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Engaging Caregivers in Family-Centered Pediatric Occupation Therapy

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Engaging Caregivers in Family-Centered Pediatric Occupational Therapy

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Approval Page

This Scholarly Project Paper, submitted by Sidney Carlson and Sarah Schwartz in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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-Sidney Carlson, MOTS, & Sarah Schwartz, MOTS

ABSTRACT

Purpose

Family-centered care is considered the gold standard when working with children and their families (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2010). Despite there being a strong push toward family-centered care, there remains a disconnect in outpatient pediatric settings when working with children ages 3-18. The purpose of this scholarly project is to raise awareness of the need for caregiver engagement in pediatric, outpatient occupational therapy and identify best practice principles for caregiver engagement.

Methods

An extensive literature review was conducted in order to understand caregiver engagement in pediatric occupational therapy. The information obtained from the literature review was analyzed and placed into emerging themes: (a) background information, (b) caregiver/therapist barriers, (c) caregiver/therapist perspectives on engagement, (d) methods of engagement, and (e) models and theories for caregiver engagement. The Adult Learning Theory of Andragogy (Merriam, Caffarella, & Baumgartner, 2007) was used to organize the information and guide the creation of the product.

Results

The analysis of information indicated multiple best practice and evidence-based strategies to engage caregivers in their child's occupational therapy services. Based on this conclusion, the researchers created an *OT Practice* article to inform occupational therapy practitioners of the current lack of engagement in occupational therapy, the barriers to engagement and best practice methods for engaging caregivers. Best practice strategies are presented throughout the therapeutic process. Additionally, a handout was created to inform occupational therapy practitioners and caregivers of their specific roles throughout the therapeutic process.

Conclusion

The purpose of this product is to raise awareness of the lack of caregiver engagement in practice and provide best-practice strategies to promote engagement, however it does not give specific steps for how to implement these strategies throughout the therapeutic process. Additionally, there was a lack of occupational therapy literature that contributed to our literature review. Overall, these products were designed to reach a wide variety of occupational therapy practitioners and are intended to promote collaboration between the therapist and caregiver, thus increasing the outcomes for the child.

CHAPTER I

Introduction

The goal of occupational therapy is to maximize independence and increase quality of life of the client (American Occupational Therapy Association [AOTA], 2014). The profession is known for its client-centered practice when working with clients across the lifespan (AOTA, 2014). However, the service delivery method for pediatric occupational therapy uses family-centered care, as the client in pediatric therapy is seen as the family unit (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2010). A unique aspect of family-centered care is the imperative need meet the needs of the caregiver and child, improving overall quality of life of the family unit. Implementing family-centered care not only includes involving the family in care, but 'engaging' the family in the therapeutic process. Engagement is a reciprocal process, and a child's engagement is enhanced by their caregiver's engagement, thus further enhancing positive therapeutic outcomes (D'Arrigo et al., 2017).

Despite the evidence indicating a need for engagement of caregivers in pediatric therapy, there remains a disconnect in practice. Only 38% of caregivers report being able to make the final decisions about their child's goals (Watts Pappas, McLeod, McAllister & McKinnon, 2008). According to Rone-Adams, Stern, and Walker (2004), it is estimated that approximately 50% of parents do not comply with recommended

therapeutic programs, 66% of caregivers report some level of non-compliance, and only 34% of families follow the home programs appropriately. Lack of involvement in intervention sessions results in a high rate of nonadherence and decreased engagement, which ultimately leads to decreased therapeutic outcomes (Case-Smith, 2015; Rone-Adams et al., 2004).

To raise awareness of this need and bridge the gap between the evidence and lack of engagement, an *OT Practice* article and handouts for caregivers and occupational therapy practitioners have been developed. These resources aim to identify and define the need, while providing best practice strategies for therapists to engage caregivers. The best practice, evidence-based strategies implemented by practitioners facilitate engagement of caregivers. This product also aims to define and raise awareness of the importance of the role of the caregiver on the team.

The resources and product were guided by the adult learning theory. The adult learning theory supports the individual learning styles of occupational therapy practitioners and caregivers. It focuses on the situation the adult learner may be in; incorporating experiences and knowledge into the learning styles. This theory encompasses a range of learning styles to address the needs of all adult learners. With the emphasis on individuality and independent learning, this theory is suitable to guide a product educating caregivers and practitioners of best practice strategies for engagement (Merriam, Caffarella, & Baumgartner, 2007).

Key Terminology

The following terms and concepts used throughout the literature review and product have been defined below.

- **Family-centered care:** Family-centered care is an element common across pediatric care. It emphasizes relationships and collaboration between caregiver and practitioner, as well as family-identified goals, in order to improve the quality of life of families (Dunn et al., 2012).
- **Caregiver:** A caregiver is the legal and primary caretaker of the child. The product may also be used with secondary caregivers of the child, such as other family members that care for the child and attend therapy.
- **Child:** For the purpose of this product, a child is defined as aged 3-18 years old and receiving care in an outpatient pediatric therapy setting.
- **Engagement:** Engagement is an internal process comprised of three components: (a) affective, (b) cognitive, (c) behavioral (D'Arrigo et al., 2017). It is defined on a continuum as deliberate efforts to positively benefit from the healthcare received (Carman et al., 2013). Caregiver engagement in their child's occupational therapy is seen as their deliberate efforts for their child and family to benefit from therapy.
- **Novice Therapist:** For the purpose of this study, a novice therapist is defined as an occupational therapist in his or her first 1-3 years of practice.

The following chapters address aspects of the identified product. Chapter II consists of a literature review providing an overview of pediatric occupational therapy, family-centered care, research supporting caregiver engagement, and the identified need.

Chapter III describes the methodology regarding the product in relation to the literature review. Chapter IV is the product of the *OT Practice* article and the handouts for caregiver and practitioner. Chapter V consists of a summary of the scholarly project, including limitations, implementation proposal, recommendations, and a final conclusion. References utilized in this scholarly project are included following Chapter V.

CHAPTER II

Literature Review

Occupational therapy is a diverse healthcare field that works with clients across the lifespan. The goal of occupational therapy is to assist clients to maximize independence in meaningful activities in everyday life. Occupational therapists work not only with clients, but with the families and caregivers of the clients. The functioning of the family unit is a primary goal in pediatric care. Occupational therapy practitioners assist children and families with various needs to work on gaining independence in activities of daily living, social participation, and improve overall sensory, cognitive, and motor functioning (American Occupational Therapy Association [AOTA], 2014). Occupational therapy practitioners have the clinical knowledge of childhood development and the skills to incorporate meaningful activities of both child and family in order to facilitate skill acquisition and minimize the consequence of disability (Jaffe & Cosper, 2015; Moore & Lynch, 2018).

Occupational therapy practitioners work with pediatric clients in various settings including: early intervention, schools, home health, outpatient clinics, and acute care. Across these settings, occupational therapy is an essential component of an interdisciplinary team, often working alongside physical therapy and speech language pathology. All three disciplines are of equal importance in ensuring positive outcomes when working with children with disabilities; however, the most important, and often overlooked member of the team, is the caregiver of the child. Caregivers of children

have a unique understanding into the behaviors, mannerisms, habits, and routines of their child. Caregivers can provide insight regarding the child's functioning in all aspects of therapy. A caregiver's engagement in therapy enhances the child's engagement, thus promoting and increasing positive therapeutic outcomes (D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017). With that being said, the clinical expertise of the occupational therapy practitioner, jointly with the knowledge and engagement of the caregiver, is the optimal approach to ensure positive therapeutic outcomes for the child and overall functioning of the family. However, there remains a lack of understanding regarding methods of caregiver engagement in the therapeutic process of pediatric occupational therapy.

Caregiver Engagement in Occupational Therapy Practice

Occupational therapy practitioners strive to collaborate with family members, follow their lead, and support efforts in promoting the well-being and development of the child (Jaffe & Cosper, 2015). By engaging in meaningful occupations together, caregivers and their children are able to fulfill the functions necessary to participate in daily life (Jaffe & Cosper, 2015). Engagement is a critical element to the therapeutic process in occupational therapy. It goes far beyond simply 'attending' or 'participating' (D'Arrigo et al., 2017). Engagement it is a multi-faceted state affected by both internal and external processes (D'Arrigo et al., 2017). Engagement is a reciprocal process, and a child's engagement is enhanced by their caregiver's engagement. It is therefore essential to engage both caregiver and child in pediatric occupational therapy. Each family is unique, and occupational therapy practitioners must be prepared to alter and adapt therapeutic approaches in order to address the needs of both the child and the family.

