caregiver was experiencing at the time; in other words, the higher the stresses in the caregiver's life, the less likely he/she was to complete the home program with the child. There exists the need to discover what can help increase the likelihood of caregiver's delivering home programs to his/her children even when the caregiver is under stress. Uncovering the caregiver's experience in learning the home program for the child with special needs will help provide information about one piece of this larger puzzle. The problem is that, at this time, therapists do not fully understand a caregiver's experience learning and trying to carry out the OTHP with their child; therefore, therapists are missing information that can help

increase the likelihood of the OTHP being successfully carried out and furthering the progress of the child.

Research Questions

The question then becomes whether therapists know how to educate others in an effective manner. Lawlor and Mattingly (1998) found that “practitioners feel a strong lack of formal training or available models for addressing family needs” (p. 264). This would seem to indicate that therapists themselves do not feel prepared to educate the families of the clients with whom they work. This is detrimental to the therapy process as “caregivers need to feel empowered to shape recommendations to fit their life-styles, values and goals so that they can adapt and successfully use treatment recommendations beyond the period of service delivery” (Clark, Corcoran & Gitlin, 1995, p. 588). It is important to study from the caregiver’s perspective, whether or not the therapist is able to impart knowledge effectively and if the caregiver feels the experience of learning the home program is what they need it to be. The major research questions of this study therefore were:

1. What are the lived experiences of caregivers of children with special needs when learning about delivery of an occupational therapy home program to their child from the occupational therapist?
2. How did the caregiver learn the home program?
3. What helped or hindered the caregiver in learning the home program from the therapist?

In answering these questions, this study allowed for insight into the caregiver’s experience in learning the home program and what caregivers felt their needs were. This contributes to the existing body of research on the subject by addressing a piece which has been thus far missing.

Purpose of the Research

The purpose of this research study was to examine the lived experiences of a family caregiver learning a home program from a pediatric occupational therapist for his/her child with special needs. Many viewpoints exist on the educational process of the parent learning to deliver a home program and why it succeeds or fails. One viewpoint that has not been studied in depth has been from the view of the parent, the person that was asked to execute the OTHP with his/her child. For example, the literature provides guidelines on family-centered delivery of services including considering how to develop effective relationships, how to establish shared goals for intervention, and the influence of the therapist (Clark, Corcoran & Gitlin, 1995; Hanna & Rodger, 2002; Humphry, 1989; Peterander, 2000). Both Segal and Hinojosa (2006) as well as Novak and Cusick (2006) proposed strategies of how to increase compliance of caregivers through the construction of effective home programs. Additional research has focused on the shift in how relationships between therapists and caregivers of children with disabilities have changed over time (Brown, 2004; Hinojosa, Sproat, Mankhetwit, & Anderson, 2002; Lawlor & Mattingly, 1998; Peterander, 2000). There has even been literature on parent's perceptions of both home programs and therapists which provides a view as to how parents view the influences of these in their lives (Green, 2001; Harrison, Romer, Simon, & Schulze, 2007; Hinojosa, 1990; Hinojosa & Anderson, 1991; Jones, Rodger, Broderick & Monte, 2009; King, King & Rosenbaum, 1996; King, Law, King & Rosenburg, 1998; Knox, Parmenter, Atkinson & Yazbeck, 2000; Piggot, Hocking & Paterson, 2003; Piggot, Paterson & Hocking, 2002; Reid, Imrie, Brouwer, Clutton, Evans, Russell & Bartlett, 2011; Segal & Beyer, 2006).

One of the missing pieces has been to look at the relationship from the caregiver point of view and examine how they experience the actual act of learning how to execute the home

program for the child from the therapist. Only two studies have considered this piece thus far. Harrison, Romer, Simon and Schulze (2007) considered factors influencing mothers' learning from their therapists from the mother's perspective. Only one mother in the study reported discussing her preferred method of learning with her therapist; the rest settled for learning however the therapist chose to teach and deliver the information. Asking questions and receiving handwritten information was agreed upon by all to be important. Also, the mothers felt the stronger the relationship they had with the therapist, the easier it was for them to engage in the process of trying to learn from the therapist. The study reported limitations of having a fairly homogenous group of participants as all the mothers had been receiving therapy from the same center for an extended period of time, they were pleased with the services they were receiving and they were all female caregivers. It was recommended by the researchers that further research be conducted with other demographic groups in this same area of study. A second study by Peplow and Carpenter (2013) was set up very similar to this current study and used interviews to research the lived experiences of parents in regards to their child's home exercise program as presented by their physical therapist. The study was completed in the United Kingdom and the participants included four English-speaking parents who had a child with cerebral palsy between the ages of 3 and 11. The study reported three themes: 1) exercise program management and delivery, 2) perceived feelings and responses, and 3) external impact and support. Under the first theme, parents reported wanting to help their children become as independent as possible, however, there was wide variance in their opinions as to how the home program should be modified. Some parents wanted exercises in which siblings could be involved and others wanted a very prescriptive, logical order to their exercises. This suggested the need for individualized home programs. Parents also had strong feelings in regards to the

physical therapist and wanted a therapist who had a positive relationship with the family and who was experienced. They felt more experienced therapists could better adapt the exercises to different situations, as well as, set more realistic therapy goals and manageable exercise routines for the child. Under the second theme, perceived feelings and personal responses, the parents reported feeling “under a lot of pressure to carry out the exercises and this led to feelings of stress and isolation” (Peplow & Carpenter, 2013, p. 291). The parents discussed the considerable time commitment it took to carry out the home program and the significant impact it had on family relationships. They also stated that the tactics used by their children to avoid doing the exercises led to additional negative feelings of isolation, frustration, and guilt causing the parents to feel overwhelmed and emotionally upset. On the more positive side, the parents also did feel pride in their child’s achievements and when they saw improvements as a result of the exercise. Lastly, under the third theme of external support and impact, parents felt the lack of appropriate equipment to support exercise, as well as, lack of support from the therapists were both issues. Parents expressed frustration at not having the right equipment or not knowing where to obtain or purchase the pieces. The parents wanted support from their physical therapist in regards to communication about the use of equipment and on their behalf when dealing with other health care professionals. The authors of the study recommended physical therapists take an approach of empowering parents and families in order to have the therapy be guided by the unique needs of the parents and the children. As this study only had four participants, it was suggested by the researchers that it was unlikely saturation had been reached. They recommended further research be carried out in this area.

Korfmacher, et al. (2008) stated the need for studies to begin examining the caregiver’s experiences in relation to home services being provided (termed home visiting in the article) as a

suggestion for future research. Novak (2011) declared her research to be the first study examining the parents' perspective to allow therapists to learn from the caregivers. This study reported the parent's views on what the therapists should consider in providing participation-based home programming. However, this study did not look in depth at the actual experience the parent had in learning from the therapist nor was it without limitations. One of the major limitations of the Novak study existed in that the researcher was already known to the participants as the person who provided their children with therapy services. This may have influenced the participants' willingness to report negative experiences regarding the home programming given to them by this therapist/researcher. In this current study, however, the purpose was to gather information from the caregiver of the child with special needs on his/her experiences learning from his/her own child's individual therapist. Participants were asked what each felt the therapist could do to help the caregiver learn how to deliver the home programs.

There are many things which may factor into a therapist being effective in providing education about home programs from the caregiver's point of view. For example, Dreeben (2010) suggested that therapists are not currently taught how to be teachers when they are students in occupational therapy programs. They are taught techniques such as verbal interviewing skills and personal interaction skills, however, the basics of having a philosophy of teaching, understanding learning and teaching theories and being given methods for teaching information are not presented in a sufficient manner. This gap in teaching and learning knowledge may have an impact on the therapist's ability to deliver pertinent information to their clients and the families of their clients in an effective manner. Another factor that may impact the success of a caregiver being able to deliver the home program after the therapist leaves would be whether the caregiver was taught any self-management skills. Self-management skills allow

the caregiver to understand how to make minor modifications to the home program on their own when problems delivering the program are encountered. It is important that caregivers experience development and strengthening of their self-management skills when being educated by the therapist. This is because:

Whereas traditional education offers information and technical skills, self-management education teaches problem solving skills. While traditional patient education defines the problems, self-management education allows patients to identify their problems and provides techniques to help patients make decisions, take appropriate actions, and alter these actions as they encounter changes in circumstances. (Bodenheimer, Lorig, Holman & Grumbach, 2002, p. 2471)

Parents want to be educated and they want to be a partner in the therapeutic process (Knox, Parmenter, Atkinson & Yazbeck, 2000). They desire information regarding their child's development, diagnosis, disability, therapeutic activities to help their child and methods to cope with the disability as well as what to expect in the future (Jaffe, Humphry & Case-Smith, 2010). Understanding the experience caregivers have when receiving this education is beneficial for all sides as the family can feel heard regarding their needs. In being willing to learn from the caregiver, the therapist can more likely ensure a higher chance and rate of success for the child the therapist is responsible for treating. This is especially true as "patient education has been shown to improve patient adherence with interventions, outcomes and satisfaction" (Dreeben, 2010, p. 35).

One additional way therapists may not be effective in teaching the caregiver of the child requiring the home program is in designing the learning environment. In setting up the environment, one must first consider the different dimensions involved in learning. Jarvis

reminds us that “the learner is a whole person made up of the mind and the body and comes to a learning situation with a history, biography that interacts in individual ways with the experience that generates the nature of the learning” (Merriam, Caffarella & Baumgartner, 2007, p. 101). The environment must support all the different dimensions of learning by relating to the whole person in a holistic manner. In other words, understanding that biological and psychological experiences have occurred in the context of the surrounding societal influences is imperative if the adult student is going to make the connections from the new material that they are trying to learn to their pre-existing base of knowledge. The learning environment must not be centered on what Friere would term banking education in which “the ‘all-knowing’ teacher deposits knowledge into the passive students who serve as receptacles for this knowledge” (Merriam, Caffarella & Baumgartner, 2007, p 140). If the therapist sets up an environment in which the therapist maintains control over what will be taught to the caregiver and how the caregiver should resolve any difficulties he/she experiences, then the therapist takes away the ability for the caregiver to be self-directed in learning and in providing the home program. Instead, Dewey refers to having an environment that allows the adult student the ability to connect what he/she has learned from current experiences to those in the past as well as see possible future implications for it to be truly meaningful (Merriam, Caffarella & Baumgartner, 2007). Therefore, when deciding how to set up the environment, it is important to remember how adult learners learn. This will help the therapist understand what he/she should do to set up an environment that will promote applicable learning situations and successful outcomes for clients. Currently, therapists may not be thinking about these considerations when setting up the learning environment for the caregiver and this may be one of the barriers in the process of the therapist educating the caregiver in how to provide the home program for his/her child. The ability of the

therapist to teach, how a caretaker learns, and designing the environment to fit are only three examples, from what could be a long list of obstacles, that could make the experience caregivers have learning how to deliver the home programs less conducive to their needs. This study aimed to discover what the caregiver viewpoint on this subject was currently.

Significance of the Research

As well as adding to the body of research for the field of occupational therapy, this research study holds further significance in three ways. First of all, there are numerous children with disabilities requiring therapy services at this time that could benefit from any increased quality of therapy services. Secondly, as the healthcare field continues to stress productivity levels of therapists while expecting higher and higher measurable outcomes, having increased successful progress of the child may lessen the pressure on therapists from where it currently stands. Lastly, having information from the caregiver point of view on how therapists can better meet their needs in the experience of learning the home program will help current therapists. This information can also be considered at the curricular level of occupational therapy programs when preparing students to be future therapists. Each of these areas of significance can be explored further and more in depth.

The United States Census Bureau (U.S. Department of Commerce, 2012) reported that in 2010 there existed 289,000 children under 3 years old, 465,000 children ages 3 to 5 years old, and 4.5 million children ages 6 to 14 years old who had a disability. According to the 2009/10 National Survey of Children with Special Health Care Needs, there were an estimated 2,932,328 children in the United States who required either physical, occupational or speech therapy services. In Wisconsin alone, according to the United States Census American Community Survey 2014 data, there were 56,570 people with a disability aged from birth to 17 years old; in

Arizona for the same ages there were 57,013 people. According to the 2009/10 National Survey of Children with Special Health Care Needs, there were 50,678 children in Wisconsin and 58,092 children in Arizona who required either physical, occupational or speech therapy services. These numbers indicate a high number of potential children who may be positively affected if recommendations can be made regarding how a therapist may better help a caregiver deliver a home program to the child with disabilities from the caregiver point of view.

Secondly, this research study holds significance as the push for productivity and detailed documentation sometimes makes it difficult for therapists to develop relationships with clients beyond the superficial level (Devereaux, 1984). However, in today's healthcare field the need for proving that therapists can provide functional outcomes for the client and that the treatments are effective is high as payers demand proof of these accomplishments (Chen et al, 2004). As healthcare costs continue to soar and budgets are being cut, client education to assist in facilitating treatment can help to reduce the overall costs of treatment. For example, client education in the medical field overall has saved on costs due to reduced hospitalizations as Bartlett (1995) found in his study that "for every dollar invested in patient education, \$3-4 were saved" (p. 89). Gaining information from the caregiver on their experiences with patient education enables therapists to develop a better understanding of the needs of caregivers during the educational process. Meeting the needs of the caregivers in their learning experiences on how to deliver home programs to their children with special needs enables a more productive learning experience that in turn reduces the amount of therapy needed by allowing the child to progress in developing the needed skills at a faster rate of progress. When this occurs it helps demonstrate the effectiveness and efficiency of occupational therapy services being delivered to children with special needs.

Lastly, from inception occupational therapy education was valued when it had a broad-based foundation in the liberal arts (Colman, 1990). Leonardelli and Gratz (1986) discuss that the main conflict existing in the early field of occupational therapy regarding curriculum was the decision as to whether to have curriculum be more technical based or more focused on the development of critical thinking skills and problem-solving ability. The trend has been for the curricula of occupational therapists to be more theoretically based while the education of occupational therapy assistants is more vocationally based. The question then remains as to whether or not the training of occupational therapists to provide a quality educational experience for their clients occurs in curriculum across the country.

Humphry and Link (1990) conducted a survey of 43 occupational therapy academic programs regarding the preparation of their students to work with children with special needs. They also selected nine therapists to serve as experts to generate suggestions regarding the education of students. It is interesting to note neither the curriculum nor the expert panel's recommendations mentioned the need to educate therapists to be effective teachers of others.

Schemm, Corcoran, Kolodner and Schaaf (1993) described a curriculum based on systems theory. Their overview suggested the idea was to plan a curriculum revolving around preparing a "knowledgeable and skilled practitioner who is able to function in medical as well as community-based organizations" and who "uses the occupational therapy process, research and his or her own abilities to deliver quality client services" (p. 625). Their curriculum, however, also did not include any coursework regarding giving students the skills to be teachers of others.

In 1995, Royeen proposed a problem-based learning curriculum. She stated that this proposal was based on the idea from Dewey, an educational theorist, regarding that "reflective thinking is a self-initiated deliberation of beliefs and knowledge" (p. 338). Although the

curriculum was based on ideas from the world of education, again coursework was not added to allow students to learn to be effective teachers.

Brown, Humphry and Taylor (1997) considered the family therapist relationship and its implications for how education should be provided to occupational therapy students. In doing so they stated explicitly that “professional skills required.... include knowledge of teaching strategies for transmission of home program recommendations at a level appropriate for the family’s cultural and educational background” (p. 600). However, when making recommendations for the education of students, the strategy was focused on developing interviewing and interpersonal skills with no mention of the teaching strategies directly being taught.

In 2005, Bruder and Dunst completed a survey of special education, physical therapy, occupational therapy, speech therapy and multidisciplinary personnel programs regarding their training of students in the practices of early intervention. Early intervention practices include the practice of family-centered care which entails the therapist and the caregiver using teaching and learning skills. In total 155 surveys were returned with 69% of the 64 occupational therapy programs having responded to the survey. While the study showed the programs reflect their curriculum as covering family-centered practices, the details regarding whether the programs taught their students any information about the educational experience that occurs between a caregiver and the therapist was not examined.

In 2009, the American Occupational Therapy Association (AOTA) put together what was termed the Blueprint for Entry-Level Education and it was formally published in the January/February 2010 issue of the American Journal of Occupational Therapy (AJOT). The stated purpose of the blueprint was to identify the content knowledge that should be received by

students in their educational programs. Under the skills portion it mentions employing learning strategies, coaching, interviewing skills, written and oral communication and teaching strategies to the public. Furthermore, the Accreditation Council for Occupational Therapy Education (ACOTE) sets the standards by which occupational therapy programs become accredited. The August 2015 version of the current ACOTE Standards and Interpretive Guide has two standards specifically speaking to preparing therapists to educate others. The first standard, B.5.18 states that the student will “demonstrate an understanding of health literacy and the ability to educate and train the client, caregiver, family and significant others, and communities to facilitate skills in areas of occupation as well as prevention, health maintenance, health promotion, and safety” (p. 26). The second standard, B.5.19, states that the student must be able to “apply the principles of the teaching-learning process using educational methods to design experiences to address the needs of the client, family, significant others, communities, colleagues, other health providers, and the public” (p. 26). However, many curricula of occupational therapy programs do not cover in depth learning philosophies, learning/teaching theories or specific teaching strategies as compared to other disciplines. For example, at one large local university in the Midwest the physical therapy curriculum provides their students with an entire course on concepts related to the education of others while the occupational therapy program students are provided with only one lecture in their entire curriculum. Occupational therapy students are commonly expected to understand how to teach others based on learning skills regarding interpersonal communication, interviewing and in having a strong knowledge base regarding occupational therapy itself. Anyone who has known someone that was an expert in their field but was lacking the skills to deliver that expert information to others will know that having a strong knowledge base is not enough. Collecting information on how caregivers of children with disabilities feel about their

experience of learning how to deliver home programs from their therapists may help better inform occupational therapy programs on how to effectively prepare their students to be teachers of home programs.

Summary

In brief, this study examined the lived experiences of family caregivers as they learned a home program from an occupational therapist for his/her child. It additionally looked at how the caregivers learned the home program and what helped or hindered the process. In Chapter Two, additional literature is reviewed to establish the current knowledge that exists in relation to the focus of this study. Chapter Three covers the methodology which was used for this study as well as how data analysis was conducted. Chapter Four reports the findings of the study in answer to the research questions. Finally, Chapter Five discusses the implications of the findings of this study as well as the study limitations and areas of potential future research. Chapter Five concludes with recommendations for changes to educational curricula for occupational therapists.

Operational Definitions

Areas of Occupation – categorical system of the Occupational Therapy Practice Framework, (AOTA, 2008) to sort occupations; the categories are activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure and social participation

Activity – defined by Golledge (1998) as an activity being performed which holds no meaning or special relevance to the person completing it and used in therapy as a step towards preparing the person for purposeful activities or occupations; tend to be tasks focused on remediating the function of body components

Activity of Daily Living (ADL) – activities that are oriented towards the care of one's self; listed in the OT Practice Framework (AOTA, 2008) as bathing/showering, bowel/bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity and toileting hygiene

Child with Special Needs – child aged anywhere from six to twelve years of age who has a disability due to a congenital or acquired disease, traumatic injury or other medical condition which causes either an interruption or a difficulty in the child performing in any of the areas of occupations that they need to participate within

Client Centered Practice – defined by Law, Baptiste & Mills (1995) as an approach which recognizes both the importance of the client having choices in terms of being able to be the decision maker as to what occurs in therapy and the need to ensure therapy itself is contextual

(Family) Caregiver – the person who is responsible for the child's well-being and is the primary contact for the therapist when the child is in the therapy session

Family Centered Practice – therapy which places the entire family as the central decider of the path of therapy; often misunderstood and instead thought of as having the parents participate by providing information and/or having them complete the home program (Begun, 1996)

Health Literacy – is defined by Healthy People 2010 (U.S. Department of Health and Human Services, n.d.) as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”

Home Program – activities and occupations introduced by the therapist to the family to be performed with the child while the therapist is absent in order to continue to work on building skills needed to meet goals in therapy

Instrumental Activity of Daily Living (IADL) – activities focused on supporting home and community daily life which are considered to be more complex than those activities considered to be an activity of daily living; examples of the most applicable categories of IADL’s for children in the OT Practice Framework (AOTA, 2008) would be care of pets, communication management, community mobility, health management and maintenance, religious observance and safety and emergency maintenance

Occupation – a multi-dimensional, complex, purposeful activity being performed that holds special meaning and purpose for the person completing it (AOTA, 2008)

Primary Purposeful Activity – defined by Golledge (1998) as activities which are goal-directed and hold purpose for the person completing it but which lacks a sense of proper contextual/environmental setting.

Chapter Two: Literature Review

A Brief History of Occupational Therapy

In March of 1917, a small group of people including George Barton, William Dunton, Eleanor Clark Slagle, Susan Cox Johnson, Thomas Kidner and Isabel Newton, met to form the National Society for the Promotion of Occupational Therapy and the field of Occupational Therapy (OT) was born (Sabonis-Chafee & Hussey, 1998). In 1921 the Society's name would be changed to the American Occupational Therapy Association (AOTA), the name it still goes by today as the national organization for occupational therapists. The first OT educational program for the training of new occupational therapists was started in 1918 at Downer College, which has been subsumed at this time into the University of Wisconsin – Milwaukee.

During World War I, as soldiers were coming back wounded from the war, the field of occupational therapy had its first real boom and truly moved into the field of treating physical disabilities. Additional schools, above what already existed, were started at that time to meet the need for additional trained occupational therapists. World War II again brought the demand for more practitioners and the field continued to grow. Throughout its evolution the field of occupational therapy has expanded into many diverse areas including, but not limited to, physical rehabilitation, mental health, pediatrics, gerontology, community based services, ergonomics and assistive technology. The field of occupational therapy has continued to conduct research in order to provide the basis for evidence-based practice and grow its knowledge base.

Paradigms of OT

Over time the field of occupational therapy has undergone many transformations in its world view. The moral treatment movement in the early years of the profession provided fundamental concepts to early occupational therapists (Kielhofner, 2004). The concepts of this

movement were based upon the idea that people who were mentally ill could best be healed through involvement in activity. Participation in activities was provided as treatment for their illness. This idea was the basis of the first paradigm of occupational therapy known as the paradigm of occupation started in the early 20th century (Kielhofner, 2004). It was under this paradigm the first occupational therapists began using activities of daily living to rehabilitate people who were recovering from illness or disability. For example, the therapist may have used sewing a garment for her child as a way to rehabilitate a mother who was showing signs of depression, or he/she may have used building a birdhouse as treatment for a man interested in carpentry who had hurt his hand.

During this same time, the majority of the medical field was working under a reductionist model of medicine. When taking a reductionist view, a client is reduced to his/her illness or disability and treatment is aimed at fixing the part that is 'broken'. The person is broken down into pieces rather than viewed as a holistic and whole being. The field of medicine in the 1940's and 1950's, with this viewpoint as the central premise of thought, began to place pressure on the field of occupational therapy to explain itself in terms of a more biomedical, reductionist viewpoint. At the time, occupational therapy was considered to be an arts and crafts type of therapy. Those in the profession had not documented the successes seen with clients using the model of thought under the paradigm of occupation and the profession thus could not hold up to scrutiny from the medical field. Therefore, the second paradigm of OT, known as the mechanistic paradigm, began as therapists worked in an effort to be taken seriously and feel validated in practice (Kielhofner, 2004). This paradigm centered on the belief that dysfunction could be traced to abnormal development or damage of the neurological or musculoskeletal systems. Function could be restored by addressing those deficits or by compensating for them.

The field then focused on developing specific assessments such as range of motion measurements and forming measurable, objective goals. Many therapists stopped using meaningful occupations during this time for the treatment of their clients (Kielhofner, 2004). The interventions went from the use of meaningful occupations to structured activities such as cone stacking. These structured activities were disengaged from being meaningful. For example, a man may be asked to sand wood as therapy however it was no longer to build a birdhouse to address his love of carpentry, but was instead used only to strengthen his hand.

Over time therapists began to see the limitations of this form of practicing therapy. Clients didn't understand why they were engaging in the activities the therapists were asking them to do; it was difficult for clients to relate an activity such as cone stacking back to anything they needed to do in their daily lives. In the 1960's and 1970's, a group of occupational therapists called for a restructuring of the profession as a whole and wanted to once again have elements from the first paradigm of occupation as the basis for practice (Kielhofner, 2004). The contemporary paradigm, as termed by Kielhofner (2004), has returned to engaging clients in meaningful occupations as the basis for therapeutic interventions. It has incorporated the information learned from reducing a person to their impairment with a more holistic view of the person. The new paradigm is based upon a systems theory approach in which the whole is considered to be more than just the sum of one's parts. It is believed that "the meaning that is experienced in the therapeutic process determines the impact of the activity on the individual" (Kielhofner, 2004, p. 69). This new paradigm sets the basis for involving clients in the therapeutic process as crucial. Under the contemporary paradigm, if the therapist is to provide a meaningful experience for the client, the therapist must understand first what the client considers

to be important in life. In order to do this then, it is critical that the therapist develop a strong relationship with the client from the very beginning.

The Client Therapist Relationship

Both the therapist and the client arrive at the therapy sessions with some form of expectation regarding what the other will do and say. Under the mechanistic paradigm, therapists placed themselves in the role of the expert. This is often a role that clients feel most comfortable with as this is what they are used to encountering during medical visits with physicians. Under the contemporary paradigm however, collaboration with the client is a key factor to a successful therapeutic relationship.

The question thus arises as to how a therapist should conduct themselves in order to facilitate this collaborative interaction. Peloquin (1990) suggested that it is important for the therapist to have a blend of competence and caring. The therapist must be skillful and technically advanced and yet also show a sense of empathy for the client. If the therapist sides too much on the side of competence, they become nothing but a technician to the client and the emotional connection is lost. This emotional connection is important as it builds trust and allows the client to feel comfortable with the therapist so he/she can then open up to his/her therapist regarding the thoughts and emotions he/she has about his/her disability and about therapy. The technical therapist also tends to rely on protocol therapy versus individualized therapy. This is not beneficial as:

A focus on fixing bodily parts and functional problems leads to a tendency to disregard a patient's understanding or feelings about illness. To a patient, the disregard feels technical rather than personal. A reliance on protocols that have success, authority and reliability leads to a tendency to deny a patient's control, to

dismiss a helper's intuition about what is right. To a patient, this preeminence of protocol feels impersonal and authoritarian. (Peloquin, 1993, p. 941)

On the other hand, if the therapist becomes too caring then he/she may take on the role more similar to a parent in caring for the client and cross professional boundaries that are unethical to cross. It is very easy to become a friend to someone who shares intimate details of their life with you. However, when this occurs the therapist enters the gray area of having his/her decision making process influenced by and/or biased due to personal feelings. This leads to the therapist providing different treatment to the client because he/she is a friend and not only a client. Therefore, finding the balance between competence and caring is imperative.

In addition, for facilitation of the collaborative relationship to occur the client must feel able to understand the therapist as well as be heard by the therapist. This is one of the main ideas behind the theory of providing client-centered care, which is considered to be best practice in the field of occupational therapy. Client-centered care can be defined as:

An approach to providing occupational therapy which embraces a philosophy of respect for, and partnership with, people receiving services. Client-centered practice recognizes the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to a therapy encounter, the benefits of client-therapist partnership and the need to ensure that services are accessible and fit the context in which a client lives. (Law, Baptiste & Mills, 1995, p. 253)

Law, Baptiste and Mills (1995) defined the concepts of client-centered practice as being autonomy, partnership/responsibility, enablement, contextual congruence, accessibility/flexibility, and respect for diversity. Autonomy is based on the thought that each

client is unique and an expert on their own life and life experiences. Partnership/responsibility discusses the need to have a balance of power between the client and therapist to allow for an inter-dependent partnership to form. The client is more responsible for their own care in this model and the therapist acts more as a facilitator to achieve the client's goals. Enablement is the concept that clients need to be empowered by providing them information to allow them to make decisions regarding their own life and needs. Contextual congruence means that the client's roles, interests, environments and backgrounds must be considered in the therapy process. Accessibility and flexibility refer to providing services in a timely, accessible, flexible and dynamic manner in which the therapist exhibits openness and honesty within the relationship. Respect for diversity speaks to the therapist not imposing their own values upon clients and instead recognizing the client's own value system, strengths and resources that he/she brings to the therapy relationship. These concepts provide the framework upon which client-centered therapy is built.

