

PARENT'S PERCEPTION OF THE IMPACT OF
RECREATIONAL THERAPY ON THEIR CHILD'S
QUALITY OF LIFE WITH CEREBRAL PALSY

By

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Abstract: There is a need for research centered around recreational therapy, cerebral palsy, and quality of life. This study focused on one parent's perceptions of their child's quality of life with spastic cerebral palsy before and after receiving recreational therapy treatment. The PedsQL™ Infant Scales was utilized for this study in a pretest/posttest case report. Data was collected from the participant at a health center in Stillwater, Oklahoma. The data collected determined that the parent did perceive an improvement in quality of life of their child with cerebral palsy after receiving recreational therapy treatment. There is minimal research in the specific areas of recreational therapy for cerebral palsy and the effect that recreational therapy has on a child's quality of life with cerebral palsy, however this study helps build the foundation for future studies.

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CHAPTER I

INTRODUCTION

Rationale for the Study

Understanding how parents of children with Cerebral Palsy (CP) perceive the impact of Recreational Therapy (RT) treatment on their child's quality of life (QOL) with CP has been researched broadly in many treatment areas (occupational therapy, physical therapy, speech-language pathology, etc.), however research with CP and RT specifically should continue to grow to lead to increased understanding and improved treatments. There are studies centered around QOL and CP, but minimal published studies that include the impact of RT on QOL of children with CP and none specifically centered around the parent's perceptions of QOL on CP with RT treatment. Those who have conducted research centered around CP and recreation and leisure have examined how recreation and leisure is shaped in individuals with CP and how their physical functioning and gross motor skills effect their participation, rather than focusing on QOL as a whole (Alghamdi, Chiarello, Palisano, & McCoy, 2017; Maher, Williams, Olds, & Lane, 2007).

Statement of the Problem

The field of RT is an established field and continues to grow, as does research centered around RT. Research has been conducted with specific diagnoses and RT. Additional research is necessary to contribute to the small, but growing body of work

pertaining to RT and CP (Alghamdi et al, 2017; Delaney, Crandell, & Barfield, 2014; Maher et al., 2007). Thus, this research will seek to add to addressing the research line of RT treatment impact on QOL and CP.

Purpose and Significance of the Study

The purpose of this study was to gain understanding into how a parent of a child with CP perceives the impact of RT treatment on their child's QOL. Parents and family members of children with CP could potentially also find this information valuable, providing insight to parents and caregivers about their view treatment, their attitudes, etc.

Assumptions

For this study, the following assumptions have been made:

1. It is assumed that the participants of the study understand what RT treatment is.
2. It is assumed that the participants of the study understand the survey questions as intended and can accurately answer the questions.
3. It is assumed that the interviewers clearly understand the participants' answers and how to score their answers accurately for analysis.

Definition of Terms

The following terms have been included for increased understanding of the terms used throughout the study.

- Cerebral Palsy: Cerebral Palsy (CP) “refers to group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination (National Institute of Neurological Disorders and Stroke, 2013). CP occurs when there is “damage to or abnormalities inside the developing brain that disrupt the brain’s ability to control movement and maintain posture

and balance” (National Institute of Neurological Disorders and Stroke, p. 1, 2013).

- Quality of life: Quality of life (QOL) can be defined as “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns,” according to the World Health Organization (WHO, p. 1, 1997).
- Health-related quality of life: Health-related quality of life (HRQOL) refers to the patient's perceptions of the disease’s impact and following treatment impact on multiple domains of life, including physical, mental, and social functioning (Varni, Seid & Rode, 1999).
- Recreational Therapy, Therapeutic Recreation: According to the American Therapeutic Recreation Association, Recreational Therapy (RT) is a treatment that utilizes recreation and activity based interventions “to restore, remediate and rehabilitate a person’s level of functioning and independence in life activities to promote, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition” (ATRA, n.d.).
- Child, Children: A person younger than 18 years of age.

Hypothesis

The aim of this study was to understand a parent’s perception of the impact of RT interventions related to their child’s QOL with CP. This quantitative study collected data to analyze the following hypothesis:

H₁: The parent of the child with CP will perceive improvement in QOL of their child after RT treatment.

H₀: The parent of the child with CP will not perceive improvement in QOL of their child after RT treatment.

Limitations

Limitations of this study could include sample size, researcher experience and bias, and participants individuality when answering questions. The size of the study could limit the ability to generalize the results to the CP population, as well as other therapy treatment.