D'Arrigo et al. (2017) described engagement consisting of three main components: affective, behavioral, and cognitive. By utilizing and understanding these components, a therapist can effectively promote positive outcomes through engagement of child and caregiver.

Outcomes of therapy are often directly correlated with compliance in home programs. Home programs have become increasingly more popular and essential in pediatric therapy services over the past decades (Rone-Adams, Stern & Walker, 2004). Home programs provide an opportunity for the child to transfer skills learned in the therapeutic environment to the natural home environment (Case-Smith, 2015). Engagement of caregivers in the therapeutic environment is positively correlated to implementation of home programs and carryover of skills learned in therapy to the home environment (Case-Smith, 2015).

Due to the prevalence of multidisciplinary teams in pediatric care, it is important to study caregiver involvement in occupational therapy, speech language pathology, and physical therapy. According to Rone-Adams et al. (2004), it is estimated that approximately 50% of parents do not comply with recommended therapeutic programs, 66% of caregivers reported some level of non-compliance, and only 34% of families followed the home programs appropriately. Watts Pappas, McLeod, Mcallister, and McKinnon (2008) discovered approximately 80% of caregivers were present during their child's speech interventions, but only 35% reported being physically involved with the intervention process. In addition to the low participation rates in the therapy setting, researchers reported limited caregiver participation in home programs and activities (Watts Pappas et al., 2008). Non-compliance with home programs is a major factor

negatively affecting therapeutic outcomes of the child (Rone-Adams et al., 2004). Due to the low percentage rates of caregiver engagement in the therapeutic process, it is important for occupational therapy practitioners to understand the barriers affecting their ability to engage.

Barriers to Caregiver Engagement

There are various barriers that may inhibit caregivers' engagement in therapy services with their children. Many caregivers perceive available time for attending therapy sessions, their expectations about their role, and stress as barriers to participation (Patton & Hutton, 2016; Rone-Adams et al., 2004; Watts Pappas et al., 2008). Caregivers report limited time in their busy schedules to engage and participate in therapy sessions and are often under the impression that their role is limited to bringing their child to therapy (Jahagirdar, 2013; Watts Pappas et al., 2008). Factors that have been found to contribute to parental stress include: (a) altered family relationship, (b) the burden of increased care modifications, (c) need for compliance with home programs, (d) time-consuming treatment regimens, (e) financial strains, (f) special housing, (g) equipment needs, (h) social isolation, (i) grieving reactions, and (j) worrying about the child's prognosis and future potential (Rone-Adams et al., 2004). Furthermore, if stress can be minimized, engagement in therapy and compliance with home programs may increase (Rone-Adams et al., 2004).

Jahagirdar (2013) stated a common notion regarding all healthcare in Asian cultures is, "doctor proposes and client disposes" (p. 34). With that being said, caregivers are often under the impression that the professional knows best, and engagement and participation in their child's therapy is not always necessary. There should be an

emphasis on caregiver engagement in therapy and the responsibilities included in this role. The role of a caregiver in therapy must go beyond simply 'following instructions' in order for caregivers to truly understand their role and ways to become fully engaged in therapy (Stefandottir & Egilson, 2016). Placing an emphasis on the caregiver's role in therapy and the reciprocal positive effects on their child's outcomes may assist caregivers to better understand their role and become more engaged (Stefandottir & Egilson, 2016). Many caregivers may even find it confusing or rare to be expected to engage in the therapeutic process. Although caregivers may enjoy and benefit from engagement in their child's therapy, some caregivers report increased feelings of insufficiency and decreased confidence levels when attempting to participate (Kruijsen-Terpstra et al., 2013).

Cultural differences may also affect a caregiver's engagement. Jahagirdar (2013) reported difficulty with client-centered occupational therapy for caregivers and children of Asian cultures, specifically Indian, due to the emphasis on Western medicine and lack of awareness of Eastern medicine. Cultural differences such as this, as well as verbal and nonverbal differences, can prevent caregivers from engaging in their child's therapy. Despite standardized programs to engage caregivers, therapists must have strong critical and ethical reasoning skills to overcome socio-cultural barriers and implement client-centered therapy, engaging caregivers across cultures (Jahagirdar, 2013).

Not only are there barriers relating to caregiver engagement in the therapy process, but there are also barriers relating to the therapist. Watts Pappas et al. (2008) discovered that 11% of speech language pathologists reported time constraints, a lack of confidence, and a lack of experience as barriers for including families in interventions. Researchers suggest new graduates with decreased confidence in their clinical abilities

are less likely to include caregivers in the therapy process (Watts Pappas et al., 2008). Therefore, "a message to educators is to prepare their students with the necessary skills to work in partnership with families of children with disabilities-defining and developing helpful strategies and focusing on professional qualities and behaviors" (Egilson, 2010, p. 283). This message is crucial as it is the therapist's responsibility to overcome the barriers in order to properly engage the caregiver and the child.

Barriers may escalate as the child ages and changes through the lifespan. Difficulties faced by child and caregiver often increase throughout adolescence and puberty, as symptoms, behaviors, and family needs become more complex; making therapy and family-centered care more complex (Stefandottir & Egilson, 2016). Methods of engaging of caregivers and family-centered care changes throughout the lifespan of a child, with more needs that have to be met, and more barriers to be addressed. Therapy often has an increased focus on the bodily functions as compared to occupational participation and the functioning of the family system (Stefandottir & Egilson, 2016). It is essential to remain focused on occupational participation and family functioning throughout the lifespan as well.

Engagement from Caregivers' Perspectives

Assessing caregivers' expectations and perceptions of therapy enhances and enables the caregiver engagement in therapy, as well as establishes a collaborative relationship between caregiver and therapist (Waldman-Levi, Hirsch, Gutwillig, & Parush, 2017). Egilson (2010) conducted a study to gather an understanding of how Icelandic parents viewed the occupational and physical therapy services their children received. Caregivers reported therapists offered useful information, instructions, and

recommendations that made their daily lives easier (Egilson, 2010). However, caregivers also reported therapists being less involved once the child entered school, resulting in fewer guidelines for families (Egilson, 2010). Many caregivers reported limited communication about the goals targeted in therapy and specific interventions conducted during therapy sessions (Egilson, 2010). Caregivers reported a lack of communication in regard to fine motor activities, improving self-care performance, transfer of skills to home environment, and moving about in the community (Egilson, 2010). One mother stated, "parents need to be taught along with the children, because it's through the parents that everything flows to the child, this 'problem solving.' It can't just be the professional who has all the answers" (Egilson, 2010, p. 281). Nevertheless, perceptions of therapy differ from caregiver to caregiver. Some caregivers may want to take part in every aspect of therapy, as opposed to other caregivers who believe it is the complete responsibility of the therapist (Egilson, 2010). Many caregivers reported a desire to be involved in the decision-making process, continually informed of goals, and provided updates of the therapy session (Egilson, 2010). It is important for therapists to be mindful of 'medical jargon' and avoid providing excessive information that may confuse caregivers. Increased involvement of caregivers throughout the therapeutic process, as well as providing updates and information in terms the caregiver can understand, will increase carryover of intervention techniques to the natural environment. Gathering the perceptions of caregivers is crucial in order to adjust and improve therapeutic relationships.

Engagement from Therapists' Perspectives

Family-centered therapy should include both the perceptions of the caregivers and

the therapists. Watts Pappas et al. (2008) reported 98% of therapists strongly agree or agree that parental involvement is essential for speech intervention in order for the child to make progress, and 97% of therapists also agree that parents should be encouraged to participate in intervention sessions. Eighty-nine percent of the speech therapists agree that the family unit is considered the client as opposed to solely the child, but only 42% of therapists agree that parents should have the final say on the child's goals and intervention activities (Watts Pappas et al., 2008). Due to the multiple factors that play a part in fully being able to engage caregivers in the therapy process, as well as a lack of research regarding caregiver engagement, specific tools for measuring engagement will be discussed.