There are some difficulties in implementing client-centered care. Wilkins, Pollock, Rochon and Law (2001) found that challenges to client-centered care fell into one of three categories: problems at the level of the system, problems at the level of the therapist and problems at the level of the client. They conducted a study to look at the barriers at each of these levels. Within the system level, organizations had policies, rules and regulations which interfered with the delivery of client-centered care. There were also time and resource limitations imposed by the organization which constrained the therapist in terms of what could be done. At the level of the therapist often the concept of client-centered care was not understood well in the first place as it was noted that the majority of therapists could not give a good definition of client-centered care. The therapists also felt uncomfortable with the power

shift in which they acted as a facilitator instead of an expert. On the third level, clients could also present challenges. For example, the client may not be cognitively aware enough to participate in client-centered care. Additionally, the client needed to be willing to take an active role in making decisions regarding his/her own care; some clients, like some of the therapists, felt more comfortable with the therapist in the expert role with the client's own participation being merely to follow the instructions of the therapist.

Family-Centered Care

In the field of pediatrics, the therapist providing client-centered care is referred to as providing family-centered care. Family-centered care (FCC) is also built upon a systems theory perspective (Begun, 1996; Bjork-Akesson & Granlund, 1995); systems theory sees a complete whole system to be more than just a sum of the systems parts and holds that each part influences the rest of the system. Therefore, the family not only influences the child but the child influences the family. This relationship demonstrates why it is a necessity to involve family members as part of the care since the child is dependent on his/her caregivers and the child in turn affects the caregivers. This transfer of responsibility in which the family member is placed in a position of decision-making is based on the assumption by the therapist that the family member also believes he or she should be responsible for the solution (Bonder & Hasselkus, 1994).

The three central concepts which define family-centered care are: “(1) parents know their children best and want the best for their children; (2) families are different and unique; (3) optimal child functioning occurs in a supportive family and community context” (Case-Smith, Law, Missiuna, Pollock & Stewart, 2010, p. 27). The relationship between the family and the therapist under family-centered care is a partnership in which the family holds the decision-

making power. This means, for example, that during the evaluation it is important for the therapist to learn information from the family regarding what the family considers to be important goals for the child to reach in the future and what the top priorities of the family are. During treatment interventions, educating the caregiver on what he/she can do for his/her child with special needs when the therapist is not there is imperative for home programming. It is important that a good relationship be established between the therapist and the family member at this point; the family member must feel comfortable enough with the therapist to let them know if the home programming is unmanageable or if he/she doesn't understand what to do. Lastly, during the process of discharge, both sides must feel that there is an understanding of why discharge is happening and what the future holds for the client.

Although these methods may seem apparent and easily accomplished, they are not always followed by therapists. For example, in a study conducted by Northen, Rust, Nelson and Watts (1995) it was found that the extent to which therapists involved clients in goal setting varied greatly. They hypothesized this was due to the fact that therapists used different techniques and theories on which to base their practices. Also, some of the therapists reported time as a constraining factor in their decisions. Other difficulties have been found in the therapist providing family-centered care. Research which has examined the perspective of the caregiver versus the health care professional on the views of their relationship has found discrepancies between their values, ethics and priorities (Hasselkus, 1988, 1991). Clark, Corcoran and Gitlin (1995) pointed out the importance of understanding family member's concerns; if his/her concerns are different from the therapist's concerns, then family-centered care is not being given and the caregivers may not use treatment recommendations in an effective manner. These

differences in ideas may cause a form of disconnect to occur between the therapist and the caregiver which would preclude the forming of an effective therapeutic relationship.

A study conducted by Blue-Banning, Summers, Frankland, Nelson and Beegle (2004) found another problem as there were gaps between what therapists desired to do and what their actual practices were, leading to caregivers not truly being equal partners with the therapist in the collaborative relationship. A similar study by Campbell and Sawyer (2007) analyzed videotapes submitted by fifty early intervention specialists (both teachers and therapists) as an example of their typical treatment session and found 70% of the sessions to be centered around the interventionist primarily interacting with the child while the caregiver was in the role of observer. They termed these differences to be traditional based therapy (caregiver observing) versus participation based therapy (caregiver involved in learning). If the caregiver is only involved minimally in the session or the decision making process then the tenets of family-centered care are being ignored.

Lawlor and Mattingly (1998) also identified multiple dilemmas in carrying out family-centered care. First of all, Lawlor and Mattingly (1998) found that as therapists were used to being viewed as the experts, their idea of involving the family tended to be addressed by feeling the need to persuade the family to see things from the therapist's point of view rather than engaging in a true collaboration. This finding was supported in a later research study conducted by Rosa and Hasselkus (2005). Secondly, Lawlor and Mattingly (1998) found that therapists often did not find the communication time with the families to be considered "real" work. More often it was viewed as time spent away from being able to provide the interventions which the therapists considered to constitute real therapy work. The therapists were found to start to question who the actual client was, whether the client was the child or the parent. Lawlor and

Mattingly (1998) found therapists to be wary of becoming involved in the concerns of the family for fear they would not be prepared to handle them. Along with these quandaries, Edwards, Millard, Praskac and Wisniewski (2003) found that caregivers reported the feeling that family-centered care experiences were limited due to the barriers of lack of time and support systems.

A newer study, conducted by Bellin, Osteen, Heffernan, Levy and Snyder-Vogel (2011), compared the perspectives of the health care professionals and the family to study how much each thought family-centered care principles were being used during their interactions. The study included 92 parents and 43 health care professionals, a mix of social workers (12), occupational therapists (12), speech therapists (11) and physical therapists (7). It was found that the parents and professionals agreed on which areas of family-centered care were being addressed and which weren't, with the therapists admitting they could do more in some areas. In general, families agreed that the professionals were treating them respectfully and in a supportive manner, however, the families did not feel they had access to as much information as they would like to have or that the relationship always felt like a partnership. In addition, it was noted that a significant limitation of this study was the convenience sampling of the health care professionals which could have led to professionals who perceived themselves as more engaged in family-centered care to participate in the study. The researchers suggested the inconsistency in carrying out FCC practices could be due to multilevel barriers in provider attitudes, family factors and institutional culture as supported by previous research.

Even in recognizing all of these difficulties, the use of family-centered care is still considered to be best practice in the field of pediatric occupational therapy and having a strong collaboration occur between the client/family and the therapist is considered essential in effective service delivery for children (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004;

Bruder, 2000). Rosa and Hasselkus (1996) studied the nature of therapist-client interactions and found that the therapists were able to collaborate more effectively with clients the therapists felt a connection with. This can be seen in the following statement:

Like their clients, therapists who perceive that their relationships are not meaningful may disengage and decline in function. Alternatively, therapists who perceive their help as meaningful, and who are able to connect with patients and enter into partnerships that are mutually supportive, stand to thrive and grow, personally and professionally. (Rosa & Hasselkus, 1996, p. 257)

Therefore, participating in collaboration not only helps the client through empowerment, but also helps the therapist by allowing him/her to strengthen his/her own professional skills.

The Impact of a Child's Disability on a Family

A therapist must also remember that caring for children can easily impact any family's life and this is even truer in the case where the family has a child with a disability. Although the vast majority of families do not perceive having a child with disabilities as having a negative effect on their family (Dunlap and Hollingsworth, 1977), there is still an impact upon the family. Johnson and Deitz (1985) found that mothers of preschool children with physical handicaps spent significantly more time engaged in child care activities (feeding, personal care, and transportation) than mothers of preschoolers without physical handicaps. Crowe, VanLeit and Berghmans (2000) suggested that "mothers especially may not be able to maintain a balance of roles if the parenting role becomes too time consuming, which may negatively affect parental and family relationships, health and wellness" (p. 57). This idea is supported by the study conducted by Lucca and Settles (1981) which found that families that have a child with

disabilities participated in fewer family activities than families that do not have a child with disabilities.

There are many implications for therapists as therapy services should not be a wearisome experience for the family. For example, Greene (1999) reported, from the viewpoint as a mother of a child with disabilities, it was a burden to have to complete one and a half hours of home program activities a day. This is where collaboration is crucial as it is necessary for the therapist to know what is unrealistic and what is manageable from the caregiver's point of view. A study by Larson (2010) examining indicators of well-being in caregivers suggested that "it is important therapists recognize that the caregivers' primary priority is the family's functioning" (p. 37). Hinojosa (1990) found that mothers were most successful in completing home program activities when they incorporated adaptations into their daily activities to make those activities therapeutic for their child with special needs. Therapists should consider this carefully and plan accordingly when working with the families of children on deciding what the family could work on with the child when the therapist is not present as research does show that home programs are effective when used. A systematic review completed by Novak (2011) looked at the effectiveness of home programs used across a wide variety of adult patients from differing diagnostic groups. The review found high level evidence (grade IA) supporting home programs to be effective at improving function, strength and abilities of the patients while reducing pain and symptoms. A second systematic review completed by Novak and Berry (2014) focusing on home program effectiveness for children with cerebral palsy or autism found similar results with gains seen in motor abilities, cognitive performance and developmental skills. This study concluded that home programs for these children were effective if:

(a) the program content is designed upon proven effective interventions; (b) the program is devised so as to respect parent implementation preferences; and (c) the parent is supported and coached to implement the program. (Novak & Berry, 2014, p. 388)

These studies emphasized the need for providing home programs for families who have children with disabilities in a manner which meets their needs, for when the home programs were completed, gains were made.

Client Education

The success of pediatric occupational therapy practice is considered in the field to be dependent upon the family members playing an active role in treatment. Parent education is defined in the following statement:

Typically refers to systematic activities implemented by professionals to assist parents in accomplishing specific goals or outcomes with their children. Our definition of parent education includes the expectation that parents will acquire knowledge and skills that allow them to mediate or extend the intervention with their child. Typical goals of parent education include teaching parents strategies to assist children in attaining developmental skills, helping parents manage children's behavior in the course of daily routines, and enhancing parents' skills in engaging their children in play and social interaction. (Mahoney, et al., 1999, p. 131)

Therapists are considered to be responsible for educating their clients and their clients' families. However, in a study by Knox, Parmenter, Atkinson and Yazbeck (2000), 40% of families found out pertinent information not from their therapists but instead through their friendships with other families who had children with disabilities. With only 60% of therapeutic information

coming from the therapist, this brings forth questions of the therapist's understanding of his/her responsibility for educating his/her clients. The first question becomes how responsible do therapists actually feel for educating their clients and the families of their clients. A second question is also raised as to how much knowledge therapists really have regarding how the family is experiencing learning from the therapist; having this information helps the therapist to better meet the needs of the family. Unfortunately, literature is sparse in the area of occupational therapy regarding pediatric therapists and the delivery of home program information to the parents of the children they serve. Overall, occupational therapy literature has very limited reporting of the teaching of caregivers or of caregivers learning experiences (Colyvas, Sawyer & Campbell, 2010). As noted previously, the majority of studies related to strategies on how to build effective relationships, information on family-centered care, the parent's views on the influence of therapy on their life, and tactics on how to increase compliance of caregivers. All of these studies researched everything except the caregivers' point of view. Very few studies considered other pieces regarding the education of clients in occupational therapy. A study by Haines (2006) which considered the relationship of education in preventing falls found there to be positive evidence to support the effectiveness of the education program in reducing the occurrence of falls. In a study conducted by Kaplan (1985) on the education techniques used at burn centers, therapists indicated good success with the use of a combination of verbal instruction and written materials given to their clients. The study reported more frequent use of educating clients through the use of verbal instructions and handwritten instructions possibly indicated a lack of preparedness on the part of the therapist for educating the client as the therapists had not brought prepared handouts to give to the client as instructions. Kaplan (1985) also found that therapists did feel education of the client was necessary and that they were

responsible for it. However, the therapists reported needing more patient education materials, additional time and the participation of other disciplines. Banford, et al. (2001) examined the methods being used by occupational therapists to provide education to the caregivers of stroke survivors via a questionnaire mailed to the therapists. They found demonstration and verbal instruction to be the most frequently used methods and the methods considered to be effective by the therapists. However, there was no follow-up to determine if the education provided to the caregivers had truly been effective in making a difference from the caregiver point of view. Another study by Caretto, Topolski, Linkous, Lowman and Murphy (2000) also considered methods being used by therapists to deliver patient education. They used questionnaires to gain information regarding current practices from therapists treating in the neonatal intensive care unit (NICU). The most commonly reported education delivery methods were demonstration, discussion, handouts and hands on practice. Although this study stated parents were able to demonstrate independence in learned skills before the child was discharged, it also reported further research was needed to determine the level of comfort and anxiety felt by the parents in regards to the ability to carryover the skills they learned in the NICU to the home setting. One other study by Graham, Rodger and Ziviani (2009) proposed a process termed Occupational Performance Coaching (OPC) in which a problem-based learning strategy was used to coach parents towards meeting self-identified goals for themselves or their child. In conducting qualitative research on using OPC, Graham, Rodger and Ziviani (2010) found parents of children with special needs reported they felt they had gained valuable new information. The parents stated that using OPC had led to having a calmer and more optimistic environment in the home, and how, though hard work, OPC was rewarding and empowering. While the researchers suggest the OPC framework poses a possible method for future client education, it was

acknowledged that in being a small case study with only three participant families, further research was needed. Overall, a review of the occupational therapy literature shows that research is lacking in the area of looking at the education of caregivers from the caregiver point of view. However, examining other fields of literature can perhaps provide some insight into the education of clients.

Other Fields of Literature. In medical literature, the education of clients is referred to as patient education and thus it will be referred to using this same term in this section also. The field of physical therapy, being another rehabilitation discipline, has many similarities to occupational therapy and will be discussed first. The American Physical Therapy Association has long considered the role of patient educator to be a role for physical therapists as can be seen by considering the history of their accreditation requirements (Chase, Elkins, Readinger & Shepard, 1993). One of the first studies in the field of physical therapy calling for patient education skills to be taught at the curricular level of physical therapy programs was a study by May (1983) in which therapists reported patient education as an important skill. However, the therapists also stated they had not been adequately trained how to educate others. This was further supported by Sotosky (1984) who put forth the idea that not only should curricula be changed but that perhaps a second implication should be that continuing education should be offered to current physical therapists regarding how to strengthen their patient education skills. Chase, Elkins, Readinger and Shepard (1993) reported that although educational skills had always been important, the 1990 evaluative criteria put forth for the accreditation of educational programs for the preparation of physical therapists placed an increased emphasis on physical therapists being able to be teachers of their patients. This had an impact as the Chase study showed that greater than 75% of the therapists in their study considered the development of their

patient education skills to be from “interaction with colleagues, continuing education courses and clinical instruction within the physical therapy program” they had attended (p. 792). The study also found that 95% of the therapists used verbal discussion and demonstration as the method of delivering information and 96% had the patient demonstrate back to the therapist what was being taught. The therapists reported time and patients’ attitudes as being the greatest barriers to delivering the education. Gahimer and Domholdt (1996) conducted a study to determine what types of patient education were being provided by physical therapists. The five categories of which patient education information was given by the physical therapist, in order of highest to lowest frequency, were 1) illness, 2) home exercises, 3) advice and information, 4) health education and 5) stress counseling. This is a broad range of educational areas and shows the diversity of information being provided by the physical therapist, although it should be noted the last two categories were rarely addressed. They also found, interestingly enough, that the amount of patient education given tended to decrease over time as the therapist continued to see the patient. The reason for this decrease over time was not discovered. In 2009, Rindflesch conducted a grounded-theory approach to investigate the current practice of patient education in the field of physical therapy. Four themes emerged from his research. The first was the inability of the therapists to separate patient education from providing physical therapy; the therapists believed that one could not be delivered without providing the other. Secondly, the therapists felt the process of patient education empowered the patient to have the ability to manage his/her own disability/illness care at a higher level than the patient was previously able to before the education. Next the therapists felt that the content of the patient education had to be what was termed patient-centered or, in other words, based upon the patient’s needs. Lastly, the therapists assessed the patient’s level of learning the information provided by the education process by

evaluating whether the patient was able to demonstrate functional understanding by incorporating the information into how he/she carried out activities. The study suggested future research should be conducted to confirm these results as the study used a small, purposive sample. Overall, the field of physical therapy appears to place a high value on patient education.

The field of nursing has constantly provided education to patients regarding their health. Burkhart (2008) found that patient satisfaction levels increased by providing nurses with the skills to teach. Marcum, Ridenour, Shaff, Hammons and Taylor (2002) stated that “education of the health care consumer provides the benefits of enhancing patient autonomy, increasing confidence in the patient’s self-care, and decreasing complications” when referring to patient education by nurses thus highlighting again the importance of education (p. 112).

It has been recognized that patient education is completed by nurses on an intermittent basis and is a required competency for them (Blevins, 2001). Stanton (1988) found that the majority of nurses reported spending between 10 to 20 percent of their time participating in patient education activities. This places patient education as one of the major responsibilities of nurses in working with patients. Research shows that nurses consider themselves to hold a high level of responsibility for patient education (Honan, Krsnak, Petersen & Torkelson, 1988; Kruger, 1991; Marcum, Ridenour, Shaff, Hammons & Taylor, 2002). At the same time, the average nurse has not had any courses in the principles and methods of the learning/teaching process and therefore lacks the formal knowledge of teaching skills (Close, 1988; Boswell, Pichert, Lorenz & Schlundt, 1990). When discussing patient education Burkhart (2008) stated that nurses “are in need of coaching skills, teaching skills, and tools for identifying comprehension. Nurses are taught to be caregivers; they are not taught to be educators” (p. 504).

Information regarding patient education in the nursing literature was varied and covered the types of material that should be given to caregivers. For example, studies covered specific curriculum information (such as delivering a fall prevention program), teaching continuing education courses to other nurses and the nurse's role in educating patients. In addition, there were articles found on nurses learning how to teach effectively, a few of which are addressed here. One article by Palmer and Heaston (2009) focused on teaching nurses how to teach in order to allow the nurses to be able to deliver more effective continuing education to other nurses. Pryor (2009) described the process of using coaching skills to teach patients self-care skills; it was recommended this process should be researched further. A third article by Woodring (2000) put forth specific educational principles that should be followed when teaching patients such as determining the patient's learning style, modifying information given to match the patient's level of needs and abilities, and evaluating the patient's current level of knowledge. Another article by Boswell, Pichert, Lorenz and Schlundt (1990) found that after conducting a course on teaching skills to nurses and dieticians, their abilities to communicate information to their patients increased significantly. An older article by Murray and Zentner (1976) provided guidelines for teaching skills such as suggestions for effective teaching, overcoming barriers to teaching skills, and the techniques of teaching patients; however, considering the article is older and from only one journal, it is not unreasonable to assume that many nurses have never seen or read the article.

Early intervention literature shows similar themes to physical therapy and nursing. A study by Hancock, Kaiser, and Delaney in 2002 as well as one by Woods, Kashinath, and Goldstein in 2004 supported the use of teaching strategies to caregivers which can be embedded in their daily routines; in doing so both studies found positive changes were made in children's

use of language skills from the practice given through a home program. Scales, McEwen and Murray (2007) reported that parents agreed that instruction provided by therapists which included the caregiver interacting with the child during the therapy session was, although more stressful, more beneficial. A study by Rush, Sheldon and Hanft (2003), reminiscent of the 2009 Pryor study in the nursing literature, promoted and discussed the use of coaching to collaborate and educate families and caregivers. One final article by Kaiser and Hancock (2003) focused on strategies to teach parents of children with special needs new skills; it also discussed the need to provide education to professionals on how to be effective parent educators.

Overall, the research relating to various health professionals and their skills in effective teaching is scarce compared to other topics such as increasing patient compliance. This lack of research should not be surprising in that Pigg (1982) conducted a national study concerning health care professionals learning how to conduct patient education. The study found that less than 18 percent of the 228 institutions surveyed offered even one course in patient education. Even in fields where patient education is considered integral to the process and is discussed more, there is a need for research which examines the process of learning information from the client/patient/caregiver point of view.

Home Programs for Children with Cerebral Palsy. The beginnings of client education research examining home programs carried out with children has been primarily focused upon the population of children with cerebral palsy, therefore, this study builds upon this foundational knowledge. Imms (2008) and van Meeteren, Roebroek, Celen, Donkervoort, and Stam (2008) looked into the functional levels of children with cerebral palsy and found reduced levels of participation in everyday life globally, with those having the greater functional impairment being the most restricted. This demonstrated the need of these children to have successful therapy

outcomes. In 2007, Novak, Cusick and Lowe conducted a pilot study investigating the impact of occupational therapy home programming on children with cerebral palsy using a pre-test, post-test design and found statistically significant results on multiple assessments of skills. However, maturation effects were unable to be determined due to having no control group. Novak, Cusick and Lannin (2009) conducted a randomized control trial and found that having an occupational therapy home program for children with cerebral palsy produced a statistically significant difference in function and parent satisfaction levels compared to children with no occupational therapy home program. Katz-Leurer (2009) also found a statistically significant difference between having a home program in comparison to a control group with no home program when considering the outcomes of improved motor and balance performance. Multiple studies have shown the efficacy of home programs in having statistically significant results in producing higher outcomes for the population of children with cerebral palsy (Bar-Haim, et al., 2010; Picciolini, et al., 2009; Poutney, Mandy, Green & Gard, 2009).

Another consideration is the prevalence of children with cerebral palsy in the general population. Rogers (2010) stated that there are 1.4 to 2.4 children born with cerebral palsy per 1000 live births. According to the 2009/10 National Survey of Children with Special Health Care Needs, there were an estimated 175,873 or 1.6 % of children in the United States who were reported as having the diagnosis of cerebral palsy. In Wisconsin, also according to the 2009/10 National Survey of Children with Special Health Care Needs, there were 3,975 children who had the diagnosis; in Arizona, there were 5,731. Prematurity accounts for the majority of the cases today although also associated are a range of other diagnoses including but not limited to having an in utero cerebral vascular accident (stroke), brain abnormalities, or maternal exposure to environmental toxins. Typically, children with cerebral palsy may have secondary disorders

which may be cognitive, sensory or psychosocial in nature. Early diagnosis and treatment has helped to prevent the onset of these secondary disorders which highlights the importance of the need for effective occupational therapy services (Rogers, 2010). It is also especially important to address this population as the research showed decreased health and quality of life in caregivers of children with cerebral palsy (Brehaut, et al., 2004; Eker & Tuzun, 2004; Raina, 2005).

Factors Which May Influence the Caregiver's Experience

There are many reasons that a caregiver's experience in learning a home program for his/her child with special needs may be difficult. A few of the top factors which may have an influence on the experience a caregiver has when learning a home program for his/her special needs child include the various stressors in his/her life, the support he/she feels he/she is receiving, his/her background and, last but not least, the experience of being a caregiver itself.

Stressors. Research has shown that families with a child with special needs have stressors in their life which other families do not experience. Stressors have been found to include emotional strain, difficult developmental transitions, marital discord, sibling conflicts and unresponsive service delivery systems concerns (Mccallion & Toseland, 1993). Emotional strain begins once the child is discovered to have special needs as any parent would have concerns over the extra complexity this will add to his/her child's life. The strain continues as constant challenges occur and adaptations must be made as the child develops and changes. This may contribute to difficult developmental transitions since when a transition occurs, the parent may be reminded that his/her child is different in the life experiences the child may encounter due to having special needs. This strain may be related to the child's disability itself. Leonard, Johnson and Brust (1993) conducted a study specifically looking to identify the factors that contributed to a caregiver's ability to manage care. The key factor found to distinguish the group

able to manage care from the group who were not able to manage care was the severity of the child's disability. This suggested more emotional strain may be present as the severity of the disability increases. Marital discord may also be exacerbated when dealing with new and shifting roles in the household and due to the increased financial burden needed to raise a child with special needs. Crowe, VanLeit, Berghmans and Mann (1997) conducted a study on the roles of mothers of children with special needs compared to mothers of typically developing children. The mothers of special needs children had significantly less roles in their life. They also significantly differed in the number of roles they lost when comparing the number of roles they had before having their child with special needs to the number of roles they had after having the child. The two most commonly lost roles by the mothers were the roles of student and worker.

Other stressors exist as the siblings also may experience friction in the family structure. It is not uncommon for the siblings to either feel jealousy at the amount of attention and time the child with special needs gets or to feel unhappy about being given extra responsibilities to help with child care and household management tasks if they are older. Lastly, unresponsive service delivery systems have required the caregiver to actively advocate for his/her child's needs. This advocacy may have placed extra strain upon the caregiver as it requires time, the finding of new knowledge and the necessary communication skills to receive help.

Support. Another factor that has influenced the caregiver's learning experience is whether they feel they have received the support they wanted in general from the therapist. Boswell, Pichert, Lorenz and Schlundt (1990) interviewed parents and found that, in everyday interactions with the health care professional, there were three characteristics the parents felt were necessary. They expected the service provider to know current best practices in the field

and how to carry them out in an effective manner. The parents wanted the provider to acknowledge his/her limitations, however, and tended to respect the provider who was open about needing to learn more and willing to take the time to do whatever was necessary to be sure his/her skills matched the child's needs. This included acknowledgement by the provider as to the caregiver's own expertise on the background and needs of the child. Lastly, the parents wanted the professional to be willing to develop a meaningful relationship with the child that went beyond a superficial level as the parents felt this helped the professional really know the child. Lindblad, Rasmussen and Sandman conducted a phenomenological examination in 2005 into parents' experiences of being supported when having a child with special needs and found similar themes. They also found an overarching need for the family to feel as if they are valuable in the therapist's eyes. If a caregiver is not receiving these basic levels of support from their therapist, it may cause them to be less engaged in wanting to collaborate in learning the home program.

General background of the caregiver. The background of the caregiver has a significant impact on his/her ability to engage fully in the learning experience. Health literacy is a concern as information must be given to clients in a manner which allows them to not only understand it but to also be able to act on it (DeSilets & Dickerson, 2009). It was recommended that all written information be given at the fifth- to sixth- grade level to optimize readability (Plack & Driscoll, 2011). There are various methods to assess the caregiver's literacy level as well as to evaluate educational materials, all of which should be considered by the treating therapist. If the caregiver is unable to understand the education being provided to them then their experience learning from the therapist could safely be assumed to be negatively affected.

Age of the caregiver is not as big of an influence as compared to the age of the child in pediatrics. The young child with special needs will often view completing home programs, which are difficult, as punishment rather than as a means of progressing (Muma, 2012). If the caregiver comes from a background where he/she prefers not to cause his/her child discomfort, this may lead to him/her being less interested in learning the home program.

Cultural and racial-ethnic background of the caregiver. The cultural background of the caregiver also plays an important part in how he/she experiences learning the home program from the therapist. Cultural aspects, including ethnicity, gender, socioeconomic status, lifestyle diversity, religious choices and many other factors, all mean that a therapist needs to gain knowledge of how the caregiver's cultural background will impact his/her views on being taught. The therapist must work to be culturally knowledgeable in order to help the caregiver feel comfortable during the learning experience.