The researchers' prior experience and bias associated with CP and RT could influence the overall approach to the study and analysis of data collected. The participant's individual backgrounds could influence the answers to survey questions, as well as the interpretation and understanding of participant responses by the researcher.

CHAPTER II

LITERATURE REVIEW

Introduction

The purpose of this study was to gain understanding into how a parent of a child with CP perceives the impact of RT treatment on their child's QOL. A review of current research related to the topic revealed common themes that gave importance to understanding the impact of RT treatment on QOL of children with CP. Themes discussed in this section include: cerebral palsy, quality of life and health-related quality of life of children with cerebral palsy, treatment and therapy, RT, therapy approaches and interventions with cerebral palsy, instrumentation, and theoretical perspective.

Cerebral Palsy

Cerebral Palsy (CP) refers to “a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination. CP occurs when there is “damage to or abnormalities inside the developing brain that disrupt the brain's ability to control movement and maintain posture and balance” (National Institute of Neurological Disorders & Stroke, p. 1, 2013). CP affects the cerebral cortex, the outermost layer of the brain that controls muscle movement, either through damage or abnormal growth during fetal development. Damage to the cerebral cortex can occur during fetal development, during birth or after birth, which

results in permanent damage and disabilities. The symptoms of CP are wide ranging in type and severity and can include lack of muscle coordination (ataxia), variations in muscle tone, either stiff or floppy muscles, exaggerated reflexes (spasticity), impaired gait, difficulties speaking, swallowing or drooling, shaking and random involuntary movements, difficulty with precise movements and delays in reaching motor skill milestones (National Institute of Neurological Disorders & Stroke, 2013).

Diagnosis of CP typically occurs within the first 2 years of life, however diagnosis can be delayed if the child's symptoms are mild. As children grow doctors continually monitoring development, including coordination, muscle tone, motor control. If the child does not reach age-appropriate milestones or shows abnormal development, tests will be administered, such as x-ray, computed tomography (CT scan), magnetic resonance imaging (MRI), electroencephalogram (EEG), genetic tests, or metabolic tests, to rule out other possible diagnoses that may have similar symptoms as CP. Conducting these tests can help to eliminate other diagnoses and potentially help diagnosis the specific type of CP the child has (National Institute of Neurological Disorders & Stroke, 2013). Continual developmental monitoring, screening and evaluations, combined with eliminating other possible diagnoses, a CP diagnosis and specific type of CP diagnosis can be reached (Centers for Disease Control & Prevention [CDC], 2019).

There are four main types of CP: spastic, dyskinetic, ataxic, and mixed depending on where the damage and/or abnormality of the brain occurred and severity of the damage and/or abnormality. Spastic CP is characterized by muscle stiffness and tight, jerky movements and is the most common type of CP. Spastic CP can be further categorized into three categories: hemiplegia affecting one side of the body, diplegia

affecting the legs primarily and possibly affecting the arms to a lesser degree, and quadriplegia affecting all 4 limbs and is the most severe form of CP (National Institute of Neurological Disorders & Stroke, 2013).

Dyskinetic or athetoid CP is characterized by slow writhing or jerky movements. Dyskinetic CP can include difficulty in sitting upright straight and walking, hyperactivity of the face and tongue resulting in a grimace or drooling and could impact hearing, breathing and speaking. Ataxic CP is characterized by shaky movements and impacts balance and depth perception. Ataxic CP can lead to unsteadily walking typically with a wide-based gait and poor coordination, as well as difficulty with controlling precise and voluntary movements. Mixed CP is characterized by a combination of symptoms from multiple CP types, such as having both tight and relaxed or floppy muscles (National Institute of Neurological Disorders & Stroke, 2013).

This study focused on spastic quadriplegia CP, and how a parent of the child with spastic quadriplegia CP perceived the impact of RT treatment on their child's QOL. Typically with spastic quadriplegia CP there is also moderate to severe intellectual disabilities present due to the widespread brain damage or significant brain malformation affecting many areas of the brain. Children diagnosed with spastic quadriplegia CP tend to have severe muscle stiffness in their limbs while having flopping neck movement, rarely able to walk, have difficulty speaking and being understood and can have frequent seizures (National Institute of Neurological Disorders & Stroke, 2013).