Tools for Measuring Engagement

There are various tools available for occupational therapy practitioners to utilize to promote engagement with caregivers. Dyke, Buttigieg, Blackmore, and Ghose (2006) emphasized the importance of gaining both caregivers' and therapists' perspectives using a standardized tool. The Measure of Process of Care (MPOC) is a survey designed to specifically measure the extent to which services are family-centered, from the view point of caregivers (MPOC-56) and service providers (MPOC-SP) (Dyke et al., 2006). This tool utilizes self-reflection and self-assessment to gain insight into the perceptions of family-centered services (Dyke et al., 2006). The MPOC may be implemented into development of a standardized program for engagement of caregivers, as well as measuring the extent of family-centered services in a possible pre-existing program. The use of a standardized program can be a good starting point to effectively engage caregivers and children in therapy and promote positive outcomes.

Parents as Partners in Intervention (PAPI) Questionnaire (Waldman-Levi et al., 2017) was developed collaboratively by pediatric occupational therapists from the Maccabi Child Developmental Center in Israel and faculty members of the School of Occupational Therapy at Hebrew University. The PAPI Questionnaire may be utilized to measure caregivers' engagement in therapy and may be a major component in a standardized program for engagement of caregivers and family-centered practice (Waldman-Levi et al., 2017). Waldman-Levi et al. (2017) stated PAPI is a valid tool to address caregivers' expectations, engagement in goal setting, and overall satisfaction with treatment.

Fingerhut (2013) created an assessment tool called the Life Participation for Parents (LPP) that is intended to measure a parent's ability to participate in chosen occupations. The purpose of the LPP is to "facilitate family-centered pediatric practice by ensuring the ability of parents to participate in life occupations while raising a child with special needs" (Fingerhut, 2013, p. 37-38). Fingerhut (2013) created this assessment with the idea in mind that families are interdependent, and interventions need to not only address the needs of the child, but the family as a whole. The LPP consists of 22 questions that are scored on a 5-point Likert scale, with space for extra comments from parents (Fingerhut, 2013). The LPP is a reliable and valid source for evaluating parent's satisfaction, helps occupational therapy practitioners to design family-centered interventions, and contains a life participation component easily understood by caregivers (Fingerhut, 2013). This tool would enable therapists and therapy managers to further understand perceptions of caregivers, as well as enable caregivers to reflect upon their

experiences and perceptions.

Lastly, the Family-Centered Care Assessment Tool (FCCA; Wells, Bronheim, Zyzanski & Hoover, 2015) was created through a collaborative process by families and health leaders. The FCCA can be used to evaluate family-centered care. It is a valid tool used to gather perceptions of both the families receiving services and the occupational therapy practitioner, in hope to promote positivity in the therapeutic relationship (Wells et al., 2015). The FCCA can also help guide occupational therapy practitioners in understanding what is best practice for engaging caregivers in the treatment of their family member (Wells et al., 2015). Many of the tools discussed can be used to facilitate family-centered care in the therapeutic process.

Occupational Therapy Process

Occupational therapy is known for its client-centered practice; however, the service delivery method for pediatric occupational therapy is slightly different. Pediatric occupational therapy is family-centered (Darrah, Wiart, Magill-Evans, Ray & Andersen, 2010), as the client in pediatric care is often considered the family unit throughout the occupational therapy process. The occupational therapy process includes "evaluation and intervention to achieve targeted outcomes" (AOTA, 2014, p. S10). As highlighted previously, the level of caregiver engagement has been inconsistent throughout the occupational therapy process, as well as knowledge of best practice for engaging caregivers from the therapist's perspective. Engagement of caregiver throughout the occupational therapy process will be discussed below.

Evaluation

Throughout the evaluation process, it is the occupational therapy practitioner's

responsibility to get to know the child and the family unit, in order to understand the child's occupational history, patterns of daily living, specific interests, and concerns of the family (AOTA, 2014). The next step in the evaluation process is to assess the child's performance and identify targeted goals to further guide the process (AOTA, 2014). Currently there have been limited studies conducted to evaluate caregiver involvement in the occupational therapy process. Watts Pappas et al. (2008) reported 84% of caregivers indicated they were present during their child's initial speech evaluation, and 67% of caregivers were involved in goal-setting. Although over half of the participates reported involvement in the goal setting process, only 38% reported being able to make the final decisions about goals (Watts Pappas et al., 2008). This indicates a need for increased engagement of both caregiver and child in the evaluation process.

It is essential that occupational therapy practitioners are not only including caregivers in the evaluation process, but ensuring caregivers understand the results of the assessments performed. Makepeace and Zwicker (2014) discovered many therapists identify caregivers as an intended audience when writing up evaluation or assessment reports; however, not all therapists identify caregivers as the primary audience. As a result, caregivers often have a difficult time understanding the meaning behind the results, leading to a limited ability to contribute to goal setting. With this in mind, it is important for therapists to go into detail when explaining assessment results, making it easier for a caregiver to understand. One parent stated, "it explained what a percentile means because sometimes it just says that and you think what on earth does that mean? But it explains what a percentile means and whether it is below average or above average. That was very good, that explanation" (Makepeace & Zwicker, 2014, p. 541). Caregivers

also identified therapists providing recommendations and activity ideas that they can begin to implement within their homes as a strength to the evaluation process (Makepeace & Zwicker, 2014). One parent stated, "it gives me ideas… and things to look into. And it just makes me feel better that I can do things to try to help him" (Makepeace & Zwicker, 2014, p. 452). Including caregivers in the evaluation process and ensuring they understand assessment results is crucial in order to prevent them from feeling helpless with their child's care.

Mastoras, Climie, McCrimmon, and Schwean (2011) presented the C.L.E.A.R. approach that offers guidelines that could be applicable for occupational therapists when writing up evaluation reports. Each letter in C.L.E.A.R. represents a writing component that should be included when writing a report: "'C' for child-centered perspective; 'L' for linking referral questions, assessment results, and recommendations; 'E' for enabling the reader with concrete recommendations; 'A' for addressing strengths as well as weaknesses and, lastly, 'R' for readability" (Makepeace & Zwicker, 2014, p. 544). The C.L.E.A.R. approach assists therapists to include relevant client-centered information, as well as verify the assessment is readable for the caregivers of the child. Having an assessment report that is easy for caregivers to understand is essential to the goal setting process.

Goal setting is an aspect in therapy crucial to promoting caregiver engagement and family-centered care. Goal setting allows caregivers and therapists to work together to establish goals, therefore, paving the way for effective therapeutic interventions and caregiver engagement. Not only should families have a say in setting goals, the goals should reflect the main priorities of the family (Jaffe & Cosper, 2015). Collaborating with

parents to set goals, specifically attainable goals, promotes autonomy and competency for the caregiver and child (D'Arrigo, 2017). Setting achievable goals allows the child and caregiver to experience success, therefore promoting competency and motivation to engage in therapy (D'Arrigo et al., 2017). It is critical to consider the environment and other services concurrently being received by the family unit. For example, families with a child receiving school-based therapy may already have goals set with regard to school functioning, but day-to-day home life remains unaddressed, such as self-care goals (Dunn, Cox, Foster, Mische-Lawson & Tanquary, 2012).

Darrah, Wiart, Magill-Evans, Ray, and Andersen (2010) identified functional goals and the goal setting process as one of the most important aspects for family-centered care and engagement of caregivers. Twenty-three percent of families surveyed experienced a formal goal setting process, as compared to other forms of goal setting more focused on therapists' clinical reasoning and judgement (Darrah et al., 2010). Whether the goal setting be more formal or informal, caregivers stated their biggest concern was increasing the child's functional independence, both physically and socially (Darrah et al., 2010).

Certain tools can be used to set achievable, functional, and client-centered goals. The Goal Attainment Scaling (GAS; Kiresuk & Sherman, 1968) can be used by therapists with caregivers in order to identify goals and measure progress (Dunn et al., 2012). The Canadian Occupational Performance Measure (COPM; Law et al., 2005) is another tool that can be used to set client-centered goals, while measuring progress on a scale of satisfaction (Dunn et al., 2012). The COPM is a more client-centered instrument that can measure both progress and satisfaction and can be used jointly with an objective

assessment such as the Assessment of Motor and Process Skills (AMPS; Fisher & Jones, 2014). Kang et al. (2008) reported the AMPS and COPM collectively detect sensitive changes in occupational performance while remaining client-centered and occupation-based. However, it is important to note that while using occupation-based and client-centered tools such as the COPM, it is essential to provide education to caregivers in the use and meaning of the tool to ensure proper use and outcomes (Kang et al., 2008).

