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Occupational Therapist-Led Parent Support Group Using an Occupational Therapy Approach

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Occupational Therapist-Led Parent Support Group Using an Occupational Therapy Approach

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

Sean Brim
2019

EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

Certification

We hereby certify that this Capstone project, submitted by Sean Brim, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

This project, written by Sean Brim under direction of Dr. Leslie J. Hardman, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

CAPSTONE COMMITTEE

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Date

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12-16-19
Date

Committee Member

Executive Summary

Background: Intervention research aimed at reducing stress levels of parents of children with disabilities is limited.

Purpose: The purpose of this study was to introduce an occupational therapy led pilot support group for parents who have a child with a disability and improve parent's abilities to manage stress levels.

Theoretical Framework. The Model of Human Occupation (MOHO), guided this study.

Methods. This quantitative study utilized the Parental Stress Scale (PSS) to assess parental stress at baseline and upon completion of the four support group sessions. There were six participants in the support group meeting the inclusion criteria. The objective of this non-blinded study was to reduce stress for parents who have a child with a disability using a support group incorporating an occupational therapy approach. Parents committed to attending a minimum of three out of four sessions.

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Results. 5 out of the 6 participants had a decrease in their individual score as per the PSS from pre-to-post-test. The results of the t-test comparing mean for total participants pre and post scores resulted in a p-value = 0.014

Conclusions: The results of this pilot study demonstrate that participation in the four support group sessions effectively reduced self–reported stress as measured by the PSS These findings suggest that utilizing meaningful and engaging activities, peer support groups led by an occupational therapist, can lead to reductions in perceived stress among parents who have a child with a disability. Importantly, by incorporating an occupational therapy approach parent can develop stress management skills that can potentially aid them in establishing greater occupational balance.

Acknowledgements

I would like to express my deep gratitude to Dr. Leslie J. Hardman, research mentor, for her patience and guidance, enthusiastic encouragement and useful critiques of this research work. Dr. Hardman was able to shape my whole thought process during this capstone experience. My idea was huge, and she was able to assist me with being more focused. I would also like to thank Dr. Spira for her advice and time spent giving me suggestions during my capstone journey. My grateful thanks are also extended to the Noel Writing Center at Eastern Kentucky University for critiquing my manuscript. Thanks to Dr. Carol Lambden, Dr. Amy Paul-Ward, and Katherine Perdomo who provided me with many suggestions on how to improve this manuscript.

I would also like to extend my thanks to the participants that were willing to participate in this study. It took a lot of time out of their busy schedules to devote four Fridays in a row for a support group. I am appreciative of the time they spent during those sessions.

Finally, I wish to thank my fiancé, Christina Perez for all her encouragement, love, and firmness during this process. Without Christina being so understanding it would have been an even more challenging process. Additionally, I would like to thank my parents and sister for their support and encouragement throughout my study.

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CERTIFICATION OF AUTHORSHIP

Submitted to (Faculty Mentor's Name): Dr. Leslie J. Hardman
Student's Name: Sean Brim
Title of Submission: Occupational Therapist-Led Parent Support Group Using Occupational Therapy Approach

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

Student's Signature: __________

Date of Submission: 1/31/2020

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Section One: Nature of Project and Problem Identification

There has been a rise in childhood disabilities across the world (Kogan et al., 2009; Houtrow et al., 2014). Autism spectrum disorder (ASD) and other childhood disabilities can be one of the most demanding challenges for families because these children often require around the clock parental support (Bitsika, Sharpley, Andronicos, & Agnew, 2017). There has been research examining the epidemiology of various pediatric disabilities and as well as best practices to improve the lives of children living with these disabilities (Elder, Figlio, Imberman, & Persico, 2019; Newschaffer et al., 2007). Research has shown parents who have a child with a disability experience more significant stress and present with more depressive symptomatology than parents of typically developing children (Pottie & Ingram, 2008). In combination with increased stress levels, parents of children with disabilities have also reported a lower quality of life, decreased marital satisfaction, and poorer mental health (Bitiska et al., 2017; Houtrow et al., 2014). There is limited research exploring effective stress reducing interventions for assisting these parents.

Relevant to the project reported below, there are gaps in the literature regarding programs and resources in the community to help parents who have a child with disabilities cope with high-stress levels and assist them with improving their overall quality of life. One of the strengths of occupational therapy is its client-centered approach. A client-centered approach includes empowerment and guiding of the client to achieve a solution by means of a balance of power between the therapist and patient (Maitra & Erway, 2006). The focal points of intervention that are used during this approach are an individual's volition and habituation, concepts that are utilized in the Model of Human Occupation (Maitra & Erway, 2006). Rouse and Hitch (2014) support the concept that occupational therapy can be beneficial in group settings involving individuals who are suffering from a wide variety of diagnoses; however, there is limited empirical evidence on using an occupational therapy approach with parents who have a child with a disability. Therefore, due to the limited literature involving an occupational therapy-led support group, this study aimed to provide additional literature in this area. This innovative study utilized an occupational therapy-led parent support group, drawing on relevant occupational therapy frameworks to reduce perceived stress levels in parents who have a child with a disability.

Problem Statement

- There is limited research on parent support groups for parents with children who have a disability.
- There are limited parent support groups in Miami Dade County for parents with children who have a disability.
- There is limited research on occupational therapist-led support groups for parents with children who have a disability.

Purpose Statement

The purpose of this study was to introduce an occupational therapist-led pilot support group for parents who have a child with a disability and improve parents' abilities to manage stress levels.

Project Objectives

As a result of participating in a support group for parents that have a child living with a disability, participants will perceive reduced stress after attending a minimum of three out of four occupation-based support group sessions.

Theoretical Framework

The Model of Human Occupation (MOHO), guided this study. MOHO explains how the occupation is motivated, patterned, and performed (Taylor, 2017). MOHO theorizes individuals are driven by three interrelated components: 1) volition, 2) habituation, and 3) performance capacity (Taylor, 2017). Volition is an individual's motivation and values for occupation (Taylor, 2017). Habituation refers to the development of how the occupation is prepared into patterns or routines (Taylor, 2017). Performance capacity examines an individual's physical, mental and communication abilities and how they impact the occupational performance of the individual (Taylor, 2017). MOHO also takes into account the relationship between an individual's occupation and their physical and social environments. Parents might have the volition to develop healthier ways to improve their mental health; however, their children and lifestyle may not allow them to make these changes (Pottie & Ingram, 2008). Maladaptive daily routines, habits, and schedules may affect these families' abilities to access opportunities that would improve their overall mental health (Pottie & Ingram, 2008).

Utilizing MOHO as a framework can guide researchers to build strong rapport and begin the process of family-centered care with the participants. As seen in the O'Brien et al. (2009) study involving parents who have a child living with a disability, the MOHO framework allowed researchers to establish a strong rapport with parents. The MOHO framework was used as a guide, leading the investigator to understand the barriers parents who have a child living with a disability may face in their day-to-day lives. Parents report having limited time, financial barriers, lack of freedom, and stress as barriers that become challenging to maintain their values and desires (Resch et al., 2010). Ultimately, the overwhelming responsibilities of caring for a child with a disability may affect the parents' personal causation, values, hobbies, and roles.

Volition may also be affected if parents do not feel competent to care for a child with a disability (Wimpenny, Forsyth, Jones, Matheson, & Colley, 2010). Importantly, this may also affect their motivation (Wimpenny, Forsyth, Jones, Matheson, & Colley, 2010).

The feelings of incompetence and frustration some parents experience may make managing daily activities difficult, mainly when they are unable to control the situations with their children; thus, affecting their personal causation (Wimpenny et al., 2010). Improving parents' ability to effectively resolve challenging situations involving their children, may potentially assist them with their perceived personal causation.