Quality of Life and Health-Related Quality of Life of Children with Cerebral Palsy

Defining QOL can be difficult at times due to the many areas QOL encompasses. According to the World Health Organization, QOL can be defined as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns,” (WHO, p. 1, 1997). There is agreement across disciplines that QOL is multidimensional, however there are disagreements about the contents of the domains, particularly for QOL of children with disabilities (Gilson, Davis, Reddihough, Graham, & Waters, 2014). Health-related quality of life (HRQOL) refers to the perceptions of the disease’s impact and following treatments impact on multiple domains of life, including physical, mental, and social functioning on an individual or group (CDC, 2018; Varni, Seid & Rode, 1999). While HRQOL and QOL are related each can be very different to assess and report on, especially for children with disabilities and when proxy-reports of QOL or HRQOL are completed (Varni et al., 1999).

Many studies have researched independent predictors of QOL domains, such as physical or psychosocial wellbeing, although focusing on specific domains can lead to an impartial view of QOL. Children with CP who had more severe motor impairments were associated with poor QOL in physical functioning and autonomy while there was not an association to poor QOL in the psychosocial domain. Lower IQ scores were associated with poor social domain scores but not lower scores in moods, emotions and self-perception domains. While lower IQ and severity of motor impairment did not affect multiple domains, pain was associated with poor QOL in multiple domains, including physical wellbeing, psychological wellbeing, and self-perception (Gilson et al., 2014).

There appears to be a connection between how HRQOL affects overall QOL and how health affects QOL. As discussed earlier HRQOL is an aspect of QOL that specifically relates to health. A higher HRQOL is typically also associated with higher QOL. While health impacts HRQOL, HRQOL impacts QOL, thus health impacts QOL regardless of if looking specifically at HRQOL (CDC, 2018; Varni, Seid & Rode, 1999). Areas of life including comfort, emotions, communication and social interactions could predict overall QOL greater than personal care and transfer mobility among non-ambulatory children, adolescents and young adults with CP (Kolman, Glanzman, Prosser, Spiegel, & Baldwin, 2018). Significant predictors of overall QOL include the child's understanding of the parent, if the child attends school, and how often the child was unhappy or sad, while overall QOL and frequency of pain and discomfort while seated were also found to be predictors of overall health (Kolman et al., 2018). If HRQOL is rated highly, then overall QOL is typically also rated highly (Gilson et al., 2014; Kolman et al., 2018; Varni et al., 1999).

During the literature review process, previous research concerned with QOL and/or HRQOL measured QOL and/or HRQOL through the patient's perspective and did not measure QOL and/or HRQOL through a parent or caregiver perspective. While completing the literature review seven articles were found to relate to parent perceptions of QOL and/or HRQOL. Arnaud et al. 2008; Dobhal, Juneja, Jain, Sairam, & Thiagarajan, 2014; Laporta-Hoyos et al., 2017; Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2008; Varni, 2019; Varni et al., 2011; Varni et al., 1999).

The literature review examined articles from numerous databases (Google Scholar, ProQuest, PubMed, PubMed Central, Academic Search Premier, Center for

Disease Control, MEDLINE, SAGE, PsycARTICLES, PsycINFO and PsycTESTS) with key search words and phrases centered around parent perceptions of QOL of their child, as seen in Table 1.

Of the articles examined in the literature review seven articles were found to be related to parent's perceptions of QOL or HRQOL of their child. There were found to be four articles directly pertain to parent's perceptions of QOL or HRQOL of their child: Arnaud et al. (2008), Dobhal, Juneja, Jain, Sairam, & Thiagarajan, (2014), Laporta-Hoyos et al. (2017), and Majnemer, Shevell, Law, Poulin, & Rosenbaum, (2008). The remaining three articles are related to parent perceptions of their child's QOL or HRQOL due to pertaining to the PedsQLTM assessment, which was created by Dr. Varni and associates (Varni 2019; Varni et al, 2011; Varni et al., 1999). Arnaud et al. (2008) had parents complete the KIDSCREEN assessment, which is self-reported QOL measure validated for children ages 8-18 years old. Dobha et al. (2014) utilized the LAQ-CP parent version for children ages 3-10. Laporta-Hoyos et al. (2017) utilized the CP QOL proxy-report for children 12-18 years old (although the CP QOL is validated for children ages 4-18 years old). Majnemer et al. (2008) is the only article that utilized the PedsQLTM, however completed their study about children with CP between 6-12 years old. These articles or lack thereof show there is a clear gap in the literature pertaining to parent's perception of QOL of their child, and especially pertaining to children of much younger ages (0-4 years old).