Intervention

Throughout the therapeutic process, the therapist will develop a plan of action collaboratively with the child and caregiver (AOTA, 2014). The plan developed will be implemented into the intervention process to ensure positive outcomes of desired goals (AOTA, 2014). Interventions in pediatric occupational therapy, as well as many other settings, are often trial and error learning. Therapists may try many different approaches to attain set goals with families and children. Collaboration between therapist and caregiver enables teamwork in order to effectively decipher which interventions may or may not be working (Dunn et al., 2012).

Involving caregivers in intervention programs has been shown to speed up the achievement of goals (Rone-Adams et al., 2004). With an emphasis on a strengths-based approach, collaboration, and coaching, therapists can support and probe parents in a reflective discussion of child's functioning in the home and therapeutic environment. This reflective discussion will assist the caregiver to distinguish and better understand behaviors of their child (Dunn et al., 2012). Throughout intervention and goal attainment, the therapist and caregiver should continually have open discussions of child's progress and functioning.

It is common for therapy sessions in pediatric care to be video-recorded. Therapeutic interventions using video recording have been found to be more effective with caregivers as opposed to interventions without video recording (Van der Voort, Juffer, & Bakermans-Kranenburg, 2014). Video recording can be utilized for both caregivers and therapists to observe what went well and what did not go well in each session. It allows both therapist and caregiver to reflect on their actions and improve. An important aspect enhanced by video recording is the ability to further observe and understand a child's behaviors in order to better understand their needs and how to best respond (Van der Voort et al., 2014). Open communication with families is equally important in the outcome process.

Outcomes

The outcome process includes determining success in reaching the desired goals set by the family and plan for the future (AOTA, 2014). According to Case-Smith (2015), evidence has shown that child outcomes, or their ability to reach their goals, may be shaped by how well occupational therapy practitioners communicate with families, as well as how well the partnership between them has been established. Caregiver engagement has been shown to have a direct relation to satisfaction of expectations and outcomes (Waldman-Levi et al., 2017). A positive correlation between addressing caregivers' concerns and expectations and satisfaction, thus further positively influencing therapeutic outcomes (Waldman-Levi et al., 2017).

Methods of Engagement

The majority of therapists agree on the importance of caregiver engagement but remain unsure of the specific role of the caregiver and best practice methods of

engagement (Watts Pappas et al., 2008). There is not one clear best practice method of engaging caregivers, as the needs of each caregiver and child are multi-faceted and complex. Consequently, best practice approaches will differ from family to family. Support, effective communication, continuous feedback, and collaboration are various methods that may engage caregivers, enhance the therapeutic relationship, and promote positive outcomes in the child.

The optimal relationship between caregiver and therapist is a collaborative team with open communication throughout the therapeutic process. A collaborative relationship fosters honesty, trust, and support (Waldman-Levi et al., 2017). Common collaborative service delivery approaches between families and therapists include: home programs, parental education, and direct intervention (Patton & Hutton, 2016). Reflective discussion of caregiver and therapist expectations and satisfaction of therapy outcomes can serve as a measurement of family-centered care (Waldman-Levi et al., 2017). It is essential to engage caregivers in therapy with the use of reflection and open discussion, as well as directly addressing expectations, concerns, and satisfaction (Waldman-Levi et al., 2017). Reachers reported decreased parental satisfaction with group therapy as opposed to individual based therapy, as caregivers are not able to develop an alliance and a collaborative relationship with the therapist as well in a larger setting Waldman-Levi (2017).

Patton and Hutton (2016) studied the collaborative approach in relation to home programs and caregiver perceptions of the effectiveness of home programs. The level of desired caregiver involvement varied throughout. Many caregivers wanted to be involved in their child's therapy program, while some caregivers did not want to be involved in

therapy if it demanded too much time and energy (Patton & Hutton, 2016). One caregiver reported, “sometimes it was a struggle to get work carried out- just due to general family commitments and having to work with other siblings...day to day life…” (Patton & Hutton, 2016, p. 273). Open communication and frequent contact with the therapist enhanced home exercise program completion (Patton & Hutton, 2016). Another caregiver reported that despite having good intentions the home program, their busy schedule got in the way of completing the program accordingly (Patton & Hutton, 2016). This caregiver reported it would be helpful to have frequent contact with a therapist to hold them accountable and motivate them to follow through with the home program (Patton & Hutton, 2016). This highlights the importance of collaboration between the therapist and the caregiver. The therapy process cannot rely solely on the therapist or solely on the family unit. Direct contact between the therapist and the caregiver is required to hold the caregivers accountable for their involvement in therapy, offer them support throughout, and, as a result, increase the carryover of the program (Patton & Hutton, 2016).

As stated previously, stress levels of caregivers can be related to how well the home programs are carried out. It is critical that therapists are offering support and guidance to reduce overall stress levels and increase compliance with home programs (Patton & Hutton, 2016; Rone-Adams et al., 2004). There are many different methods occupational therapy practitioners can implement and teach caregivers to help reduce stress. Recommendations for stress reduction include: (a) regular exercise, (b) autogenic training, (c) breathing techniques, (d) visual imagery, (e) progressive relaxation exercises, and (f) participation in meaningful occupations in which the caregiver enjoys or finds relaxing (Rone-Adams et al., 2004).

Giving caregivers support and instilling confidence when implementing home programs is encouraged to improve home program effectiveness (Patton & Hutton, 2016). Before making recommendations for home programs, it is important for the occupational therapy practitioner to ask caregivers about the child's daily routines and the typical flow of family activities during the week (Case-Smith, 2015). In order to prevent caregivers from becoming overwhelmed with home programs, it is essential to recognize the family's stage of readiness to implement a change in behavior (Case-Smith, 2015). The readiness continuum consists of 5 stages, in the following order: (a) pre-contemplation, (b) contemplation, (c) preparation, (d) action, and (e) maintenance (Case-Smith, 2015). For instance, if a caregiver is contemplating whether or not they are ready to commit to the extra responsibility of implementing a home program into to their daily routine, the overall compliance may be low. In order to ensure successful carryover, the caregivers must be ready and committed, as well as fully supported by the therapist. Communicating regularly with caregivers is one method an occupational therapy practitioner can implement to ensure a caregiver is ready and fully supported.

Effective communication between the caregiver and the therapist is essential to promote a positive therapeutic relationship. Caregivers place heavy emphasis on the information provided by the therapist (Stefandottir & Egilson, 2016). Darrah et al. (2010) stated both therapist and family report a lack of satisfaction with accessible information regarding supports and services. Caregivers state a need for both specific and general information regarding their child (Dyke et al., 2006). General information provided may be regarding the initial diagnosis, symptomology, common interventions, therapeutic outcomes, and duration of treatment. Specific information often relates to progress of the

child, fluctuations in behaviors, long and short-term goals, and various treatment options available (Dyke et al., 2006). General and specific information is a component in therapy that must be client-centered, provided in a manner that is understood by the family, and devoid of medical jargon (Dyke et al., 2006). Information provided differs from family to family, depending on the needs and goals identified.

Communication between the occupational therapy practitioner and the caregiver is essential to the therapeutic relationship. It is important for occupational therapy practitioners to include all caregivers when communicating about the child to ensure that information is transmitted accurately and reduce the burden on one caregiver to accurately transmit the information (Jaffe & Cosper, 2015). It is challenging to predict how much information to share, as a therapist must understand a family's priorities and their readiness to assimilate information about the child's needs (Hummelinck & Pollock, 2006; Piggot, Hocking & Paterson, 2003). However, the more parents know about the development of their child, the more responsive and supportive they become when interacting with their child and promoting optimal development (Wacharasin, Barnard & Spicker, 2003). When trying to understand the family's readiness to accept information, occupational therapy practitioners must be prepared to actively listen, observe, be flexible and, as a result, be aware of how much information to provide (Jaffe & Cosper, 2015). It is crucial for the occupational therapy practitioner to remain humble, not assume they have more knowledge about the child than the caregiver, respect the family unit, and empower the caregiver to make recommendations for their child's care (Kadlec, Coster, Tickle-Degnen, & Beeghly, 2005).

Not only is it important for therapists to collaborate and communicate with

caregivers, but it is just as important for therapists to collaborate and communicate with other members of the child's multidisciplinary team. This team may consist of practitioners, respite care, speech language pathologists, physical therapists, teachers, and most importantly, caregivers. Communication is essential in regard to occupational therapy in the school setting, in order to transfer learning from the therapeutic setting, to school, to home (Egilson, 2010). This transference of learning goes hand in hand with continuity of care. Continuity of care is stated as a major concern for both caregivers and therapists (Dyke et al., 2006). There is a need for constant communication and exchange of information between all disciplines on the team, while continuously involving the caregiver.