In addition, depending upon the racial-ethnic background of the caregiver, he/she will have different perspectives on interacting with a medical provider, being a caregiver, and raising children. In regards to working with health care professionals, research has shown that African Americans have a higher level of mistrust of the medical system overall than other racial/ethnic groups (Armstrong, Ravenell, McMurphy, & Putt, 2007; Benkert, Peters, Clark, & Keves-Foster, 2006; Doescher, Saver, Franks, & Fiscella, 2000; Halbert, Armstrong, Gandy, & Shaker, 2006; Moseley, Clark, Gebremariam, Sternthal, & Kemper, 2006; Stepanikova, Molborn, Cook, Thom, & Kramer, 2006). A study conducted by Horn, Mitchell, Wang, Joseph, and Wissow (2012) examined African American parents and the trust level they had in their child's primary care provider, as well as, the effect the physician's communication style had on the level of trust. It found that although this population had a lower level of trust than whites in regards to medical

providers, trust increased when the provider used a more patient centered or partnership-building communication style. This suggests it is more important when working with an African American caregiver to be cognizant of communication styles and making the caregiver feel involved with the process. Decreased levels of trust in medical providers have also been found in the Hispanic population although this population has not been researched as in depth as the African American population in this area and therefore the same conclusions cannot be drawn regarding the importance of patient centered communication (Armstrong, Ravenell, McMurphy, & Putt, 2007; Kaiser, Rauscher, Jacobs, Strenski, Ferrans, & Warnecke, 2011; Lopez-Cevallos, Harvey, & Warren, 2014). It should also be noted that the research on the Hispanic population in regards to trust was completed with patients regarding their direct experiences and their own level of trust in healthcare providers and not with people who were caregivers of others.

Research has additionally been conducted exploring the differences of perspectives between caregivers of differing racial/ethnic backgrounds. Janevic and Connell (2001) performed a literature review investigating the racial, ethnic and cultural differences that exist regarding aspects of providing care for a person with dementia and found 21 studies which were conducted in this area. In reviewing these studies, Whites were found to report greater levels of depression and considered caregiving to be more stressful than African Americans. Latinos were found to have more depressive symptomatology than Whites and to report higher levels of personal burden and role strain than African Americans. A study by Dilworth-Anderson, Brummett, Godwin, Williams, Williams, and Siegler (2005) that examined the differences between African Americans and Whites in respect to their attitudes towards caregiving found that African Americans more strongly identified with valuing providing care to dependent people in their family. Dilworth-Anderson et al., (2005) suggested African Americans were more

highly culturally socialized to provide care to family members. African Americans were thus less likely to view caregiving towards family members as burdensome. Clark and Huttlinger (1998) reported similar views among Mexican American families in their study which reflected that the families reported cultural expectations of close family ties, a strong sense of support, intergenerational reliance, and meeting family responsibilities. However, Zsembik and Fennell (2005) cautioned that Latino groups, including Mexicans, Cubans, and Puerto Ricans among others, can differ greatly from one another in their experiences which then further affect their health and health behaviors. Therefore, the research put forth on one group of Latinos is difficult to generalize to the entire population.

Little research is available at this time which examines the differences between racial/ethnic groups regarding mothers' attitudes towards caregiving for their child with a disability or disease. One study by Pruchno, Patrick and Burant (1997) compared African American and White mothers who were caring for adult children with developmental disabilities in regards to their levels of caregiving burden and satisfaction. This study found the White mothers reported statistically significant higher levels of caregiving burden and lower levels of caregiving satisfaction as compared to the African American mothers. Another study by Hinojosa, Knapp, Madden, Huang, Sloyer and Shenkman (2012) explored the differences in impact of caregiving on Latino, African American and White families when caring for their children with life-threatening illnesses. As shown by previous research on Latino caregiving in regards to adults, this study found that although Latino parents reported greater levels of stress and caregiver burden as compared to White parents they also feel a greater sense of duty toward caregiving. Additionally, African American parents reported having lower feelings of burden and depression when compared to White parents which also reflected what has been seen in the

literature on racial/ethnic differences in regards to adult caregiving. Although only minimal studies have been completed in this area, the results suggested that caregiving in regards to children reflect the same attitudes by the different racial and ethnic groups as what has been shown in the research on caregiving for adults for these different populations.

One final area which must be considered when comparing the perspectives from caregivers of differing racial and ethnic backgrounds is the approach to parenting and the level of stress felt by parenting by each population. Research has consistently shown that parenting practices and beliefs differ between racial and ethnic groups with minority groups more commonly using authoritarian parenting practices (Bulcroft, Carmody & Bulcroft, 1996; Chao & Kanatsu, 2008; Dixon, Graber & Brooks-Gunn, 2008; Ferrari, 2002; Hill & Sprague, 1999; Portes, Dunham & Williams, 1986). Authoritarian parenting practices involve teaching and controlling children's behaviors through coercive methods, directives and physical punishment while demanding respect and obedience from the child to the parent (Nomaguchi & House, 2013). A study conducted by Dixon, Graber and Brooks-Gunn (2008) found that Hispanic and African American mothers scored significantly higher in terms of using restrictive behaviors with their daughters than did White mothers. At the same time, the study also found that White daughters demonstrated the lowest levels of respectful behavior towards their mothers in contrast with Hispanic and African American daughters. Lastly no differences were found in the study in regards to nurturance or relationship quality in comparing the three groups. This can further be seen in the frequency of use of forms of discipline such as spanking. Gershoff, Lansford, Sexton, Davis-Kean, and Sameroff (2012) found that African American mothers reported significantly more use of spanking (40%) at the third-grade level than both Hispanic and White mothers, with Hispanic mothers reporting a higher level of spanking (28%) than White mothers

(24%). These differences in philosophy towards parental strategies and practices are important to note because research has shown that punitive practices can lead children to perform worse rather than better in terms of academic achievement (Robinson & Harris, 2013). Therefore, therapists working with caregivers of children from differing racial and ethnic backgrounds should discuss with the caregiver what strategy is the best to use if the child is not completing the home program as expected.

It also has been shown that African American mothers report higher levels of parenting stress as compared to White mothers due to use of these authoritarian parenting practices as well as structural disadvantages (Cardoso & Sampson, 2010; Franco, Pottick, & Huang, 2010; Nam, Wikoff, & Sherraden, 2015; Nomaguchi & House, 2013). On the other hand, the research regarding the levels of parenting stress reported by Hispanic mothers shows higher levels of stress as compared to White mothers, however, the stress is related more to structural disadvantages and social support than parenting practices (Cardoso & Sampson, 2010; Franco, Pottick, & Huang, 2010; Nam, Wikoff, & Sherraden, 2015; Nomaguchi & House, 2013). These higher levels of parental stress are important to note as a study by Raphael, Zhang, Liu and Giardino (2010) found higher levels of parental stress to be associated with a greater utilization of emergency care services when examining healthcare utilization for children by parents. This study suggested higher levels of stress may interfere with a parent's ability to seek timely medical care for his/her child. Therapists need to be aware that these caregivers are most likely facing higher levels of stress than a White caregiver may be facing and consider that fact carefully when working to develop a home program for the child with the caregiver. It would not be beneficial to either the parent or the child to build a home program that would increase the level of parental stress already being experienced by the caregiver.

Being a caregiver. There are many studies examining the impact of being a caregiver on a person. Sawatsky and Fowler-Kerry (2003) put forth that the experience of caregiving could be described through three dominant themes: loss and grieving; adapting and coping; and the short- and long-term impact. Loss and grieving spoke to the realization made by the caregiver that several significant changes had occurred in his/her life. These changes included having to give up employment, relying on others for financial support and changes in his/her relationships with others in his/her life. A loss of roles (identity) was felt and social isolation was at times felt. Grief occurred due to the changes themselves such as a loss of privacy and control, and the lack of spontaneity that was now part of his/her life. Adapting and caregiving occurred as the caregiver learned to need a strong support system and to ask for help. Some caregivers reported relying on his/her sense of spirituality to help get through difficult times while all the caregivers stressed the need to try to find time for himself/herself as often as possible. All the caregivers also worried about the short and long term impacts that caregiving would have on each one's own health, finances and overall quality of life. These same types of issues face the caregivers of a child with special needs in their daily lives and may have implications for how they approach learning a home program from the therapist.

Level of Willingness. The caregiver's being willing to engage in the experience of learning from the therapist has always been an obvious and necessary factor influencing the interaction between the two. Plack and Driscoll (2011) differentiated between readiness and motivation of the learner. Readiness referred to the fact that the caregiver was both emotionally and physically able to participate. Motivation referred to the fact that he/she had a drive to learn. If the caregiver is not ready on any level, then it may be necessary for the therapist to wait until they are in a more prepared state of mind to learn, depending on the situation.

Additional factors. Gajdosik (1991) reviewed the literature on parental compliance to home programs given by pediatric occupational and physical therapists and discussed a variety of factors which could have had an influence on compliance. It was noted that there was greater compliance by mothers of children with severe delays when compared to mothers of moderately delayed children. The study additionally found lower compliance when home programs were complex and greater compliance with short term regimens. Lastly, frequent supervision or contact with the mother and the therapist increased compliance on the part of the parent according to the research. However, an experimental study completed by Gajdosik and Campbell (1991) showed that a weekly review completed by the therapist with the family did not make a significant difference in compliance when compared to families who did not receive this weekly review of the home program. This may have been due to the short time period of the study or the fact that the study had a small sample size. This was discussed to be an area which needs more research in the future.

Factors Which Influence Caregivers of Children with Cerebral Palsy

Additional newer research has examined factors which have influenced the caregiver's adherence to the home program, specifically focusing in on caregivers of children with cerebral palsy. Basaran, Karadavut, Üneri, Balbaloglu and Atasoy (2014) surveyed 147 caregivers of children with cerebral palsy regarding adherence to their home exercise program. They found 96 of the caregivers to be carrying out the home program with their child daily and 51 were poorly adherent. The responses as to why they did not carry out the home program from those who poorly adhered to the home program were:

‘I think attending a state-funded regional children's rehabilitation center is sufficient’:

39.2% (n=20); ‘I think it is not helpful’: 5.9% (n=3); ‘I think I carry out enough’: 3.9%

(n=2); 'I have no more time': 29.4% (n=15); and 'I feel burned out': 21.6% (n=11).

(Basaran et al., 2014, p. 87)

The study found factors such as age, marital status, socioeconomic status and family size had no significant relation to adherence. However, it did find almost two-thirds of the participants experienced mild to severe depression and mild to severe anxiety. Although there was no link found between these symptoms and the levels of adherence, it was found that when the participants had difficulty overcoming stress and experienced exhaustion, adherence went down as would be expected. The study recommended health care professionals focus on providing more support to caregivers to achieve home programs that do not lead to exhaustion on the part of the caregiver.

A final study by Reid et al. (2011) used a descriptive interpretive approach to have parents reflect on their past experiences raising a young child with cerebral palsy. Nine parents were interviewed with their children ranging from the age of 17 to 22. The parents expressed many needs unrelated to home programs such as the need for support, the importance of promoting their children's independence and self-advocacy, as well as external, formal supports in the school and in the community. In regards to home programming, the families discussed the importance of being given information and having the opportunity to ask questions. They considered key aspects of support from their health care providers to be providing honesty, clear communication and collaboration. These findings supported the significance of the premises of family-centered care and showed that families appreciate when the concepts of FCC are carried out even years later when reflecting back on their experiences.

Theories of Learning and Teaching

As stated previously, occupational therapists are often not taught or given adequate information regarding theories of learning or teaching during their educational preparation. There are many theories in both areas which would be beneficial to consider when discovering what caregivers of children with special needs believe would best help them learn how to deliver the OTHP. Perhaps the best learning theories that would fit for therapists to use when working with their clients or the families of their clients would be the theories of andragogy, experiential learning and transformational learning. These theories have components that fit appropriately with a client-centered, or in this case family-centered, point of view. This is due to the fact that they all consider that the adult learner has experiences upon which they have learned skills and knowledge. Each of these theories has its own benefits to offer.

Malcolm Knowles, the father of andragogy, criticized pedagogical techniques in the context of adult education because pedagogy ignores the experience of learners (Merriam, Caffarella & Baumgartner, 2007). Andragogy, on the other hand, emphasizes that adults have experiences which can be important sources of learning. This is supported by Jarvis who reminds us that the adult is a whole person that is learning, not just a mind or skill that has been changed (Jarvis, 2009). Instead an adult learners' biography and history can have an impact on how they learn and incorporate new concepts and behaviors in with the ones that have already been established from their previous life experiences. When working with the caregiver on the home program that will work on the skills his/her child needs, it is important to remember that the caregiver has his/her own experiences with his/her child and that he/she is the expert on what will work for the child and what won't. If the therapist acts only as an expert then the therapist is ignoring the breadth of knowledge and personal experience that the caregiver already possesses.

Under experiential learning theories, the teacher acts as a facilitator, a role that fits well with family-centered care. It encompasses two concepts which are important for the occupational therapist to consider when thinking about how the caregiver may be learning: reflective practice and situated cognition. Reflective practice allows for the “ability to make judgments in ambiguous, contradictory, or complex situations” with increased experience leading to the ability to reflect not only after a situation has occurred but then also as a situation is unfolding (Merriam & Clark, 2006, p. 47). In working with the families of children with special needs, allowing the caregiver to engage in reflective practice when pondering how to carry out working on a skill with his/her child will allow the caregiver to develop the problem-solving skills needed to be able to more effectively deal with situations that may come up when the therapist is not present. Secondly, situated cognition holds that “knowledge is not an objective entity distinct from the context in which it is learned but rather is an integral component of the context in which it is constructed and of the activity in which the learner is engaged during construction” (Griffin & Griffin, 1996, p. 293). This speaks to the idea that the therapist must understand that learning occurs in context. When working with the families of children with special needs, the therapist should thus teach the caregiver by having him/her do what he/she should be doing when the therapist isn’t there. If, as discussed before, the therapist plans to have the home exercise program built into the daily activities of the family then the therapist should actually have the caregiver perform those daily activities and practice those skills while the therapist is present. This gives the caregivers a greater chance to actually learn the skills the therapist is trying to impart and acquire confidence that he/she is performing the skills adequately.

Another perspective on setting up the learning environment for the caregiver would be bearing in mind the point of view of transformational learning which refers to helping the learner have an entirely different perspective and changing what they know to be true (Mezirow, 2000). Designing a learning environment around transformational learning concepts, similar in this way to andragogy, allows the learner to be self-directed and draw upon past experiences. From this standpoint, Brookfield states that “having learners exercise control over all educational decisions needs to be a consistent element of self-directed learning” (Merriam, Caffarella & Baumgartner, 2007, p. 109). The self-directed learner will be motivated to critically reflect on his/her own background and experiences as they relate to the new skills or knowledge he/she is trying to gain. This is crucial in that critical reflection is an important piece of every step of learning under transformational theory (Brookfield, 2000). Two perspectives that offer strategies for supporting transformational learning are the constructivist and situated cognition viewpoints. From a constructivist point of view, reflective practices should be encouraged during which the caregiver could engage in examining those experiences in the past during which he/she had difficulty delivering the home program, how he/she could have handled it differently and what ways would have given him/her more control over those situations. Facilitating this type of reflective approach also then uses the ideas of situated cognition, as discussed in experiential learning above, where the caregiver can learn through the experience of cognitive apprenticeships. In cognitive apprenticeships, while the caregiver would reflect on the best way to maintain control in his/her present situation, the therapist could coach the caregiver more in the beginning and then slowly remove his/her own presence and allow the caregiver to self-direct the level of control. Another strategy would be problem-based learning which involves problem solving with real-life situations that stimulate critical thinking such as in role-plays or learning

exercises where the caregiver would solve a dilemma. Other techniques that may help facilitate self-directed learning include simulation exercises, skill-practice exercises, and demonstrations. Whichever learning technique is used, it is clear from a constructivist viewpoint that the therapist must promote the use of reflection if he/she wishes to see the development of critical thinking skills by the caregiver in processing the information being given by the therapist.

In relation to learning theories, teaching theories consider the stance of how the educator should conduct oneself. Pratt conducted research studying 253 teachers of adults from Canada, China, Hong Kong, Singapore and the United States. The teachers were interviewed with questions focusing on what it meant to teach and details surrounding teaching (Pratt, 1998). Out of this research Pratt (1998) put forth five perspectives on teaching which were termed transmission, apprenticeship, developmental, nurturing and social reform. Of these five, the three which may be the best for therapists to teach from would be apprenticeship, developmental and nurturing.

Johnson and Pratt (1998) discussed the apprenticeship perspective as one in which the teacher is an expert and guides the learner in slowly developing his/her own skill set through observing the teacher and practicing the skills; as the learner gains skills, the teacher role changes and the teacher offers less guidelines and allows the learner to take control of the situation and be more independent. In the beginning the learning occurs as the learner builds simple schemas regarding the information being provided by the teacher. As his/her knowledge builds, these simple schemas become more complex. It is important to note that in this perspective, the schemas are situated in contexts and these contexts and the content of the schema form the concept of situated learning. Thus it is considered best to teach in the context in which the learning will be used. Teachers must focus on providing learning opportunities

which are active, authentic and social to facilitate successful learning. The teacher can coach the learner and scaffold the level at which assistance is provided until the teacher is able to move from working side by side with the learner to slowly fading as a presence. This allows the learner to become a full member of the community of practice the teacher is introducing the learner to and to build his/her new identity as a member. The teacher helps the learner to be able to eventually generalize the skills he/she has learned to new contexts.

The developmental perspective as discussed by Arseneau and Rodenburg (1998), is based on the idea that good teachers consider the learner's point of view and move the learner from simple to more complex tasks when teaching as well as using the practices of giving examples and problem based learning exercises. The learner must go through the process of constructing an internal conceptual model of what is being learned to form a personal meaning regarding what is being taught. It can seem at first very similar to the apprenticeship perspective, as in each the learner is progressing in moving towards being more independent as a learner. However, under this perspective the teacher concentrates on incorporating the learner's prior knowledge and helps the learner form the personal meaning needed to bring together the prior knowledge and the new knowledge into one cohesive whole. Under this perspective, learning takes time and it also, like the apprenticeship perspective, is best done with the recognition that the content being learned cannot be separated from the context. Therefore, learning should be taught in the context in which the learner will eventually be using their new knowledge. It is also best when the learner is intrinsically motivated to learn the content as extrinsic motivation will only lead to a surface approach to learning. When the learner is intrinsically motivated he/she is more prone to take a deeper approach to learning and spend more time on trying to form his/her own personal meaning and understanding of what is being learned. In the end, learning is only considered to

have occurred when learners are able to demonstrate understanding and show personal autonomy in learning. The goal under the developmental perspective is to make the teacher increasingly unnecessary. This is not to say the goal is to not have the teacher present. The learner and the teacher will be on a continuum with the teacher providing enough support to keep the learner moving forward and continually learning.

Lastly, T'Kenye (1998) discussed that the nurturing perspective puts forth for teaching to be completed through the practice of empathy and empowering others to demonstrate self-efficacy. It stems from the idea that the learner must be in a position in which learning is possible. Learners may be in a damaged state from the beginning or have pain that is raised during the learning context. This is not a state which is conducive to learning thus teachers may have to address topics which are off topic to allow the content to become accessible to the learner. The teacher acts as nurturer to aid in the growth of the learner and practices empathy to help them in understanding the learner. By working with the learner to help provide needed support and to listen to their needs, the nurturing educator is able to help the learner find success in learning and build self-efficacy.

Self-efficacy is important because according to Bandura (1997) unless people believe they are able to achieve what is desired, they will have little desire to act. A person's self-efficacy is constructed from his/her enactive mastery experiences, vicarious experiences, verbal persuasion and his/her physiological and affective states (Bandura, 1997). Enactive mastery experiences refers to the life experiences which help teach a person what type of results to expect and how much work should be put forth. Bandura (1997) suggests that if people only have easy successes they will be easily discouraged by failure whereas small difficulties and setbacks will teach a person how to persevere when under adversity and still succeed. Therefore, the educator

must ensure the learner is exposed to experiences which are at the right level of challenge to push the learner but where they will still be successful. At the same time, a learner can't judge how successful they are without a point of reference. Vicarious experiences allow a person to have comparisons with others for self-appraisal to occur of one's own capabilities with different activities (Bandura, 1997). This judgment of one's capabilities through this self-appraisal can be reinforced or even strengthened via social cues. Bandura (1997) states "it is easier to sustain a sense of self-efficacy, especially when struggling with difficulties, if significant others express faith in one's capabilities than if they convey doubts" (p. 101). Although this verbal persuasion from others has its limits and can't convince a person that he/she is capable of achieving an unrealistic goal, it can lead a person to try hard enough to succeed when he/she is doubting the ability to achieve a realistic goal. This emphasizes the point that a teacher must provide positive verbal reinforcement and praise to a learner in a valid and appropriate manner. Lastly, people rely partly on information they receive from their own physiological and emotional states when judging their own level of self-efficacy (Bandura, 1997). A person will be more likely to foresee success if he/she is not struggling with a stressor to his/her system such as fatigue, pain or psychological stress. The importance of self-efficacy can be seen in what Bandura (1997) termed parental efficacy and what has also been referred to as parenting self-efficacy. Parenting self-efficacy was defined by de Montigny and Lacharite (2005) as "beliefs or judgements a parent holds of their capabilities to organize and execute a set of tasks related to parenting a child" (p. 390). Research supports that higher parental efficacy correlates with lower levels of familial stress and contributes to higher levels of emotional well-being of both the parents and the children (Bandura, 1997; Coleman & Karraker, 1998; Halpern & McLean, 1997; Montigny & Lacharite, 2005; Salonen, Kaunonen, Astedt-Kurki, Jarvenpaa, Isoaho, & Tarkka, 2009; Teti

& Gelfand, 1991). Therefore, a therapist working with a caregiver of a child with special needs must help build the caregiver's sense of parental efficacy to have a greater chance of the caregiver being successful in carrying out the home program.

Overall, each of the three perspectives from Pratt (1998), apprenticeship, developmental and nurturing, fit with both a client and a family centered point of view. Under the nurturing perspective, the therapist would provide a safe, secure environment where the caregiver can feel free to work on being independent in delivering a home program to his/her child with special needs while knowing the therapist is there to help deal with his/her fears and worries. A caregiver of a child with special needs has a history with his/her child and has lived through times of worry regarding that child. He/she may still hold significant fears regarding the child's health or future as it is human nature to be concerned about those you love. The therapist can act as nurturer and help to work through those fears and concerns to allow the caregiver to be able to focus on learning and carrying out the home program. In addition, the therapist can use this approach to help build the caregiver's sense of parental efficacy which will have a positive effect on the caregiver and the child. The apprenticeship perspective, on the other hand, permits the therapist to work from his/her base of expertise (which is knowing how to facilitate the child's development towards meeting the family's goal) while letting the caregiver build his/her own skills by learning from that base of expertise. As the therapist is the one with the training in therapy techniques and interventions, the therapist can work side by side with the caregiver and teach him/her how to use those techniques and interventions successfully. Over time the caregiver can successfully be able to apply those techniques and interventions by delivering them to the child as a home program when the therapist is not present. With the developmental perspective, the therapist would teach simpler parts of the home program first, with the most

difficult tasks being left to later; this would promote the caregiver being able to build the skill set of delivering the home program in a stepwise progression and allow for him/her to build confidence in having those skills. A feeling of success can often help boost a person's beliefs in his/her own self-efficacy. Although the therapist has the expert knowledge, the goal would be to pass on that knowledge by building on the caregiver's own knowledge base regarding what has worked in the past to allow him/her to develop personal strategies and methods that work when completing the home program with his/her child. This approach allows for the home program to have the highest chance of success as the caregiver then has an increased ability to problem solve when challenges arise in carrying out the home program and the therapist isn't present to help. The caregiver forms his/her own personal meaning regarding the construct of the home program and carrying it out with his/her child. The therapist acts as teacher by continually pushing the caregiver forward and providing him/her more knowledge to incorporate into that construct.

Each of these teaching theories work in conjunction with the theories on learning of andragogy, experiential learning and transformational learning. The teaching theories help the therapist consider his/her own role while the learning theories provide information to the therapist on the role of the caregiver. All of these perspectives should be considered when researching how a caregiver experiences learning a home program from his/her child's therapist and what the caregiver feels is needed to help deliver that home program for his/her child with special needs.

Summary

The relationship between the occupational therapist and the family is one in which mutual respect must exist with caring and collaboration as essential pieces. When delivering therapy services it is essential that the primary family caregiver learn a home program to

complete with his/her child as this will enable the child to have increased practice time which will progress their development of skills at a faster rate. In the model of family-centered care, the family is viewed as having background experience with the child which is an invaluable source of knowledge. This fits with adult learning theories as the learner is considered a person with a history upon which new knowledge is built. Therefore, as the caregiver is a learner and family member with this knowledge and experience base, his/her perspective and background play a role in the learning of the home program for his/her child from the occupational therapist. As of yet, studies on the whole have not focused on the caregiver's point of view regarding the experience of learning a home program. Understanding how the caregiver experiences learning the home program can provide insight for occupational therapists as to how the experience may be improved for the caregiver. This study helps add to the literature on this important piece of the educational process occurring between the therapist and the caregiver.

Chapter Three: Methodology

Framework of the Study

The nature of research is such that, depending on the research questions and the answers one seeks, there are many decisions to be made regarding the methodology of a study. The first decision to be made is whether to conduct a quantitative, qualitative or mixed methods study. Quantitative studies often look to generate information regarding the cause and effect interactions between different variables of interest; these studies tend to have answers focused on generalizing a solution to a larger population. Qualitative studies, on the other hand, are conducted to gain a detailed understanding regarding the object of study being examined, including the surrounding context (Creswell, 2007; Denzin & Lincoln, 1998; Patton, 2002). The emphasis of qualitative research is on naturalistic, interpretive and descriptive methods of research. For this study, a quantitative approach was not appropriate as it would not be sensitive enough to pick up on the details needed to answer the research questions. A qualitative approach enabled the researcher to answer the research questions in a manner which provided a rich, thick description from the participants' own unique perspective.

One of the methods involving understanding participant's experiences within the natural environment is called phenomenology. Phenomenology is the art of understanding the essence of the lived experience. It seeks to draw meaning through the analysis of first-person accounts in order to better understand a person's reality. It is usually conducted through in-depth interviews and sometimes through observations of the participants involved. This data is then analyzed for meaning and common threads in the experiences of the participants. For this research study, a phenomenological philosophical stance was taken. With this stance there are two main approaches, one by Husserl and the other by his student Heidegger. Walters (1995)

differentiated between the two in his discussion on using a phenomenological approach to research. Husserl believed in the use of phenomenological reduction (questioning one's presuppositions about the world) and phenomenological epoche (suspending beliefs about the world). Both of these have been further termed bracketing, which is done in an effort to allow the information that is gained to be epistemological in nature; in other words, Husserl developed what is known as transcendental or descriptive phenomenology in an effort to go for absolute truth via description (McConnell-Henry, Chapman & Francis, 2009, Husserl and Heidegger). Under a Husserlian philosophical approach, context is considered only peripherally in order to gain further understanding (Wojnar & Swanson, 2007). In this more traditional philosophical approach, the use of a methodological device known as a hermeneutical circle provides a way for learning about existing meanings which are thought to be objective entities waiting to be discovered (Schwandt, 1998). In contrasting Husserl with Heidegger, Walters (1995) explained that Heidegger offered a disparate view as his philosophy is one of hermeneutical phenomenology. This is an existential approach in which understanding of a person cannot be considered as separate or in isolation from their world. Heidegger felt it was not possible for research to be independent of the views of the researcher conducting it and, therefore, viewed Husserl's insistence on bracketing as being impossible to achieve. Heidegger termed these views of the researcher to be called fore-structure or fore-conception and felt they were necessary as this prior knowledge of the researcher allows him/her to ask questions that are relevant to learning about the phenomena. McConnell-Henry, Chapman and Francis (2009, Husserl and Heidegger) discussed this *being-in-the-world* of the participant as Heidegger considered having these background views as necessary for the researcher to be able to correctly interpret what the participants in the research were saying. McConnell-Henry, Chapman and Francis (2009,

Unpacking Heideggerian phenomenology) further discussed another central concept of Heidegger known as *dasein*, or *be-in-the-world*, also known as *being-there*. This central concept speaks to the idea that every human being is a meaningful being with meaningful views to offer on phenomena. Under a Heideggerian philosophical approach, context is considered to be a central concept without which full understanding of a phenomenon cannot occur (Wojnar & Swanson, 2007). Context is considered to be much more than the physical environment and space; it also is made up of time, social factors and other determinants of context. In the end, Heidegger saw no discernable difference between epistemology and ontology (McConnell-Henry, Chapman & Francis, 2009, Husserl and Heidegger). He felt that knowledge is “primarily subjectivist and is therefore removed epistemologically from Husserl’s objective approach” (Annells, 1996, p. 708). With this subjectivist view of knowledge, Heidegger’s view of the hermeneutical circle was also different; he took an ontological approach which means there is no verification process for the interpretations which are arrived at as they are all part of subjective reality (Schwandt, 1998). Smith (2007) and Koch (1995) both discussed the Heidegger hermeneutical circle as being one in which a systems perspective of the person, context and phenomenon exists, and in which the researcher’s understanding of this perspective is “made from a given set of fore-structures which cannot be eliminated but only corrected and modified” (Koch, 1995, p. 832). For the purposes of this study, a Heideggerian phenomenological philosophical approach was taken to conduct the research study.