Another frustration for these parents is having limited free time for leisure activities. Many parents are required to travel to therapy and doctor appointments for their child, consequently disregarding their own needs (Pottie & Ingram, 2008). Improving parents' performance capacities may assist them in managing the daily stresses of having a child with a disability (Pottie & Ingram, 2008). Education and reflection could allow parents to understand stressors, therefore, potentially identifying when they may perceive stress. Improved performance capacity for handling stressors could potentially assist them in recognizing stressful situations and assist them in utilizing stress management techniques to resolve any issues.

This study addressed all three components of MOHO during the sessions: 1) volition, 2) habituation, and 3) performance capacity (Taylor, 2017). The support group could have potentially increased the volition of the parents by creating an atmosphere in which they could freely speak, discuss, and share common concerns. Having a safe environment may have potentially increased the volition of parents to share feelings. During the three components of the support group, parents received suggestions about developing healthier routines and habits while at home. To address relevant aspects of routines, each parent received education on stress, physical techniques to reduce stress, time management, and organizational skills. In addition to the aspects mentioned above, some real-life scenarios were examined, by role-playing to improve the stress levels of these parents.

The MOHO framework was utilized to guide the study and allow the lead investigator to understand the participants from their comments and discussions. By understanding each participant's perspective in this study, it allowed us to understand their habituation which is comprised of habits and roles. Often habits and roles are resistant to change (Wimpenny et al., 2010). In order for habits to develop, actions must be repeated to be able to establish a pattern and there must be consistency in the environment (Wimpenny et al., 2010). Parents who want to reduce their stress may benefit from an environment that offers them more consistency. An occupational therapy-led parent support group could potentially provide parents a more comfortable environment to allow them to identify healthier habits and routines thereby, potentially reducing their perceived stress levels.

Significance of the project

The Centers for Disease Control and Prevention (CDC) has shown in the past 10 years there continues to be a steady rise in children being diagnosed with ASD and various other disorders (Kogan et al., 2009; Centers for Disease Control, 2019) Over 24.1 million people have a severe disability (Brault, 2012). In the state of Florida, over 50,000 individuals are living with a disability who are registered with the Agency for Persons with Disabilities (APD) (Brault, 2012). Lyons, Leon, Phelps, and Dunleavy (2010) have shown a correlation that many families of children with disabilities face higher than normal stress levels.

Based on a review of existing services in Miami-Dade County, only two support groups for parents who have a child living with a disability were identified. There might have been more support groups; however, at the time of research, there was no central database to locate these support groups. One of these support groups was facilitated by the Parent to Parent Community Parent Resource Center. This organization provides services to parents of children with disabilities in Miami-Dade and Monroe County. Parent to Parent assists parents with advocacy, attaining proper documents, and finding resources (Parent to Parent Miami, 2019). The other support group identified in the search by this lead investigator was coordinated by Miami-Dade and Monroe Counties' Family Friendly Hands, which advocates for children and adults with special needs (King et al., 2012; Miami Family Friendly Hands, 2018).

Even though Miami-Dade County is home to 2.752 million population, it contained a limited number of support groups for parents who have a child living with a disability at the time of this research (Brault, 2012). Additionally, both of these resources did not have occupational therapists leading their support groups. Therefore, this study could potentially offer a new approach by having an occupational therapist lead the support group. This new approach offered an opportunity for parents to share personal experiences, feelings, coping strategies, and firsthand information regarding having a child with a disability. As a result of this study it could possibly create a positive outcome for participants and their families. If in the end parents find the support group beneficial the continuation could service as another resource for parents in the Miami-Dade County community.

Section Two: Literature Review

Parents who have a child living with a disability tend to report higher levels of stress than parents of typically developing children do (Mawdsley, & Hause, 2015). Mothers of children with a developmental disability report having higher stress levels and more negative child characteristics than mothers of children without disabilities (Mawdsley, & Hause, 2015). In particular, mothers of children living with autism have shown higher stress and lower levels of parenting competency (Woodman, Mawdsley, & Hauser, 2015). Woodman, Mawdsley, & Hause (2015) discovered that the levels of stress experienced by the parents of a child with a developmental disability should be considered when providing services to their child. If stress continues it can develop into chronic stress. Chronic stress can lead to many health-related conditions. Stress could potentially lead to a mental health disorder, which could cause communicable and non-communicable diseases, as well as unintentional and intentional injury (Craig et al., 2016; Prince et al., 2007).

Stress Factors

Parental stress is often related to the severity of a child’s diagnosis. Bitsika et al. (2017) found the severity of a child's diagnosis was linked to parents’ stress levels. Bitsika et al. (2017) determined that a possible link existed between the frequency of self-injurious behaviors in children with a developmental disability and stress felt by their parents. This link could potentially cause acute and chronic bouts of stress for parents who have a child living with a disability. Additionally, parents who have a child with a disability may not receive the same type of social and emotional reinforcement compared to parents with a child who is typically developing. Parents who have a child living with a disability have faced challenges from society that may result in them feeling isolated (Rizk, Pizur, & Darragh, 2011). Parents expressed feeling isolated because of the lack of understanding society has about a child with autism or a disability and the amount of time that is spent caring for the child (Woodgate, Ateah, & Secco, 2008). This leads to many of the parents feeling stress due to society not understanding what they are going through (Woodgate, Ateah, & Secco, 2008). Parents who have a child living with a disability reported feeling that society placed less value on the lives of their children, which contributed to them experiencing stress related to being isolated from a "normal" way of life (Woodgate, Ateah, & Secco, 2008). Society may become uncomfortable around a child who has a disability, thus exasperating further isolation (Rizk, Pizur, & Darragh, 2011).

Furthermore, due to their child’s diagnosis, parents who have a child living with a disability may feel they are unable to meet other parents who are in a similar situation. Additionally, the costs associated with paying for medical expenses and rehabilitative services for their child may result in the parents not being able to participate in their desired leisure activities. This inability to participate in desired activities that they would normally engage in translates into perceived stress for parents who have a child living with a disability (Rizk, Pizur, & Darragh, 2011).

The severity of a child's disability can act as a stressor. In some instances, a child may be unable to communicate as a result of their disability (Myers, Mackintosh, & Goin-Kochel, 2009). In these situations, many parents may have challenges communicating with their child. These challenges to communicate may potentially increase perceived stress levels (Myers, Mackintosh, & Goin-Kochel, 2009). The severity of a child's diagnosis can affect the parent to child relationship in these familial units. Researchers have shown clinicians who interact with these families need to be sensitive to the needs of these parents and make sure to provide adequate social support to them. (Solomon, Pistrang, & Barker, 2001).

In addition, parents who have a child with a disability have more stressors than just communication challenges. Resch et al. (2010) found parents identified four areas in which they perceived stress: (a) obtaining access to information and resources, (b) financial barriers to obtaining services, (c) school and community inclusion, and (d) family support. Resch et al. (2010) found parents wanted accurate, timely information and resources upon learning that their child has a disability. These researchers found many parents believed the process of finding information and resources to meet their child's needs was an ongoing process, which was complicated by the service system (Resch et al., 2010).

Additionally, parents who have a child with a disability also reported that extended family contributed to added stress (Resch et al., 2010). Extended family members, such as grandparents, aunts, and uncles, would handle situations differently than the child’s parents, which resulted in problem behaviors in their child. These problem behaviors would oftentimes lead to increased stress. Parents experienced feelings of being isolated from their extended family members due these members having a lack of understanding about what challenges they faced (Woodgate, Ateah, & Secco, 2008). Moreover, other causes of stress linked to extended family members involved these members not providing practical support and assistance.

