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Title: Health Literacy in Early Intervention:

Assessing Documentation of E.I. Therapists

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Abstract

This doctoral capstone experience aimed to explore the readability of early intervention therapist notes to improve health literacy in a pediatric therapy clinic. As defined by the American Occupational Therapy Association (AOTA) health literacy is "the ability of individuals to gather, interpret, and use information to make suitable health-related decisions" (AOTA, 2011). Documentation was evaluated from each of the four disciplines represented at this clinic including occupational, physical, speech, and developmental therapies. Therapy notes from each child were evaluated over a three-month period. This information was then entered into an online software that generates a readability score based on the grade level of the writing. Documentation should aim to be written at a 6th-8th grade level (Smith & Gutman, 2011). Averages over all four disciplines ranged from a grade level of 5.6-15. These outcomes emphasize the importance of health literacy specifically for this setting. Overall, this doctoral capstone experience looked to establish a way in which to improve health literacy for the clinic to ensure quality services are being provided to the pediatric client and their family. This paper further examines the implications of health literacy on early intervention therapists and families.

Literature Review

The American Occupational Therapy Association (2011) defines health literacy as, "the ability of individuals to gather, interpret, and use information to make suitable health-related decisions." Health literacy affects all areas of health care as we encourage patients, parents, and caregivers to obtain the best information for their own health and wellbeing as well as that of the individuals they are caring for. There are multiple components to health literacy described in the Health Literacy Guidebook (2014) as schooling, general literacy, culture, language, personal history, state of mind, illness, medication side effects, eyesight, stress, and degree of trust. They further explain that health literacy isn't just the ability to read and write. We need to, as a population, have the ability to read prescription labels, understand instructions from doctors and other health professionals, follow through with referral information, and have a basic understanding of our results from testing. These skills allow for more clear communication between the patient or client and the health professional (Abrams et al, 2014). The purpose of this literature review is to examine current resources surrounding the topic of parent health literacy and how parent's literacy affects carry over of treatment at home.

Health Literacy and Occupational Therapy

Health literacy and occupational therapy are complimentary to each other. As a profession, we strive to understand how an individual's abilities coincide with their context and interactions in each situation. One of the key factors of health literacy is encouraging individuals to develop more control over their own health (Levasseur & Carrier, 2012). Levasseur & Carrier (2012) describe how health literacy may be a more appropriate predictor of health status than, "education, socioeconomic status, employment, race, or gender." If an individual has poor health literacy they may be less likely to use health services thus impacting economic, social, and

cultural factors. Levasseur and Carrier (2012) give an example that if a therapist asks you not to use the stairs but you continue to use them anyway due to lack of understanding of the given instructions and then suffer an injury, then this behavior overtime leads to more health services being used that could be prevented. Countries such as the United States, Australia, and Canada have an estimated 40-60% of their populations falling within a low health literacy level (Levasseur & Carrier, 2012). On average, an American citizen reads at a 6th grade level, but most health information is written at a 10th grade level (Smith & Gutman, 2011). Another study by Keim-Malpass, Letzkus, and Kennedy (2015) found that nearly 36% of adults in the United States have limited health literacy and this number is closer to 50% with individuals from low-income backgrounds. The above researchers state that limited health literacy of adults is a key indicator of adverse health outcomes such as increased measures of morbidity, poor adherence to medications, limited levels of shared decision-making, more unintended readmissions, and higher utilization of health care resources compared to adults with more functional levels of health literacy (Keim-Malpass, Letzkus, & Kennedy, 2015). As a whole, our population would benefit from an increase in health literacy to improve overall quality of life in the United States.