The use of phenomenology in the field of occupational therapy is considered to be an accepted and promoted practice (Barber, 2004; Clarke, 2009; Mattingly, 1994; McLaughlin Gray, 1997; Wilding & Whiteford, 2005). Mattingly (1994) perhaps put it best when he suggested that occupational therapy’s focus on being holistic and meaningful in a therapy session

is using a phenomenological perspective, as is getting occupational profile information from a client. This phenomenological perspective can also be seen when a therapist is working with a client and discusses with the client his/her own personal experiences of disability and how the client is making sense of it in his/her life. In summary, the benefit for using a qualitative, Heideggerian phenomenological philosophical framework for this study was that it allowed for a rich, thick description of the participants' experience of the phenomena and still acknowledged the researcher's previous experiences and the influences those experiences may have had on the interpretation of the data.

Research Questions

The major research questions were:

1. What are the lived experiences of caregivers of children with special needs when learning about delivering an occupational therapy home program to their child from the occupational therapist?
2. How did the caregivers learn the home program?
3. What helped or hindered the caregiver in learning the home program from the therapist?

In answering these questions, this study allowed for insight into the caregiver's experience in learning the home program and what each caregiver felt was needed from the therapist to do to allow him/her to be able to learn from the therapist in a more effective manner.

Researcher Reflexivity

It should be remembered that under the Heideggerian phenomenological philosophy bracketing was considered to be impossible as Husserl would have it completed. Van Manen (1990), a follower of Heideggerian phenomenology, stated:

If we simply try to forget or ignore what we already ‘know’, we may find that the presuppositions persistently creep back into our reflections. It is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character. (p. 47)

This leads a researcher to, instead of bracketing, perform researcher reflexivity which “refers to the engagement by the qualitative researcher in continuous self-critique and self-appraisal and the provision of an explanation of how his/her own experiences did or did not influence the stages of the research process” (Dowling, 2007, p. 136). This next section, therefore, is the researcher engaging in researcher reflexivity.

I practiced as a pediatric occupational therapist providing in home and in clinic (primarily in home) therapy services for nine of the fifteen years in my career. Throughout this time, I noted parents of children with special needs having difficulty with completion of home therapy programs given to them by myself. Often I attributed this to difficulties with time, resources or other factors such as siblings being present or family support. I often struggled with this part of therapy as I felt the parents understood the importance of their child progressing and that they would progress faster if the home program was completed; why then did parents not complete the home program was a question of mine. Over time, I moved on from being a practicing therapist to becoming a professor teaching students about the field of occupational therapy. I noted students having difficulty with certain classes based on how the professor of the class was delivering the information. At the same time, I attended school to work on gaining my doctoral

degree in Urban Education. As I learned about theories of learning I began to question why I taught students the way I did and how my approach should consider what these theories had taught me. I began to modify my own practices and also to continue to observe the practices of other professors with whom the students seemed to have more difficulty learning from. It became clear to me that knowing these learning theories and applying the principles related to them made an impact on how well the students were able to learn the material. I started to wonder how much the learning process itself was affected by consideration of the teacher towards the student in terms of how they best learned and what their own needs were. I then related this wondering back to the original question of why parents of children with special needs did not always follow through on completing home programs. Therefore, I became curious to find out more about the learning process as it is lived by caregivers of children with special needs as they learn a home program from their child's occupational therapist in the hopes that knowledge can be gained which will help future therapists understand the process more fully.

Study Design

Phenomenology is the art of understanding the essence of the lived experience. It seeks to draw meaning through the analysis of first-person accounts in order to better understand a person's reality. It is usually conducted through in-depth interviews and sometimes through observations of the participants involved. This data is then analyzed for meaning and common threads in the experiences of the participants. The design of this study was a phenomenological methodological design. This design allowed the participants to have a voice in describing what the essence was of the lived experience of having learned a home program for their child from their child's occupational therapist from their perspective (Creswell, 2007; Mapp, 2008). Six

research activities were put forth by van Manen (1990) as the methodology for conducting a phenomenological study:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating the experience as we live it rather than as we conceptualize it;
3. reflecting on essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering the parts and the whole. (p. 30)

The first activity involves addressing presuppositions while working to identify a phenomenon to transform into a textual expression of its essence. The second uses personal experience as a point to decide which data to collect. Some of the methods suggested by van Manen are interviewing, observing, literature reviews, diaries, journals, and considering objects of art. Once collected, the data must be reflected upon in order to determine which themes capture the essence of the phenomena. Van Manen describes three ways in which this can be done including: “(1) the wholistic or sententious approach; (2) the selective or highlighting approach; (3) the detailed or line-by-line approach” (p. 92). The first method looks at the text as a whole, the second picks out certain phrases and analyzes those separately and the third picks out themes sentence by sentence. These last three steps speak as to how to write phenomenological research results in a manner which allows for the essence of the experience, as relayed by the participants, to be conveyed to others. This is discussed more under the data analysis section.

Participants

Participants for this study were recruited via gatekeepers at five different pediatric rehabilitation clinics across the greater Milwaukee, Wisconsin area and nine different pediatric rehabilitation clinics across the greater Phoenix, Arizona area (recruitment letters which were given by the gatekeepers to the parents can be found in Appendix A). The gatekeepers at the Wisconsin clinics were therapists with whom connections had been made by the researcher via conducting previous research with therapists at these clinics. The gatekeepers at the Arizona clinics were the head therapists which the researcher connected with via cold calls or via connections from colleagues at the researcher's place of employment. As the researcher had difficulty finding participants in Arizona, a change was made to the protocol of the study and the researcher also recruited for participants via five online support groups for parents of children with cerebral palsy on social media (Facebook) in the area. Participants were given a \$50 dollar Target gift card to thank them for their time at the end of their participation in the research study. Confidentiality is being maintained as all participants have been given a pseudonym by the researcher when reporting their data and the researcher is the only one to know their true names. All printed data is kept in a locked file cabinet in the researchers own home. Electronic data is stored on the researchers own personal computer which is protected by a password known only to the researcher. The study underwent the review and gained the consent of the University of Wisconsin – Milwaukee IRB before being conducted.

In terms of number of participants, Dukes (1984) recommends three to ten for a phenomenological study, while others recommend adding participants until saturation is reached. Patton (2002) states “the validity, meaningfulness, and insights generated from

qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (p. 245). As this study had time limitations, nine participants in total were recruited, six of which were from the different therapy centers, one via a work connection and two via social media.

Children with different diagnoses have differing needs in terms of home programs, some of which are easier to deliver than others. Due to the possibility of this being a confounding factor, this study focused on caregivers of children with cerebral palsy. Therefore, the sample included nine primary family caregivers for children, aged 1 to 12 years old, with cerebral palsy who were receiving occupational therapy and using a home program given by the therapist. Children with cerebral palsy may have differing types and severity; therefore, this study focused on parents of children with mild to moderate spasticity (see table of common characteristics of the different types of cerebral palsy as given by Rogers, 2010 in Appendix B). Inclusion criteria for participating in the study was that the caregivers’ first language was English, their child must have been receiving occupational therapy services including a home program for a minimum of six months in either the home or clinic environment, and the occupational therapist must have at least two years of experience practicing in the field of pediatric therapy. Exclusion criteria included if the caregiver had never been taught a home program by their occupational therapist. Criterion sampling was used as Patton (2002) states the “logic of criterion sampling is to review and study all cases that meet some predetermined criterion of importance” (p. 238); this type of purposeful sampling was necessary as the participants must all have experienced the phenomenon of learning a home therapy program for their child with cerebral palsy from the occupational therapist to be able to report on the lived experience.

Data Collection Procedures

The principal method of data collection was interviews which took place in the participant's home. In total there were three meetings, either in person or via phone, between the researcher and each participant. The primary interview during the second meeting always occurred in person. During the first meeting the recruitment letter was reviewed with the participant in order to ensure he/she understood the purpose and the requirements for his/her participation in the study. The researcher checked to ensure the participant met the standards for inclusion/exclusion criteria and then had him/her sign an informed consent form. The participants were then requested to fill out two critical incident guides and to begin work on a diary before the next meeting.

Critical incident reporting is helpful in healthcare as it allows for the capturing and identification of an important experience the client had which provides useful feedback to the healthcare professional to learn from (Kemppainen, 2000; Schluter, Seaton & Chaboyer, 2008). In this study, two critical incident guides were provided to each participant, one of which asked for a positive experience he/she had when learning a home program for his/her child from the occupational therapist and one of which asked for a negative experience. The critical incident guides (which can be found in Appendix C) were derived from the critical incident technique developed by Flanagan (1954) who described the method as "a procedure for gathering important facts concerning behavior in defined situations" (p. 335). The steps of this technique involved first developing a general aim of what was expected of the individual, which in this case was having experienced the phenomena this study was researching. Secondly, it was important to decide on the precise instructions which should delineate the situation observed, allowing the participant to make judgment calls regarding the relevancy of his/her experience to

the general aim, and deciding if the experience had a positive or negative effect. The next step was the actual collection of the data, for which the guides were used. The last steps included analyzing the data, and then interpreting and reporting it.

As noted before, each participant was also asked to begin to keep a diary after the first meeting. The participant was given the choice between keeping a paper or electronic diary record. If he/she chose paper, he/she was given a journal. If he/she chose electronic, the forms were emailed to him/her. Either way each caregiver was asked to answer specific questions for the diary (a copy of the question sheet given to the participants can be found in Appendix D) relating to learning the home program from the therapist. He/she was asked to document each time he/she had therapy with his/her child over the three weeks data was being collected, for a total of three entries. This diary was collected at the second or third meeting of the researcher and the participant, dependent upon the timing of the participant's therapy sessions with his/her child's therapist.

The second meeting occurred after the initial meeting, once the researcher had collected the critical incident guides from the participant, again in the home of the participant. During this meeting the researcher interviewed the participant regarding his/her experience learning a home program for his/her child with cerebral palsy from an occupational therapist. The interview was semi-structured using open-ended questions followed by probes (verbal and non-verbal) to obtain full understanding of the experience of each participant and lasted approximately 60 to 90 minutes. The interviews began with ice-breaker questions in order to build rapport while the researcher maintained a neutral stance on the subject in order to not provide direction to the participant on how to answer the interview questions. Patton (2002) suggests a combined approach using a standardized format for what has to be asked while leaving other items as

topics to be discussed at the researcher's discretion, thereby ending the interview with an informal conversational tone. The interview guide for this meeting can be found in Appendix E. The interview also covered a review of the critical incident guides in order to ensure the researcher gained an accurate understanding of the information in the guides. This review also allowed for clarification to occur where needed. The data from this interview was recorded and then transcribed by hired help with the transcriptions being checked for accuracy by the researcher.

The third and final meeting occurred one to two weeks after the interview and consisted of a member check being conducted regarding the validity of the information collected during the interview. The member check involved verbally summarizing information provided during the interview and asking whether the content reflected an accurate description of the participant's thoughts and feelings. The diary entries were also reviewed with the participant at that time if they had not yet been completed at the time of the second meeting. The interview guide for the third and final meeting can also be found in Appendix E. This meeting occurred over the phone with all the participants.

All participants in the study completed all of the steps with one exception. The only missing data in the study was one diary entry from one family; the therapist for that family was in a car accident a few days before the caregiver was to meet with her for the session where the third diary entry would have been completed. As the therapist was to going to be out for an extended period of time on medical leave, the researcher made the choice to move ahead without the third diary entry.

Data Analysis

There are many approaches to analyzing phenomenological research including the process described earlier by van Manen. Both Creswell (2007) and Patton (2002) recommended the more structured approach designed by Moustakas for phenomenological data analysis. This approach involves five main steps (Moustakas, 1994). The first step is horizontalizing the data, in which the data is processed to find significant phrases, statements or quotes that provide a description of the phenomena being experienced by the participants. These statements are all treated to be of equal value in finding the essence of the experience. From the horizontalized statements, meaning units are listed. These meaning units are then placed into meaningful clusters and analyzed through the method of imaginative variation, a procedure by which the researcher examines the data from different perspectives to determine what is essential and what is not to the description of the phenomena. This systematic varying of perspectives provides a range of possible meanings from which the researcher must begin to recognize the underlying themes that account for the essence of the phenomena. These meaningful clusters are then combined to provide a textural description of the phenomena. The clusters are also used to write a structural description in the next step; this description goes a step further than textural description as it looks deeper than the statements given by the participants to find the thread that connects the group and provides meaning to the phenomena. The textural and structural descriptions are lastly synthesized to create a composite description which presents the essence of the phenomena to the reader. The researcher completed these steps first by color coding each interview with a different color ink when printing them. The critical incident questionnaires and the diary entries had been discussed with each participant during the interviews, therefore, the information reported in the questionnaires and diaries were incorporated directly into the

interview transcripts. Each color coded interview was first cut into its different statements. These statements were slowly clustered into different meaning units to find common areas from the different participants. Lastly, the meaning units were clustered into three overall themes which will be discussed in more detail under the results section.

Trustworthiness and Quality Control

Lincoln and Guba (1985) discussed trustworthiness as being comprised of four pieces: credibility, transferability, dependability and confirmability. They contrasted each of these as being comparable to various terms of rigor in quantitative research with credibility being comparable to internal validity, transferability to external validity, dependability to reliability and confirmability to objectivity. Each of these will be considered in turn here as they related to quality control used in this study.

Credibility depends on three distinct elements: rigorous methods, the credibility of the researcher, and the philosophical belief in the value of qualitative inquiry (Patton, 2002). In terms of rigorous methods, various forms of triangulation were used in this study to substantiate the data. The first was methodological triangulation which consisted of confirmation of the theme being seen across different data collection methods; in this case the different methods included the caregiver's diary, the critical incident reports, and the interviews. The accuracy of the critical incident reports and the diary can be judged by their completeness. All critical incident reports and diaries provided a full and thorough picture which confirmed the information provided in the interviews. A second form was triangulation of sources of information, which for this study was finding a confirmation of the theme across multiple participants, which this study did find. Lastly, in terms of the credibility of the researcher, the first indication was the use of constant comparative method by the researcher as this was a

method previously used by the researcher. Therefore, the researcher had experience and a level of comfort in using this data analysis method again. A second sign was the reporting of researcher reflexivity. Although Heidegger did not support the assumptions of bracketing as he believed the researcher is as much a part of the research as the participant and that the researcher's ability to interpret the data is reliant on their prior knowledge, this does not imply a lack of neutrality on the part of the researcher. This neutrality was instead shown through the researcher maintaining a neutral stance throughout the data collection process and by reporting the data using thick, rich descriptions and using quotes edited only for grammar. One last method to demonstrate credibility of the researcher was through the use of researcher reflexive journaling to lay an audit trail through the keeping of a field log. After each interview the researcher talked into a voice recording device to keep this field log. When the data was analyzed the researcher compared the field notes to the data and found collaborations across what was coming across to the researcher at the time of the interview and what themes were found later during data analysis. In conjunction with the member checking, this process helps to show how conclusions were made by keeping record of how and when hypotheses emerged, data that supported them, and how the hypotheses were refined and expanded (Willis, 2007). Finally, in terms of credibility, the philosophical belief of the researcher can be summed up in the words of Patton (2002) when he stated "the point, however, is not to be anti-numbers. The point is to be pro-meaningfulness" (p. 573). This addresses the researcher's belief that qualitative research is an integral part of learning about the deeper meaning of phenomena.

Transferability was addressed as when using the constant comparative method, the core category (phenomenon) emerged from the subsidiary categories. The more abstract and broad these subsidiary categories are the more applicability the data has; therefore, the more we will

know about the lived experience of caregivers of children with cerebral palsy when learning a home program for their child from an occupational therapist (Corbin & Strauss, 1990). This study has provided as much information regarding this lived experience as was able to be collected from the participants. In the end, it is left to reader to analyze how the results are interpreted for use in his/her own life.

In regards to dependability, an audio recording was used to allow for the exact words of the participants to be documented. The data is reproducible insofar as it is verifiable. It is possible to take the relationships found in this study through coding and test them, however, the ability to replicate the exact relationships is limited as the exact conditions will never again exist in a new study (Corbin & Strauss, 1990).

Last but not least, in terms of confirmability, member checking was completed to demonstrate neutrality during the third meeting with the participants in order to check emerging conclusions with the participants. Confirmability was also strengthened as the process of open coding breaks through subjectivity and bias (Corbin & Strauss, 1990). The researcher took an extra step and also contacted three of the nine participants after the final data analysis was complete and the themes were clear to review the overarching themes of the nine interviews with them. The three participants confirmed being able to relate to each of the three themes and each supported the themes as being reflective of his/her own experience of learning the home program for his/her own child from the occupational therapist.

Summary

In short, a phenomenological approach was used for this study to allow the researcher to search for what the experience of being a caregiver of a child with cerebral palsy while learning a home program from the child's occupational therapist constitutes. This was completed by

using in-depth interviews with the participants as well as having the participants complete critical incident guides and diaries of their individual experiences. These three sources of data were analyzed and coded to discover the overall themes which represented the findings. Member checking, steps to ensure researcher reflexivity, triangulation and the use of an audio recording device were all employed as the means to increase the trustworthiness of the data. In the end, three themes were found which will be discussed in detail in the next chapter.

Chapter Four: Results

In total nine participants completed the research process. Decisions about whether a sample size is adequate in qualitative research are difficult to make as there are no rules. As Patton (2002) stated “the validity, meaningfulness and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (p. 245). Therefore, in qualitative research, when using a flexible sampling approach, it is recommended to collect data until saturation is reached. Data saturation is considered achieved when no new concepts or topics are identified through continued interviews and the new data fits with already identified themes (Carpenter & Suto, 2008). Saturation was determined to be reached with these participants as demonstrated by the fact that the last three of the nine interviews conducted did not bring forth new concepts or themes above what the researcher had heard in the first six interviews. Pseudonyms have been given to all participants quoted in this chapter to protect their confidentiality.

Participants

Of the total participants, 8 were women and 1 was male ranging in age from 32 to 53 years old. Seven of the participants identified themselves as White, one as Black/African American and one as Hispanic. Of the nine participants six of them live in the Midwest and three live in the Southwest part of the country. Table 1 provides a full accounting of the demographic information regarding all nine participants.

Table 1

Demographic Information for Participants of Study

Family	Gender of Participant	Age of Participant	Number of Children in Household	Age of child	Race/ Ethnicity	Geographic Area	Level of Education	Employment Status	Annual Household Income
A	F	43	3	22 mos.	White	Midwest	Bachelor's degree	Not employed by choice	\$60,000 - \$70,000
B	F	46	13	6 y.o.	White	Southwest	Some College	Full-time, self-employed	Above \$100,000
C	F	53	2	11 y.o.	White	Midwest	Associate's degree	Not employed by choice	Not provided
D	F	35	3	3 y.o.	Black	Midwest	Bachelor's degree	Not employed by choice	Above \$100,000
E	F	32	2	2 y.o.	Hispanic	Midwest	High School graduate	Not employed, seeking work	\$0 - \$10,000
F	M	53	3	12 y.o.	White	Midwest	Bachelor's degree	Retired	\$40,000 - \$50,000
G	F	33	3	22 mos.	White	Midwest	Bachelor's degree	Not employed by choice	\$80,000 - \$90,000
H	F	48	3	12 y.o.	White	Southwest	Bachelor's degree	Not-employed by choice	Above \$100,000
I	F	41	1	4 y.o.	White	Southwest	High School graduate	Full-time, employed	\$20,000 - \$30,000

Note. mos. = months; y.o. = years old

Although seven out of the nine participants held college degrees or had attended college, only one of these seven worked and she was self-employed and worked out of her home. One of the remaining six (the male) was retired and the other five chose to stay home rather than work. All seven of these participants reported deciding previously with their respective families that it was more beneficial for everyone if he/she stayed home and was able to focus on providing the extra care that was needed for the child/children with special needs in the family. The two participants without college experience had graduated from high school. One high school graduate was employed full time and the other was unemployed but seeking employment at the time of her participation in the study. The reported household annual income varied widely as the family with the lowest income fell into the \$0 - \$10,000 range and the families with the highest income reported their income as being above \$100,000 annually.

Of the nine households, seven of the participants were biological parents to the child with cerebral palsy, one was a biological grandmother and the last was an adoptive mother. The number of total children in each household ranged from one child to thirteen. Seven of the nine households had only one child with special needs living with them. The eighth household had two children with special needs as the child with cerebral palsy had been a twin and his twin sister also had medical difficulties. The ninth household held a total of 13 children, 7 of which had special needs of some form; these seven children had all been taken in through the foster care system and had later been adopted by the family. The age of the child with cerebral palsy in each household ranged from the youngest at 22 months old to the oldest child being 12 years old. Each of these children were noted as receiving occupational therapy since birth or near birth in all cases.

Findings

In horizontalizing the data, interviews of the nine participants were processed and separated into 155 significant phrases and statements. The interviews included discussions of the critical incident guides and the diaries, thus the 155 significant phrases and statements included data from these two sources. These statements were separated into 13 sections with two sections (historical information and off topic information) being set aside and the other 11 considered to be meaning units. The 11 meaning units were titled as follows: guilt, criticized, misunderstood, need this to work, make my child happy & make me happy, communication, communication blockers/ helpers, helping others learn also, methods to learn home exercise program, strategies that helped/hindered learning, and other factors that helped/hindered learning. Although the diary and critical incident guide data was incorporated into the interviews, they were also used to verify the meaning units. Each participant's full and separate diaries and guides were compared to the meaning units to verify the units were capturing the essence of what had been reported. The 11 meaning units were examined and eventually combined into three clusters which were felt to represent the themes of the interview data collected from the participants. The first cluster revolved around feelings the caregivers experienced in learning the home program and held 39 statements. The second was in regards to the caregivers' view on the importance of communication in learning the home program and held 68 statements overall. The third cluster covered other factors the caregivers felt helped or hindered the learning of the home program and held 48 statements to that effect. Each of these three clusters will be described below.

Feelings of Caregivers: A Parent's Hurt. In discussing the experience of learning the home program from the child's therapist, caregivers on the whole reported a wide range of negative emotions. These emotions encompassed not only the time during which the caregiver

was initially learning from the therapist but also when he or she was trying to complete the learned home program in between therapy visits and when it was time to discuss the home program on subsequent visits from the therapist. The emotions included guilt in varying forms and feeling misunderstood as well as criticized by the therapist. The caregivers did report feelings of happiness when their respective child met a goal or was successful, however these feelings seemed to be overshadowed in the interviews by the negative emotions.

Guilt was expressed by the caregivers as being felt for multiple reasons surrounding the home program experience. One mother, Amy, reported feeling both guilty and good for taking her older daughter to the daycare in order to spend additional time working with her twins who had special needs. Amy stated “the daycare aspect I struggle with it, because I feel guilty sort of off and on but it makes me feel good that I’m spending more quality time with these two.” Both Amy and Julia, another mother of three, voiced concerns regarding whether their other older children were able to understand the need for their younger sibling to receive higher levels of attention from the parents. Guilt seemed to revolve, in these particular instances, around the caregiver questioning if she was making the right choices in how her time was spent in mothering one child versus another. Although only two of the caregivers used the word “guilty”, five of the nine described feeling guilty in having to complete the home program with their child. One mother, Emma stated the following:

We were going to therapy six days a week. So six days a week we were going somewhere after school. So, then there’s school and then there’s therapy and by the time he is done, he’s done. I feel like once he walks through the doors of our house, or wheels through the door of our house, it’s his free time. And I feel guilty constantly harping on

him. Sit the other direction, do this. I'm the squawk person in the background. And I feel like the kid never gets to be a kid and just play.

This expression of guilt over having to constantly correct their child and place themselves in the position of constantly being the giver of critical feedback was a concern over whether the child should just be able to relax in any way the child wanted to while the child was having downtime. Caregivers wanted the child to have time to have a regular childhood. Frank described it by saying:

I feel like she needs time to be a kid too though. She goes to school all day. I pick her up for therapy after school on Mondays, Tuesdays and Thursdays so we're getting home just when Megan [the wife/mother] is. And it's a long day for Alison. She doesn't have homework, she's in a special education class and they don't send anything home, but she still has been in school all day and then with the therapy after, she comes home tired. I feel like she needs some time to relax too and just be a kid. Plus, sometimes we have extra things in the evenings for her sister or her brother. There's a limited amount of time that we can do things on any given day.

There was also the concern aired that if the caregiver did do as he or she was supposed to and correct the child or work with the child on something that was difficult for the child, then guilt was felt over having done so. One parent, Katie, when asked if she had spoken to her therapist about these feelings reported:

I don't know if I've specifically said this is her least preferred activity. Like this is really hard for her. No, I'll kind of make a joke is kind of my tactic. I use jokes a lot when things are uncomfortable. I'll be like, 'Oh, great, I have to be the mean mom' [to the therapist]

The caregivers who discussed guilt around this area seemed to feel uncomfortable regarding the position completing the home program was putting them in with the child. They felt guilty over either interrupting the child's down time or for making the child do something the child obviously did not enjoy or want to do thereby taking away the child's down time for disliked activities. This reasoning led into the most common expression of guilt from the group which was the caregiver reporting guilt over not having completed the home program work learned from the therapist for their child. Two participants, Katie and Susan were able to put it in the most concrete terms during their interviews. Susan stated:

I know that I should be doing things that she [the therapist] wants us to do. Sometimes I lie awake at night thinking I should have fit in some more work with Regan and I can't sleep because I feel so torn up about it. Then the therapist comes and I know she might ask and it makes me not even want to talk to her. Because I'm already feeling bad about it. I don't need her to make me feel worse. I don't think she is trying to make me feel bad but I do...

Katie voiced similar feelings in saying:

I guess I wish if therapists knew anything it would be that as a parent I will always be harder on myself than anyone else can be on me. If you come and I didn't do something you asked me to do, then trust me I'm feeling guilty about it. I've lost sleep over it and cried about it and stressed about it. I love my kids and don't want to see any of them struggle or have a hard time and I want to help her [the child] as much as I can. But it's not always that easy and I'm trying. I'm really, really trying.

These feelings of guilt over not being able to fit in work on the home program due to time limitations and other factors which constrained the caregiver were felt almost universally with

six of the nine families relaying negative feelings around this area. When the caregivers were unable to work on the home program it bothered them even when they acknowledged that it was the right choice to make by not working on it. This could be seen in multiple caregivers reporting the negative feeling of being misunderstood by the therapist.

The feelings of being misunderstood by the therapist were described by some of the caregivers in regards to trying to fit the extra home program work given by the therapist into an already busy family life. This was at times seen by the caregivers as the therapist not truly understanding or being realistic about what the family could reasonably do. Frank reported:

They've been working on Alison being able to feed herself but it will take the whole session for her to eat a handful of snack foods. We don't have time for that at home. In the morning, she gets up at 6 and the bus comes by 7. I have just enough time to get her dressed and fed and everything before it's time for her to leave. If she was going to feed herself then she wouldn't get a good breakfast before it was time for her to go.