Physical Health

Cantwell, Muldoon, and Gallager (2014) examined the psychosocial aspects of poor health in those parents caring for a child with a disability. These researchers used a cross-sectional study of two groups: parents of children living with a disability and non-parents of children living with a disability. Cantwell et al. (2014) indicated concerns for those parents who had a child with a disability because they had high-stress levels linked to poor mental health.

Their findings showed that stress and mastery were linked to physical health (Cantwell et al., 2014). The researchers described mastery as the belief that one has control over life's obstacles. Cantwell et al. (2014) found parents of children with a disability reported higher perceived stress, lower mastery, less social support, and more physical health problems than the parents in the control group. In addition to the previous findings, Cantwell et al. (2014) found a correlation between perceived stress and poor physical health.

Research has also shown that inadequate coping mechanisms impact the stress levels of parents whose child is living with a disability. Dabrowska and Pisula's (2010) study found that parents used different styles of coping mechanisms dependent on their child's diagnosis. The findings determined there is a direct linkage between the coping styles of parents and the amount of stress these parents can endure (Dabrowska, & Pisula, 2010). They identified three different styles of coping: Task-oriented, emotion-oriented coping, and escape avoidance. Dabrowska and Pisula's (2010) study found parents using emotion-oriented coping demonstrated a higher level of stress compared to the other two. The results of this study partly confirmed earlier reports pointing to the negative correlation between emotion-oriented coping and escape-avoidance. If parents poorly cope with stress throughout their day-to-day lives it could lead to many health-related issues.

Parents who have a child living with a disability have been found to have poorer physical health in comparison to parents who have a typically developing child (Cantwell, Muldoon, & Gallagher, 2014). This could be due to parents having limited time to take care of their own health needs. As a result of chronic stress, these individuals could be experiencing high corticosteroid levels, which is linked with impaired memory, concentration, and learning (Cantwell, Muldoon, & Gallagher, 2014). Additionally, chronic stress can potentially lead to poor physical health (Cantwell, Muldoon, & Gallagher, 2014). Therefore, this study included a physical activity to address this concern.

Perciavalle et al. (2017) found the use of diaphragmatic breathing can reduce the stress felt by people in their daily lives. Diaphragmatic breathing has also been shown to counteract the fight-or-flight response symptoms that are often associated with stress. When parents perceive a challenge or have low self-confidence from previous experiences, they may experience symptoms associated with the fight-or-flight response. These symptoms may include increased heartrate, respiration, blood pressure, muscle tension, and gastric discomfort (Fotiou et al., 2016). Meditation can be used to counteract stressful situations because it increases concentration and awareness, both of which produce a calming effect (Fotiou et al., 2016). The central piece of mediation is diaphragmatic breathing (Fotiou et al., 2016). Due to deep breathing being helpful in stress management, it was incorporated into this study. Although deep breathing may be an effective component to reducing stress, support groups are also effective at reducing stress in parents who have a child living with a disability (Law, King, Stewart, & King, 2002).

Effectiveness of Support Groups

One research group explored parents' perceptions about the effectiveness of parent-led support groups that focused on improving parents' abilities to deal with the disabilities of their children (Law et al., 2002). This particular study included four sessions (Law et al., 2002). Twenty parents were interviewed to determine the benefits and limitations of their participation in the group (Law et al., 2002). The study concluded these parents perceived more essential skills, power, and a sense of belonging to a group after attending the sessions. Furthermore, the results of the study showed parents belonging to a support group could feel more significant emotional support through meeting with others who face similar issues (Law et al., 2002). The improved sense of power and belonging felt by these parents could potentially reduce overall stress and improve mental health (Law et al., 2002). Another study that looked at parents who have a child with a disability showed that the use of a peer-to-peer intervention could improve the overall quality of life of these parents (Peterson et al., 2008). This study also concluded that this type of intervention motivated the parents (Peterson et al., 2008). Peterson et al. (2008) stated that peer-to-peer interventions using a problem-based method could be useful and an inexpensive tool for alleviating stress and burnout. Additionally, Peterson et al. (2008) determined it was sufficient only to have five to eight participants to ensure each participant was heard.

One study has shown parents who have a child with a disability and experience high-stress levels want to attend therapy support groups for themselves (Duppong, January, & Lambert 2017). Duppong, January, & Lambert (2017) evaluated 52 parents and examined caregiver strain to determine if that would predict participation in a phone-based peer-to-peer support intervention. This study revealed 23 of the families that were considered highly strained parents participated in 50% more of the group therapy interventions in comparison to the parents with less stress. Duppong et al. (2017) had parents attend five sessions. Regarding future research, this literature indicated that using mental health professionals to lead support groups would be even more significant than peer-to-peer support groups (Duppong et al., 2017).

The type of professional that can be a facilitator for a parent support group could be an occupational therapist who is skilled with working with individuals in a group or one-on-one setting (American Occupational Therapy Association [AOTA], 2008). Occupational therapy utilizes MOHO as a guide to understanding an individual’s behaviors. Through behaviors, an individual creates an identity, accepts various concepts, and builds motor ability (Wimpenny et al., 2010). Utilizing occupational therapy can potentially alter an individual's thought process, which could engage this individual in a new behavior. In this study, occupational-based activities were performed to give parents an opportunity to learn new skills. By engaging in new behaviors, an individual can begin to reshape themselves (Wimpenny et al., 2010). This reshaping will alter their occupational identity (Wimpenny et al., 2010). Through consistent practice, an individual can progress to the level of mastery, therefore creating occupational competence (Wimpenny et al., 2010). During this capstone as mentioned in the methods section, parents were encouraged to practice their newly learned skills throughout the week. By continuously reshaping and refining both occupational identity and occupational competence can result in an individual increasing their occupationally adaptiveness (Wimpenny et al., 2010).

Although parents who have a child living with a disability express interest in support groups, Baker, Arnold, and Meagher (2011) found parent-led support groups experienced in poor attendance rates. The parents of this study reported a preference for the support aspect of the group instead of the educational aspect; the parents enjoyed being able to meet other parents and share their feelings. Although parents reported they would attend the support group, only 30% of the parents attended (Clifford & Minnes, 2013). Many of the factors leading to not attending the group were due to a lack of childcare, poor subject choice, and scheduling (Clifford & Minnes, 2013). Therefore, when creating a support group, it has been beneficial to examine subject choice and scheduling.

Many child-care professionals and health care workers are not referring parents who have a child with a disability in the direction of local parental resources, even though they may be significantly stressed (Clifford & Minnes, 2013). To assist these families, Mullins, Aniol, Boyd, Page, and Chaney (2002) had parents admitted to a week-long respite care facility. The focus of this study was to see if a week-long respite care facility could potentially reduce parents' perceived stressed levels. After receiving treatment, these parents reported reduced stress levels (Mullins et al., 2002). Because parental stress and childhood development are oftentimes linked, Mullins et al. (2002) concluded these findings could make a remarkable impact on a child's progress and development. Unfortunately, high-stress levels in these parents returned after several weeks of being back with their families. Mullins et al., (2002) indicated future research should examine the effect of ongoing respite opportunities to enhance the benefits of stress reduction. The study carried out by Mullins et al. had its subjects complete one week of respite care (2002).

Not all support groups follow the same type of intervention. Hoagwood et al. (2010) have shown differences and similarities between professional and family-led groups. In regard to the similarities, parents have reported that both types of groups provided them with needed information about mental illness and its treatment options and improved their overall mental health (Hoagwood et al., 2010). Professional-led groups placed a greater emphasis on the problems that their members experienced and methods that they could use to cope with their emotions (Hanna & Rodger, 2002). In contrast, family-led groups placed a greater emphasis on advocacy. Although there has been research to substantiate the effectiveness of parent support groups, many organizations in communities have not provided such services (Hanna & Rodger, 2002).