As a profession, occupational therapy would benefit from working to improve health literacy in order to generate increased carryover and understanding of treatment either for the direct therapy recipient or the parent of a child. In 2011 the *American Journal of Occupational Therapy* published an article by Dr. Diane Smith and Dr. Sharon Gutman in which the issue of health literacy in occupational therapy practice was specifically addressed. Smith and Gutman (2011) discuss that as a profession we have the ability to make a difference in the promotion of client health literacy. This is accomplished through the unique lens of occupational therapy when looking at the person, environment, and occupation of each individual. The article also provides

an example of looking at each of these aspects, "…the complex interaction of the person and the health care environment and how this interaction facilitates or hinders performance of the tasks necessary for people to effectively manage their health" (Smith & Gutman, 2011, p.368).

Family Centered Care

Historically health professionals have focused on bringing changes to the child as separate from the family. In the 1970s and 1980s this changed to what we expect to see of parents today which is parents carrying on the treatment programs at home (Hanna & Rodger, 2002). This is especially important in early intervention services (birth to three) where the therapist works with the child for one hour each week thus requiring the parents to follow through with therapy to see major gains. Hanna and Rodger (2002) describe this idea of family-centered care specifically in early intervention settings in order to provide optimal care to the child. Parenting, from an occupational therapy perspective, is an occupation, also known as an everyday activity that brings purpose and meaning to one's life. Therapists need to be understanding of parents' perspectives on parenting and the impact of therapy on the parenting process (Hanna & Rodger, 2002). Without this viewpoint, we are unable to truly establish a family centered approach to therapy.

Health Literacy of Parents

Health literacy of parents can have unforeseen impacts on a therapist's goals. Hassan and Heptulla (2010) specifically looked at parents who have a child with the diagnosis of diabetes. They found that parents with lower levels of health literacy led to their child having a higher A1C (blood test to diagnose diabetes) number of 10.4% than individuals with adequate health literacy who had an A1C number of 8.6%. This specific example details the effect of parent literacy on the child. A similar study involving children with glaucoma found that decreased

parent health literacy contributed to decreased medication adherence (Freedman et. al., 2012). It is also important to have a good understanding of the health literacy of each individual parent. Lyons, O'Malley, O'Connor, and Monaghan (2010) examined the expectations and experiences of parents who had children receiving early-intervention services. Parents felt uncertain what role they would play in therapy and if they were expected to follow through on exercises with the child at home. According to Smith and Gutman (2011) nearly half of all Americans have problems understanding and following through with given health information.

Throughout this project I will be using the Model of Human Occupation (MOHO) to guide my thinking. The design of this model focuses on the volition of the individual. Our volition, or internal drive, guides what we do with our time spent in occupations (Kielhofner, Burke, & Igi, 1980). This will correlate with my project in that my goal is to determine how to adapt therapists notes to better suit the needs of the parents. The therapists already have the internal drive to improve the lives of their pediatric clients. My hope is that the therapists see a carryover in treatment from parents, thus encouraging them to continue to adapt their note writing. This model can be used as a framework to guide therapists into determining not only their own internal volition, but also the volition of the child and his or her family members.

In conclusion, literature was found that addressed health literacy in occupational therapy, family centered care, and health literacy of parents. Pediatric occupational therapy relies heavily on the buy-in and understanding of parents. Health literacy coincides with occupational therapy in that through therapy we are looking to address the individual to provide the best possible outcome while health literacy looks at providing the best outcomes of an individual through understanding their own health. Family centered care is an important tenant of early intervention services. Families are often unsure of their role when they have a child receiving early

intervention services. As previously stated, in the United States the average adult is reading at a 6-8th grade level. It is important for therapists to recognize this as they complete documentation for families. There is ample literature on health literacy in pediatrics among the nursing and speech therapy perspectives, but little that addresses occupational therapy. In the studies that did address pediatric occupational therapy and health literacy they focused more on one specific diagnosis. This doctoral capstone experience will examine occupational, physical, speech, and developmental therapists early intervention notes to determine their current level of readability. This will be compared to the national average reading level of the American adult. Therapists will be educated on ways to adapt their documentation to better suit the needs of the parents with the hope that parents will be more likely to carryover treatment at home to provide better outcomes for the pediatric clients.