Caregivers who did talk to the therapist about this mismatch of expectations and what was realistic for the family reported that the therapist response would be to continue to stress how important the home program was and to try to fit it in. This conversation with the therapist seemed to serve only to lead the caregivers to feel more misunderstood. A single mother, Tammy, who participated said the following when asked if she had talked to the therapist about not being able to fit in the home program work:

Yeah, I mean she [the therapist] knows I'm busy. She keeps saying to me to try to fit it in because it's important. Don't get me wrong, she's a good therapist. I'm just not sure she completely understands how hard it can be to try to make it all happen with what she wants me to do and still live the rest of our life.

Multiple caregivers attributed the therapist's lack of understanding as being due to the fact that they knew their therapist was not a mother herself yet. Katie expressed this viewpoint:

Again, and I hate to keep saying this because not every OT is going to be a parent but it's just been tougher for me to deal with therapists that don't have children. The understanding is just a piece I can't give you. I can't explain to you what it's like to have multiple children or misspeak a medication. It's just mom brain. I'm dealing with 14 thousand kids. So sometimes I do feel like [pause for expression], and then the expectations. The goals are set and I think a mom would be more realistic saying the kid gets home at 4:00, she goes to bed at 7:00. That's a 3 hour window. How much do I hit this kid with? So, that's just my opinion. I think a lot of her things are unrealistic because she just doesn't have the experience.

This was also felt by other caregivers. Amy, directly comparing her present therapist who wasn't a mother to her previous therapist who had been one, said:

Well, I'll tell you something else, she's not a mom. So right there is a huge piece missing. And she's got an okay kind of rapport with the kids and stuff, but not, you know. My first OT, she was a mom of five kids and she would literally help. She would tell me how to help nap train them and all kinds of stuff. I mean, she had all kinds of ideas for me, for the kids.

The caregivers who discussed the therapist not being a parent all directly attributed it as a cause behind the therapist not being able to understand what life with a child is like. Thereby these caregivers felt the therapists were not able to give home programs which would fit well into the life of the caregiver and the child.

Along with feelings of guilt and being misunderstood, a third feeling reported by caregivers was the feeling of being criticized. This feeling of being criticized seemed to occur during the therapy sessions when the parent was first learning a new item from the therapist and then again when the therapist was checking in on how the home program was going. An example of a parent expressing this feeling when first learning a new item from the therapist was when Tammy voiced:

I think as a mom with therapists when you guys are telling us what to do, it's easy to feel like you're being criticized and so it takes a really good person to have that finesse to say to you 'it's fantastic that you're doing this but let me show you an easier way, or a better way, or a more efficient way' or something.

This feeling was also expressed by caregivers discussing how they felt when the therapist was checking in on whether they had completed the home program. During the interview with Katie discussion occurred around how the therapist could make completing the home program easier. Katie was asked if it would help if the therapist discussed how difficult the process might be with her ahead of time. Katie responded by saying "For sure, because then it wouldn't feel like all or nothing. Like if you didn't hit the 60 [repetitions], you just failed. Hey we did 15, yay! That's wonderful!" Another mother, Megan, also expressed similar feelings and stated "I think the best (therapists) say to me 'look, do the best you can'." Caregivers in both scenarios seemed to be expressing that they were not only feeling criticized, but that they were interpreting that criticism as a reflection of their parenting abilities. These caregivers seemed to express a need for validation from their therapists to recognize that in just trying, the caregivers were being successful. Katie perhaps said it best when she stated:

I think it's just approach, you know. I think therapists need to say to me and say to families, look, I know that she doesn't like it and that as a mommy it's painful to hear her crying. It's painful but really make your goal 15 minutes and let's try to increase it by 5 minutes or something. That gives you the option. Whereas if they come back next week and they're like 'were you able to stand her an hour?', then no.

In Katie's statement, you can see her feeling guilt and criticized over not being able to complete the hour. She also had a clear feeling of being misunderstood by the therapist with the therapist not presently validating her feelings of not wanting to do something that makes her daughter uncomfortable. Katie wanted the therapist to work with her to find something more realistic that will fit into their life and to validate that what really matters was that Katie was trying.

As stated before even when caregivers acknowledged happiness in seeing their child make progress and reach goals, these feelings seemed to be overshadowed in the interviews by the negative emotions of guilt, being misunderstood and/or feeling criticized. Only two of the nine participants, Betty and Diana, reported not having any of these feelings currently but Betty acknowledged she did have negative feelings when the therapist had first started working with her son. Those feelings had also revolved around not wanting to make her son participate in a home program that he did not enjoy doing. She reported "in the beginning I was kind of, I was like irritated and angry because to me it felt like they were hurting him and [now I know] it wasn't." Betty attributed her change in perspective to her learning to trust the therapist and stated "She just taught me step by step how to do my therapy and take my time and let him learn that what we are doing is not to be scared, that it's for his well-being." Diana had been with the same therapist for her child for a very long period of time. She reported, in passing, being

unhappy with other therapists in her past but at the time of the interview she felt her therapist had been around so long she was “like a member of the family.”

In summary, although the caregivers reported feelings of happiness when goals were reached in therapy, the majority of the feelings reported by the caregivers in regards to the home program experience were the negative feelings of guilt, being misunderstood, and feeling criticized by the therapist. These feelings were underscored by the fact that none of the caregivers, even the one who did not seem to have a very good relationship with her therapist, wanted to necessarily change to a new therapist. Each caregiver felt it would be harder to have a new therapist as the current therapist already had a relationship with the family, and in particular, with the child. This makes it apparent that it is more important than ever for therapists to be cognizant that these feelings can arise and to be sensitive to the caregiver’s feelings in all situations.

Importance of Communication: Tell me more. A second theme emerged when caregivers were questioned regarding what they felt helped or hindered the learning of the home program and the responses all revolved around communication in one form or another. The caregivers expressed how communication could help the process, hinder the process, and what they felt their needs were in regards to the area of communication.

Betty, who as mentioned before reported being very happy with her therapist in all aspects, was able to explain how communication from her therapist helped her develop trust in her therapist over time when she stated:

I would just get terrified. Every little thing she was doing, it would scare me like I would literally tell her to stop doing the therapy because he would have like spaz attacks real bad and that. But she taught me that what she was doing was professional and it was

necessary because he was basically a vegetable baby. He wouldn't, didn't know how to crawl. He didn't know how to roll over. He didn't know how to sit up. And she taught me how to do that and with a year and a half with that I noticed he was sitting up by himself, he was. It took a lot of time to teach him to roll over but he did it. She taught me how to start teaching him to let go and start learning how to take his first steps and he's just barely two and he's just barely learning how to walk as a two-year-old. So, she's taught me a lot.

When Betty was asked what she felt the therapist did to make things easier for her it again came back to communication as she responded:

How she explains everything to me, step by step because there's times when I have a hard time comprehending some stuff and they explain it and breaks it down for me step by step and they show me, physically show me how to do it, what to do and what the outcome will be. It might hurt, it might not hurt, but it's for his well-being.

Betty's therapist had been able to build up trust through communication and working with Betty over time to the point where Betty now was able to be more accepting of learning a home program that may be more difficult to carry out or that her son may not enjoy completing due to muscle pain or other factors. Diana, the other participant who seemed to have developed a high level of trust with her child's long term therapist, reported similar feelings and stated that the relationship affected learning from the therapist a great deal "cause if you don't like your therapist, you're not going to learn from them." Diana and five other parents, Julia, Frank, Emma, Susan and Tammy, all discussed how they had developed a level of trust through communicating with the therapist that allowed them to know the therapist had the child's best interests at heart and allowed them to feel open to being able to ask questions of the therapist

when they had them. Diana, Julia, Emma and Tammy also expanded upon that by reporting their therapist built that trust and open communication over time by being willing to explain the reasoning behind why a therapist was asking them to do something. Julia reported that she felt she and her husband were more likely to follow through on something the therapist had given them to do if the therapist took the time to give the explanation. Tammy expressed wanting the therapist to tell her more saying “educate me, tell me, teach me. I don’t know if I’m just unusual but I would think all parents want to know why you’re doing what you’re doing with their kids.” These parents wanted to be viewed as partners in the process and have the communication from the therapist reflect that partnership. Diana stated “she’s learning from me too and I’m learning from her too.” Emma, one of the caregivers who had been through therapy with her 12-year-old child his whole life, stated:

I have had therapists that portray themselves as the expert and don’t have patience with me asking questions and I don’t keep them very long. They’re gone rather fast. If they portray themselves as a tool and a partner in growth and can tell me what the long-term outcome is gonna be, like we’re doing this because we want him to be able to do this, then we have a good relationship. You know, I need to know the why.

These parents wanted the therapist to communicate in a manner that made it clear they were working together and both an important part of the process. As might be expected from the negative emotions expressed when they didn’t feel understood, the caregivers felt it helped them learn when communication was conducted in a way that the caregiver felt the therapist was listening. Susan stated, “I know she has a lot of experience and you can tell she knows her stuff. But she listens to me when I have questions.” Emma, when asked at the end of the interview if

she had anything to else she wanted to say about the process of learning home programs, expressed:

I think one of the biggest things is communication as far as having the OT try to have the parent open up about the problems that they're having. What do they see? And make the parents feel validated. Not that, 'oh well, that will just work itself out, he will figure that out.' You know, listening to parents. Like I said that one doctor that gave me that don't you ask questions sort of thing. That always kind of plays in my head that I'm sure there's a lot of therapists out there that have this God syndrome. That, 'I know, you don't, so just listen to me.' I think just listening to the parents because the parents are the ones that are with them all the time and know how they're doing things. So just listen to the parents I think.

Communication that was open, built on trust, and where the parent felt viewed as a partner seemed on the whole to help the caregivers feel more open to being able to learn the home program from their child's therapist in a more effective manner.

Interestingly, some caregivers also reported that the close bond that was built up to allow free flow of communication could also hinder learning from the therapist. Three of the parents, Emma, Julia and Susan, felt that because the relationship with their therapist was at the point where the communication was very open, at times this led to conversation that was not centered on the child or the therapy and that concerned them that perhaps their child was not getting the attention they should be. Susan said:

It goes both ways. Sometimes, I feel like I may become too relaxed and we start to chit-chat and get off subject when we shouldn't. Honestly, because they know, you know, my mom just passed away last week. Okay, so we're talking about that. Or, you

know, we're going to a wedding in August and we'll be talking about that. Or they just came back from vacation. We kind of get off focus. And that's probably my fault too. I need to stay on task. But it's hard when you see somebody once a week for a long time, not to have some sort of relationship with them.

Julia and Emma reported similar scenarios with all three expressing concern around the fact that the therapist was there for the child and that in the end they didn't want the focus of therapy to be off the child for extended periods of time. Other than with this concern, eight of the nine caregivers felt the communication in their relationship with the therapist of their child only served to help them learn the home exercise program.

The ninth caregiver, Katie, reported being in a unique situation as the communication between herself and the therapist was strained and she did feel it hindered her learning from the therapist. The therapist had been seeing the child for years and had previously interacted and been friends with the first wife of Katie's spouse. The spouse, Bonnie, had divorced and was remarried to Katie and they had primary custody of the child Annie. Katie felt perhaps the therapist had difficulty adjusting to the new family structure and accepting her because of the circumstances. However, she reported other factors of communication as hindering her learning from the therapist. Primary among these other factors was that the therapist was viewed as being defensive whenever questioned as to why a choice was being made in the treatment plan for the home program for Annie. Katie felt this defensiveness led to a situation where the therapist always made the decision of how the passing of information regarding the home program was going to occur. Katie felt she was unable to play a part in the decision, with Katie saying "I think that she just does it the way she does it and you have to just get on board."

Katie's spouse Bonnie, also an occupational therapist herself, came in towards the end of the interview and agreed with Katie that the therapist was defensive when questioned. Bonnie further reported that the therapist had always presented herself in this manner ever since she had initially worked with Annie up through present day. Bonnie stated "I think that's just her personality. She feels challenged. She doesn't feel like people are looking for information. She feels like she is being questioned" with Katie agreeing saying "That's exactly it." This defensive response from the therapist when Katie asked her questions led Katie to feel she couldn't discuss the home program with the therapist. This unique situation seems to support how important it is for the caregiver to feel able to openly communicate with their therapist.

Lastly, in regards to communication, four of the caregivers reported needing more from the therapist in regards to communication beyond themselves and in particular with their spouse. Amy discussed how she didn't want to have to teach her husband John about what happened in therapy with the son Michael because of the extra pressure involved in the change in roles. Over the course of the conversation she stated:

You know it looks like Dad's not a very active participant because they [the therapists] go 'I've never met dad' and around the holidays they both got to meet him....they just had a lengthy conversation which kind of overwhelmed him a little bit but maybe we need to do more of the what can we do week to week related exactly to our goals [with him]...cause that's really all I'd want....and in an easy way for me to understand and explain to John cause he does not like it when I sit there and go 'ok, this is what we did with Michael today and this is how you do it Dad and can you hold him like this.' He has fun with them. He does the fun stuff with him. You know, I wouldn't mind if he did a little bit of whatever it is we're working on, if it's the grasping or something then. You

know but he doesn't like it when I'm like 'here's what we did and here's why we need to do it.' He doesn't want to listen, especially after working all day.

This family decided to put up a white board in their house and they asked their therapists to write down things for them to work on over the week. This strategy allows for John to get communication straight from the therapist and feel involved without Amy having to convey the information and feel like she needs to teach him. Emma also reported having difficulty communicating the information to her spouse saying:

My husband doesn't go to the therapy with us. And for me to come home, you know, I got dinner and laundry and everything else, so I'm not necessarily teaching him the way I should be teaching him.

Emma stated she has started videotaping the sessions using her cell phone so that she can show her husband later. She also stated she liked it when the therapist would give handouts because then she can show them to her husband. Julia reported "her husband is very inventive and always comes up with ideas of new things to try" with their son so she felt it was important he also understand why the therapist was wanting them to do certain things for the home program. Since her husband was typically at work during therapy sessions it fell on her to try to communicate to her husband what the therapist had taught her that day and she felt this was difficult for her to do. Frank reported similar sentiments in regard to telling his wife Megan what occurred in therapy. Both Frank and Megan attributed an extra stress factor from the fact that when Megan came home from work in the evenings there was always already a lack of time. Spending that time with him teaching her was not their first choice of how to make use of the little time they had available. They also expressed a wish that the therapist could find a way to

communicate directly with Megan more rather than relying on Frank to do all the transfer of information.

Unsurprisingly, communication was an important thread which the caregivers placed emphasis on throughout the interviews. Interestingly, when asked if the therapist had ever discussed the caregiver's preferred method of learning with them, only one of the nine, Diana, reported it as being discussed. Diana did state that it was something she had brought up by telling the therapist that she was a hands-on learner and preferred to be able to practice having her hands on her grandson when trying to learn something new from the therapist; the therapist had not brought up the subject with her. Overall, in regards to what helped or hindered the learning of the home program from the therapist, all nine caregivers placed the most emphasis on communication as the key factor to the process being successful.

Helping or Hindering the Learning Process: Thinking Outside the Box. The caregivers reported various strategies and methods as either helping or hindering the process of learning the home program. Most of the caregivers reported wanting more handouts and more hands on time from the therapist. Other than Diana, six of the other eight parents reported their preference as wanting to be able to put their hands on their child and try out the interventions while the therapist was there but that their therapist was not offering this as an option. Amy stated:

I'm really surprised that not many of the ladies [therapists] have handed the child over and said 'Here.' I don't know if it's because they know I'm always running around chasing the other two? And if they would do more with a mom with one child around or something? But, I'm surprised that, knowing how strict Birth to Three is and why they're

doing in-home, that they don't say 'here I'm going to hand Michael over to you and you try it.' I'm really surprised by that. No one has really done that.

The other five stated similar feelings and that they felt it would help them "remember some things later when trying to remember how to position" the child as Susan put it. The remaining two, Julia and Betty had different experiences. Although Julia stated she spent very little time with her hands on her child when the therapist was present she also felt that her preferred method of learning was as a visual learner and in her mind watching the therapy worked well for her.

Betty, one of the caregivers who was very happy with her therapist, stated "she'll [the therapist] do it first, show me and then let me practice with him, one on one and then she'll do it and then I'll know how to do it when he comes home and when we're on weekends." Whereas Betty, Diana and Julia had found success in learning in a way that suited them via one method or another, the other caregivers wanted to be able to have the best chance possible of completing the home program with their child later and therefore wanted to try it out in front of the therapist but didn't feel that was available for them to do. In place, they often reported wanting more handouts to help them remember what they needed to do. All the caregivers except Betty and Diana wanted more thorough handouts from their therapist. Betty felt her therapist gave her sufficient handouts. Diana reported not wanting them and not really looking at them when she was given them because she learned best doing things hands on when she said:

She's [the therapist] given me papers and then I remember her first giving them and I said 'I don't like these.' So, she said like 'take it anyway.' (Laughing) I remember her saying that to me. I don't like to keep a lot of papers and stuff. I'd rather do hands on.

Betty did use her handouts and stated the therapist would give her handouts on "what therapy she's doing and how to do it and on the paper, it will break down how to do it and like pictures

and stuff.” Betty also expressed that in her experience, if she ever didn’t feel she could follow through on the home program on her own after trying it in front of the therapist and using the handouts, that she would just call the therapist and let her know and the therapist would sit down and go through it all again step by step until she did feel confident. Her therapist seemed to be very thorough in ensuring Betty understood how to carry out the home program and Betty felt so also saying “she’s basically doing everything she should be doing.” On the other hand, the other five caregivers all wanted more handouts; they reported their therapists often writing something down for them during the session but it was completed in the moment informally. They wanted handouts with pictures to help them remember positioning and sequencing of the home program.

The caregivers did appreciate the other resources therapists provided for them. During the interviews caregivers reported resources being provided such as toys, connections to organizations that provided equipment, books, sign language videos, referrals to other professionals when needed and even a dictionary. The families appreciated the extra help from the therapists in finding what was needed and saw it as the therapist going above what he/she needed to do necessarily. Even Katie, who reported not having very good communication with her child’s therapist, felt her therapist really cared when she described a time that the therapist helped her find a chair for Annie:

I sent her a picture and said this is what school uses....so then she was like get me the serial number. So, I did...so I sent her the serial number and she looked it up online and she said that’s a commercial one. Only for school. It’s too heavy and it’s too big. But here are some other options. So, we kind of walked through that together.... she was really good about it. And she really kind of told me this is what we needed.

Caregivers valued that the therapist was taking extra time outside of the therapy session to help them meet their needs and help their child receive what was needed to progress forward.

The caregivers had different opinions on the importance of the setting. Two caregivers, Julia and Amy, felt having the therapist come to the home made life easier while Emma appreciated the extra equipment available for the therapist to use with her son in the clinic. It is important to note that Julia and Amy both had children who were young enough that they had only received OT in the home and had not been in the situation to have to seek treatment in a clinic setting. Although the setting was disagreed upon, universally all the caregivers felt it was important for the therapist to help come up with strategies and methods for the home program to be successful. All of them reported it was a certainty that things would arise in their lives that would make it difficult for them to carry out the home program. They reported a variety of factors as interfering: time, home and work responsibilities, and being fatigued at the end of the day. In being aware that there would always be something in their life that would get in the way of them being able to carry out the home program, the caregivers reported looking to their therapist to help them find ways to be successful. Emma perhaps said it best when she said the following about her therapist:

She has taught me a lot about thinking outside of the box. Don't just go with the normal adaptive things. Think outside the box. Watch him, study him. Find out, you know, what works for one person may not work for everybody, and find that one thing that works for him. And try not to make it work, try to make it fun.

It was important to the caregivers that they were able to help their children succeed and make progress and they looked to the therapist to help them do so.

Summary

The three themes discussed can be seen relating directly back to the original research questions of the study. The first question, what are the lived experiences of caregivers of children with special needs when learning about delivery of an occupational therapy home program to their child from the occupational therapist, can be seen in the emotions expressed by the participants during the interviews. Being a caregiver who is trying to learn and successfully carry out a home program for your child is a difficult position to be in. The caregivers as a whole report living a life filled with guilt over many choices from making their respective child work on the home program and being the 'mean mom', to not finding the time to carry out the home program among their many other responsibilities, to not being able to spend as much time with other children in the effort of carrying out the home program. In approaching the therapist about these difficulties, the caregiver often only had the importance of the home program reemphasized to them, leading to feelings of being misunderstood. Often when working with the therapist the caregiver was left feeling criticized, even to the point where the caregiver took it as a personal reflection of his/her own parenting skills. As these caregivers wanted only the best for the child, each caregiver struggled with these negative feelings as they occurred and took what joy they could in the successes that were made.

In terms of the other two research questions, how did the caregiver learn the home program and what helped or hindered the caregiver in learning the home program from the therapist, these were answered by the other two themes concurrently. Communication played a key role in the learning and either helped or hindered the learning as it occurred. Therapists were praised by the caregivers for times when the therapist showed patience, compassion and for when they truly listened to the caregivers needs or went out of the way to meet those needs.

Caregivers appreciated when things were explained step by step and when reasons were given behind why an intervention was being used. Learning occurred primarily through watching the therapist and caregivers seemed to want more time to participate in the therapy and more opportunities to be able to learn through hands on methods. The caregivers appreciated the handouts that were given and being given access to resources and ideas that would help the home program be successful as the caregivers were very aware that there would always exist factors in life that would get in the way of them being able to carry out the home program. It hurt the learning process when therapists were defensive, critical or when they let unrelated topics of conversation get them off track from providing therapy. Tangentially, in discussing the learning process, primary family caregivers reported needing more communication and learning to occur between the therapist and the secondary caregiver (i.e., the spouse) who was not present during therapy sessions.

Principally, it was important to caregivers that the learning occurred as a partnership as the caregiver held the expertise regarding the child and the therapist held the expertise regarding interventions and treatments. If therapists keep this in mind it can go a long way towards making the caregiver feel heard. Chapter Five will discuss further implications for therapists and the field of occupational therapy.

Chapter Five: Discussion and Future Research

Through his/her educational curricula, OT's have long been prepared to utilize theories directly relating to rehabilitation; however, this study has brought out an area of theories in which OT's may need more preparation: teaching and learning theories. By directly analyzing each theme found in this study, the implications for education at both the OT and the caregiver level became apparent. Each theme will be explored as it relates to education below.

The Feelings of the Caregivers

The caregivers of children with special needs are in a position where continual pressure can potentially be felt to help the child participate in his/her daily occupations and grow in order to enable the child to lead a healthy, productive and meaningful life. The level of stress caused by the pressure the caregiver is exposed to is above what may be encountered by a parent of a child without special needs. In the pediatric therapy team, the caregiver of the child is an integral member, because the child cannot or will not independently complete follow through outside of the therapy session on what is being worked on during therapy sessions. This also then places additional responsibilities on the caregiver above that of a typical parent. In the interviews conducted in this study, it was clear to see in listening to the emotions being expressed by the caregivers that, although the caregiver was always pleased and happy when goals were met and successes occurred, the extra responsibilities associated with learning the home program from the therapist were more typically associated with a number of negative emotions for the caregiver. Guilt was expressed regarding not being able to always be successful in carrying out the home program, in losing time with other family members because of completing the home program and in taking away the child's free time to do the home program. Some caregivers reported when discussing the difficulty of carrying out the home program with

the therapist, the feedback that was given only emphasized the importance of the home program. This led the caregiver to feel misunderstood because the caregiver was fully aware of the importance of the home program and only wanted the best for his/her child. In responding by only emphasizing the importance of the home program, the therapist concentrated attention on providing information the caregiver already possessed and understood. This action ignored what the caregiver was actually saying which was that he/she wanted to carry out the home program but couldn't find a way to make it work for the family and this was causing him/her guilt and stress. This led to the caregiver feeling the therapist did not understand how difficult it was to try to complete the home program or what it was like to be a caregiver of a child with special needs.

In addition to these feelings of guilt and misunderstanding, caregivers often felt criticized by the therapist when the caregiver was letting the therapist know the home program hadn't fully been carried out. When the therapist in response expressed disappointment and stressed the importance of completing the home program, the caregiver seemed to take this as a negative reflection of his/her parenting abilities. This is concerning for two reasons. First, caregivers of children with special needs have already been shown to be under more stress than caregivers of children who are developing normally. These caregivers look to the health care professionals in their life for guidance and support. If a health care professional is perceived as suggesting the caregiver is not doing an adequate job as a parent, the caregiver could internalize that suggestion thus increasing his/her guilt, stress and other negative emotions. Caregivers are already more prone to feelings of depression than the general population and therapists need to be cautious as to not add a burden which could increase the chance of depression occurring. Therapists must work to validate the caregiver and let him/her know that in just trying to do all he/she can to

carry out the home program, he/she is being successful. Secondly, there is clearly a need for the caregiver and the therapist to have an open and supportive relationship. If the caregiver feels criticized by the therapist, even if the caregiver is strong enough not to take the criticism personally, it is bound to damage the relationship between the two. The caregiver will be less likely to want to speak to the therapist about difficulties he/she may be having in carrying out the home program. Criticism, even constructive criticism, can be difficult to take and for the caregiver of a child with special needs, this criticism strikes in a personal area. Therapists must be supportive in their actions and words when the caregiver reports not completing the home program.

It is essential to remember that these caregivers are parents being pulled in two opposite directions. On one side, each caregiver was a mother or father who cares for his/her child and wanted to be loving and understanding of the child's need for down time. He/she wanted the child to have time to 'just be a child' and live a life like any other child might. On the other side, each caregiver was a teacher, wanted the best for his/her child and was determined to help the child succeed no matter the level of disability and at any cost. He/she understood this meant the child had to do therapy, complete exercises and participate in extra work above what the average child would be expected to do on a regular basis. This required the parent to take the stance of armed love put forth by Friere (2005). These parents were willing to do what was difficult and go against the caring side of themselves by working on skills that challenged the child and which made the parent feel like a 'mean' parent. When the caregiver didn't push his/her child to work on these skills, he/she felt guilty and was critical of making that choice, even when he/she made a logical choice to let the child not work on a home program because of a reasonable excuse. Friere (2005) defined armed love as "the fighting love of those convinced of the right and the

duty to fight, to denounce and to announce” (p. 74). This is precisely the stance these parents took as they struggled between how much to ask the child to work on therapy tasks in what little free time the child had. Despite being pulled in two opposite directions by his/her own feelings, each caregiver knew what he/she felt to be right for his/her child and made the choice in the moment that he/she felt the duty to make for the child out of his/her love for the child.

However, it must be recognized that these caregivers also experienced fear out of this position in being pulled in two directions. Even as each caregiver fought for what he/she believed to be right for his/her child at that moment, each caregiver also doubted and feared he/she may have made the wrong choice. He/she was concerned that the child’s needs would not be met because the home exercise program wasn’t carried out or that the child would be further delayed in skills. Friere (2005) spoke to this fear also, stating:

Teachers have as much right to fear as learners do. The educator is not invulnerable. He or she is as human as the learner. An inability to fight to overcome fear would speak against one’s qualification as an educator, but the fact that one might experience fear does not. (p. 87)

Therapists must help the caregiver recognize that these types of feelings and his/her fears are normal to have. It should be reinforced that the caregiver is not a bad parent in the therapist’s eyes and that the caregiver should be forgiving of himself or herself when the home program is unable to be carried out. Considering the wide range of negative emotions reported by the caregivers in this study, it suggests that when as therapists are trying to balance between competence and caring as described by Peloquin (1990) there may not be enough caring put in the equation. Caregivers are not feeling supported by the therapist and instead are walking away from therapy sessions feeling guilty, misunderstood and criticized. Therapists must

acknowledge that caregivers of children with special needs are involved in a tug of war imposed by the need to show love for the child and the need to push the child to achieve new skills. The caregiver being involved in learning from the therapist and then acting as a teacher to his/her own child is a dynamic and complex relationship which involves a mixture of love, fear and courage to succeed. Friere (2005) perhaps said it best when he stated the following regarding being a teacher and a learner:

To study is to uncover; it is to gain a more exact comprehension of an object; it is to realize its relationships to other objects. This implies a requirement for risk taking and venturing on the part of a student, the subject of learning, for without that they do not create or re-create. (p. 40)

The caregiver is forever taking risks as he/she balances back and forth between caring and teaching. At all times he/she is only working to do what is best for his/her child and hoping he/she is making the best choices in the process.