Support groups can influence how individuals structure their routines. Yolam and Leszcz (2005) found support groups can increase structure and routine for most individuals. These support groups can facilitate engagement in purposeful activities that allow individuals to explore and develop strengths and opportunities that can build social skills, confidence, and social connections (Yolam & Leszcz, 2005). Parents living with a child who has a disability have demonstrated improvements from parent-led support groups; however, researchers have indicated future research should examine the effects that a mental health professional has on these groups (Yolam & Leszcz, 2005). Yolam and Leszcz (2005) stated that support groups typically include approximately 10 to 15 individuals. During sessions, parents can share their personal experiences, offer emotional comfort, and provide moral support. Although occupational therapy services have shown successful results in support groups, there has been limited empirical evidence utilizing these services with parents who have a child living with a disability (Duppong, January, & Lambert 2017).

Occupational therapy services. The field of occupational therapy utilizes various interventions to enable individuals to engage in occupations and participate in their daily lives (Maitra & Erway, 2006). Occupational therapy services develop client-centered interventions to increase client satisfaction and support clients in becoming active members of their decision making (Maitra & Erway, 2006). Occupational therapy strives to be a family-centered profession that includes both the parents and children within the intervention (Hanna & Rodger, 2002). The process of family-centered practice is based upon the collaboration between parents and therapists during the decision-making in program planning.

Additionally, during occupational therapy services involving a child who is living a with disability, the parent is also an important aspect of the therapeutic process (Hanna & Rodger, 2002). This therapeutic process of involving the whole family is the premise of family-centered care. The parent-therapist partnership works on how therapeutic services are delivered and the evaluation process, which are more relevant and meaningful to both the child and family. The occupational therapist is the facilitator by providing therapeutic strategies for the parent to utilize with their child, which optimizes the best outcome (Edwards, Millard, Praskac, & Wisniewski, 2003). Additionally, the occupational therapist must be able to recognize the needs, strengths and weaknesses of their clients. Therapists are, therefore, challenged to strive for equality in collaboration when designing a treatment plan with the understanding that the child's individual needs are of the utmost importance (DeGrace, 2003). To assist during the client-centered treatment process, the occupational therapist understands that a parent plays an essential role in family-centered care and the intervention process (DeGrace, 2003). During family-centered care, occupational therapists are promoting empowering families (DeGrace, 2003). Additionally, an occupational therapist also facilitates growth-producing behaviors rather than treating problems. Furthermore, during family-centered care, occupational therapists enable development upon family capabilities (DeGrace, 2003). However, when parents are stressed, this may affect their ability to parent (Hanna & Rodger, 2002). This could lead to caregiver burnout, which can occur when a person is under a long period of stress. This can consequently threaten or stop an individual from his or her performance role that is central to the person's identity. Caregiver burnout can lead to many illnesses and fatigue; therefore, if a parent attempts to complete a home activity given to them by the therapist, they may not be able to complete it because they are suffering from caregiver burnout from chronic stress. There is limited evidence for the effectiveness of education interventions aimed at reducing burnout levels in this population (Bilgin & Gozum, 2009).

An occupational therapist is equipped to assist these parents with caregiver burnout during support group sessions. Occupational therapists are educated to provide services that support mental and physical health (American Occupational Therapy Association [AOTA], 2012). Many occupational therapists work in the field of early-intervention services within the mental health sector, using a variety of interventions and tools (AOTA, 2012). Occupational therapy interventions for stress can primarily train clients to learn new skills for managing stress or eliminating the things from their lives that cause them stress. Through stress management, relaxation, and sensory processing–related techniques (American Occupational Therapy Association [AOTA], 2014). A potential intervention technique used by occupational therapists is role-playing. An individual can gain a sense during role playing that an approach to a situation is effective. Additionally, being able to role-play can give an individual the experience and confidence necessary for handling certain real-life situations (Forgatch, Bullock, Patterson, & Steiner, 2004). During a real-life situation, the individual will be able to address the situation with correct reactions rather than maladaptive techniques.

An occupational therapist's focus is on replacing individuals' unhealthy activities, such as maladaptive patterns of coping with stress, with healthy, meaningful activities. This process can be achieved by relaxation therapy, motivational interviewing, and mediation (Bassett & Lloyd, 2001). More importantly, an occupational therapist is knowledgeable about organizing daily activities in a way to assist individuals with developing an occupational balance. Occupational therapy strives to assist individuals with attaining a balance of sleep, play, work, and rest. Adolf Meyer, the founder of occupational therapy, believed occupational therapy rests on the belief that there is an essential balance necessary for healthy living that relies on these elements (Christiansen & Matuska, 2006). Occupation is a means by which balance is achieved. Engagement in a desired occupation leads to the attainment of a physical and mental well-being. The importance of a healthy, balanced lifestyle in developed nations is advocated regularly. However, it has been found the demands of modern living and the process of raising a child who has a disability makes it difficult for parents to have a healthy balanced lifestyle. Researchers have shown an individual's daily patterns of occupations that are chosen by an individual may create a balance or an imbalance that could influence an individual's state of mind (Christiansen & Matuska, 2006). These services could potentially be beneficial because parents who have a child living with a disability suffer from high-stress levels and a poor balance amongst the four areas of sleep, play, work, and rest. Therefore, utilizing MOHO to guide this study the lead investigator was able to examine each parent’s four areas of occupational balance along with the parent’s values, hobbies, and roles to determine if there were any imbalances in their day-to-day lives.

Parental Stress Scale

The Parental Stress Scale (PSS) was utilized for this study to determine the perceived stress levels of parents who have a child living with a disability. PSS is a reliable and valid method of measuring perceived stress for adults. Zelman & Ferro (2018) performed a series of studies during the development of the PSS, which indicated it has acceptable psychometric properties. During these studies, it indicated a strong internal consistency (α =.83). In addition, it had a good 6-week test-retest reliability (r =.81) and a convergent validity (r =.41) (Zelman & Ferro, 2018). The PSS also demonstrated effectiveness at testing for parental stress, such as the areas of anxiety, loneliness, marital satisfaction, and social support (Zelman & Ferro, 2018).

Limited Resources

In Miami-Dade County, approximately 26% percent of adults and children are living with a disability. This percentage is significantly higher than the national average (Statistical Atlas, 2017). In Miami-Dade, there is a total of 2.7 million residents (Statistical Atlas, 2017). Even though Miami-Dade County contains a sizable population, there are only two support group organizations, and neither of these are facilitated by an occupational therapist (Statistical Atlas, 2017). There is no apparent central database for parent support groups, which makes the process of identifying them challenging. As previously discussed in this paper, one of these organizations is called Parent to Parent. Parent to Parent is a community parent resource center that serves the parents of children with disabilities in both Miami-Dade and Monroe County. Parent to Parent assists parents with building advocacy skills, attaining proper documents, and finding resources. The other of these two organizations is called Miami-Dade and Monroe Counties' Family Friendly Hands. This organization advocates for children and adults with special needs. Neither of these are using an occupational therapy-based approach. Therefore, creating a parent support group in such a large metropolitan area is a novel opportunity to assist these parents in handling their day-to-day stressors of raising a child with a disability

Section Three: Methods

Project Design

This study used a quantitative approach utilizing the Parental Stress Scale (PSS) to collect pre-and-post-test data. The support group contained a total of six participants, all of whom met the inclusion criteria. The objective of this non-blinded study was to reduce the stress of parents who have a child living with a disability through the use of a support group encompassing an occupational therapy approach. Parents committed to attending a minimum of three out of four sessions. The sessions lasted for 90 minutes and consisted of three components: 1) group discussion; 2) occupational-based intervention, and 3) a physical activity. The occupation-based intervention topics were determined based on the needs of the participants.