Screening and Evaluation Processes

A random selection of three therapists from each discipline were contacted via email to describe the reasoning and details of the project. A letter of agreement was attached to this email for each therapist to sign allowing the student to access the providers early intervention notes. After receiving signed approval from the therapists, the early intervention documentation was reviewed for one client covering a three-month time period. Each note was then transcribed into an online program called Readable (www.readable.io) that establishes the reading level of the note. This website assesses the average reading level of text and offers suggestions for how to simplify the text (Conquer Your Readability Today, 2018). Suggestions are highlighted in the note and tips are given to make the text more readable. Each therapist's notes over the three-month time period were compared to find the average reading level with comparisons made to the national average.

As mentioned above in the literature review the average reading level of an adult in the United States is at a 6th-8th grade level, while most health information is written at a 10th grade level (Smith & Gutman, 2011). The impact of low health literacy affects each discipline of therapy. Pediatric occupational therapists have the opportunity to adapt their note writing and handouts to improve health literacy in order to promote the optimal environment for learning and growth of both the child and the parent (Levasseur & Carrier, 2011).

Impact of Low Health Literacy

The impact of low health literacy affects multiple facets of therapy. Rehabilitation professionals put focus on the capacities, functioning, participation, and empowerment of clients in their everyday lives (Levasseur & Carrier, 2010). Improving health literacy of individuals, or making our information suitable to the individual's needs could lead to an increase in the general populations health, decline in the use of health services, reduction in average costs of treatment, decline in work accidents, increased productivity, growth in the economy, and an overall reduction of health inequities (Levasseur & Carrier, 2010). These are a few examples that highlight the importance of health literacy and are issues that were evaluated when evaluating the topic of this capstone project. A study by Frauenholtz, Conrad-Hiebner, and Mendenhall (2015) states that many health care providers did not believe that parent health literacy influenced their work. While pursuing their education, healthcare providers need to understand how health literacy can impact their work with families. Providers who adapt their services to meet the needs of the individual could possibly provide more effective services for the child and their family (Frauenholtz, Conrad-Hiebner, & Mendenhall, 2015).

Framework

The occupational therapy practice framework (OTPF-3) is the document that guides our practice. The OTPF-3 provides definitions to help the reader further understand the OT process. One of these terms is occupational performance which is, "the accomplishment of the selected occupation resulting from the dynamic transaction among the client, the context and environment, and the activity or occupation" (Occupational Therapy Practice Framework: Domain and Process, 2014). This term can be incorporated into this capstone project as the gathered information from analyzing the therapist's early intervention notes is used to collaborate with each therapist to produce more readable documentation. Readable documentation standards will be determined through best available evidence. Occupational participation is another term of value in the OTPF-3. This refers to a client on an individual or group level and the amount of assistance they need to participate in a given task (Occupational Therapy Practice Framework: Domain and Process, 2014). With this project we will be assessing occupational participation of the therapists. Participation for the therapist involves first agreeing to having their documentation utilized for the project and then accepting feedback on how to make these notes more parent applicable. The goal is that this project will lead to further occupational participation from parents of the child receiving services, but that will need to be further assessed in the future.

Further diving into the OTPF-3 allows us to examine the specific overarching roles of the therapist and the parents. This project is specifically looking at the instrumental activity of daily living (IADL), or the activity that supports daily life in the home and community, care of others. The therapists are providing care to the child to enhance their development. They are also educating their clients' parents to ensure carryover of treatment in the home. While verbal discussions occur within the home, the documentation of these discussions occurs within the

therapy note. If the parent does not understand this note, they are unable to fully participate in supporting their child through therapeutic intervention. This requires parents to use the process skill of sequencing (Occupational Therapy Practice Framework: Domain and Process, 2014). Sequencing in this regard involves the parent understanding what is being demonstrated and explained by the therapist in a logical progression of skills. If the occupational therapist wants the parent to work on their baby bringing more toys to the mouth they should walk the parents step by step through how to accomplish this. The first step in the sequence might be getting the baby to bring their hands to their mouth and exploring their fingers. The next step would be to have them grasp a toy and work on bringing the toy to their mouth. If the baby will accept it, they could also work on accepting a pacifier.