Parent-reports of their child's QOL have been debated concerning the validity of the parent's report of their child's QOL. Children and adolescent self-reports of their

Table 1

Quality of Life Literature Review Key Words and Phrases

| Child QOL & HRQOL | Perception of QOL & HRQOL | Cerebral Palsy | Parent & Caregiver | Recreational Therapy |
|------------------------------|--------------------------------------|--|-------------------------------|--------------------------------------|
| Child/Children QOL | Parent Perception(s) of QOL | Child CP, Child CP QOL & HRQOL | Parenting Theory/Theories | RT/TR and CP |
| Child/Children HRQOL | Parent Perception(s) of HRQOL | Pediatric CP, Pediatric CP QOL & HRQOL | Caregiver Theory/Theories | RT/TR and QOL |
| Pediatric QOL | Caregiver Perception(s) of QOL | Child Physical Disability/Disabilities QOL & HRQOL | Parenting Choices/Decisions | RT/TR and HRQOL |
| Pediatric HRQOL | Caregiver Perception(s) of HRQOL | Pediatric Physical Disability/Disabilities QOL & HRQOL | Caregiver Choices/Decisions | RT/TR and Child/Pediatric QOL |
| | Perception(s) of QOL & HRQOL | Illness/Chronic Illness, QOL & HRQOL | | RT/TR and Child/Pediatric HRQOL |
| | | | | CP Treatment(s) |
| | | | | CP Therapy/Therapies |
| | | | | Child/Pediatric CP Treatment(s) |
| | | | | Child/Pediatric CP Therapy/Therapies |

QOL tend to score higher than parent-reports of their child's QOL (Radsel, Osredkar, & Neubauer, 2017), however scores are also generally comparable between parent-reports and child self-reports on the child's QOL (Majnemer, 2008). It is not always possible to rely on child self-reports of QOL for various reasons (severe intellectual impairments, difficulties communicating, etc.), so the use of parent-reports of the child's QOL is necessary. It is important to note that parent-reports of their child's QOL are not considered a direct equivalent of child self-reports of QOL but rather a different perspective of the child's QOL (Arnaud et al., 2008).

Treatment and Therapy

Treatment and therapy for CP could impact the child's QOL and HRQOL in all domains of life. While CP cannot be cured and there is not a single all-encompassing standard treatment protocol for every patient with CP, there are treatments that could improve the child's capabilities. Treatment protocols or plans often depend on the child's specific CP diagnosis type and their needs, and can be tailored to include many therapy disciplines (National Institute of Neurological Disorders & Stroke, 2013).

In many cases medications will be utilized first to help alleviate stiff, contracted or overactive muscles. Generally oral medications are appropriate for children with mild to moderate muscle stiffness or who have widespread spasticity as some drugs have an increased risk of side effects such as drowsiness, blood pressure changes and risk of liver damage. Botulinum toxin (BT-A) may be injected locally into overactive muscles in children with spastic movement, as BT-A helps to relax contracted muscles by blocking nerve cells from activating muscles. BT-A is typically most effective in children who have some control over their movements, no fixed or rigid muscles, and a limited number

of muscles to treat, and when followed by a stretching program. Depending on the specific needs of the child orthopedic surgery and/or surgery to cut nerves may be necessary and in most cases assistive devices are also utilized, such as wheelchairs, rolling walkers, braces, splints, computer voice synthesizers (National Institute of Neurological Disorders & Stroke, 2013).

Physical therapy (PT) utilizes exercise-based activities and may be utilized to maintain or improve muscle strength, balance, gross and fine motor skills, and mobility in individuals with CP. In PT orthotic devices may also be utilized to improve mobility and stretch spastic muscles. Occupational therapy (OT) is focused on helping individuals with everyday activities and activities of daily living in many life areas, such as changing clothes, eating and going to school (National Institute of Neurological Disorders & Stroke, 2013).

Speech and language therapy, referred to commonly as SLP, may improve speaking abilities and improve swallowing disorders. SLP may help patients speak more clearly and possibly learn to communicate in new ways through sign language and/or with communication devices. Communication devices can include a computer voice synthesizer or a communication board that has symbols of objects, activities, emotions, etc. for the child to point at to communicate (National Institute of Neurological Disorders & Stroke, 2013).

Recreational Therapy

Recreational therapy (RT) may also be utilized in treatment for CP. According to the American Therapeutic Recreation Association, RT is a treatment that utilizes recreation and activity-based interventions “to restore, remediate and rehabilitate a

person's level of functioning and independence in life activities to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition" (ATRA, n.d.). RT may be utilized for a wide range of disabilities, diseases, and illnesses, and is tailored to meet the individual needs of the patient with the Recreational Therapists (CTRS) following the RT process (Austin, Crawford, McCormick, & Van Puymbroeck, 2015).