Setting

This capstone study took in place Kendall, Florida, a Miami-Dade County suburb. A rehabilitation company in Kendall that has three small private outpatient clinics was the host of the support group. The owners provided written permission to the lead investigator to utilize their outpatient clinic after business hours (see Appendix A for written permission). This environment was ideally suited for the hosting of a support group because it supported privacy and a comfortable meeting atmosphere for parents, which encouraged them to openly share their personal information.

Inclusion Criteria

- Parents who have a child living a disability between zero to 18 years old

- The child must have had a diagnosis under the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
- Parents or caretakers must have been over the age of 18 years old
- Participants agreed to and attended three out of the four project support group sessions
- Participants agreed to attend the first session
- Participants' primary language was English
- Participants must have had an active email address

Exclusion Criteria

- Unable to attend the scheduled project sessions
- English was not their primary language

Ethical Considerations

This study was approved by an Institutional Review Board (IRB) at Eastern Kentucky University (see Appendix B for IRB document). Participants expressed an interest to participate in this study after seeing fliers. Once participants informed the lead investigator of wanting to join the study, the lead investigator explained the study individually to each participant. Study objectives were reviewed, and parents verbalized their understanding. Parents were given the opportunity to ask questions to the lead investigator regarding this research study. Once parents felt comfortable about participating in the research study, they signed the informed consent forms. Participants stated they understood they could withdraw from the research study at any time. Participants also understood they were participating voluntarily. All data collected was stored in a locked cabinet at the location of the faculty advisor office, with only access by the faculty advisor and lead investigator. All information collected from assessments and surveys were de-identified with a code given to each participant by the lead investigator for privacy and confidentiality purposes. Following the study, all information collected from the assessments, and surveys were shredded.

Timeline of Project Procedures

Weeks 1-2

- Fliers disseminated for recruitment to the three clinics.
- Participants that were interested contacted the lead investigator via phone or email.

Weeks 3-4

- Lead investigator contacted each participant over the phone to determine eligibility for the study.
- Lead investigator contacted participants to inform them they were selected for the study
- Participants introduced to the study and signed informed consent forms.
- Lead investigator informed each participant of the support group's first meeting date in September 2019

Week 5

- Lead investigator organized the room for set up
- Initial PSS given to each participant via paper copy. The PSS was returned by each participant to the lead investigator when they were finished.

Week 6-9

- 1-4 support groups were held

Week 9

- Lead investigator administered the post PSS and exit survey at the end of the 4th session

Weeks 10-14

- Lead investigator analyzed the quantitative data collected

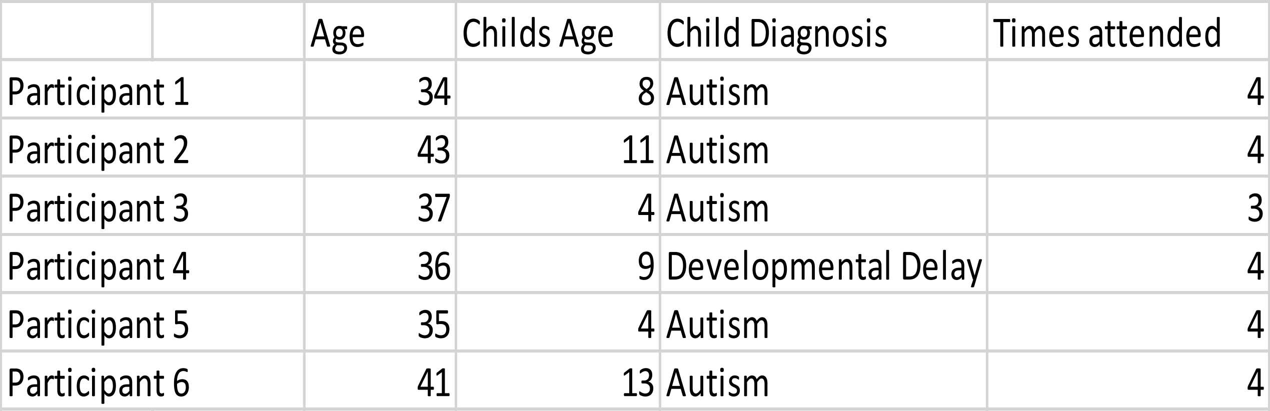
Week 15

- Written capstone was completed and reported on.

Participants

There was a total of six participants included in the study, six females. Participants varied in age. The average age of the participant's was 37 years old. Additionally, the median age of each participant's child living with a disability was eight years old. Five out of the six participants had a child diagnosed with Autism Spectrum Disorder (ASD). One of the parents had a child diagnosed with a developmental delay (see Table 1 for the breakdown of parental demographics).

Table 1: Participant Demographics



	Age	Childs Age	Child Diagnosis	Times attended
Participant 1	34	8	Autism	4
Participant 2	43	11	Autism	4
Participant 3	37	4	Autism	3
Participant 4	36	9	Developmental Delay	4
Participant 5	35	4	Autism	4
Participant 6	41	13	Autism	4

Outcome Measures Used

The study used the Parental Stress Scale (PSS) as the quantitative measurement for the evaluation process. The pre-PSS was administered to the parents before the first session and after the series of four sessions. Each parent was administered the post-PSS after attending a minimum of three support group sessions. The PSS measures 18 different items using a 5-point Likert scale, which examined the domains of parenting: stressors, rewards, loss of control, and satisfaction (Zelman & Ferro, 2018). The PSS addressed the parent's perception of stress, instead of the assessment of stressors. The quantitative data for this study consisted of these dependent variables and included the stress levels of parents determined by the PSS (Zelman & Ferro, 2018) (see Appendix C for the PSS).

Procedures

This quantitative study addressed whether an occupational therapy approach during a support group could reduce the perceived stress of parents who have a child living with a disability. A total of six participants were determined to meet the inclusion criteria. The support group met four times on four separate Friday nights. These support group sessions were 90 minutes long.

Each participant was given a copy of the pre-Parental Stress Scale (PSS) to complete prior to their start date. Participants were asked to fill out an initial intake form. The initial intake form asked participants to write a minimum of five challenges related to raising a child living with a disability that they faced in their day-to-day lives and their expectations related to participating in a pilot parent support group. At the end of the fourth session, parents completed the post-PSS.

The first group session with all six participants included a focus group component which discussed the needs of each participant moving forward with the group. This information was gathered to determine meaningful topics for the next four sessions. The lead investigator facilitated the focus group by providing examples of potential occupational-based interventions.

Furthermore, the lead investigator discussed the role of an occupational therapist. With the assistance of the lead investigator, the parents determined four topics for the occupation-based intervention. The four topics that were chosen for the occupation-based activities included addressing prioritizing, time management, how to handle stressful situations, and organization.

Following the initial focus group, the next 10 minutes were devoted to a warm-up activity involving group unity building. The warm-up activity had each parent spend time with another parent for eight minutes to learn about each other. Following that, the parents had to introduce the other parent to the group and share what they had learned about them. During the next 30 minutes, the group had a group discussion. The group discussion revolved around different stressors in each participant's life, how each person handles their stress and a discussion about each person's activity levels throughout the week. The lead investigator facilitated the group's discussion. The next component was the occupational based intervention, which consumed another 30 minutes of the session. The final component, physical activity, lasted for approximately 10 minutes. The remaining minutes of the group focused on the closing remarks.