Health Literacy in the Other Settings

Health literacy looks different within individual settings of occupational therapy. In early intervention, as mentioned throughout this paper, the focus of health literacy is on the parents. The parents need to be able to understand the given information from the therapist in order to provide the best level of developmental care for their child. In a traditional hospital setting, the focus is placed on the actual client receiving services because they are typically an adult who is responsible for his or her own care. This leads occupational therapists to adapt education and communication style based on their work setting.

One study examined two different settings, a rehab facility and a skilled nursing facility (SNF), to determine their ability to meet the health literacy needs of the clients they serve. The results of this study by Smith, Hendrick, Earhart, Galloway, and Arndt (2010) demonstrate the impact of low health literacy in the in-patient rehab setting. They found that the average reading level of the resources they provided to clients was at a 10^{th} grade level. This is significant for

their clients in that the national average reading level is at the 6th grade level. Through the survey, they found that the clients would prefer the therapist to use plain, everyday language, instead of the medical terminology taught to each discipline in the hospital. Within the skilled nursing facility there were many areas for improvement found. These areas included maps that were not at the eye level of an individual in a wheelchair, no translation services offered, and confusing admission paperwork that was written at a grade 14 level (Smith, Hendrick, Earhart, Galloway, & Arndt, 2010). The suggestion for improvements at both facilities included reassessing the materials for clients on a readability scale, and then modifying this to the recommended reading level. The suggestions for staff improvement was that they use clearer, less medical based language when speaking with clients and families (Smith, Hendrick, Earhart, Galloway, & Arndt, 2010). This study gives a good insight into the similarities and differences between pediatric occupational therapy and adult-based occupational therapy. Looking at the OTPF-3 to compare the early intervention setting with the hospital and skilled nursing setting can give us a better understanding of how these areas differ. The occupation in a hospital or SNF is based on what the client is trying to regain in their day to day life, rather than on care of others in the early intervention setting. A more common performance skill in these settings may be looking at a client's motor skills. In an in-patient rehab center many clients are there to receive care after a medical incident such as a stroke or cardio-vascular accident. This requires the occupational therapist to assess the client's motor skills and thus how they interact with and move about their environment to perform day-to-day tasks.

Little research was found regarding health literacy in the emerging practice areas of occupational therapy. An area of interest in emerging practice areas is community therapy with older adults. This setting would likely include people with varying levels of health literacy,

making it challenging to determine the reading level of individuals in the community. One study found that a common factor among individuals with lower health literacy was their age (MacLeod et. al., 2017). With the number of older adults increasing it is important that we are aware of their understanding of their own healthcare to ensure they are receiving the full benefits of the provided service.

Implementation Phase

Each therapist who turned in a signed consent form identified one client of theirs that had reports due in either November or December of 2017 and/or January or February of 2018. This established a period of approximately three months worth of documentation to analyze. The number of notes for each therapist differed due to client cancellations. Approximately six notes from each therapist was entered into the online software, Readable.IO. This software, as mentioned above, gives the average of several different readability formulas to establish a baseline grade level for the note. Each note was independently transcribed verbatim to discover its readability. The grade levels were then entered into a word document to keep track of each note. Notes were identified by the therapists' initials and discipline (OT, PT, SLP, and DT) while client identifying information was omitted.

Once a score was given for the note the software generates a tip for each note, identifying ways in which to improve the documentation. Information is also given on a readability report that identifies factors that could improve the readability score. This information includes text statistics, text composition, text quality, content composition, and keyword density. One report for each therapist was saved to provide an example for them. After the notes were entered into the software the average for each therapist was established to determine their average writing level.