It is important that the therapist be cognizant that the caregiver may be walking into the therapy session with this and other burdens and that the therapist hear the caregiver when he/she expresses difficulties with the home program. This is the time where the therapist could be more successful by educating the caregiver using the nurturing perspective discussed by Pratt (1998). This perspective recognizes that the learner must be prepared to learn if a teaching session is to be successful, which includes being in a state of mind where learning is possible. A caregiver who has feelings of guilt and being misunderstood and/or being criticized would not be considered to be in the optimal condition to be ready to then sit down in a therapy session and learn from the therapist. It is important, according to Pratt, for the teacher (therapist) to keep in mind the primary principles, responsibilities and commitments of this perspective to help

facilitate the learner's (caregiver's) success. Pratt states the following regarding the principles of this perspective:

First, it must be a trusting and safe place where learners can take risks and not be humiliated or diminished for mistakes. Second, it must be a place where learners can attribute success to their own effort and ability, rather than luck or the sympathetic kindness of a teacher. Finally, it must be a place where the relationship between learner and teacher is both caring and challenging. Collectively, these beliefs bring the emotional aspects of the learner into sharp relief for the first time. (p. 241)

Pratt elaborates that under these principles the primary responsibility of the teacher is acting as one who encourages expressions of feeling and reinforces effort as well as achievement. This commits the teacher to respect the learner while nurturing the learner's self-esteem and pursuing the learner's self-efficacy as a goal. Parental self-efficacy is important because the caregiver must believe his/her actions are going to make a difference in helping his/her child or the home program will most likely not be completed. The therapist can build a caregiver's sense of self-efficacy by considering the conditions that help create self-efficacy. The therapist should provide the right level of challenge for the caregiver to ensure mastery experiences occur and provide verbal encouragement to the caregiver to reinforce that he/she is capable of what is being asked of him/her. By using the nurturing perspective the therapist is already working with the caregiver to ensure he/she is in a positive emotional state, however, the therapist should also confirm the caregiver is in a healthy physiological state before learning occurs. Lastly, the therapist should speak directly to the caregiver about his/her perceived level of self-efficacy regarding the home program on a regular basis as a gauge to determine in what areas the caregiver may need further support from the therapist.

By understanding teaching the caregiver from this nurturing perspective, it would help the therapist be sensitive to the feelings being expressed and allow the focus to be on nurturing the caregiver to a place where, instead of feeling misunderstood, the caregiver can feel valued for the effort he/she has put forth. As this study and previous research (Lindblad, Rasmussen, & Sandman, 2005) found that caregivers need positive feedback and need to feel valuable in the process, taking this approach would help the caregiver feel his/her concerns are being heard and taken seriously. In feeling understood, the caregiver would not only be more likely to receive the help he/she truly needs to make the home program successful but he/she would be in an emotional state where he/she would be prepared to learn from the therapist. In order for pediatric occupational therapists to be prepared to effectively teach from the nurturing approach, they must not only learn about the nurturing teaching perspective but it would also be helpful for them to have knowledge of Knowles' approach termed andragogy. Andragogy would help therapists consider how learning occurs for an adult. Knowles set forth assumptions regarding the adult learner acknowledging that the adult learner is a mature person with a background. Andragogy emphasizes respect for the learner's wealth of experiences and how those experiences influence the learner's ability to learn. If the therapist is taught to consider learning from this viewpoint, then a healthy respect for the caregiver and the experiences the caregiver will be developed and form the foundation for the educational process which occurs between the therapist and the caregiver. With the therapist demonstrating respect for the caregiver's knowledge and experiences with the child, the caregiver may feel secure enough in that respect to then be less likely to interpret feedback from the therapist as criticism or as a negative reflection on their parenting abilities.

In summary, one approach which can be taken towards addressing the negative feelings being experienced by caregivers of children with special needs is educating therapists. By giving therapists an understanding of the theoretical underpinnings of andragogy and teaching them how to using a nurturing perspective, they may have greater success in decreasing these negative feelings and placing the caregiver in a state where he/she is prepared to learn. This will thereby also increase the likelihood that the therapist will be teaching the caregiver in a way that is conducive to the needs of the caregiver, leading to greater overall success.

The Importance of Communication

The necessity for therapists to understand the underpinnings of andragogy can also be seen when considering the results of the second theme found in this study. Similar to the results Knox, Parmenter, Atkinson and Yazbeck found in 2000, the caregivers in this study stated that they were seeking a partner in the therapy process when it came to the relationship with the therapist. Another assumption put forth by Knowles' was that "adults need to know why they need to learn something" (Merriam, Caffarella, & Baumgartner, 2007, p. 84). The caregivers did not want the therapist to play the role of the expert who knows everything and lays out the plan to be followed. Instead caregivers wanted a partnership where the therapist and the caregiver came together with each of their various levels of expertise: the therapist's understanding of rehabilitation and the caregiver's knowledge their child. The caregivers viewed the relationship as a partnership. Instead of blindly following anything the therapist would give for the home program, the caregivers wanted to have explanations given for why the therapist was recommending a specific intervention or treatment for the home program. This is an understandable request when considering the situation from the perspective of the caregiver. Not only does the caregiver want respect afforded to him/her as a partner in the process, but other

benefits are that the caregiver knows the child best as he/she lives with the child and has known the child for an extended period of time and therefore is in the best position to know what will motivate or interest the child. If the caregiver understands why an activity is being proposed as an intervention for the child, he/she may be able to suggest another activity that would be more appealing to the child and thus be less of a hardship to carry out as a home program while still achieving the goals the child needs to meet. As discussed earlier when reviewing the literature, research has shown that therapists have difficulty in implementing client centered care and often the caregiver falls into the role of observer only. Also, multiple studies had found that the therapist, instead of engaging in a true collaboration, involved the family by turning to persuasive techniques to convince the family what the therapist was suggesting was the best approach to the home program. This past research in conjunction with the caregivers expressing in this study the wish to communicate and have a relationship with the therapist as a partner, supports the need for therapists to take a developmental teaching approach when educating caregivers.

Under the developmental teaching approach, the key for learning and teaching to occur is in “finding effective ‘bridges’ between present and desired ways of thinking” (Pratt, 1998, p. 234). Pratt discusses the beliefs of this approach with the first one being that prior knowledge is key to learning. The idea is that learners consider all new content through the lens of their own existing belief structures regarding the rules for understanding the world they live in. This is why if a therapist suggests an activity for a home program that the caregiver doesn’t believe will work, there is likely to be little follow through or buy in from the caregiver. The therapist using the developmental teaching approach acknowledges that there is a pre-existing set of rules the caregiver possesses and the therapist attempts to ensure new content would be able to be

incorporated into that set of rules. This is not to say that under this approach the therapist could not work to help the caregiver change and grow their outlook. The second belief put forth by Pratt addresses that the individual is not immovable in their beliefs and preconceptions. This approach considers the role of the teacher to be one who challenges the learner's understanding and fosters growth in the sophistication of the learner's thinking. However, this is very different from the persuasive techniques found to be used by therapists in the research conducted by Lawlor and Mattingly (1998) where families were persuaded that the therapist's suggestions were the right way to go. In those cases, the therapist gave the families no other choice. Under the developmental approach the therapist helps to provide new content in a way which allows the learner to mold and change their own rules and beliefs about what is the right choice. This places the power on the side of the caregiver instead of on the side of the therapist. An example of this approach was seen with one of the participants in this study, Betty. Betty discussed how when therapy had first began she had fears regarding the effects of the therapy and did not necessarily see the benefit of what was being suggested she do for her son. However, her therapist was patient and took the time to explain what she was doing and why she was doing it that way. This allowed Betty to reach the point where she is now an enthusiastic participant in the home program regimen and a supporter of her therapist's techniques. Caregivers in this study wanted the therapist to take the time to communicate with them about what was being done, why the therapist believed it was important and to have a two-way communication where ideas and thoughts could be shared and developed from both sides. Using a developmental approach to teaching helps to achieve this.

As with andragogy, therapists need more education in how to use the developmental approach and they could also benefit from being educated regarding theories around

transformational learning, including using constructivist reflective practices. Transformational learning begins to occur when the learner has an experience, termed a disorienting dilemma, which cannot be easily incorporated into the learner's existing knowledge base built from past experiences (Mezirow, 2000). When the learner reflects on how the new experience can be understood, there are three types of reflection which can occur according to Mezirow. The learner can reflect on the experience itself termed content reflection, on how to deal with the experience (process reflection), or they can engage in premise reflection. Premise reflection is the deepest form of reflection and is evident when the learner examines their beliefs and values about the experience. Using Betty as an example, she had to reflect upon the therapy experience and come to change her meaning around her son crying. Betty changed her viewpoint from seeing her son having difficulty performing activities and wanting to rescue him, to instead seeing that her son was being challenged and by working through those challenges with him she was helping him grow and progress. In going through this process, Betty's belief structure regarding how she should respond to her son's crying was transformed. Therapists need to be given more knowledge regarding the role of the educator from the transformative theoretical point of view to allow them to be successful in fostering deep reflection on the part of the caregivers. As a result of fostering this reflection, power is shifted to allow a more equitable relationship between the therapist and the caregiver which can only serve to improve the communication. This is important because the caregiver not only needs to feel valued by the therapist, but the caregiver needs to value the therapist in return. In order to have a true collaboration and partnership, the relationship between caregiver and therapist needs to be more respectful, trusting and amicable. This is vital for as Diana pointed out in her interview, if the caregiver doesn't like the therapist, it will be impossible for learning to occur.

To sum up, communication is key and helped or hindered the learning as it occurred between the therapist and the caregiver. Caregivers wanted to be heard and feel as if they had a partner who would work with them in their therapist. Therapists who take a developmental approach to teaching caregivers may be more likely to meet the needs and expectations of the caregiver by showing respect for the caregiver's experiences and views. The education of therapists should include information on the developmental approach and how to use it as well as knowledge regarding the transformative learning theory put forth by Mezirow. This would better prepare the therapist to meet the communication needs of the caregivers they encounter in practice.

The Helping or Hindering of the Learning Process

It is essential that the therapist be prepared for the teaching/learning processes which occur during therapy sessions because caregivers truly want to be successful in carrying out the home program. Caregivers reported looking to the therapist to help find interventions and resources that supported their child in progressing and reaching goals. The majority of the caregivers in this study were seeking time during the session where they could have their hands on the child and be guided by the therapist; the caregivers reported feeling as if having their hands on would help them remember later what they needed to do on their own. They appreciated the step-by-step breakdown of information that was more complex and most caregivers wanted handouts to guide them also. These requests could be more adroitly met by therapists if the apprenticeship teaching approach was used when teaching caregivers direct skills and tasks.

The apprenticeship teaching approach as discussed by Pratt (1998) is "based on the belief that expert knowledge is best learned in contexts of application and practice" (p. 226). Teachers

using this approach are considered to be expert practitioners and their role is to teach others about their content expertise through coaching. As discussed previously, this coaching is delivered through demonstrating and then scaffolding the skill to allow the learner to practice and feel comfortable in completing the skill. The teacher gradually fades the amount of assistance given as the learner becomes more competent. This approach is often, for example, seen during fieldwork type scenarios where occupational therapy students are under the supervision of a practicing clinician and the student gradually takes over more of the caseload until they are competent at carrying the caseload of a full practicing therapist. Obviously, the caregiver is not expected to learn the skills from the therapist to the level where he/she could be a practicing therapist. However, the therapist was asking the caregiver to perform certain stretches, exercises and other activities with his/her child which required a certain level of competency to complete. These home programs require knowledge which is more complex than a simple demonstration can get across effectively. By using the apprenticeship teaching approach the therapist would have the parent practice carrying out the home program during the therapy session. This would allow the coaching to occur when the caregiver is completing it with his/her child and questions arise. This would likely increase the confidence on the part of the caregiver for him/her to be able to carry the home program out again later with the child when the therapist is not present.

The apprenticeship teaching perspective also places great emphasis on the context and considers knowledge to be inseparable from the context (Pratt, 1998). Best practices of this approach suggest that learning is best done within simulated or real contexts of application, meaning the learning should be carried out either in the environment that the caregiver will be completing the skill later independently or in an environment which simulates the location where

the skill will be carried out. In a way, this is not a new concept for occupational therapists. The theories and models of the field of occupational therapy all recognize that the environment cannot be separated from the person and therapists are taught this concept in their educational curricula. From this standpoint, therapists are prepared to take context into consideration.

Where therapists do need more preparation is not only in fully understanding the apprenticeship teaching approach but they would also then benefit from being educated in experiential learning theories. These theories encompass two concepts, reflective practice and situated cognition, which fit well with family-centered practice as discussed earlier. The more the therapist understands about the effects of reflection-in-action and the environment as it pertains to the ability to learn, the better the therapist would be able to plan learning experiences for the caregivers when teaching him/her the home program for his/her child. In learning about experiential learning theories, therapists would gain knowledge regarding using cognitive apprenticeships and anchored instruction to be more aware of how building problem-based learning into the experiences they have with caregivers would likely make the caregivers more successful in carrying out the home program.

In summary, as Emma expressed, caregivers wanted the therapist to help them “think outside the box”. This is important to the caregivers because they are aware that life will get in the way of trying to complete the home program and the caregivers wanted the best chance at being successful. By providing education to therapists in understanding experiential learning theories and the apprenticeship teaching approach, therapists would then have the knowledge needed to see the benefit of using problem based learning and the importance of also considering the environment in regards to the teaching learning context. The therapist could use this

knowledge in his/her practice to structure teaching the caregiver in a manner that which helps meet the goal of “thinking outside of the box” in carrying out the home program.

Limitations of the Study

As with any phenomenological study, in order to ensure a richness of data that can only come from spending more time with the participants, the sample size was small with only nine overall participants. Thus, the main limitation of the study is an inability to state that all caregivers of children share the same feelings and perspectives that the caregivers in this study reported having. However, this study does provide insight into situations a pediatric occupational therapist may encounter when working with caregivers of children with special health care needs and the reader can interpret and decide which pieces of this research best fit into their own practices.

Implications for Future Research

This research opens up many new avenues for research. As it is a qualitative study which cannot be generalized it would be helpful to have larger quantitative study, possibly using a survey methodology, to see if caregivers of children with special health care needs as a whole share similar feelings and perspectives as the caregivers in this study did regarding the learning of the home program from the therapist. As the literature review demonstrated, the amount of home program materials and instruction provided by the therapist to the family tends to decrease the longer a therapist is with a family. This is another area where a quantitative study would be useful.

It would also be very interesting to conduct a mixed methods study to see if the effect of additional education on teaching and learning theories would have an impact on how occupational therapists deliver home program information. The amount of home program

information delivered and the methods used to deliver it could be examined quantitatively. The perceptions of the therapist before and after the additional education could be considered from a qualitative perspective. This research could also include how the perceptions of the caregivers differ regarding the delivery of the home program before and after the therapist received this additional education.

Lastly, completing a participatory action research (PAR) study involving the therapist and the caregiver together could provide additional insight into the teaching and learning process which occurs as it is a complex and multi-faceted situation. A PAR study would especially be a good fit as the therapist and the caregiver both have a stake in the outcome of the research because they are both affected by the issue in question. In taking this approach, a study could be conducted in which therapists and caregivers are brought together and both given information regarding the teaching learning process. They could then interact in the process of the therapist working with the caregiver in building a home program for his/her child. The therapist and the caregiver could collaborate to generate knowledge for how the teaching and learning of a home program can best occur between the two. This potential study would take a qualitative approach to completing the participatory action research.

Implications for the Preparation of Occupational Therapists

The findings of this study hold multiple implications in regards to considering the education and preparation of students learning to be occupational therapists. Although each occupational therapy program may have its own approach and philosophy, there are standards and requirements as to what the program must teach in order to remain accredited. As mentioned earlier, the Accreditation Council for Occupational Therapy Education (ACOTE) has two standards specifically speaking to preparing therapists to educate others. The first standard,

B.5.18 states that the student will “demonstrate an understanding of health literacy and the ability to educate and train the client, caregiver, family and significant others, and communities to facilitate skills in areas of occupation as well as prevention, health maintenance, health promotion, and safety” (p. 26). The second standard, B.5.19, states that the student must be able to “apply the principles of the teaching-learning process using educational methods to design experiences to address the needs of the client, family, significant others, communities, colleagues, other health providers, and the public” (p. 26). These standards are very broad and do not provide much guidance on the metrics which would constitute the student demonstrating the ability to educate others well. The standards also do not discuss which principles of teaching and learning should be covered to help ensure the student’s ability to educate others. ACOTE should consider revising these standards and adding other standards to provide more specific guidelines to OT programs.

Secondly, it would be recommended that OT program curricula build in more education on the principles of teaching and learning for students. Although therapists are not thought of as educators, in truth they are educating clients every time they are in a therapy session. The problem is that besides knowing what to teach clients, therapists must learn how to teach it. If OT programs had a three-credit course dedicated to educating students on teaching and learning theories and principles, this would at a minimum help provide students with exposure and a foundation to consider how to more successfully help impart knowledge to future clients. This is needed as this study suggests the current reliance on teaching students interpersonal skills and client/family-centered practice principles in OT curriculum is not helping therapists meet the educational needs of their clients; it is giving students the principles without teaching them how to effectively put them into practice when educating clients. In addition to this foundational

course on teaching/learning, it would benefit students if OT curriculum built in assignments where students could rehearse these teaching/learning skills in the traditional OT ‘practice’ courses in the areas of mental health, physical rehabilitation, pediatrics and geriatrics and later reflect upon the experiences during those courses.

Lastly, a common complaint of practicing therapists is the lack of follow through by clients in regards to the home program. This indicates another implication for the education of therapists is that there is a need for a continuing education program for existing, practicing therapists. A one week continuing education class could be constructed to provide these therapists with foundational knowledge in the theories and principles of teaching and learning.

Summary

In conclusion, in this study caregivers of children with cerebral palsy experienced a wide range of negative emotions when learning the home program from the occupational therapist including feelings of guilt, being misunderstood and feeling criticized. The caregivers felt communication is key as it helped or hindered the process. They reported it helped when the therapist was patient, compassionate and made the caregiver feel heard. It hindered learning when the therapist was defensive or said things which contributed to the caregiver having negative feelings. Caregivers wanted to understand and have the therapist explain why he/she was asking them to do the activities they were being asked to do in the home program. They wanted information, more resources and handouts, and more time learning how to do what the therapist believes will help the child in the therapy session. Most importantly, caregivers wanted the therapist to be a partner and they wanted to be viewed as an equal partner themselves.

Therapists, on the other hand, could benefit from receiving education on teaching and learning theories. By having a firm foundation of understanding theories of learning such as

andragogy, experiential learning and transformational learning, the therapist would be better prepared to incorporate teaching approaches such as the nurturing, developmental or apprenticeship perspectives. With an increased command of these concepts, therapists would be better prepared to enter the teaching and learning environment of the therapy session and work with their clients.

This higher level of preparation would hopefully allow the client to have an improved experience in the therapy session and create a more optimal learning environment which would then permit the client to take the information learned from the therapist and incorporate it into his/her own knowledge base. As indicated previously, Burkhart (2008) noted that nurses are taught to be caregivers and not educators. In conclusion, this study suggests the same is true for occupational therapists. Therapists are taught to be rehabilitators and not educators. Study results indicate the field of occupational therapy would benefit if therapists were taught to be both.

References

- Accreditation Council for Occupational Therapy Education. (2015). *2011 accreditation council for occupational therapy education standards and interpretive guide: August 2015 interpretive guide version*. Baltimore, MD: Author.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62(6), 625-683.
- American Occupational Therapy Association. (2010). Blueprint for entry-level education. *American Journal of Occupational Therapy*, 64(1), 186-203.
- Annells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing*, 23, 705-713.
- Armstrong, K., Ravenell, K. L., McMurphy, S., & Putt, M. (2007). Racial/ethnic differences in physician distrust in the United States. *American Journal of Public Health*, 97(7), 1283-1289.
- Arseneau, R., & Rodenburg, D. (1998). The developmental perspective: Cultivating ways of thinking. In D. D. Pratt (Ed.), *Five Perspectives on Teaching in Adult and Higher Education*. Malabar, FL: Krieger Publishing Company.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman and Company.
- Banford, M., Kratz, M., Brown, R., Emick, K., Ranck, J., Wilkins, R., & Holm, M. B. (2001). Stroke survivor caregiver education: Methods and effectiveness. *Physical & Occupational Therapy in Geriatrics*, 19(1), 37-51.

- Bar-Haim, S., Harries, N., Nammourah, I., Oraibi, S., Malhees, W., Loeppky, J., Perkins, N. J., Belokopytov, M., Kaplanski, J., & Lahat, E. (2010). Effectiveness of motor learning coaching in children with cerebral palsy: A randomized controlled trial. *Clinical Rehabilitation*, 24, 1009-1020.
- Barber, M. D. (2004). Occupational science and phenomenology: Human activity, narrative and ethical responsibility. *Journal of Occupational Science*, 11(3), 105-114.
- Bartlett, E. E. (1995). Cost-benefit analysis of patient education. *Patient Education and Counseling*, 26, 87-91.
- Basaran, A., Karadavut, K. I., Üneri, S. Ö., Balbaloglu, Ö, & Atasoy, N. (2014). Adherence to home exercise program among caregivers of children with cerebral palsy. *Turkish Journal of Physical Medicine and Rehabilitation*, 60, 85-91.
- Bazyk, S. & Case-Smith, J. (2010). School based occupational therapy. In J. Case-Smith & J. Clifford O'Brien (Eds.), *Occupational Therapy for Children*, 6th ed., St. Louis, MO: Elsevier Mosby.
- Begun, A. L. (1996). Family systems and family-centered care. In P. Rosin, A. D. Whitehead, L. I. Tuchman, G. S. Jesien, A. L. Begun, & L. Irwin (Eds.) *Partnerships in Family-Centered Care: A Guide to Collaborative Early Intervention*, Baltimore, MD: Paul H. Brookes Publishing.
- Bellin, M. H., Osteen, P., Heffernan, C., Levy, J. M, & Snyder-Vogel, M. E. (2011). Parent and health care professional perspectives on family-centered care for children with special health care needs: Are we on the same page? *Health & Social Work*, 36(4), 281-290.

- Belsky, J., Goode, M. K., & Most, R. K. (1980). Maternal stimulation and infant exploratory competence: Cross-sectional, correlational and experimental analyses. *Child Development, 51*, 1163-1178.
- Benkert, R., Peters, R. M., Clark, R., & Keves-Foster, K. (2006). Effects of perceived racism, cultural mistrust, and trust in providers on satisfaction with care. *Journal of the National Medical Association, 98*(9), 1532-1540.
- Bennett, T., & DeLuca, D. A. (1996). Families of children with disabilities: Postitive adaptation across the life cycle. *Social Work in Education, 18*(1), 31-44.
- Berlin, L. J., & Cassidy, J. (2001). Enhancing early child-parent relationships: Implications of adult attachment research. *Infants & Young Children, 14*(2), 64-76.
- Bjork-Akesson, E., & Granlund, M. (1995). Family involvement in assessment and intervention: Perceptions of professionals and parents in Sweden. *Exceptional Children, 61*, 520-535.
- Blevins, C. (2001). There really is a difference: Home care competencies. *The Journal of Continuing Education in Nursing, 32*(3), 114-117.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*(2), 167-184.
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association, 288*(19), 2469-2475.
- Bonder, B. R., & Hasselkus, B. R. (1994). Families and professionals: Therapeutic considerations. In B. R. Bonder, & M. B. Wagner (Eds.) *Functional Performance in Older Adults*. Philadelphia, PA: F.A. Davis Company.

- Bornstein, M. H., Haynes, O. M., O'Reilly, A. W., & Painter, K. M. (1996). Solitary and collaborative pretense play in early childhood: Sources of individual variation in the development of representational competence. *Child Development, 67*, 2910-2929.
- Bornstein, M. H., Haynes, O. M., Pascual, L., Painter, K. M., & Galperin, C. (1999). Play in two societies: Pervasiveness of process, specificity of structure. *Child Development, 70*(2), 317-331.
- Boswell, E. J., Pichert, J. W., Lorenz, R. A., & Schlundt, D. G. (1990). Training health care professionals to enhance their patient teaching skills. *Journal of Nursing Staff Development, September/October*, 233-239.
- Brehaut, J. C., Kohen, D. E., Parminder, R., Walter, S. D., Russell, D. J., Swinton, M., O'Donnell, M., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics, 114*(2), 182-191.
- Brookfield, S. D. (2000). Transformative learning as ideology critique. In J. Mezirow (Ed.), *Learning as transformation: Critical perspectives on a theory in progress*. San Francisco: Jossey-Bass.
- Brooks-Gunn, J., & Lewis, M. (1984). Maternal responsivity in interactions with handicapped infants. *Child Development, 55*, 782-793.
- Bruder, M. B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20*(2), 105-115.
- Bulcroft, R. A., Carmody, D. C., & Bulcroft, K. A. (1996). Patterns of parental independence giving to adolescents: Variations by race, age and gender of child. *Journal of Marriage and the Family, 58*(4), 866-883.

- Burkhart, J.A. (2008). Training nurses to be teachers. *The Journal of Continuing Education*, 39(11), 503-510.
- Campbell, P. H., & Sawyer, L. B. (2007). Supporting learning opportunities in natural settings through participation-based services. *Journal of Early Intervention*, 29(4), 287-305.
- Cannon, S., Boswell, C., & Thigpen, A. (2009). Filling gaps in knowledge: Educating nurses to provide appropriate patient materials. *The Journal of Continuing Education in Nursing*, 40(4), 148-149.
- Cardoso, J. B., Padilla, Y. C., & Sampson, M. (2010). Racial and ethnic variation in the predictors of maternal parenting stress. *Journal of Social Service Research*, 36(5), 429-444.
- Caretto, V., Topolski, K. F., Linkous, C. M., Lowman, D. K., & Murphy, S. M. (2000). Current parent education on infant feeding in the neonatal intensive care unit: The role of the occupational therapist. *The American Journal of Occupational Therapy*, 54(1), 59-64.
- Carpenter, C., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: A practical guide*. Oxford: Blackwell.
- Case-Smith, J., Law, M., Missiuna, C., Pollock, N., & Stewart, D. (2010). Foundations for occupational therapy practice with children. In J. Case-Smith & J. Clifford O'Brien (Eds.), *Occupational Therapy for Children*, 6th ed. St. Louis, MO: Elsevier Mosby.
- Cassidy, J. (1999). The nature of the child's ties. In J. Cassidy & P. R. Shaver (Eds.), *Handbook of Attachment: Theory, Research and Clinical Applications* (pp. 3-20). New York, NY: Guilford Press.

- Chao, R., & Kanatsu, A. (2008). Beyond socioeconomics: Explaining ethnic group differences in parenting through cultural and immigration processes. *Applied Developmental Science, 12*(4), 181-187.
- Chase, L., Elkins, J. A., Readinger, J., & Shepard, K. F. (1993). Perceptions of physical therapists towards patient education. *Physical Therapy, 73*(11), 787-796.
- Chen, C. C., Heinemann, A. W., Bode, R. K., Granger, C. V., & Mallinson, T. (2004). Impact on pediatric rehabilitation services on children's functional outcomes. *American Journal of Occupational Therapy, 58*(1), 44-53.
- Christiansen, C. H., & Haertl, K. (2014). A contextual history of occupational therapy. In B. A. Boyt Schell, G. Gillen, & M. E. Scaffa (Eds.), *Willard & Spackman's Occupational Therapy, 12th ed.* Baltimore, MD: Lippincott, Williams & Wilkins.
- Clark, C. A., Corcoran, M., & Gitlin, L. N. (1995). An exploratory study of how occupational therapists develop therapeutic relationships with family caregivers. *American Journal of Occupational Therapy, 49*(7), 587-594.
- Clark, M., & Huttlinger, K. (1998). Elder care among Mexican American families. *Clinical Nursing Research, 7*(1), 64-81.
- Clarke, C. (2009). An introduction to interpretative phenomenological analysis: A useful approach for occupational therapy research. *British Journal of Occupational Therapy, 72*(1), 37-39.
- Close, A. (1988). Patient education: A literature review. *Journal of Advanced Nursing, 13*, 203-213.
- Coleman, P. K., & Karraker, K. H. (1997). Self-efficacy and parenting quality: Findings and future applications. *Developmental Review, 18*, 47-85.