Session 1

- Focus Group/Warm-up activity- 10 minutes
- Group Discussion- 30 minutes
- Occupational Based Intervention- 30 minutes (Eisenhower Matrix)
- Physical Activity - 10 minutes (Deep Breathing)
- Closing Remarks- 10 minutes
- Total of 90 minutes

Sessions 2-4

- Warm-up activity- 10 minutes
- Group Discussion- 30 minutes
- Occupational Based Intervention- 30 minutes
    - Session 2 Developing Occupation Based Balance
    - Session 3 Role Playing Routines
    - Session 4 Filling Out Agenda
- Physical Activity - 10 minutes (Deep Breathing)

- Closing Remarks/ 4th session PSS given- 10 minutes
- Total of 90 minutes

Group Discussion: - Each group discussion was 30 minutes long during sessions 1-4. The group was facilitated by the lead investigator, an occupational therapist. During the group discussions, parents could freely share thoughts, questions, and concerns with one another. The lead investigator attempted to create an environment for parents that gave them a sense of emotional support, an opportunity that helped them cope with their child's disability. The lead investigator facilitated the groups by asking open-ended questions which supported the parent's interaction with one another. Additionally, the group discussion offered each parent the ability to interact with other parents who share the same experiences and family stresses (Law, King, Stewart, & King, 2002). Each session, the lead investigator was able to address the previous week's occupation-based intervention to determine if parents had applied any suggestions or knowledge gained throughout the week.

Occupational-Based Intervention-Following the group discussion component of the support group, the occupational-based intervention continued for an additional 30 minutes. The occupational-based interventions objective was to facilitate group work and collaboration with one another. The information gathered during the initial focus group was used to develop the occupation-based intervention for the next three group sessions. The goal of the occupation-based intervention was to have participants engage in valued occupations in their group context. Participating in an occupation-based activity promoted satisfaction and capacity within the group and potentially reduced perceived stress. Each week, the interventions were designed to build off one another in a way that would potentially assist parents with developing an occupational balance. When developing the occupation-based activities MOHO was utilized to analyze the parent’s volition, habituation, and performance capacity. The four occupation-based interventions were 1) the Eisenhower matrix; 2) occupational balance; 3) role playing; and 4) organization.

The Eisenhower Matrix. Named after the 34th president of the United States, the Eisenhower matrix has been utilized in other populations as a tool to assist with stress and procrastination (Batra, 2017). This tool has also been referred to as the Urgent-Important Matrix because it can help individuals prioritize tasks by urgency and importance. It helps individuals prioritize tasks by having them sort out less urgent and unimportant daily activities that the person should be delegating to others or not doing at all. The matrix is divided into four different categories: important and urgent, important but not urgent, urgent, but not so important, neither urgent nor important. Underneath the first box, it states, "Do First." These are the daily activities that are the most important and, if not done, could have consequences. The next box is the "Schedule" quadrant, this box is for daily activities that are important but could be scheduled at another time. The third quadrant is for the daily activities that an individual can “Delegate” as they are less important but are still considered urgent. The fourth quadrant called the "Don't Do" quadrant, contains activities that should be removed from an individual's routine (Batra, 2017). During the focus group, each participant discussed the issues that they had with prioritizing their day-to-day lives. Each parent was asked to reflect upon their daily activities and fill out all four boxes on the sheet. The lead investigator asked each parent to find one or two activities throughout the week that they could potentially move to the "Delegate" or "Don't do" box (see Appendix D for the Eisenhower Matrix)

Occupational Balance. During the focus group, the parents discussed how they had minimal time to complete leisure activities throughout the week. The second occupation-based intervention had the parents analyze four areas of their lives: work, play, rest, and sleep. Therefore, during the session, parents were asked to fill out these four areas on the chart. Parents were asked to bullet point the different work they had to do throughout the week. Additionally, for the area of leisure, the lead investigator had parents write several leisure activities they enjoyed doing. For the area of rest, the lead investigator gave the parents an opportunity to write down when they could potentially rest throughout the week. For the area of sleep, the lead investigator had the parents write down how many hours of sleep they would want to receive each night. The lead investigator asked parents to analyze their Eisenhower matrix to determine which daily activities they could move to the “Delegate” or “Not do” quadrants so that they could complete one to two leisure activities during the next week.

Role Playing. Role-playing is widely used as a method in the field of education. The concept of role-playing allows an individual to explore how another person would likely respond to different situations. Role-playing scenarios have shown to be an effective means of teaching (Forgatch, Bullock, Patterson, & Steiner, 2004). During the focus group, parents discussed concerning situations, such as bathing, and meal-time, that they perceived as stressful. According to the parents, these activities were stressful because previous iterations of them led to their children having emotional outbursts. Each parent discussed wanting to learn new techniques to assist them during certain routines.

During the role-playing activity, each participant had about five to ten minutes to role-play. The lead investigator was the child during the scenario. Each participant selected a daily activity they found most stressful to them. Throughout the activity, the lead investigator was able to coach each parent by providing them with helpful suggestions such as how to handle a certain behavior, what do during certain situations, and how to grade up or down the activity for the parents.

Organization. Disorganization has been found to be one of the biggest problems reported by all the participants interfering with occupations such as health management, child-rearing, cleaning and maintaining the house, and financial management (Woodman, Mawdsley, & Hauser-Cram, 2015). During the focus group, parents discussed how they have many daily activities to complete throughout the week an ultimately ended up missing appointments because they forgot about them. Agendas have been found to be a tool for stress management because they help individuals place all their ideas and activities in one place (Varvogli, & Darviri, 2011).

Therefore, session four focused on having each parent fill out an agenda that was given to them by the lead investigator. Through utilizing an agenda, parents were able to write everything in one place. This provided parents the opportunity to clearly see what upcoming daily activities they had, when these activities were, and how these activities would be accomplished. Additionally, the lead investigator gave the parents instructions for utilizing the Eisenhower matrix and the occupational balance worksheet. The latter of these two might potentially reduce their stress by helping them better schedule their leisure time. The lead investigator had them schedule one or two leisure activities before scheduling other tasks. The parents were encouraged to examine what daily activities they could potentially delegate to others to allow them to schedule leisure time. The lead investigator suggested that the parents analyze their calendars on a weekly basis instead of a monthly basis.

Physical Activity. The physical activity involved stress reducing techniques commenced right after the occupational-based intervention for 10 to 15 minutes. Perciavalle, et al., (2017), found the use of deep breathing techniques has shown effective improvements in the stress of people's daily life, and therefore, could exert positive influences on the stress conditions. The physical stress reducing techniques consisted of deep breathing exercises. The six participants completed the deep breathing exercises led by the lead investigator. The critical part to this component was the deep breathing exercises that were taught and needed to be performed at home throughout the week. The parents were given a daily checklist, or they could log it into their cellphone every time they complete the routine at home. Each participant was encouraged to complete the deep breathing, five out of the seven days for the four weeks which was recorded on their phones or on a sheet given to them during the session.

Section Four: Results and Discussion

Results

The Parental Stress Scale (PSS) potential total score ranges from 18-90; the lower the score the less stress indicated, and the higher the score, the greater stress. Five out of the six participants perceived a reduction in stress. One of the participants individual scores show they perceived no change in stress after completing the study. A paired one-tailed t-test was completed in Excel, which compared pre-and post-PSS mean scores for the six participants to determine if the study was significant. Since the study investigated whether a group occupation-based intervention approach affects parents' perceived stress, the paired t-test was used to determine whether the intervention had a positive or negative effect on the participant group by analyzing the mean scores. The t-test measures change in mean from all participant pre-and post-PSS scores. The results of the t-test computed a p-value = 0.014. If a p-value is less than 0.05, the results are considered significant. Therefore, the p-value for this study indicated the results of the t-test were significant (see Table 2 for the Parental Stress Scale raw scores). Additionally, the pre-PSS indicated the participants (n=6) had moderate stress levels with an average raw score of 46. The post-PSS average raw score for participants (n=6) was 42.