Finally, a handout was formulated that identified common items seen in the notes that could be altered to change their readability. This information was researched to provide the best evidence-based information available. Since the next clinic staff meeting will not be held until May, each therapist was emailed a copy of their results of the readability check. They were also given an attached handout that identified how to improve their note writing.

Leadership

As a doctoral student I understood the importance of improving my leadership skills and found the Doctoral Capstone Experience to be an excellent challenge. Through this project I was able to collaborate with multiple disciplines to provide the best possible outcomes for my project as well as for the work of therapists and through them the families we serve. Working with individuals who have been practicing for multiple years and perfecting their craft in their perspective fields was a daunting task, but an accomplishable one. I started the project off by sending a professional email to the therapist thoroughly describing my project and my expected outcomes. I insisted that they contact me with any questions or concerns regarding their involvement in this project.

It was important to not rely heavily on outside sources for help, but to work through problems independently as they came up. This was a big shift from being a student where you have professors as your backbone to finishing up my capstone experience and stepping out of that comfort zone. The idea for this project was developed after discussions with the co-owner of the clinic. She mentioned her interest in providing the most family centered care available to the families that use their services. Through this starting point we determined to assess the health literacy of therapy notes to go forward with increasing family centered care.

The service provision model that guided this project is the consultative model. The consultative model focuses on meeting all individuals involved in a projects needs (Dunn, 1988). With this project we focused on meeting the needs of the therapist, the pediatric client, the family, and the therapy clinic through addressing the needs of the child and the family first. This was accomplished by looking at the therapy notes to see where alterations can be made to make them more readable.

Staff Development

As a way to ensure that the staff would benefit from this project, research was found on ways to make documentation more readable. This information was then distributed to the therapists. The therapists also received the scores of each of their documents from the three month period in order to see their overall range of writing. A readability report (Readable.IO) was also given to them to show the breakdown of one of their notes. All of this information was made available to ensure the greatest carryover of the project. Each individual had varying levels of readable documentation and differed in needed changes to be made to their style of documentation. This was communicated to each of them on an individual basis as no two therapists are alike. One of the key job responsibilities of an early intervention therapist is communication with parents or guardians of their client. This project allowed us to work towards communication that is able to be understood by parents of all backgrounds.

Information on health literacy was distributed to the therapists involved in this project and made available to the entire clinical staff. Evidence-based literature allowed the student to create a handout that offered a definition of health literacy, what the importance of this topic is, how therapists can contribute to improving health literacy, and tips to improve health literacy. Tips included using plain language, respecting the cultural diversity of your client, limiting the

number of messages you are trying to get across, provide specific actions and recommendations for the reader, check for understanding using the "teach-back" method, write the way you talk, and involve the reader (Pontius, 2013, U.S. Department of Health and Human Services, n.d., and Levasseur & Carrier, 2010).

Discontinuation and Outcome

At the end of this project the overarching goal was to improve readability of early intervention notes to improve carryover of treatment in home pediatric therapy. This required specific objectives to achieve this goal. One way in which I had planned to achieve this goal was discussing with the therapists on an individual basis, either by email or in-person, the results received from Readable.IO over a three-month period of note writing. Each therapist received a word document that had the grade level of each note provided as well as possible tips on how to improve the individual notes as provided by the software. At the bottom of each document the therapist could see their average writing level. Averages over all four disciplines ranged from a grade level of 5.6 to a grade level of 15. This demonstrates the importance of educating each therapist differently. Some therapists had levels that were well within the 6^{th}-8^{th} grade level which is recommended by the U.S. Department of Health and Human Services (n.d.). Each therapist was also given a health literacy fact sheet. This sheet was created by the student to include a definition of health literacy, why health literacy needs to be a point of interest, how health care professionals can contribute to improving health literacy, and tips to improve health literacy of documentation. This sheet also provided an overview of the averages of each discipline's writing level at this specific clinic. The results are discussed below.