- Colman, W. (1990). The curriculum directors: Influencing occupational therapy education, 1948-1964. *American Journal of Occupational Therapy*, 44(4), 357-362.
- Colyvas, J. L., Sawyer, B., & Campbell, P. H. (2010). Identifying strategies early intervention occupational therapists use to teach caregivers. *The American Journal of Occupational Therapy*, 64(5), 776-785.
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*, 2nd ed. Thousand Oaks, CA: Sage Publications.
- Crowe, T. K., VanLeit, B., & Berghmans, K. K. (2000). Mothers' perceptions of child care assistance: The impact of a child's disability. *The American Journal of Occupational Therapy*, 54(1), 52-58.
- Crowe, T. K., VanLeit, B., Berghmans, K. K., & Mann, P. (1997). Role perceptions of mothers with young children: The impact of a child's disability. *The American Journal of Occupational Therapy*, 51(8), 651-661.
- Daunhauer, L. A., Coster, W. J., Tickle-Degnen, L., & Cermak, S. A. (2007). Effects on caregiver-child interactions on play occupations among young children institutionalized in Eastern Europe. *American Journal of Occupational Therapy*, 61(4), 429-440.
- Denzin, N. K., & Lincoln, Y. S. (1998). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Landscape of Qualitative Research: Theories and Issues*. Thousand Oaks, CA: Sage Publications.
- DeSilets, L. D. & Dickerson, P. S. (2009). Filling gaps in knowledge: Educating nurses to provide appropriate patient materials. *The Journal of Continuing Education in Nursing*, 40(4), 148-149.

- Devereaux, E. B. (1984). Occupational therapy's challenge: The caring relationship. *American Journal of Occupational Therapy*, 38(12), 791-798.
- Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *Journal of Gerontology*, 60(5), S257-S262.
- Dixon, S. V., Graber, J. A., & Brooks-Gunn, J. (2008). The roles of respect for parental authority and parenting practices among African American, Latino and European American families. *Journal of Family Psychology*, 22(1), 1-10.
- Doescher, M. P., Saver, B. G., Franks, P., & Fiscella, K. (2000). Racial and ethnic disparities in perceptions of physician style and trust. *Archives of Family Medicine*, 9, 1156-1163.
- Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44, 131-142.
- Dreeben, O. (2010). *Patient education in rehabilitation*. Sudbury, MA: Jones and Bartlett Learning.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion and Health*, 23(3), 197-203.
- Dunlap, W. R., & Hollingsworth, J. S. (1977). How does a handicapped child affect the family? Implications for practitioners. *The Family Coordinator*, July, 286-293.
- Edwards, M. A., Millard, P., Praskac, L. A., & Wisniewski, P. A. (2003). Occupational therapy and early intervention: A family-centred approach. *Occupational Therapy International*, 10(4), 239-252.
- Eker, L., & Tuzun, E. H. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*, 26(23), 1354-1359.

- Ferrari, A. M. (2002). The impact of culture upon child rearing practices and definitions of maltreatment. *Child Abuse & Neglect*, 26, 793-813.
- Fiese, B. H. (1990). Playful relationships: A contextual analysis of mother-toddler interaction and symbolic play. *Child Development*, 61, 1648-1656.
- Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin*, 51(4), 327-358.
- Franco, L. M., Pottick, K. J., Huang, C. (2010). Early parenthood in a community context: Neighborhood conditions, race-ethnicity and parenting stress. *Journal of Community Psychology*, 38(5), 574-590.
- Friere, P. (2005). *Teachers as cultural workers: Letters to those who dare teach*. Boulder, CO: Westview Press.
- Gajdosik, C. G. (1991). Issues of parent compliance: What the clinician and researcher should know. *Physical & Occupational Therapy in Pediatrics*, 11(3), 73-87.
- Gajdosik, C. G., & Campbell, S. K. (1991). Effects of weekly review, socioeconomic status, and maternal belief on mothers' compliance with their disabled children's home exercise program. *Physical & Occupational Therapy in Pediatrics*, 11(2), 47-65.
- Gahimer, J. E., & Domholdt, E. (1996). Amount of patient education in physical therapy practice and perceived effects. *Physical Therapy*, 76(10), 1089-1096.
- Gershoff, E. T., Lansford, J. E., Sexton, H. R., Davis-Kean, P., & Sameroff, A. J. (2012). Longitudinal links between spanking and children's externalizing behaviors in a national sample of white, black, Hispanic and Asian American families. *Child Development*, 83(3), 838-843.
- Golledge, J. (1998). Distinguishing between occupation, purposeful activity and activity, Part 1: Review and explanation. *British Journal of Occupational Therapy*, 61, 100-105.

- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16-23.
- Graham, F., Rodger, S., & Ziviani, J. (2010). Enabling occupational performance of children through coaching parents: Three case reports. *Physical & Occupational Therapy in Pediatrics*, 30(1), 4-15.
- Green, J., & Goldwyn, R. (2002). Annotation: Attachment disorganisation and psychopathology: New findings in attachment research and their potential implications for developmental psychopathology in childhood. *Journal of Child Psychology and Psychiatry*, 43(7), 835-846.
- Green, S. E. (2001). 'Oh, those therapists will become your best friends': Maternal satisfaction with clinics providing physical, occupational and speech therapy services to children with disabilities. *Sociology of Health & Illness*, 23(6), 798-828.
- Greene, M. (1999). A parent's perspective. *Topics in Early Childhood Special Education*, 19(3), 149-151.
- Griffin, M. M., & Griffin, B. W. (1996). Situated cognition and cognitive style: Effects on students' learning as measured by conventional tests and performance assessments. *Journal of Experimental Education*, 64(4), 293.
- Haines, T. P., Hill, K. D., Bennel, K. L., & Osborne, R. H. (2006). Patient education to prevent falls in subacute care. *Clinical Rehabilitation*, 20, 970-979.
- Halpern, L. F., & McLean, W. E. (1997). "Hey mom, look at me!" *Infant Behavior and Development*, 20(4), 515-529.

- Hancock, T. B., Kaiser, A. P., Delaney, E. M. (2002). Teaching parents of preschoolers at high risk: Strategies to support language and positive behavior. *Topics in Early Childhood Special Education, 22*(4), 191-212.
- Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal, 49*, 14-24.
- Harrison, C., Romer, T., Simon, M. C., Schulze, C. (2007). Factors influencing mothers' learning from paediatric therapists: A qualitative study. *Physical & Occupational Therapy in Pediatrics, 27*(2), 77-96.
- Hasselkus, B. R. (1988). Meaning in family caregiving: Perspectives on caregiver/ professional relationships. *The Gerontologist, 28*(5), 686-691.
- Hasselkus, B. R. (1991) Ethical dilemmas in family caregiving for the elderly: Implications for occupational therapy. *American Journal of Occupational Therapy, 45*(3), 206-212.
- Hill, S. A., & Sprague, J. (1999). Parenting in black and white families: The interaction of gender with race and class. *Gender & Society, 13*(4), 480-502.
- Hinojosa, J. (1990). How mothers of preschool children with cerebral palsy perceive occupational and physical therapists and their influence on family life. *The Occupational Journal of Research, 10*(3), 144-162.
- Hinojosa, J., & Anderson, J. (1991). Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *The American Journal of Occupational Therapy, 45*(3), 273-279.
- Hinojosa, J., Anderson, J., & Strauch, C. (1988). Pediatric occupational therapy in the home. *American Journal of Occupational Therapy, 42*(1), 17-22.

- Hinojosa, J., Sproat, C. T., Mankhetwit, S., & Anderson, J. (2002). Shifts in parent-therapist partnerships: Twelve years of change. *American Journal of Occupational Therapy*, 56(5), 556-563.
- Hinojosa, M. S., Knapp, C. A., Madden, V. L., Huang, I., Sloyer, P., & Shenkman, E. A. (2012). Caring for children with life-threatening illnesses: Impact on white, African American, and Latino families. *Journal of Pediatric Nursing*, 27, 500-507.
- Honan, S., Krsnak, G., Petersen, D., & Torkelson, R. (1988). The nurse as patient educator: Perceived responsibilities and factors enhancing role development. *The Journal of Continuing Education in Nursing*, 19(1), 33-37.
- Horn, I. B., Mitchell, S. J., Wang, J., Joseph, J. G., & Wissow, L. S. (2012). African-american parents' trust in their child's primary care provider. *Academic Pediatrics*, 12(5), 399-404.
- Humphry, R. (1989). Early intervention and the influence of the occupational therapist on the parent-child relationship. *The American Journal of Occupational Therapy*, 43(11), 738-742.
- Humphry, R., & Link, S. (1990). Preparation of occupational therapists to work in early intervention programs. *American Journal of Occupational Therapy*, 44(9), 828-833.
- Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation*, 30(24), 1867-1884.
- Jaffe, L., Humphry, R., & Case-Smith, J. (2010). Working with families. In J. Case-Smith & J. Clifford O'Brien (Eds.), *Occupational Therapy for Children*, 6th ed. St. Louis, MO: Elsevier Mosby.
- Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist*, 41(3), 334-347.

- Jarvis, P. (2009). Developments in learning theory. *International Journal of Continuing Education and Lifelong Learning*, 2(1), 1-14.
- Johnson, C. B., & Deitz, J. C. (1985). Time use of mothers with preschool children: A pilot study. *American Journal of Occupational Therapy*, 39(9), 578-583.
- Johnson, J., & Pratt, D. D. (1998). The apprenticeship perspective: Modelling ways of being. In D. D. Pratt (Ed.), *Five Perspectives on Teaching in Adult and Higher Education*. Malabar, FL: Krieger Publishing Company.
- Jones, F., Rodger, S., Broderick, S., & De Monte, R. (2009). Living with juvenile idiopathic arthritis: Parents' experiences of treatment regimens and home exercise programmes. *British Journal of Occupational Therapy*, 72(6), 249-258.
- Kaiser, A. P., & Hancock, T. B. (2003). Teaching parents new skills to support their young children's development. *Infants & Young Children*, 16(1), 9-21.
- Kaiser, K., Rauscher, G. H., Jacobs, E. A., Strenski, T. A., Ferrans, C. E., & Warnecke, R. B. (2010). The import of trust in regular providers to trust in cancer physicians among white, African American, and Hispanic breast cancer patients. *Journal of General Internal Medicine*, 26(1), 51-57.
- Kaplan, S. H. (1985). Patient education techniques used at burn centers. *American Journal of Occupational Therapy*, 39(10), 655-658.
- Katz-Leurer, M. (2009). The effects of a 'home-based' task-oriented exercise programme on motor and balance performance in children with spastic cerebral palsy and severe traumatic brain injury. *Clinical Rehabilitation*, 23, 714-724.
- Kemppainen, J. K. (2000). The critical incident technique and nursing care quality research. *Journal of Advanced Nursing*, 32(5), 1264-1271.

- Kielhofner, G. (2004). *Conceptual foundations of occupational therapy*. Philadelphia, PA: F. A. Davis Company.
- King, G., King, S. M., & Rosenbaum, P. (1996). How mothers and fathers view professional caregiving for children with disabilities. *Developmental Medicine and Child Neurology*, 38, 397-407.
- King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers' perceptions of the family-centredness of children's rehabilitation services. *Physical & Occupational Therapy in Pediatrics*, 18(1), 21-40.
- Knox, M., Parmenter, T.R., Atkinson, N., & Yazbeck, M. (2000). Family control: The views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 13, 17-28.
- Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21, 827-836.
- Korfmacher, J., Green, B., Staerkel, F., Peterson, C., Cook, G., Roggman, L., Faldowski, R. A., & Schiffman, R. (2008). Parent involvement in early childhood home visiting. *Child Youth Care Forum*, 37, 171-196.
- Kruger, S. (1991). The patient educator role in nursing. *Applied Nursing Research*, 4(1), 19-24.
- Larson, E. (2010). Identifying indicators of well-being for caregivers of children with disabilities. *Occupational Therapy International*, 17, 29-39.
- Law, M., Baptiste, S., & Mills, J. (1995). Client-centered practice: What does it mean and does it make a difference? *Canadian Journal of Occupational Therapy*, 62(5), 250-257.
- Lawlor, M.C., & Mattingly, C.F. (1998). The complexities embedded in family-centered care. *American Journal of Occupational Therapy*, 52(4), 259-267.

- Leonard, B. J., Johnson, A. L., & Brust, J. D. (1993). Caregivers of children with disabilities: A comparison of those managing “OK” and those needing more help. *Children’s Health Care, 22*(2), 93-105.
- Leondardelli, C. A., & Gratz, R. R. (1986). Occupational therapy education: The relationship of purpose, objectives and teaching models. *American Journal of Occupational Therapy, 40*(2), 96-102.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Thousand Oaks, CA: Sage Publications.
- Lindblad, B. M., Rasmussen, B. H., & Sandman, P-O. (2005). Being invigorated in parenthood: Parents’ experiences of being supported by professionals when having a disabled child. *Journal of Pediatric Nursing, 20*(4), 288-297.
- Lopez-Cevallos, D. F., Harvey, S. M., & Warren, J. T. (2014). Medical mistrust, perceived discrimination, and satisfaction with health care among young-adult rural Latinos. *The Journal of Rural Health, 30*, 344-351.
- Lucca, J. A., & Settles, B. H. (1981). Effect on children’s disabilities on parental time use. *Physical Therapy, 61*(2), 196-201.
- Mahoney, G., Boyce, G., Fewell, R., Spiker, D., & Wheeden, C. (1998). The relationship of parent-child interaction to the effectiveness of early intervention services. *Topics in Early Childhood Special Education, 18*(1), 5-17.
- Mahoney, G., Kaiser, A., Girolametto, L., MacDonald, J., Robinson, C., Safford, P., & Spiker, D. (1999). Parent education in early intervention: A call for a renewed focus. *Topics in Early Childhood Special Education, 19*(3), 131-140.

- Mapp, T. (2008). Understanding phenomenology: The lived experience. *British Journal of Midwifery*, 16(5), 308-311.
- Marcum, J., Ridenour, M., Shaff, G., Hammons, M., & Taylor, M. (2002). A study of professional nurses' perceptions of patient education. *The Journal of Continuing Education in Nursing*, 33(3), 112- 118.
- Mattingly, C. (1994). Occupational therapy as a two-body practice: The lived body. In C. Mattingly & M. H. Fleming (Eds.), *Clinical Reasoning: Forms of Inquiry in a Therapeutic Practice*. Philadelphia, PA: F. A. Davis Company.
- May, B. J. (1983). Teaching: A skill in clinical practice. *Physical Therapy*, 63(10), 1627-1633.
- McCallion, P., & Toseland, R. W. (1993). Empowering families of adolescents and adults with developmental disabilities. *Families in Society: The Journal of Contemporary Human Services*, 74, 574-587.
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice*, 15, 7-15.
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Unpacking Heideggerian phenomenology. *Southern Online Journal of Nursing Research*, 9(1).
- McLaughlin Gray, J. (1997). Application of the phenomenological method to the concept of occupation. *Journal of Occupational Science Australia*, 4(1), 5-17.
- Merriam, S. B., Caffarella, R. S., & Baumgartner, L. M. (2007). *Learning in Adulthood: A Comprehensive Guide*. San Francisco: Jossey-Bass.
- Merriam, S. B. & Clark, M. C. (2006). Learning and development: The connection in adulthood. In C. Hoare (Ed.), *Handbook of Adult Development and Learning*, Oxford: Oxford University Press.

- Mezirow, J. (2000). Learning to think like an adult: Core concepts of transformation theory. In J. Mezirow (Ed.), *Learning as transformation: Critical perspectives on a theory in progress*. San Francisco: Jossey-Bass.
- de Montigny, F., & Lacharite, C. (2005). Perceived parental efficacy: Concept analysis. *Journal of Advanced Nursing*, 49(4), 387-396.
- Moseley, K. L., Clark, S. J., Gebremariam, A., Sternthal, M. J., & Kemper, A. R. (2006). Parents' trust in their child's physician: Using an adapted trust in physician scale. *Ambulatory Pediatrics*, 6(1), 58-61.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks: Sage Publications.
- Muma, R. D. (2012). An approach to patient education. In R. D. Muma & B. A. Lyons (Eds.), *Patient Education: A Practical Approach*, 2nd ed. Sudbury, MA: Jones & Bartlett Learning.
- Murray, R., & Zentner, J. (1976). Guidelines for more effective health teaching. *Nursing*, 6(2), 44-53.
- Nam, Y., Wikoff, N., & Sherraden, M. (2015). Racial and ethnic differences in parenting stress: Evidence from a statewide sample of new mothers. *Journal of Child and Family Studies*, 24, 278-288.
- National Survey of Children with Special Health Care Needs. (2005). *Children with special health care needs ages 0-17 needing physical, occupational or speech therapy, past 12 months: Nationwide*. Retrieved February 10, 2011 from:
<http://www.cshcndata.org/DataQuery/DataQueryResults.aspx?q=84&r1=0&r2=-1>

- National Survey of Children with Special Health Care Needs. (2005). *Children with special health care needs ages 0-17 needing physical, occupational or speech therapy, past 12 months: Nationwide vs. Wisconsin*. Retrieved September 23, 2016 from:
<http://www.childhealthdata.org/browse/survey/results?q=1995&r=1>
- National Survey of Children with Special Health Care Needs. (2005). *Children ages 0-17 with cerebral palsy: Nationwide vs. Wisconsin vs. Arizona*. Retrieved September 23, 2016 from: <http://childhealthdata.org/browse/survey/results?q=1878&r=4&r2=51>
- Nomaguchi, K., & House, A. N. (2013). Racial-ethnic disparities in maternal parenting stress: The role of structural disadvantages and parenting values. *Journal of Health and Social Behavior, 54*(3), 386-404.
- Northen, J.G., Rust, D.M., Nelson, C.E., & Watts, J.H. (1995). Involvement of adult rehabilitation patients in setting occupational therapy goals. *American Journal of Occupational Therapy, 49*(3), 214-220.
- Novak, I. (2011). Effective home programme intervention for adults: A systematic review. *Clinical Rehabilitation, 25* (12), 1066-1085.
- Novak, I. (2011). Parent experience of implementing effective home programs. *Physical & Occupational Therapy in Pediatrics,*
- Novak, I. & Berry, J. (2014). Home program intervention effectiveness evidence. *Physical & Occupational Therapy in Pediatrics, 34*(4), 384-389.
- Novak, I., & Cusick, A. (2006). Home programmes in paediatric occupational therapy for children with cerebral palsy: Where to start? *Australian Occupational Therapy Journal, 53*, 251-264.

- Novak, I., Cusick, A., & Lannin, N. (2009). Occupational therapy home programs for cerebral palsy: Double-blind, randomized controlled trial. *Pediatrics*, 124(4), 606-614.
- Novak, I., Cusick, A., & Lowe, K. (2007). A pilot study on the impact of occupational therapy home programming for young children with cerebral palsy. *The American Journal of Occupational Therapy*, 61(4), 463-468.
- Palmer, S. P., & Heaston, S. (2009). Teaching the teacher program to assist nurse managers to educate nursing staff in Ecuadorian hospitals. *Nurse Education in Practice*, 9, 127-133.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*, 3rd ed. Thousand Oaks, CA: Sage Publications.
- Peloquin, S. M. (1990). The patient-therapist relationship in occupational therapy: Understanding visions and images. *American Journal of Occupational Therapy*, 44(1), 13-21.
- Peloquin, S. M. (1993). The patient-therapist relationship: Beliefs that shape care. *American Journal of Occupational Therapy*, 47(10), 935-942.
- Peplow, U. C., & Carpenter, C. (2013). Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: A qualitative study. *Physical & Occupational Therapy in Pediatrics*, 33(3), 285-299.
- Peterander, F. (2000). The best quality cooperation between parents and experts in early intervention. *Infants & Young Children*, 12(3), 32-45.
- Picciolini, O., Albisetti, W., Cozzaglio, M., Spreafico, F., Mosca, F., & Gasparroni, V. (2009). "Postural management" to prevent hip dislocation in children with cerebral palsy. *Hip International*, 19(1), S56-S62.
- Pigg, R. M. (1982). A national study on professional preparations in patient education. *American Journal of Public Health*, 72(2), 180-182.

- Piggot, J., Hocking, C., & Paterson, J. (2003). Parental adjustment to having a child with cerebral palsy and participation in home therapy programs. *Physical & Occupational Therapy in Pediatrics, 23*(4), 5-29.
- Piggot, J., Paterson, J., & Hocking, C. (2002). Participation in home therapy programs for children with cerebral palsy: A compelling challenge. *Qualitative Health Research, 12*(8), 1112-1129.
- Plack, M., & Driscoll, M. (2011). *Teaching and learning in physical therapy: From classroom to clinic*. Thorofare, NJ: Slack Incorporated.
- Portes, P. R., Dunham, R. M., & Williams, S. (1986). Assessing child-rearing style in ecological settings: Its relation to culture, social class, early age intervention and scholastic achievement. *Adolescence, 21*(83), 723-735.
- Pountney, T. E., Mandy, A., Green, E., & Gard, P. R. (2009). Hip subluxation and dislocation in cerebral palsy—a prospective study on the effectiveness of postural management programmes. *Physiotherapy Research International, 14*(2), 116-127.
- Pratt, D. D. (1998). *Five perspectives on teaching in adult and higher education*. Malabar, FL: Krieger Publishing Company.
- Pruchno, R., Patrick, J. H., & Burant, C. J. (1997). African American and white mothers of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations, 46*(4), 335-346.
- Pryor, J. (2009). Coaching patients to self-care: A primary responsibility of nursing. *International Journal of Older People Nursing, 4*, 79-88.

- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B. & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), 626-636.
- Raphael, J. L., Zhang, Y., Liu, H., & Giardino, A. P. (2009). Parenting stress in US families: Implications for paediatric healthcare utilization. *Child: Care, Health and Development*, 36(2), 216-224.
- Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D. (2011). "If I knew then what I knew now": Parents' reflections on raising a child with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*,
- Rindflesch, A. B. (2009). A grounded-theory investigation of patient education in physical therapy practice. *Physiotherapy theory and practice*, 25(3), 193-202.
- Robinson, K., & Harris, A. L. (2013). Racial and social class differences in how parents respond to inadequate achievement: Consequences for children's future achievement. *Social Science Quarterly*, 94(5), 1346-1371.
- Rogers, S. L. (2010). Common conditions that influence children's participation. In J. Case-Smith & J. Clifford O'Brien (Eds.), *Occupational Therapy for Children*, 6th ed., St. Louis, MO: Elsevier Mosby.
- Rone-Adams, S. A., Stern, D. F., & Walker, V. (2004). Stress and compliance with a home exercise program among caregivers of children with disabilities. *Pediatric Physical Therapy*, 16, 140-148.
- Rosa, S.A., & Hasselkus, B.R. (2005). Finding common ground with patients: The centrality of compatibility. *The American Journal of Occupational Therapy*, 59(2), 198-208.

- Royeen, C.B. (1995). A problem-based learning curriculum for occupational therapy education. *American Journal of Occupational Therapy*, 49(4), 338-346.
- Rush, D. D., Shelden, M. L., & Hanft, B. E. (2003). Coaching families and colleagues: A process for collaboration in natural settings. *Infants & Young Children*, 16(1), 33-47.
- Sabonis-Chafee, B., & Hussey, S. M. (1998). *Introduction to occupational therapy*, 2nd ed. St. Louis, MO: Mosby.
- Salonen, A. H., Kaunonen, M., Astedt-Kurki, P., Jarvenpaa, A., Isoaho, H., & Tarkka, M. (2009). Parenting self-efficacy after childbirth. *Journal of Advanced Nursing*, 65(11), 2324-2336.
- Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10, 277-286.
- Scales, L. H., McEwen, I. R., & Murray, C. (2007). Parents' perceived benefits of physical therapists' direct intervention compared with parental instruction in early intervention. *Pediatric Physical Therapy*, 19, 196-202.
- Schemm, R.L., Corcoran, M., Kolodner, E., & Schaaf, R. (1993). A curriculum based on systems theory. *American Journal of Occupational Therapy*, 47(7), 625-634.
- Schluter, J., Seaton, P., & Chaboyer, W. (2008). Critical incident technique: a user's guide for nurse researchers. *Journal of Advanced Nursing*, 61(1), 107-114.
- Schwandt, T. A. (1998). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Landscape of Qualitative Research: Theories and Issues*. Thousand Oaks, CA: Sage Publications.

- Segal, R., & Beyer, C. (2006). Integration and application of a home treatment program: A study of parents and occupational therapists. *American Journal of Occupational Therapy*, 60(5), 500-510.
- Segal, R., & Hinojosa, J. (2006). The activity setting of homework: An analysis of three cases and implications for occupational therapy. *American Journal of Occupational Therapy*, 60(1), 50-59.
- Slade, A. (1987). A longitudinal study of maternal involvement and symbolic play during the toddler period. *Child Development*, 58, 367-375.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*, 2, 3-11.
- Sotosky, J. R. (1984). Physical therapists' attitudes toward teaching. *Physical Therapy*, 64(3), 347-350.
- Stanton, M. (1988). Nursing time for patient education. *Today's OR Nurse*, 10(11), 26-30.
- Stepanikova, I., Mollborn, S., Cook, K. S., Thom, D. H., & Kramer, R. M. (2006). Patients' race, ethnicity, language and trust in a physician. *Journal of Health and Social Behavior*, 47, 390-405.
- Teti, D. M., & Gelfand, D. M. (1991). Behavioral competence among mothers of infants in the first year: The mediational role of maternal self-efficacy. *Child Development*, 62, 918-929.
- T'Kenye, C. (1998). The nurturing perspective: Facilitating self-efficacy. In D. D. Pratt (Ed.), *Five Perspectives on Teaching in Adult and Higher Education*. Malabar, FL: Krieger Publishing Company.

- U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau. (2012). *Americans with disabilities: 2010*. Retrieved February 10, 2011 from: <http://www.census.gov/hhes/www/disability/sipp/disable05.html>
- U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau. (n.d.). *American FactFinder Quick Tables*. Retrieved September 23, 2016 from: http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_5YR_S1810&prodType=table
- U.S. Department of Education, Office of Special Education Programs' (OSEP's) IDEA Website. (n.d.). Retrieved February 10, 2011 from: <http://idea.ed.gov/explore/search>
- U.S. Department of Education, Special Education & Rehabilitative Services. (2007). *Archived: A 25 year history of the IDEA*. Retrieved February 10, 2011 from <http://www.ed.gov/policy/speced/leg/idea/history.html>
- U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (n.d.). *Quick guide to health literacy*. Retrieved February 10, 2011 from: <http://www.health.gov/communication/literacy/quickguide/factsbasic.htm>
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London: State University of New York Press.
- van Meeteren, J., Roebroek, M. E., Celen, E., Donkervoort, M., Stam, H. J., & Transition Research Group South West Netherlands. (2008). Functional activities of the upper extremity of young adults with cerebral palsy: A limiting factor for participation? *Disability and Rehabilitation*, 30(5), 387-395.
- Walters, A. J. (1995). The phenomenological movement: implications for nursing research. *Journal of Advanced Nursing*, 22, 791-799.