The RT process, often referred to as APIE, includes four phases, assessment, planning, implementation and evaluation, is systematic and necessary for person-centered, goal-directed interventions. The RT process is cyclical in nature starting with an initial assessment of the patient's needs, planning and implementing the intervention based on the patient's needs, followed by evaluating the efficacy of the intervention and evaluating the patient's progress. Based on the patient's progress and goals the intervention program may need to be adapted (Austin et al., 2015). As is the overarching goal with many treatments and therapies, RT hopes to improve the overall QOL of patients, thus improving HRQOL as HRQOL is a piece of QOL and should improve as QOL improves. RT can be utilized to meet the specific needs of patients to improve or maintain functioning to help patients lead a successful life outside of therapy (Austin et al., 2015).

An important part of life that can impact overall QOL and potentially HRQOL is play, recreation and leisure. Determining how leisure and recreation is shaped in individuals with CP is important in understanding how their participation in recreation and leisure will influence the RT outcome and thus impact QOL. Children diagnosed with CP who had higher levels of gross motor and communication skills participated in

recreation activities more frequently and reported more enjoyment compared to children with CP and lower functioning skills; this could be due to many factors including, family, child and environmental factors (Alghamdi et al., 2017). Multiple family and child factors have shown to have influence over leisure participation in children with CP. Particularly participation is increased in intensity if there is an increase in enjoyment, adaptive behavior, gross motor skills, and family orientation. Family characteristics such as activity orientation, structure and relationships, primary caregiver education and family income could all influence participation in recreation and leisure activities, however were not found to be statistically significant in this study though the general consensus agrees that family factors do influence participation in recreation and leisure activities. Many of these factors have yet to be examined in depth (Palisano et al., 2011).

Adolescents with CP have a desire to participate in recreation and leisure activities, although they often participate less in activities that require physical activity due to their lower levels of gross motor skills (Majnemer, Shikako-Thomas, Schmitz, Shevell, & Lach, 2015). Participation in physical activities often decreases as individuals with CP age and is believed to be related to their overall level of gross motor skills (Maher et al., 2007). These findings tend to follow a similar path as related to recreation and leisure, as recreation and leisure often involve some type of physical activity and gross motor skills (Majnemer et al., 2015). As individuals age the interest and desire to participate in activities that require more physical activity and gross motor skills increases, with individuals diagnosed with CP seeing decreased participation in strenuous recreation and those without physical disabilities seeing increased participation (Maher et al., 2007; Majnemer et al., 2015). Gross and fine motor skills, as well as other domain

areas, can be addressed in RT treatment and potentially allow for children diagnosed with CP to participate in activities they could not previously participate in before, thus leading to a higher HRQOL and QOL (Majnemer et al., 2015).

Therapy Interventions and Approaches with Cerebral Palsy

There are numerous therapy interventions and approaches in RT. This case report focused on aquatic interventions that include the Watsu and Bad Ragaz, as well as general aquatic stretching, upper extremity (UE) and lower extremity (LE) strengthening, body awareness, head control, standing, range of motion (ROM) and flexibility. The therapist leads the patient through various interventions during the session to increase flexibility and ROM of all joints, UE and LE strength, bodily awareness, improve head control, and standing ability.

The Watsu is an intervention that focuses on decreasing muscle tension and increasing relaxation through various therapist assisted movements in the water, referred to as “swinging”, “accordion”, and “swirling”, while the patient is physically supported by the therapist. The Watsu, also referred to as water Shiatsu, utilizes massage, pressure, stretching, and anatomical manipulations within the aquatic environment (Becker, 2009; Becker & Cole 2011; Passmore, T., Gbur, Lindenmeier, Price & Passmore, J., 2018; Robinson, Lorenc, & Liao, 2011). The Bad Ragaz is an intervention that involves the patient floating in a supine position with flotation aids at the pelvis and neck while the therapists holds the patient’s bent knees to slowly move the patient side-to-side. Benefits of the Bad Ragaz include reduced pain and muscle tone, improved strength, coordination, joint stability, ROM and endurance and improved physiological functioning of joints,

muscles, and anatomical positions (Burton & Brigham, 2013; Kim, E., Lee, & Kim, Y., 2015; Salzman, 2007; Passmore et al., 2018).