The speech therapists at this clinic had the highest readability level. The average of the three therapists' notes that participated was a grade level of 12.85. This number may be high due

to the fact that speech therapists need to include instructions for teaching children language, which is a high-level skill. The average of the physical therapists' notes was a grade level of 7.5. Based on reviewing these notes they may be more readable due to the skills they are looking at in therapy such as walking, standing, and kicking. Most of the physical therapists had removed words from their notes such as gait or ambulate which may be more difficult for the reader to understand. The average for the developmental therapists was a grade level of 6.3. These therapists' notes typically are focused on things that kids like to do such as playing, building, and throwing. Only one occupational therapist elected to participate with an average note writing level of 7.85. These notes included items like dressing, playing, and throwing.

Quality Improvement

The ideal plan for ongoing quality improvement is to reassess the therapist notes in the future. This would give the site an idea if the given information has been helpful to the therapists and has reduced their average writing level. The notes should be assessed approximately three months after receiving their health literacy scores and tips to improve documentation. Due to the time constraints of this doctoral capstone experience this project would have to be completed by another student or staff member. In the future, if a student attends this clinic for their doctoral capstone experience they would be able to continue with this project and take it a step further by implementing health literacy workshops, assessing the health literacy of handouts for parents, and looking at clinic notes in addition to early intervention notes. Health literacy is a topic that should be addressed by every healthcare professional, and the more we stress that to the therapists the better we will be able to serve our clients.

Occupational Therapy's Response

As the population of our country continues to increase in diversity, therapists need to continue to be sensitive to the needs of a diverse culture. There are varying races, ages, education and socioeconomic levels with each family dynamic. It is important to remain aware of the differences between families and treat each family individually to ensure quality services are being provided. Occupational therapy is one discipline that needs to respond to these changing needs of society. The American Occupational Therapy Association (AOTA) released a statement on cultural competence and ethical practice stating that, "occupational therapy practitioners should take a leadership role not only in disseminating knowledge about diverse client groups but also in actively advocating for fair, equitable, and culturally appropriate treatments of all clients served" (AOTA, 2015). This statement can and should be applied to all therapy disciplines. Health care professionals have the opportunity to be leaders in cultural competence and this includes meeting the needs of families without judgement (Buchhorn & Lynch, 2010). Best practice for all disciplines means following the principles of client-centered care and acting with cultural competence to ensure that this is not overlooked.

Overall Learning

This project allowed for development of communication skills through email and in person. As a way to provide initial interaction with the therapists in the clinic I sent a professional email. This email included information on why I was at the clinic, what I would be doing during my time there, and what my goals were. Each therapist was encouraged to contact me via phone call, email, or in person at the clinic if any questions arise. Several therapists sent back questions via email and it was determined, after discussion with my site educator, that we would discuss the concerns together and she would send the email back to her staff. This showed the therapists that their co-worker was involved in this project and understanding of the questions

they had. There were several therapists who I personally responded to in order to verbally demonstrate my excitement and commitment to this project. Questions were handled appropriately and in a timely fashion as they were received. Therapists had questions regarding HIPPA and were reassured that I was included under the HIPPA regulations of the clinic and would be following these guidelines. Also, a signed consent form was issued and returned by each therapist as a requirement for involvement in this project.

As the project came to a close, I emailed each therapist to thank them for their participation. This email also included the information promised to them including their readability scores, tips to improve their health literacy on a note-to-note basis, and a health literacy handout. Further dissemination is planned for the entire clinic staff. The next staff meeting is held in May in which this information will be shared with all therapists including those that did not participate in this project. The health literacy handout will be provided to all therapists at this meeting to give them the resources needed to improve the health literacy of their documentation.

Overall the doctoral capstone experience has been a tremendous learning experience. I have further developed skills in advocating for both myself as a future therapist as well as the parents in children in which I work with. Leadership skills have grown as I have been able to discuss my project in multiple settings and with many individuals. Scholarly dissemination is planned for an oral presentation in May, submission to journals, and poster submissions to professional conferences.

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