- Wilding, C., & Whiteford, G. (2005). Phenomenological research: An exploration of conceptual, theoretical, and practical issues. *OTJR: Occupation, Participation and Health*, 25(3), 98-104.
- Wilkins, S., Pollock, N. Rochon, S., & Law, M. (2001). Implementing client-centered practice: Why is it so difficult to do? *Canadian Journal of Occupational Therapy*, 68(2), 70-79.
- Willis, J. W. (2007). *Foundations of qualitative research: Interpretive and critical approaches*. Thousand Oaks, CA: Sage Publications.
- Wojnar, D. M., & Swanson, K. M. (2007). Phenomenology: An exploration. *Journal of Holistic Nursing*, 25(3), 172-180.
- Woodring, B. (2000). If you have taught—have the child and family learned? *Pediatric Nursing*, 26(5), 505-509.
- Woods, J., Kashinath, S., & Goldstein, H. (2004). Effects of embedding caregiver-implemented teaching strategies in daily routines on children's communication outcomes. *Journal of Early Intervention*, 26(3), 175-193.
- Zsembik, B. A., & Fennell, D. (2005). Ethnic variation in health and the determinants of health among Latinos. *Social Science & Medicine*, 61, 53-63.

APPENDIX A:
Recruitment Letters

To: Parent of a child with cerebral palsy receiving occupational therapy services

From: Michelle Finet

Doctoral Student in the Administrative Leadership concentration of the Urban
Education Doctoral Program at UWM

My name is Michelle Finet and I am interested in finding out about your learning home program content for your child from your child's occupational therapist. I am conducting interviews with caregivers to gain information about this topic. I believe this topic is an important area to research because if therapists can understand your lived experience it hopefully will help them be more effective therapists. Please consider giving your time for me to learn about this important topic.

In order to participate in this study, you must be the primary person engaging in participating with your child in the occupational therapy sessions. Your child must be between the ages of 6 to 12 with a diagnosis of cerebral palsy classified as either mild or moderate spasticity. Your child must have been receiving occupational therapy services in either the home or clinic for at least six months and your therapist must be providing you with information for a home program. Your primary speaking language must be English and your therapist must have practiced in the field of pediatric occupational therapy for a minimum of two years.

The process would involve three steps. The first meeting would involve signing the consent form, asking you to fill out two worksheets (each would take approximately 10 minutes to complete) and asking you to fill out a short diary entry after each therapy session you have with your child's therapist for the next three sessions. If you live in a different area than myself this portion can be completed via email. The second meeting would be an interview that would last approximately an hour and would take place at a time and place of your choice. If you live in a different area than myself the interview can occur over a webcam. The interview would be audio-taped or recorded to allow for the most accurate information to be processed when I am going through the data collected from this research. There is no right or wrong answers to these interview questions and it is important that I gather information from people of varied backgrounds and perspectives so that a complete picture may be received. The third and final meeting would involve my reviewing the three diary entries with you and also discussing my interpretations of the information reported by you in the interview to ensure I am understanding your point of view completely and accurately. This third meeting can occur in person or over the phone, whichever is more convenient for you, and should only take approximately 10-15 minutes.

Thank you very much for taking the time to read this letter. If you decide to participate in appreciation you will be given a \$50 Target gift card at the end of your participation. If you are interested in participating, please contact me by phone at 480-280-2342 (please leave a voicemail if I do not answer) or via email at finetm@uwm.edu. Thank you again and I hope you have a great day!

Regards,

Michelle Finet, MS OT/L

APPENDIX B:

Common Characteristics of Children with Cerebral Palsy Table

Table 2

Common Characteristics of Children with Cerebral Palsy

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Quality of tone	Severely increased tone; flexor and extensor co-contraction is constant, tone is high at rest, during sleep, or when awake; tone pattern is more proximal than distal	Moderately increased tone; near normal at rest but increases with excitement, movement attempts, emotion, speech, sudden stretch; agonists and distal muscles more spastic	Mildly increased or normal tone at rest increases with effort or attempts to move or attempts at quicker movements	Fluctuation of tone from low to normal; no or little spasticity; no co-activation of flexors extensors	Fluctuates from normal to high; some ability to stabilize proximally; moderate proximal spasticity and distal athetosis	Unpredictable tone changes from low to very high; either all flexion or extension of extremities	Constant fluctuations from low to high with no co-contraction; jerky involuntary movements more proximal than distal	Fluctuating, markedly low muscle tone; seen at birth, or toddler initially classified as flaccid, later classified as spastic, athetoid, or ataxic	Ranges from near normal to normal; increased tone, when present, usually involves lower extremity flexion
Distribution of tone	Quadriplegia, but may also manifest as diplegia or paraplegia	Same as in severe spasticity	Same as in severe spasticity, but diplegia and hemiplegia more common	Quadriplegia with occasional hemiplegia	Same as in athetosis	Quadriplegia, hemiplegia, or monoplegia	Quadriplegia	Quadriplegia	Quadriplegia

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Range of Motion	Abnormal patterns can lead to scoliosis, kyphosis, hip/knee/finger deformity; forearm pronation contracture, hip subluxation, heel cord subluxation with equinovarus or equinovalgus; decreased trunk, shoulder, and pelvic girdle mobility; limited midrange control where co-contraction is least balanced	More available movement and more flexor/extensor imbalance can lead to kyphosis, lordosis, hip subluxations or dislocations, hip and knee flexion contractures; tight hip internal rotators and adductors; heel cord shortening; foot rotation	Limitations more distal than proximal; minimal deformities	Transient subluxation of joints such as shoulders and fingers; may have valgus on feet or knees; rarely any deformities	Incidence of scoliosis; some flexion deformities at hips, elbows, and knees; usually full range of motion proximally and hypermobile distally	More pronounced scoliosis; more dislocation of arm because of flailing spasm; possible kypho-scoliosis, hip dislocation, or skull dislocation, flexion contracture on hips/knees, subluxation of hips, fingers, or lower jaw	Many involuntary movements with extreme ranges but no control at midrange; deformities rare, but tendency for shoulder and finger subluxation	Hyper-mobile joints that tend to subluxate; flat chest; later, range limitations due to limited movement	Range usually not a problem; decreased range, when present, usually in flexion

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Quality of movement	Decreased midrange, voluntary, and involuntary movements; slow and labored stereotypical movements	May be able to walk; stereotypical, asymmetric, more associated reactions; total movement synergies	Often able to walk; seems driven to move; has increased variety of other movements, some stereotypical	Writhing involuntary movements, more distal than proximal; no change with intention to move; many fixation attempts caused by decreased ability to stabilize	Decreased ability to grade movements; decreased midline control and selective movement; proximal stability and distal choreo-athetosis; varies with case	Extreme tonic spasm without voluntary control; some involuntary movement, distal more than proximal	Wide movement ranges with no gradation; jerky movements more proximal than distal; no selective movement or fixation of movement; weak hands and fingers	Upgraded movements ; slow movements difficult; many static postures; as if hanging on to anatomic structure instead of active control	Lacks point of stability, therefore co-activation is difficult; uses primitive rather than abnormal patterns, hence gross, total patterns; incoordination, thus dysmetria disdiadochokinesia, tremors at rest, symmetric problems

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Reflexes and reactions	Obligatory primitive reflexes (positive support, ATNR, STNR, neck righting); protective, righting, and equilibrium reactions are often absent	Strong primitive reflexes—Moro, startle, TNR, TLR, positive support prominent; decreased neck righting; associated reactions strong; righting may be present, but equilibrium reaction develops to sitting and kneeling	Primitive reflexes used for functional purposes and not obligatory; righting, protective, and equilibrium reactions delayed but established; may not develop higher level reactions	Primitive reflexes not usually obligatory or evoked; protective and equilibrium reactions usually present but involuntary movements affect grading	TNR/TLR strong but intermittent and modified by involuntary movements; equilibrium reactions, when present, unreliable and may or may not be used	Strong ATNR, STNR, TLR; protective and equilibrium reactions absent during spasm, otherwise present, unreliable, or absent	Intermittent TNR; righting and equilibrium reactions present to some extent, but abnormal coordination; abnormal upper extremity protective extension possible, but often absent	Usually less reactive because of decreased tone; righting is delayed; delayed protective extension more available than equilibrium reaction	May develop righting reactions, but these are uncoordinated, and poorly used; equilibrium reactions, when developed, are not coordinated; needs wide base of support because of poor weight shifting

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Oral motor	Immobile, rigid chest; shallow respiration and forced expiration; lip retraction with decreased lip closure and tongue thrust; communication through forced expiration	Not as involved as in severe spasticity	Increased mobility, thus more respiratory function for phonation; shortness of breath limits sentence length; better ability to dissociate mouth parts, but poor lip closure causes drooling	Fluctuations adversely affect gross and fine motor performance ; volume of speech may go up or down with breath; feeding may be decreased due to instability & tongue/jaw/ swallow incoordination	Difficult with head control, thus decreased oral motor, strained speech; decreased coordination of suck/ swallow, resulting in decreased feeding and speech	Feeding may be difficult because aspiration is unpredictable; severe language and speech impairment caused by decreased control	Facial grimaces, dysarthria, irregular breathing, difficulty sustaining phonation, poor intraoral and extraoral surfaces	Quiet, soft voice because of decreased respiration; delayed speech; increased drooling; often expressionless face	Speech is monotone, very slow; uses teeth to stabilize tongue or hold cup to mouth when drinking; decreased articulation
Associated Problems	Seizures, cortical blindness, deafness, ID, malnutrition, prone to UTRI	Seizures, ID, perceptual motor problems, imbalance of eye musculature	Seizures, less ID, perceptual problems	Hearing loss, less ID	Same as in athetosis	Same as in athetosis	Same as in athetosis	Obesity, sensory impairment , URTI	Nystagmus, MR, sensory problems; uses vision for righting and as reference point for movement

Clinical Feature	Severe Spasticity	Moderate Spasticity	Mild Spasticity	Pure Athetosis	Athetosis With Spasticity	Athetosis with Tonic Spasms	Choreoathetosis	Flaccidity	Ataxia
Personality	Passive, dependent; resistant and adapts poorly to change; anxious and fearful of being moved; generally less frustrated than athetoid individuals	Lesser degree of traits seen in severe spasticity	More frustrated and critical about self because of awareness of better performance ; more patient than children of same age	Emotional lability; less fearful of movement; more outgoing, but tends to be frustrated	Same as in athetosis	Same as in athetosis	Same as in athetosis	Visually attentive, cannot move, therefore is a “good” baby; decreased motivation	Does not like to move

Note: Adapted from Rogers, S. L., 2010, p. 157-159

APPENDIX C:
Critical Incident Guides

Critical Incident Questionnaire

Directions: Take 10-12 minutes to respond to each of the questions below about your experiences in learning a home program for your child from your child’s occupational therapist. This information will be discussed during our second meeting in order to understand how these experiences positively or negatively impacted you as a caregiver for your child.

Think back over the entire time your child has received occupational therapy services. Choose a **positive event** involving learning home program content from the therapist for your child. The event should be one that kept you feeling cheerful and encouraged for the entire day or night, excited about how you participated in the therapy session, and had a positive impact on your life or your child's life in terms of the home program. Write some notes regarding this incident and include the following details:

1. What happened?
2. When and where did it happen?
3. What was it about the event that was so positive and affirming to you?

Critical Incident Questionnaire

Directions: Take 10-12 minutes to respond to each of the questions below about your experiences in learning a home program for your child from your child’s occupational therapist. This information will be discussed during our second meeting in order to understand how these experiences positively or negatively impacted you as a caregiver for your child.

Think back over the entire time your child has received occupational therapy services. Choose a **negative event** involving learning home program content from the therapist for your child. The event should be one that caused some distress, kept you awake at night thinking about how you should have handled the situation, or had you spending an extensive amount of time worrying or having anxiety over it. Write some notes regarding this incident and include the following details:

1. What happened?
2. When and where did it happen?
3. What was it about the event that was so distressing for you?

APPENDIX D:
Diary Questions

Please take 10-15 minutes to answer the following questions in your diary as soon as possible after the therapy session and on the same day as when your child receives occupational therapy:

1. Describe the details of your learning about the home therapy program for your child from the therapist:

2. How do you feel about the experience?

3. What is your opinion about how the experience occurred? What did you like and what would you have changed?

APPENDIX E:
Interview Guides

Interview Guide for Second Meeting

This interview is being conducted in order to gain a perspective on your learning about your child's home program from their occupational therapist. You have received a consent form to sign during our preview meeting, which indicates your consent to this interview and that the interview will be recorded. Before we begin I would like to assure you that the information you tell me will be confidential, meaning that I will be the only one who knows the specifics of who said what in this research study. Do you have any questions before we begin?

Icebreaker question: Tell me about (child's name).

1. In looking at your critical review guides this is what I am hearing you say. Does that sound correct? Could you please elaborate on (add in anything which is unclear from the review guides)? Is there anything you would like to add?

2. What have you experienced in terms of learning the home program for your child from the occupational therapist?

a) How do you feel about the way the therapist portrays himself/herself in the process of teaching you the home program?

b) How do you feel about the way the therapist meets your own learning needs in the process of teaching you the home program?

c) How do you feel about the methods the therapist uses to teach you the home program?

d) What acts as a barrier to the educational relationship between the therapist and yourself?

e) How do you feel the educational relationship and experience could be improved?

Your comments are really helpful. We're about halfway through the interview and from my point of view it's going very well. You've been telling me some important things. How's it going for you?

3. What contexts or situations have typically influenced or affected your experiences of learning the home program for your child?

a) More specifically, what barriers are encountered to learning about delivering the home program for your child during the experience of learning it?

b) What does the therapist do which provides support for you delivering the home program to your child?

c) What does the therapist do which acts as a barrier for delivering the home program to your child?

In the last hour we have talked about your experiences with learning home programs for your child from the occupational therapist. In our next meeting I will have a better understanding of what you have said after I have time to reflect, however, here is my understanding of what you have told me thus far.... (insert reflection of what they have reported). Do you feel I understand what you have reported to me correctly?

That covers the things I wanted to ask. Is there anything you feel is important that we haven't discussed and that you would like to add?

Thank you very much for spending this time with me. Let's schedule our next and final meeting where we can review what we discussed today in further detail.

Thank you again and I hope you have a great day!

Interview Guide for Third Meeting

Last time we met we discussed what it is like to experience learning a home program for your child from your child's occupational therapist.

As I reviewed your interview information, I was hoping you could tell me some more about (add in anything that is unclear from data processing of the second meeting interview).

I want to make sure I understand what you've been telling me in our previous meeting and in this meeting. These are the themes I am seeing as coming out from your interview and the interviews I am conducting with other caregivers of children with cerebral palsy. (List themes found).

Do you feel I am correctly expressing the essence of the experience you have when learning a home program for your child?

If not, could you help correct my perceptions please? (if needed) Now that you've explained this is what I'm hearing you say...does that sound correct now? (if needed)

At this point, I'd like to review and discuss your diary entries. (Informal discussion based off of what is written in order to gain clarification on anything that was written).

Do you feel there is anything that we haven't discussed in our meetings up until now that you feel is important for me to know?

I want to thank you so much again for being willing to spend all of this time with me. This will help further research on understanding the experiences of caregivers of children receiving occupational therapy when learning about a home program for their child. Hopefully this will be helpful to therapists in providing better services. Would it be alright if I give you a call if I have any questions that come up as I continue to reflect on everything that you've said?

(Give Target gift card) Please enjoy this gift as a token of appreciation for your time and effort in participating in this research study. Thank you again for everything and have a great day!

MICHELLE FINET, Ph.D., OT/L

EDUCATION

Ph.D., University of Wisconsin – Milwaukee, December 2016

Concentration: Urban Education, Specialization Area in Adult and Continuing Education
Leadership

Dissertation: Examining the Lived Experience of Caregivers Learning a Home Program from a
Pediatric Occupational Therapist

M.S., University of Wisconsin-Milwaukee, May 2001

Concentration: Occupational Therapy

Thesis: Determining the Accuracy of a Psychophysical Approach to Grip Force
Measurement

Certificate of Ergonomics, University of Wisconsin-Milwaukee, May 2001

Design Project: Ergonomics Workplace Analysis completed at Kohler in Kohler,
Wisconsin

B.S., Occupational Science, University of Wisconsin-Milwaukee, December 1999

EXPERIENCE

Assistant Professor

Feb. '16 – Present

A. T. Stills University, Mesa AZ

Responsible for a teaching and service oriented workload. Serving as the advisor to the Student Occupational Therapy Association to help guide students in their projects for that organization and on various department and university committees. Responsible for also advising students one-on-one and leading a research group of a minimum of six students each year.

Owner / Occupational Therapist

Sept. '13 – Present

Owner of Alexander Pediatric Therapies, LLC, a home therapy-based business specializing in occupational, speech and physical therapy catering to clients supplied through an Arizona state contract. Also working as an Occupational Therapist treating clients in the age ranges from three years to thirty-four years old in home and day program care settings. Responsible for maintaining own daily progress notes, billing and progress reports on clients. Also responsible for evaluations on clients and parent instruction.

Clinical Associate Professor

Aug. '07 – May '12

University of Wisconsin – Milwaukee

Responsible for maintaining a teaching and service oriented workload as well as being point of contact for ad-hoc instructors for own Instructor of Record courses. Also served on thesis/project committees for Master's level students and as graduate advisor for comprehensive exam Master's level students.

- Academic Fieldwork Coordinator* Sept. '08 – May. '12
University of Wisconsin-Milwaukee
Responsible for coordination and administration of clinical internships for Occupational Therapy students for their Level I and Level II placements. Included communication with health care facilities, maintenance of paperwork and monitoring of students while on placements.
- Professional Program Coordinator* Jan. '08 – Dec. '11
University of Wisconsin – Milwaukee
Responsible for administrative tasks in the College of Health Sciences, Occupational Therapy Department in conjunction with the Program Director including facilitating recruitment of students, monitoring course schedules/effectiveness for program and orientation of ad-hoc instructors.
- Ergonomics Consultant* Jan. '07 – Dec. '11
University of Wisconsin – Milwaukee
On staff for the Center for Ergonomics, run conjointly by the College of Health Sciences and the College of Engineering and Applied Sciences. Responsible for completing ergonomic services including on-site ergonomic job analysis, office ergonomics training and offering of the seating clinic in the Occupational Ergonomics Laboratory.
- Adhoc Instructor* Jan. '07 – Aug. '07
University of Wisconsin-Milwaukee
Working as an instructor in the College of Health Sciences, Occupational Therapy Department. Responsible for all aspects of teaching courses including formulating lectures, assignments and projects. Also responsible for grading and evaluations of students.
- CEO / Occupational Therapist* Jan. '03 – Aug. '07
CEO of Restorative Care Therapies, LLC a home therapy-based business specializing in occupational, speech and physical therapy catering to clients supplied through an Arizona state contract. Also worked as an Occupational Therapist treating children in age ranges from six months to eighteen years in home and daycare settings. Responsible for maintaining own daily progress notes, billing and progress reports on clients. Also responsible for evaluations on clients and parent instruction. Managed multiple therapists working as independent contractors for the business.
- Occupational Therapist* Mar. '02 – Jan. '03
Worked as an independent contractor treating children in age ranges from six months to eighteen years in home and daycare settings. Responsible for maintaining own daily progress notes and progress reports on clients. Also responsible for evaluations on clients and parent instruction.
- Occupational Therapist* Aug. '01 – Feb. '02
Rehab Resources, Beaver Dam, Wisconsin
Worked as therapist treating children in age ranges from six months to ten years in clinic, home and pool settings. Responsible for maintaining own daily progress notes, insurance authorizations, billing and re-certifications for clients from physicians.
- Senior Therapist* Oct. '98 – May '01
Autism Behavioral Network, Wauwatosa, Wisconsin
Worked as therapist with autistic children. Developed treatment plans to be implemented for autistic children in home-based behavioral program. Responsible for maintenance of data book and other paperwork, training of line therapists and communication with family members.

FIELDWORK

New Berlin Therapies

Mar. '01 – Jun. '01

Worked serving pediatric population ranging from ages 15 months to 8 years old. Responsible for tracking all paperwork including maintenance of daily notes, plan of cares and prior authorizations for insurance.

St. Luke's Hospital / St. Mary's Hospital

Jan. '01 – Mar. '01

At the St. Mary's location worked with an adult population in an outpatient clinic dealing with primarily hand and upper extremity injuries. Also worked with the geriatric population in the on-site nursing home and with the population at the return to work rehabilitation outpatient clinic. At the St. Luke's location worked with the adult population on an acute inpatient basis, gaining experience with cardiac rehab, orthopedic rehab with hip and knee replacements, a neurological unit with patients with traumatic brain injury and the intensive care unit.

AWARDS AND HONORS

- Graduate of the Last Decade, University of Wisconsin-Milwaukee
May 2008
- Curative Minority Graduate Student Scholarship
\$3156.65 scholarship awarded for Spring 2001 and Spring 2000 semesters
- Diverse Urban Interdisciplinary Traineeship (DUIT)
Full tuition scholarship for Spring, Summer and Winter 2000 semesters

PRESENTATIONS

A Phenomenological Approach Examining the Readiness of Regular Education Teachers to Teach Students with Disabilities, American Association for Adult and Continuing Education Conference, November 14, 2008

Living Your Life Safely: Practical Ergonomics, Senior Dining Staff Training, Ozaukee County Bureau on Aging and Disability Resources, November 2007

Determining the Validity for a Psychophysical Approach to Grip Measurement, Wisconsin Occupational Therapy Association Annual Conference, October 2001

Determining the Validity for a Psychophysical Approach to Grip Measurement, Deans Research Day, University of Wisconsin-Milwaukee, March 2001

ARTICLES

King, P. M. & Finet, M. (2004). Determining the accuracy of the psychophysical approach to grip force measurement. *Journal of Hand Therapy*, 100 (1), 1-5.

TEACHING ACTIVITY

A.T. Stills University – Arizona, Occupational Therapy Program, Masters and OTD

- OT 542, *Introduction to Testing in Occupational Therapy* (Spring 2016)
- OT 544, *Ethics and Professionalism* (Summer 2016)
- OT 545, *Occupational Analysis I* (Spring 2016)
- OT 612, *Research Directed Study* (Summer 2016-Fall 2016)
- OT 614, *Pediatric Occupational Therapy I* (Fall 2016)
- OT 624, *Pediatric Occupational Therapy II* (Winter 2016)
- OT 625, *Occupational Analysis III* (Winter 2016)
- OT 635, *Practice Management in Occupational Therapy* (Summer 2016)
- OTDE 6210, *Foundations I: History & Philosophy of Occupational Therapy* (Fall 2016)
- OTDE 6220, *Foundations II: Occupation Based Activity Analysis & Synthesis* (Fall 2016)
- OTDE 6310, *Fundamentals of Service Provision Across the Continuum of Care* (Fall 2016)

University of Wisconsin – Milwaukee, Occupational Therapy Program

- OCCTHPY 315, *Group Process in Rehabilitation* (Spring 2007)
- OCCTHPY 322, *Program Development in Rehabilitation* (Summer 2007; Summer 2008)
- OCCTHPY 323, *Program Management* (Fall 2010; Fall 2011)
- OCCTHPY 329, *Occupational Therapy with Older Adults* (Spring 2007)
- OCCTHPY 330, *Foundations of Professional Practice in OT* (Fall 2007)
- OCCTHPY 341, *Evidence for Practice II* (Summer 2008; Summer 2009, Summer 2010; Summer 2011)
- OCCTHPY 350, *Professional Development Seminar I* (Fall 2007; Fall 2008; Fall 2011)
- OCCTHPY 360, *Enhancing Health Through Activity, Occupation & Technology II* (Spring 2007, Spring 2008)
- OCCTHPY 390, *Professional Development Seminar II* (Spring 2008; Spring 2009)
- OCCTHPY 401, *Overview of Medical Conditions* (Fall 2007)
- OCCTHPY 460, *Professional Development Seminar III* (Fall 2008; Fall 2009; Fall 2011)
- OCCTHPY 541, *Evidence for Practice III* (Spring 2011)
- OCCTHPY 590, *Professional Development Seminar IV* (Spring 2009; Spring 2010)
- OCCTHPY 610, *Occupational Science* (Spring 2010; Spring 2011); course was a hybrid (approx 50% online)
- OCCTHPY 720, *Advanced Occupational Therapy Theory* (Summer 2007; Fall 2008, Fall 2009, Fall 2010; Fall 2011); course was a hybrid (more than 50% online) for Fall 2008, 2009, 2010 & 2011

Guest Lectures

- University of Wisconsin-Milwaukee, OCCTHPY 360, *Enhancing Health Through Activity, Occupation & Technology II*, The Health Professional as an Educator: Patient Education in Rehabilitation, October 21, 2011
- University of Wisconsin-Milwaukee, OCCTHPY 323, *Program Management*, Leadership: The Style Approach, November 20, 2008
- University of Wisconsin-Milwaukee, OCCTHPY 330, *Foundations of Professional Practice in OT*, Health Insurance Portability and Accountability Act of 1996, October 21, 2008
- University of Wisconsin-Milwaukee, OCCTHPY 329, *Occupational Therapy with Older Adults*, Universal Design, March 25, 2008
- University of Wisconsin-Milwaukee, OCCTHPY 280, *Applied Human Anatomy for Health Professions*, Spine and Thorax, September 10, 2007

ADVISING ACTIVITY

A.T. Stills University – Arizona, Occupational Therapy Program, Masters and OTD

- Served as major advisor for 13 Masters and 2 OTD students between Spring '16-Fall '16
- Served as major advisor for Student Occupational Therapy Association for Occupational Therapy program students, Spring '16-Present

University of Wisconsin – Milwaukee, Occupational Therapy Program

- Served as major advisor for Pi Theta Epsilon, student honor society for Occupational Therapy program students, Fall '08-Fall '11
- Served on committees for thesis students Summer '07-Summer '10
- Served as major advisor for 8 comprehensive exam students Summer '08-Summer '09
- Served as major advisor for 11 comprehensive exam students Summer '09-Summer '10
- Served as major advisor for 10 comprehensive exam students Summer '10-Summer '11

SERVICE ACTIVITY

A.T. Stills University – Arizona, Occupational Therapy Program, Masters and OTD

- Serving as President-Elect of Faculty Assembly, Oct. '16-Sept. '18
- Served on OT Program Advising Task Group, Fall '16
- Served as Judge for Inter-Professional Education Case Study Competition, Nov. '16

University of Wisconsin – Milwaukee, Occupational Therapy Program

- Served on College of Health Sciences Alumni Board as Vice President of Social Engagement, Fall '11- May '12
- Served on College of Health Sciences Faculty and Student Affairs Committee, Fall '08-Spring '11; served as Chair of this committee from Fall '10-Spring '11
- Served as Chair of Admissions Committee for OST Department, Fall '09-Fall '11
- Served as Chair of Undergraduate Curriculum Committee for OST Department, Fall '10-Spring '11
- Served on Research Committee for OT Department, Fall '08-Spring '11
- Served on Search & Screen Committee for OT Department Faculty Position, Fall '07-Spring '10
- Served as Chair of Curriculum Committee for OT Department, Summer '08-Summer '09
- Served on Marketing Committee for OT Department, Fall '07-Spring '08
- Attendance at Interdisciplinary & Innovative Instruction Committee for CHS, Fall '07

COMMUNITY SERVICE

- Rebuilding Together Volunteer, Milwaukee, Wisconsin, 2009
- Habitat for Humanity Volunteer, Phoenix, Arizona, 2006, 2016

PROFESSIONAL AFFILIATIONS

- American Occupational Therapy Association, current member
- Arizona Occupational Therapy Association, current member
- Wisconsin Occupational Therapy Association, former member

LICENSES

NBCOT	Oct. '01 – Mar. '09
AZ State OT License	Mar. '02 – Mar. '08, Mar. '14 – Mar. '18
WI State OT License	Nov. '01 – Nov. '03

CERTIFICATIONS

Protective Response Regimen Provider	Earned Feb. '02
Therapeutic Listening Provider	Earned Jan. '04
Certificate in Online and Blended Teaching	Earned from University of WI – Milwaukee in Sep. '10

ACTIVITIES AND INTERESTS

- *Taekwondo* – earned first degree black belt in July 2005
- *Scuba diving* – earned Advanced Open Water Diver License in July 2004 and have safely completed over 50 dives
- *Rescuing animals* – have four rescue dogs at home and have had many over the years

REFERENCES AVAILABLE UPON REQUEST