Overall, there remains a need to create a standardized program for engaging caregivers in all aspects of the therapeutic process. A program should consist of, but not limited to, standardized processes for parental engagement, evaluation, goal setting, transition planning, and access to information (Darrah et al., 2010). This standardized approach would set guidelines for therapists and families, set expectations and reachable goals, and define the role of the caregiver (Darrah et al., 2010). With that being said, it is critical to involve the families in initial development of a standardized program.

Models and Theories for Caregiver Engagement

Actively engaging caregivers and children in occupational therapy services is essential to contemporary occupational therapy process models and is considered best practice to enhance positive outcomes (Patton & Hutton, 2016). There are various models and theories occupational therapy practitioners use to guide the intervention process when working with children and their families. Following a literature review, the most

commonly cited models and theories to engage caregivers of children receiving therapy services include: (a) family-centered practice, (b) coaching model, (c) Relationship-based approach, and (d) Self-Determination Theory (SDT). The following models and theories are discussed below.

Family-centered practice is currently a standard of practice that results in quality healthcare services for families (Wells et al., 2015). Family-centered practice focuses on the family unit as the constant supportive component of the child's life, with the family as essential members of the team (Fingerhut et al., 2013). Interventions are aimed to enhance well-being of the child and the family unit. Family-centered practice is "a philosophy of care which embraces parental control over intervention services, considers the whole family as a client rather than just the child, and focuses on forming positive relationships between families and professionals" (Watts Pappas et al., 2008, p. 335). Family-centered practice in pediatric occupational therapy involves working with caregivers, families, and their child to facilitate engagement in occupations (Fingerhut, 2013). According to Fingerhut (2013), occupational therapy practitioners generally interpret family-centered practice as caregiver engagement when developing goals for their child, however, it goes far beyond goal setting. Family-centered focuses on changing the quality of life of the overall family, not just the child (Fingerhut, 2013). Family-centered practice allows healthcare professionals to implement services that honor the strengths, cultures, and traditions of families that result in a positive therapeutic relationship (Wells et al., 2015). Family-professional relationships are built on open and objective communication, collaborative decisions, willingness to negotiate, strength-based care, and respect for cultural differences (Wells et al., 2015).

Although the clinical expertise of the therapist is important, therapists need to keep in mind that the caregivers know their children best. The best way to promote engagement of a child with a disability is to incorporate the caregiver throughout the therapeutic process to promote carryover to the natural environment (Egilson, 2010). Egilson (2010) reported, "parents' satisfaction with services seem to be directly related to how family-based they are, while good flow of information, respect, and the support of professionals are also highly regarded by parents" (p. 277). Not only does family-centered care allow for the parents to feel more in control of their child's therapy, additional benefits include reduced stress, improved overall communication, reduced conflicts, and improved health of children with chronic conditions (Wells et al., 2015). In light of the increasing amount of evidence regarding the importance of the family unit and family-centered practice, it is critical for therapists to trust and utilize caregivers' insights, while continuously involving and engaging them in therapy (Waldman-Levi et al., 2017).

According to Little, Pope, Wallisch and Dunn (2018), the coaching model has been recognized as a best practice method in occupational therapy practice when working with the pediatric population. Coaching is an evidence-based intervention, focusing on the caregiver's strengths, designed to build self-esteem and competency in order to enhance their abilities to create their own solutions (Dunn et al., 2012). This model is based on the principles of coaching and occupation-centered reasoning (Little et al., 2018). Coaching is defined as "a reciprocal process between a coach (occupational therapist) and learner (parents) comprising of conversations focused on child outcomes that allow the learner to discover his or her own salutations for achieving the agreed

outcomes" (Case-Smith, 2015, p. 56). Coaching is a component of collaboration and family-centered care that maximizes independent functioning in the family unit (Dunn et al., 2012). With the use of coaching, therapists can strengthen the caregiver's confidence and competency, facilitating engagement and motivation to create positive therapeutic outcomes independently. The coaching model is focused on shifting the power from the healthcare professional to caregiver in order to promote a positive, therapeutic interaction (Case-Smith, 2015; Little et al., 2018). With this in mind, it is the family whom are in charge of setting goals for their child, not the healthcare professional (Little et al., 2018). The coaching model is similar to family-centered practice as it is rooted in trust, open communication, and respect, promoting a positive collaboration between the family and the therapist (Case-Smith, 2015). These components of the coaching model will lead to an increased likelihood of caregiver engagement, competency, and overall satisfaction with therapy services.

There are six steps used to guide the process of the coaching model (Little et al., 2018). These steps include: (a) setting goals, (b) exploring options, (c) planning action, (d) carrying out the plan, (e) checking performance, and (f) generalizing (Little et al., 2018). There are various strategies a therapist can apply to engage caregivers in the coaching process. Case-Smith (2018) identified the use of reflective statements and questions to facilitate discussions as a main strategy used by therapists implementing the coaching model. When facilitating these discussions, therapists promote problem-solving, resulting in caregivers becoming more aware of the child's problem areas (Case-Smith, 2018). This enhances caregivers' ability to further analyze the problem, identify goals for their child, and suggest possible strategies to address the problem (Case-Smith, 2018).

The combination of parent-identified strategies and goals, parent-implemented interventions, and evaluation of the strategies in the child's natural context is what makes the coaching model unique (Little et al., 2018). Engaging caregivers throughout the occupational therapy process, from evaluation to discharge, results in more successful and positive services for the child (Case-Smith, 2015; Little et al., 2018). "Coaching is a strength-based and family-centered model of service delivery with the potential to build self-efficacy and self-determination in families and children" (Case-Smith, 2015, p. 58), as the caregivers are more aware of their child's strengths, and are more likely to increase carryover of the strategies identified to home.

Relationship-based approach is a commonly used approach in pediatric occupational therapy, especially in the neonatal intensive care unit. There remains to be a clear definition of relationship-based approach; however, the main focus of this approach is the caregiver-child relationship, emphasizing the strengths of the child and enhancing the caregiver-child interactions (Barfoot, Meredith, Ziviani, & Whittingham, 2017). Relational connectedness enhances therapeutic outcomes and engagement for both caregiver and child, as well as enhancing crossover to therapeutic practices to the home environment (Barfoot et al., 2017). Two key phases are most apparent in this approach regarding children with developmental disabilities. The first phase focuses on the interaction between caregiver and child, encouraging positive interactions in order to best enhance development in the child (Barfoot et al., 2017). The second phase consists of developmental guidance provided by therapist, while continuously following the relational framework (Barfoot et al., 2017). This focus was initially used in infant health care services but is becoming more common in pediatric care for children with

developmental delays (Barfoot et al., 2017). This model is suitable when engaging caregivers in their child's pediatric occupational therapy, as it can reciprocally enhance caregiver engagement and the child's engagement (D'Arrigo et al., 2017). However, Relationship-based approach remains an emerging approach in pediatric care, and there is a need for further research regarding its use and effectiveness with developing children.

The Self-Determination Theory is a theory used to understand and promote engagement in therapy (D'Arrigo et al., 2017). This theory examines engagement consisting of three components: affective, behavioral, and cognitive (D'Arrigo et al., 2017). Within these three components, the Self-Determination Theory has a focus on autonomy, relatedness, and competency support (D'Arrigo, et al., 2017). Collaborative goal setting, building rapport, therapeutic alliance, and setting attainable goals are all examples of therapeutic methods of supporting caregiver's basic psychological needs and enhancing active engagement in the child's therapy (D'Arrigo et al., 2017). The Self-Determination Theory, used jointly with the Synthesis of Child, Occupational Performance, and Environment-In Time framework, incorporates these basic psychological needs, in order to utilize motivation to promote engagement (D'Arrigo et al., 2017).