Table 2: Parental Stress Scale Raw Scores

	Pre-PSS	Post-PSS	Percent Difference
Participant 1	48	46	-2.20%
Participant 2	38	30	-8.90%
Participant 3	55	55	0
Participant 4	43	37	-6.60%
Participant 5	49	45	-4.40%
Participant 6	43	41	-2.20%
Mean	46	42.33	

Discussion

Following the four support group sessions, results indicate that the occupational therapy led parent support group was effective at reducing perceived stress in parents as measured by the Parental Stress Scale (PSS). Anecdotally, it appears the group dialogue was an effective means to promote parents sharing their thoughts and concerns openly and relate with one another. Several of the parents during the support group stated, “This support group gave me the opportunity to connect with other parents.” The value and impact of such support groups are based on the solid foundation that participants in parent support groups has many benefits (Banach, Iudice, Conway, & Couse, 2010). All six participants stated they perceived a sense of empowerment, a sense of belonging to a group, and a reduction in stress after the support group. Five out of the six participants reported the group discussion gave them an opportunity to connect with other parents who are in similar situations. Parents appeared to share universality between one another. The sharing of information may have offered each of the participants a sense they were not alone in their challenging situations. Kerr & McIntosh (2000) found parents of children living with a disability are uniquely qualified to help each other. During the group discussion, many of the parents' expressed stressors were similar to the findings discussed in the literature (Resch et al., 2010). The parents in this study perceived stressors involving their needs, the needs of their families, and the services and support available to address those needs. Additionally, during the group discussion, these parents spoke about their issues regarding the accessing of information and resources. The parents were able to relate with one another challenges during the discussion and were able to share universality. This interaction between the parents through group discussion may have been a factor leading to a reduction in stress.

In the group discussion, the parents of this study discussed their own stressors. One of the stressors brought up was having financial barriers; many of them were unable to work because they had to take care of their children. Another stressor for the parents was the education of their child. Much of the perceived stress connected with this stressor involved how the educational system was not warranting their concerns. The last stressor that was discussed involved the support of family. Many of the parents reported there was no consistency between how their extended families would handle the maladaptive behaviors of their child. This lack of consistency led to undue stress in many of the parents.

The findings of this occupational therapist-led support group demonstrated the effectiveness of an occupational therapy client-centered intervention. During this study's focus group, the lead investigator created occupational activities based on the group's stated needs in combination of utilizing the theoretical background for this study, MOHO. Maitra and Erway (2006) have shown, utilizing a client-centered approach is more likely to engage clients in the whole process of change because it allows individuals to have more control. A client-centered approach focuses on achieving the individual's goals of each client based upon the best available evidence (Maitra & Erway, 2006). Anecdotally, the parents reported the occupation-based activities were engaging.

This study was able to engage participants, as evidenced by no dropouts during the study. The parents of this study shared they enjoyed the fellowship each week of being able to come to the support group to network. Due to that, the parents stated they wanted to be in attendance for each session. Rogers, Mallinson, & Peppers (2014) utilized an occupational therapy approach when working with veterans who were suffering from Post-Traumatic Stress Disorder (PTSD). One of the findings was that an occupational therapy approach contributed to increased attendance and led to minimal dropouts as a result of the participants being engaged with the intervention. At the end of the fourth session of the pilot group, all six participants anecdotally reported a desire to continue attending an occupational therapy led parent support group that uses an occupational therapy approach if it were offered by the researcher.

Additional carryover of learned strategies was also reported anecdotally from parents in that four of the six participants reported they were completing the deep breathing exercises at least four times throughout the week as part of trying to establish occupational balance. Preliminary results indicated that establishing an occupational balance may be been an effective means of reducing perceived stress in parents who have a child with a disability. This study's results align with the findings of Jerath, Crawford, Barnes, and Harden (2015), who showed that meditation and breathing techniques reduce stress, anxiety, depression, and other negative emotional states.

Implications for Occupational Therapy

The results of the study show occupational therapy in a support group can be effective in reducing perceived stress involving parents who have a child with a disability. Anecdotally, it seems the support group was effective and engaging for parents. Five out of the six participants stated following the fourth support group session reported they found the occupation-based interventions meaningful to them. Parents discussed that each of the occupation-based activities assisted them with areas they perceived as stressful in their lives.

Additionally, it seems utilizing the support group was potentially useful in assisting parents with altering routines that they perceived as stressful by utilizing role-playing. Altering routines may have allowed time for more leisure activities, whereas before the parents spent more time on perceived stressful activities which has been shown in literature to create an occupational imbalance.

Results indicate after parents utilized the Eisenhower matrix, they reported they were able to delegate and eliminate certain daily activities to allow them to complete leisure activities. Four out of the six parents discussed they had participated in leisure activities throughout the week during the support group. By using occupation-based interventions that are meaningful and engaging, it could potentially assist parents with establishing an occupation balance which may reduce perceived stress.

Limitations

It is important to consider the potential limitations of this study. The sample consisted of a homogenous group of all-females which could have affected the overall results. It should also be noted support groups consisting of just mothers are common (Resch et al., 2010). Other studies that have involved support groups have shown a similar pattern (Resch et al., 2010). Another limitation is only six participants expressed interest in the group. Therefore, there was no randomization for the group due to the small sample size. The support group only had six participants; therefore, data cannot be generalized.

Additionally, all participants knew the lead investigator which could have introduced bias, affecting the results and what was shared during the sessions. The lead investigator also facilitated the support group session, which has the potential to change the way a group functions, which could have affected the information that was shared during the support groups. One of the unexpected findings was related to the demographics in which all participants were of Hispanic descent. Additionally, another limitation is one of the participants only attended three of the four sessions. This participant could have potentially skewed the results as some of the individuals received more of the intervention. An additional limitation is due to only four sessions of occupation-based activities it cannot stated for certain that the participants were able to master skills as there is no long-term measurement. Lastly, another limitation, was this study did not collect qualitative data which limited the amount of results and perspectives of each participant.

Future Research

The findings of this study demonstrate a need for further research utilizing an occupational therapy approach during support groups with parents who have a child living with a disability. Future research could have two-parent couples as participants complete the support group together to determine if that could reduce perceived stress. During the support group, parents discussed inconsistencies with parenting behaviors in their parent dyads, which led to many of the participants perceiving greater stress. Additionally, other studies could utilize heterogeneous support groups to determine if using a mixed group may have any impact on results as research has shown gender coping mechanisms are different (Dabrowska & Pisula, 2010). Furthermore, having multiple groups going on at the same time would be useful at determining if the occupational therapy led support group is effective. Future research should also utilize longitudinal studies to determine if the effects of the support groups last over time.

Anecdotally, all the participants were Hispanic-Americans, which would be essential to further research if cultural practices affect their overall perceived stress when parenting. In hindsight different recruitment methods may have been more effective to increase future participants. Several individuals asked to participate in this study however, due to being unable to coordinate childcare services they were unable to participate in the study. Future research may benefit from offering childcare services to recruit more participants. Additionally, in the future, this pilot study could be attempted on an internet platform to have sessions virtually instead of face-to-face sessions to recruit a larger number of participants. Finally, future research should consider using a qualitative data component to utilize the perspectives of each participant.

Conclusion

It has been discussed stress levels in parents of children with disabilities are typically higher than those of parents of non-disabled children (Woodman, Mawdsley, & Hauser-Cram, 2015). This study was meaningful to the occupational therapy field as a parent's stress levels significantly influence a child's development and could impact their child's daily lives (Kogan et al., 2009). Since parental stress levels have been shown to affect a child's development it was important to examine these families holistically, including interventions for parents. The field of occupational therapy can apply a holistic approach along with MOHO when addressing the needs of parents.