Conclusion

The goal of occupational therapy is to maximize functional independence in clients' lives. The client in the pediatric setting is defined as the child and the family unit. Caregivers in the family unit are direct supports of the child and are able to provide unique insights and knowledge into the overall functioning of the child on a day to day basis. Caregivers are critical, often overlooked, members of the pediatric

multidisciplinary team. In order to address the needs and functioning of the child and the family unit, occupational therapy practitioners must collaborate with and engage the caregiver throughout the occupational therapy process. Engagement is a complex, multi-faceted element in healthcare, specifically therapeutic settings. Engagement of caregivers in therapy has a positive correlation to increased caregiver satisfaction, child engagement, and therapeutic outcomes (D'Arrigo et al., 2017; Waldman-Levi et al., 2017). However, there remains a need to define the role of the caregiver and develop a standardized program to engage caregivers in the complete occupational therapy process in pediatric care, thus enhancing family-centered practice (Darrah et al., 2010). Although there are various barriers that may inhibit caregivers' engagement, there are many motivational factors and strategies to support caregivers' engagement in the occupational therapy process. Engagement of caregivers in therapy is positively correlated to carryover of learned skills in the therapeutic environment to the natural environment, especially in regard to compliance of home programs (Case-Smith, 2015; Patton & Hutton, 2016; Rone-Adams et al., 2004). Due to the high rate of noncompliance and stress experienced by caregivers, occupational therapy practitioners must use best practice methods to promote overall engagement of caregivers, promote successful therapeutic outcomes, and address the family's needs (Rone-Adams et al., 2004). The engagement of caregivers in pediatric occupational therapy will positively enhance the overall health and wellbeing of the child, caregiver, and family unit.

CHAPTER III

Methodology

The authors of this scholarly project have a passion for occupational therapy and children, as they both chose to complete an optional level II pediatric fieldwork experience in an outpatient setting. Following this experience, coupled by various other experiences working with children with disabilities, the authors became aware of the challenges faced by families of children with disabilities. When reflecting back on their fieldwork experiences, the authors noticed a disconnect in occupational therapy practice as they observed many caregivers not being involved in their child's treatment. The authors observed that either caregivers chose to wait in the lobby or that therapists asked them to wait in the lobby during the therapy session. Caregivers are often not involved throughout the therapeutic process of their child's care, ultimately affecting the therapeutic outcomes of the child (Case-Smith, 2015; D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017; Rone-Adams, Stern, & Walker, 2004; Watts Pappas, McLeod, McAllister & McKinnon, 2008). As a result of the disengagement, caregivers lacked the confidence and knowledge to transfer skills learned in the therapeutic environment to the home environment. This disconnect sparked an interest in the authors, leading to a desire to further investigate the engagement of caregivers in the therapeutic process.

Authors conducted an initial literature review following reflection and discussion of problems identified in practiced. Scholarly articles were retrieved from databases such

as CINAHL Complete, PubMed, OT Search, and American Journal of Occupational Therapy (AJOT). The authors used search words such as "Family-centered care AND occupational therapy" "family-centered care AND engagement AND caregiver "caregiver engagement AND pediatric therapy," "engagement AND occupational therapy AND pediatrics," "occupational therapy AND models AND engagement," "engagement AND therapeutic outcomes," "engagement AND assessment tools," and "collaboration AND occupational therapy AND caregiver." Articles were critiqued using both qualitative and quantitative charts that were provided by the University of North Dakota. This critiquing process ensured the authors used evidenced-based information that was relevant to the topic in order to complete their project.

Information obtained was organized into sections of the outline that included: (a) background information, (b) caregiver/therapist barriers, (c) caregiver/therapist perspectives on engagement, (d) methods of engagement, and (e) models and theories for caregiver engagement. A thorough analysis of the information was completed by the authors. The analysis of information indicated multiple best practice and evidence-based strategies to engage caregivers in their child's occupational therapy services. In addition to having multiple best practice methods, it was also discovered that novice therapists are less confident in their ability to effectively engage caregivers in the therapeutic process (Watts Pappas et al., 2008). This led to the authors' decision to write an *OT Practice* article and create in order to inform novice therapists of the current best practice methods found in the literature. In addition to the *OT Practice* article, the authors created a handout to highlight the role of both the caregiver and therapist throughout the therapeutic process. Simultaneous education of both the therapist and caregiver role will

facilitate a collaborative relationship. It is anticipated that this handout will be utilized by caregivers in outpatient pediatric clinics that are associated with the University of North Dakota's Occupational Therapy program.

The authors chose the Adult Learning Theory of Andragogy to guide the scholarly project and development of the product. This theory emphasizes adult learning concepts, such as: (a) individuality, (b) internal motivation, (c) learning from past experiences, and (d) independent learning (Merriam, Caffarella, & Baumgartner, 2007). This theory was chosen in order to guide the product towards the adult learning audience of caregivers and occupational therapy practitioners.

The individuality of adult learners is addressed through the use of different learning methods: an article and handouts. The adult learners will be internally motivated to utilize these resources as they can be accessed through the outpatient clinics or the nationally published *OT Practice* magazine. The authors utilized case study examples within the *OT Practice* article to target past experiences and independent learning to apply knowledge to situations practitioners may see in practice. Independent learning and individuality are mainly targeted within the handout. The handout targets the individuality and past experiences of both caregiver and practitioner with concepts that apply and are may be familiar to each adult learner. The learning concepts of the Adult Learning Theory of Andragogy can be seen throughout the products developed, targeting the individual adult learning styles of caregiver and occupational therapy practitioner.

The authors began writing the *OT Practice* article by stating the importance of engaging caregivers in an outpatient pediatric therapy setting and the positive effects on therapeutic outcomes. The authors then stated and explained problems identified

throughout the literature review. This will provide the therapist a reason to continue reading in order to learn the best practice methods for engaging caregivers in practice. The authors then chose to describe the barriers of engagement from both the caregiver and the therapist perspectives. After describing the barriers to engagement, the authors created a visual image chart of "strategies for caregiver engagement in the OT process." The authors listed strategies that were identified in the literature for evaluation, intervention, and overall outcomes. Lastly, the authors created a case study to provide an example of a novice therapist facilitating engagement of a caregiver with the use of best practice strategies provided. Authors hope that the best practice strategies provided in the articles will enable adult learning of the novice therapist to engage caregivers in their child's therapy.

CHAPTER IV

PRODUCT

The purpose of our product is to raise awareness of the need for caregiver engagement in pediatric, outpatient occupational therapy and identify best practice principles for caregiver engagement. After completing a literature review, the researchers were able to identify the importance of engageing caregivers in the occupatinal therapy process, identify barriers to engagement, and lastly, identify strategies to promote best-practice when engaging caregivers. The researchers discovered engaging caregivers in the therapeutic process not only increases engagement of the child, but positively increases therapeutic outcomes (D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017). Although there is a positive correlation between engaging caregivers and therapeutic outcomes, there is a disconnect in practice as there remains a lack of caregiver engagement in pediatric therapy. In order to raise awareness of this disconnect in pracitce, the researchers created an *OT Practice* article for their first product to educate occupational therapy practitioners of their findings.

The researchers discovered that many caregivers report limited time in their busy schedules to attend therapy sessions and are often under the impression that the therapist is the "professional" and there role is limited to dropping their child off at therapy (Patton & Hutton, 2016; Rone-Adams et al., 2004; Watts Pappas et al., 2008). Many caregivers believe they would be in the way during the session, therefore often wait in the waiting room or leave during the session. It was also discovered that caregiver stress levels also

play a role in their ability to engage in therapy sessions and carry over learned skills in the home. When looking at therapist barriers, it was also discovered that time was a perceived barrier to engaging caregivers, as they would have to explain the reasons why they are doing something or teach the caregivers specific strategies during the intervention session. We was also discovered that lack of therapist confidence and experience are key barriers to engaging caregivers. Novice therapists are less likely to engage caregivers in the therapy process due to decreased confidence in their clinical abilities.

When evaluating the caregiver and therapist perspectives about engagement, the researchers discovered mixed results. There was a discrepancy of caregiver perspectives toward there willingness to engage in therapy sessions. Many caregivers reported a desire to be involved in the therapeutic process where as other caregivers who believed it is the complete responsibility of the therapist. Egilson (2010) discovered through the qualitative study he conducted that many caregivers believed the therapists offered useful information, instructions and recommendations throughout the process where as some caregivers reported there was a lack of communication regarding goals targeted in therapy and specific interventions conducted. Due to the lack of OT literature, Watts Pappas, McLeod, McAllister, & McKinnon (2008), conducted a study examining the perspectives of speech therapists and discovered that 98% of therapists strongly agree or agree that parental involvement is essential during the intervention process to ensure successful outcomes, 89% of therapists believed that the family-unit was considered the client, and only 42% of therapists believed that the caregivers should have the final say in the goal setting process.

In order to address these needs, the researchers compiled best-practice strategies for caregivers to use in practice. These strategies include: (a) having open communication between the therapist and caregiver, (b) discussing assessment results in a way caregivers understand, (c) addressing caregiver concerns, (d) using the tech back method during intervention sessions, (e) collaborate with the caregiver to create home programs, (f) offering support and guidelines to address caregiver stress levels and (g) directly and openly address expectations, concerns, and satisfaction (Case-Smith, 2015; D'Arrigo et al., 2017; Egilson, 2010; Patton & Hutton, 2016; Rone-Adams, Stern & Walker, 2004; Watts Pappas et al., 2008).

The Adult Learning Theory of Andragogy (Merriam, Caffarella, & Baumgartner, 2007) was used to guide the process of writing the *OT Practice* article. The article is designed to promote individuality of the therapist by providing multiple best practice strategies for them to integrate into their practice. The concept of experiential learning is also addressed as there is a case study in the article that illistrates how these strategies could be used in practice to promote engagement. The concepts of internal motivation and independent learning are addressed as occupational therapy practitioners are going to seek out this article on their own time to learn about the benefits of caregiver engagement, therapist and caregiver perspectives toward engagements, barriers to engagement, and the best practice strategies that have been compiled together from a literature review.

The second product the researchers created was a handout to highlight the role of both the therapist and caregiver throughout the therapeutic process. This handout is intended to inform both the therapist and the caregiver of their role throughout the therapeutic process. It is hoped that informing both the therapist and the caregiver will promote collaboration, thus increasing

therapeutic outcomes of the child. The full products are presented in their entirety on the next page.

OT Practice Article

Engaging Caregivers in Family-Centered Pediatric Occupational Therapy

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Engaging Caregivers in Family-Centered Pediatric Occupational Therapy

Abstract: The purpose of this article is to raise awareness of the need for caregiver engagement in pediatric, outpatient occupational therapy and identify best practice principles for caregiver engagement. Pediatric occupational therapy is a family-centered service, but there remains a disconnect in practice with decreased caregiver engagement. Caregiver engagement is essential to family-centered care, as an increase in caregiver engagement increases the child's engagement, therefore increasing overall positive therapeutic outcomes (D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017). Authors have outlined the need for caregiver engagement, with best-practice strategies. Best practice strategies to engage caregivers are identified and utilized throughout a case study. This article is guided by Adult Learning Theory of Andragogy to target the learning needs of occupational therapy practitioners (Merriam, Caffarella, & Baumgartner, 2007).

Keywords: Family-centered, caregiver engagement, pediatric therapy

Occupational therapy practitioners working in the pediatric setting play a key role in maximizing independence and increasing quality of life of children and their families. Family-centered care in pediatric occupational therapy involves engagement of both the caregivers and children in the therapeutic process. Engaging caregivers in the therapeutic process not only increases engagement of the child, but positively increases therapeutic outcomes (D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017). Although there is a positive correlation between engaging caregivers and therapeutic outcomes, dthere is a disconnect in practice as there remains a lack of caregiver engagement in pediatric therapy. Only 38% of caregivers report being able to make the final decisions about their child's goals (Watts Pappas, McLeod, McAllister & McKinnon, 2008). As a result,

caregivers are often not involved in intervention sessions. According to Rone-Adams, Stern, and Walker (2004), it is estimated that approximately 50% of parents do not comply with recommended therapeutic programs, 66% of caregivers report some level of non-compliance, and only 34% of families follow the home programs. Lack of engagement in intervention sessions results in a high rate of nonadherence, which ultimately leads to decreased therapeutic outcomes (Case-Smith, 2015; Rone-Adams et al., 2004).

Engagement is a critical element to the therapeutic process in occupational therapy when working with children and families. Engagement is seen on a continuum in healthcare as deliberate efforts clients make to positively benefit from the care they receive (Carman et al., 2013). In view of this, engagement of a caregiver is seen as their deliberate efforts for their family and child to benefit from therapy. The therapist's role in engagement includes involving caregivers in each step of the therapeutic process, as well as addressing their concerns and communicating throughout.

In order to achieve positive outcomes across various pediatric settings, it is essential to collaborate with the caregivers (Case-Smith, 2015). Despite the push towards family-centered care, the caregivers are often overlooked members of the team. Occupational therapy practitioners need to incorporate the caregiver's unique insight and understanding of their child and collaborate with them to guide the therapeutic process (Waldman-Levi, Hirsch, Gutwillig, & Parush, 2017). Therefore, the clinical expertise of the occupational therapy practitioner, jointly with the knowledge and engagement of the caregiver, is the optimal approach to ensure positive therapeutic outcomes for the child and overall functioning of the family

Barriers of Engagement

Both caregivers and occupational therapy practitioners are faced with barriers that inhibit effective engagement in the therapeutic process. The most commonly faced barriers for caregiver engagement include: (a) lack of time, (b) increased stress, and (c) lack of understanding regarding their role and the therapy process (Patton & Hutton, 2016; Rone-Adams et al., 2004; Watts Pappas et al., 2008). Many caregivers view the occupational therapy practitioner as the expert; therefore, engagement diminishes due to lack of confidence and communication (Stefandottir & Egilson, 2016; Jahagirdar, 2013). The therapeutic process can be overwhelming for many caregivers if the occupational therapy practitioner does not actively encourage engagement and communication, which may result in parents taking a step back from their child's care.

Occupational therapy practitioners, specifically novice practitioners, face barriers that inhibit engagement of caregivers. Watts Pappas et al. (2008) suggested new graduates have lower confidence in their clinical abilities and are less likely to include caregivers in the therapy process. Common therapist barriers include overall lack of experience, confidence, and time constraints (Watts Pappas et al., 2008). Many novice occupational therapy practitioners lack awareness of the best practice methods for how to effectively engage caregivers in therapy sessions. This implicates a need for educators to prepare occupational therapy students with the knowledge and skills necessary to implement family-centered care through collaboration and a strength-based approach (Egilson, 2010). This is crucial as it is the therapist's responsibility to overcome barriers in order to properly engage caregiver and child.

Due to the various barriers identified and lack of knowledge of best practice,

authors have compiled the following sections of best practice methods in literature to engage caregivers throughout the occupational therapy process. There is not one clear approach for engaging caregivers, as the needs of each family unit are multi-faceted and complex. Various best practice strategies for engagement of caregivers in the evaluation, intervention, and outcome process of occupational therapy are presented in ***Table 1***.

Table 1: **Strategies for Caregiver Engagement in the Occupational Therapy Process**

Evaluation
• Discuss assessment results with the caregivers in a way they understand • Assess the caregiver's readiness to accept information • Actively listen, observe and be flexible regarding how much information to share • Have open conversations about caregiver's main concerns • Use evidence-based and family centered assessments to set goals with the caregivers - Canadian Occupational Performance Measure (Law et al., 2005) - Family Centered Care Assessment (Wells, Bronheim, Zyzanski & Hoover, 2015)
Intervention
• Encourage the caregivers to come to the activity area vs. waiting in lobby • Use the coaching method to instill confidence in caregivers and enable hands-on learning • Use the "teach back method" when teaching something new • Collaborate with caregiver to create home program that fits their needs • Offer support and guidelines to reduce caregiver stress levels • Video record sessions if caregiver cannot attend • Implement a 2-way mirror to allow caregivers to observe sessions
Outcomes
• Facilitate the use of reflective and open discussion • Directly and openly address expectations, concerns, and satisfaction • Regular and continuous communication with specific review of goals

Case Scenario:

Henry is a 5-year-old boy diagnosed with Autism Spectrum Disorder (ASD). He is active and loves to play with his penguin toys, read books, and watch penguin movies. He exhibits deficits in sensory processing and delayed integration of reflexes. He dislikes

hygiene tasks such as showers, teeth brushing, handwashing, haircuts, and combing hair. Henry's verbal communication is limited to approximately six words. Jenny, his occupational therapist is in her first year of practice. The following case study illustrates Jenny's experience in applying a family-centered approach to the occupational therapy process.