This study's results indicated a reduction in perceived stress for pilot support group participant parents who have a child with a disability. Therefore, this pilot support group was an effective model for a resource in the community to assist these parents. Occupational therapists are skilled at assisting people who struggle with time management during daily activities, organization skills, and modification of maladaptive routines and habits which could assist individuals with developing an occupational balance. Further research in this area is needed to determine if the results are genuinely effective when using an occupational therapy approach during a parent support group.

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Appendix A: Informed Consent from Owner

B&V Thera-Pro Associates, Corp.
Physical
Occupational
Behavior
Speech
Therapy for Children & Adults

Letter of Support for Off-Campus Research

May 20, 2019

RE: Occupational Therapist-led Parent Support Group Using an Occupational Therapy Approach

Principal Investigator Sean Brim, MS, OTR/L
Cell: 727-564-3867
Email: sean_brim@mymail.eku.edu

Attn: Institutional Review Board.

As an authorized representative of B&V Thera Pro Associates, Corp., I grant approval for Sean Brim, MS, OTR/L to conduct research involving human subjects at my organization. This involves the recruitment of participants from B&V Thera Pro Associates, Corp. at the Kendall and Bird Road locations.

Additionally, I grant approval for Sean Brim, MS, OTR/L to use the facility as a meeting location for the 4 support groups sessions. I understand that the purpose of this research is to fill this gap of knowledge by constructing an occupational therapy led parent support group using an occupational therapy approach.

To support this research, I agree to allow Sean Brim, MS, OTR/L to conduct his study at the Kendall Facility.

Sincerely,

Bernardo J. del Riesgo, MOT, OTR/L
B&V Thera Pro Associates, Corp.

Bernie J. del Reisgo, MOT, OTR/L
B&V Thera Pro Associates
President / Owner

Appendix B: Institutional Review Board Documents

Consent to Participate in a Research Study

Occupational Therapist led Parent Support Group Using an Occupational Therapy Approach

EKU
Institutional Review Board
Protocol Number
2565
Approval Valid
7/31/19-7/30/20

Key Information

You are being invited to participate in a research study. This document includes important information you should know about the study. Before providing your consent to participate, please read this entire document and ask any questions you have.

Do I have to participate?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide to participate, you will be one of about 8 in the study.

What is the purpose of the study?

The purpose of the study is to You are being invited to take part in a research study that hopes to assist parents of children with disabilities. This study aims to fill this gap of knowledge by constructing an occupational therapy led parent support group using an occupational therapy approach to reduce stress levels in parents who have a child with a disability.

Inclusion criteria

- Parents who have a child with a disability who is between zero to 18 years old
- The child must have a diagnosis under the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
- Parents or caretakers must be over the age of 18 years old
- Participants agree to attend three out of the four project support group sessions
- Participants agree to attend the first session
- Participants' primary language is English
- Participants must have an active email address

Where is the study going to take place and how long will it last?

The research procedures will be conducted at B&V Thera Pro Associates 14291 SW 120th St Ste 103, Miami, FL 33186. You will need to come to B&V Thera Pro Associates, 4 times during the study. Each visit will take about 90 minutes].The total amount of time you will be asked to volunteer for this study is 4 times each session being 90 minutes over the next month

What will I be asked to do?

If you decide to participate in the study, you will be asked to complete an initial Parenting Stress Scale (PSS) prior to their start date. Participants will be asked to fill out an initial intake form. The initial intake form will ask participants to write a minimum of five challenges they face in their day to day lives when raising a child with a disability and what are their expectations for participation in a pilot parent support group. At the end of the fourth session parents will complete the second PSS. If participants will not be attending the fourth session the lead investigator will administer the second PSS. There will be three parts to the sessions; group discussion, occupational based intervention, and a physical activity. During the first 30 minutes, the group will begin a group discussion. The lead investigator will oversee facilitating the group's discussion. The next component will be the occupational based intervention, which will be another 30 minutes of the session. The final component, physical activity, will be for approximately 10 minutes. The remaining minutes of the group will focus on the closing remarks.

Are there reasons why I should not take part in this study?

Exclusion from the research would be due to the following reasons:

- Inability to attend scheduled project sessions
- English is not their primary language

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm or discomfort than you would experience in everyday life.

You may, however, experience a previously unknown risk or side effect.

What are the benefits of taking part in this study?

You are not likely to get any personal benefit from taking part in this study. Your participation is expected to provide benefits to others by understanding the benefits of an occupational therapist led parent support group using an occupational therapy approach.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

Now that you have some key information about the study, please continue reading if you are interested in participating. Other important details about the study are provided below.

Other Important Details

Who is doing the study

The person in charge of this study is Sean Brim MOT, OTR/L at Eastern Kentucky University. He is being guided in this research by Dr. Leslie J. Hardman There may be other people on the research team assisting at different times during the study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. Include the following statement if the data will not be recorded with identifying information: For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court Also, we may be required to show information that identifies you for audit purposes.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the University or agency funding the study decides to stop the study early for a variety of reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or get sick because of something that is done during the study, you should call Sean Brim at 727-564-3867 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study. These costs will be your responsibility.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

We will give you a copy of this consent form to take with you.

Consent

Before you decide whether to accept this invitation to take part in the study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact the investigator, Sean Brim at 727-564-3867 or sean_brim@mymail.eku.edu. If you have any questions about your rights as a research volunteer, you can contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636.

If you would like to participate, please read the statement below, sign, and print your name.

I am at least 18 years of age, have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and voluntarily agree to participate in this research study.

____
Signature of person agreeing to take part in the study Date

____
Printed name of person taking part in the study

____
Name of person providing information to subject

Appendix C: Parental Stress Scale

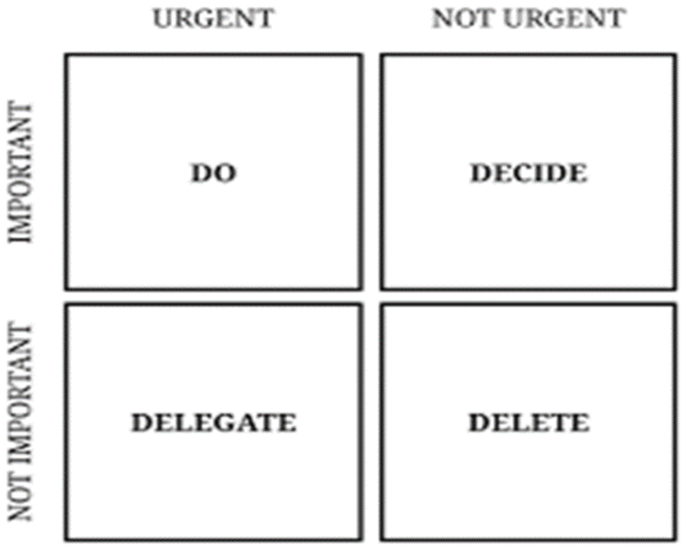
The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1	I am happy in my role as a parent	
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	
4	I sometimes worry whether I am doing enough for my child(ren).	
5	I feel close to my child(ren).	
6	I enjoy spending time with my child(ren).	
7	My child(ren) is an important source of affection for me.	
8	. Having child(ren) gives me a more certain and optimistic view for the future.	
9	The major source of stress in my life is my child(ren).	
10	Having child(ren) leaves little time and flexibility in my life.	
11	Having child(ren) has been a financial burden.	

12	. It is difficult to balance different responsibilities because of my child(ren).	
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	
14	. If I had it to do over again, I might decide not to have child(ren).	
15	I feel overwhelmed by the responsibility of being a parent.	
16	Having child(ren) has meant having too few choices and too little control over my life.	
17	I am satisfied as a parent	
18	I find my child(ren) enjoyable	

Appendix D: Eisenhower Matrix



	URGENT	NOT URGENT
IMPORTANT	**DO**	**DECIDE**
NOT IMPORTANT	**DELEGATE**	**DELETE**