Evaluation:

Jenny initially meets with the primary caregiver of Henry, his father. During the evaluation, the father appeared hesitant in setting goals for his son and comments that Jenny is the expert. He is unsure of his role as a caregiver in the therapeutic setting. Jenny often uses medical terminology the father does not understand. He rarely offers input to the goal settings process, as he does not understand what type of goals occupational therapists work towards and does not want to "sound stupid." Jenny struggles to communicate with the father through the evaluation process. She reflects on her experiences in practice and notices initial goals are often based upon deficits observed in the evaluation setting, as opposed to family-centered and strengths-based approach. She invites the father to the therapy room in the next session. She describes the purpose of occupational therapy and the assessment results in a manner he can understand, relating it to functioning in the home environment. Jenny uses coaching to instill confidence in the father by informing him that he is the expert on Henry's behaviors, not her. She attempts to develop a therapeutic relationship with the father, in which he is comfortable to provide feedback and ask questions. The therapist openly communicates and collaborates with the father, incorporating his unique insights and evaluation data in order to set strength-based goals for Henry. The father identifies goals for his son as: (a) making the

family routine easier, (b) getting dressed, (c) going to the bathroom, and (d) finishing his homework.

Intervention:

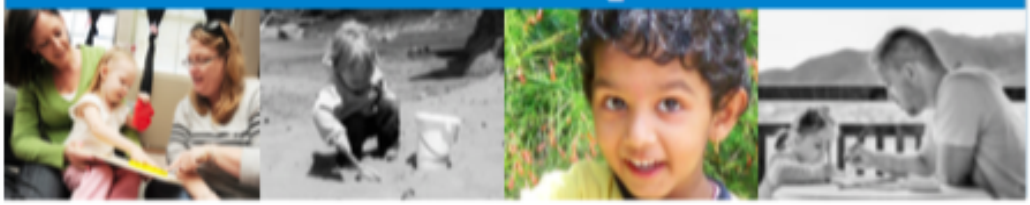
Throughout the school year, Jenny sees the father irregularly. He is working two jobs and Henry is often dropped off by the respite staff who wait in the lobby during the session. Jenny notices Henry's difficulty reaching his set goals. Skills learned in the therapeutic environment are often not carried over to the natural environment due to lack of communication and follow-through on home programs. Jenny implements a communication log of a synopsis of the session, progress towards goals, and feedback that can be used in therapy and taken home by respite staff to be given to the father. Although this method somewhat facilitates communication, there remains a lack of follow-through and engagement of father and child in therapy. Jenny adjusts the intervention by setting up a time to communicate with the father through a telehealth method once every other week. This method allows the father to express his concerns and Henry's progress at home, as well as allow Jenny to provide support and guidelines, reduce caregiver stress, and increase carryover of skills. Jenny and Henry begin working on positioning during daily activities, such as strategies for dressing, toileting, and completing schoolwork, in order to integrate reflexes. Jenny uses telecommunication to effectively demonstrate these strategies to the father. Jenny begins to utilize a family device, following consent of the father, to videotape sessions for the father to understand and implement certain techniques.

Conclusion:

Jenny was a novice therapist and was initially unsure of how to approach the situation. She utilized trial and error by implementing various techniques identified in ***Table 1*****.** Throughout evaluation and intervention, she continually incorporated various aspects of a therapeutic relationship with the father, such as: (a) open communication, (b) describing aspects in terms understood by family, (c) instilling confidence, (d) allowing time for feedback and communication. These steps were essential in the first sessions with the family in order to have a therapeutic environment and set goals. She then incorporated various techniques into the intervention to bridge the gap in communication. Although the communication log was helpful, the use of telecommunication, video recording, and continued open communication with feedback ensured follow through and decreased stress levels of both family and therapist.

HANDOUT

A Collaborative Therapeutic Process



CAREGIVER ENGAGEMENT IS AN ESSENTIAL COMPONENT when working with children and their families. Engagement in an outpatient occupational therapy setting includes involving caregivers in each step of the therapeutic process, as well as addressing their concerns and communicating throughout. Engaging caregivers in the therapeutic process not only increases engagement of the child but also positively increases therapeutic outcomes. There is no single best-practice method for engaging caregivers, as the needs of each caregiver and child are multi-faceted and complex.

Therapeutic Process	Therapist	Caregiver
Evaluation	Explain assessments results in a way the caregiver understands Provide information in small sections at a time Ask the caregivers what their main concerns are regarding their child Use assessments to facilitate collaboration	Ask questions about assessment results if you do not understand Let the occupational therapist know if you feel over whelmed and need time to process information Openly tell the OT what your main concerns are regarding your child Provide objective information to answer the questions
Intervention	Invite caregiver to come back to therapy Encourage the caregivers to participate and verbally talk the caregiver through ways to facilitate participation of the child Use the "teach back" method when teaching the caregivers something new	Ask to come back to therapy Don't be afraid to participate during the therapy sessions Communicate understanding of the information and ask clarifying questions if you need further explanation.

Therapeutic Process	Therapist	Caregiver
Intervention Continued	Offer caregiver support by asking how they are doing. Create a space for caregivers to observe therapy sessions. Ex: using a two-way mirror Include the caregiver to create a home program to fit the family's needs If caregiver is unable to attend the session, facilitate communication following therapy; ex: Using a family device to video record session or call caregiver to discuss details	Discuss stressors you are facing with the therapist Observe strategies used by therapist when working with your child and ask specific questions Ex: why did you made him reach for the crayon across his body? Share information about the child's routine and preferences and discuss feasibility of home program Read the therapist's notes and practice strategies implementing at home
Outcomes	Facilitate the use of reflective and open discussion Gather feedback on the caregiver's perceptions of child's progress in therapy Facilitate communication each week during sessions; ex: How did he/she do last week with the home exercises?	Be open and honest with the therapist Give the therapist feedback on the child's progress, your satisfaction and express concerns you are still having about the child Update the therapist about the child's functioning and progress during the week regarding the therapy goals

Created by: Sidney Carlson, MOTS, Sarah Schwartz, MOTS & Sarah Nielsen, PhD, OTR/L

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CHAPTER V

SUMMARY

The purpose of this product was to raise awareness of the need for caregiver engagement in pediatric, outpatient occupational therapy and identify best practice principles for caregiver engagement. A literature review was completed to identify the need for caregiver engagement in family-centered pediatric therapy. Evidence indicates engagement of caregivers increases engagement of child, therefore increasing overall positive therapeutic outcomes (D'Arrigo, Ziviani, Poulsen, Copley, & King, 2017). However, there remains a disconnect in practice between family-centered service and engagement of caregivers. The products created to address this need consist of an *OT Practice* article and a handout designed for practitioners and caregivers. The products were guided by the Adult Learning Theory of Andragogy (Merriam, Caffarella, & Baumgartner, 2007). Adult learning concepts were utilized and incorporated throughout the products in order to educate the adult learners of caregiver and practitioner.

There are few limitations to this product. The focus of this product is to raise awareness of the need for caregiver engagement and provide principles of implementation. A limitation of this is that it does not outline specific steps for caregiver engagement. However, with the awareness raised by this product, practitioners are encouraged to continually research and implement family-centered guidelines to engage caregivers. A second limitation is the guiding Adult Learning Theory of Andragogy. This theory was suitable fit the majority of the target audience, but it utilizes basic adult

learning concepts. With the use of this theory, one may assume that all learners learn the same, and it does not consider gender, race, or class (Merriam et al., 2007). Lastly, there was a lack of occupational therapy specific literature. The literature review and products utilized literature sources relating to speech language pathology and physical therapy. However, these sources remain pertinent as it was a family-centered service or an outpatient pediatric setting. Family-centered service and engagement of caregivers is essential across disciplines.

Authors plan to submit the *OT Practice* article written to reach a wide audience across the nation to raise awareness of the need for caregiver engagement. Authors plan to have the handouts designed for caregiver and practitioner critiqued by local pediatric occupational therapy practitioners in the area. Following these critiques and possible revisions made, authors propose to distribute these articles through the fieldwork database of the University of North Dakota Occupational Therapy Program.

The hope is that these products raise awareness of the need for caregiver engagement in pediatric outpatient occupational therapy. By utilizing these products, practitioners may facilitate caregiver engagement, enhancing overall family-centered service and the culture of family-centered care in the outpatient setting. It is recommended that practitioners continually research and implement family-centered strategies to improve the quality of the lives of both caregiver and child. It is also recommended that caregivers utilize the handout provided to introduce family-centered service, creating an environment of open communication and coordination with the caregiver.

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