While interventions are important there are various approaches and techniques that can influence the interventions and treatment. Individuals diagnosed with CP participate in many treatment types and treatment interventions, however both therapy and behavior change centered interventions with a theoretical frame applied have the same potential as physical activity participation in leisure activities (Reedman, Boyd, & Sakzewski, 2017). Using a theory while employing a specific intervention could potentially impact how the child reaches their treatment goals thus influencing HRQOL and QOL. Focusing on either context-focused, child-focused or care-focused therapy approaches in children with CP did not lead to any one approach being more effective than the others, although using a specific focused approach based on the individual child could potentially prove more effective on a case by case basis (Kruijsen-Terpstra et al., 2016). Using a more effective approach can influence the overall impact treatment has on QOL.

Children with CP who participate in newer intervention techniques centered around technology and interactive videogames or serious games, which are games that rely on meaningful play and engagement for rehabilitation, can have significant improvements in head and trunk movement compared to children who participated in traditional OT and PT interventions (Velasco et al., 2017). When using newer intervention techniques such as videogames, there has been a reported increase in intrinsic motivation for the child diagnosed with CP to participate in therapy (Sevick et al., 2016). While using technology has shown an increase in participation, utilizing sport

as part of treatment has shown an increase in affective variables, which could impact QOL (Delaney et al., 2014). Using newer intervention types can impact the overall effect of RT treatment and improve the motivation and attitudes of patients, which could potentially improve HRQOL and QOL of the child (Delaney et al., 2014; Sevick et al., 2016; Velasco et al., 2017).

Instrumentation: PedsQL™ Infant Scales

The Pediatric Quality of Life assessment (PedsQL™) is a standardized assessment consisting of pediatric self-reports and parent-reports of health-related quality of life (HRQOL) in pediatric patients with chronic health conditions and was constructed in 1999 (Varni et al., 1999). The PedsQL™ was created from empirical data of pediatric cancer patients and their parents during various stages of treatment and found to be valid and reliable when measuring HRQOL. The PedsQL™ is a 23-item assessment of generic core scales that measures physical, emotional, social and school functioning as well as physical and psychosocial health summary scores. The PedsQL™ was created initially from pediatric cancer patients and has since been validated for use with other conditions and now contains condition-specific modules that complement the generic core scales. The condition-specific modules include cerebral palsy, cancer, epilepsy, etc. and an infant scales module (Varni et al., 1999).

The PedsQL™ generic child self-reports are for ages 5-7, 8-12, and 13-18 years old, while parents can also complete reports for these ages through the parent-report versions for the corresponding ages. There are parent-reports only for ages 1-12 months, 13-24 months given that the child would be too young to complete the report (Varni, 2019). While there are condition-specific modules for older pediatric patients, there are

not condition specific modules for infants ages 1-24 months. The PedsQL™ CP module contains parent-reports for toddlers are 2-4 years old, and child and parent-reports for ages 5-7, 8-12, and 13-18 years old (Varni et al., 2011).

The PedsQL™ Infant Scales were created in 2010 following the PedsQL™ generic scales. The infant scales are generic HRQOL assessment instrument for infants aged 1-24 months to be completed by parents and includes both acutely- and chronically-ill modules, however can be used with infants of any diagnosis. The infant scales were created from parent-reports related to HRQOL of healthy, acutely-ill and chronically-ill infants. The 36-item questionnaire for ages 1-12 months and the 45-item questionnaire for ages 13-24 months measure physical functioning, physical symptoms, emotional functioning, social functioning, and cognitive functioning with higher scores indicating better HRQOL in each dimension (Varni et al., 2011).

The total scale scores were found to have internal consistency reliability, with an $\alpha = 0.92$ for both the 1-12 months and 12-24 months versions, that distinguished between healthy infants and acutely and chronically ill infants. The physical health summary for 1-12 months version has an $\alpha = 0.82$ and psychosocial health summary $\alpha = 0.90$, while the 13-24 months version has an $\alpha = 0.82$ and $\alpha = 0.89$ for physical and psychosocial health summary respectively (Varni et al., 2011).

The 1-12 months version physical functioning reliability of $\alpha = 0.78$, physical symptoms reliability of $\alpha = 0.72$, emotional functioning reliability of $\alpha = 0.87$, social functioning reliability of $\alpha = 0.81$, and cognitive functioning reliability of $\alpha = 0.89$. The 13-24 months version has physical functioning reliability of $\alpha = 0.79$, physical symptoms reliability of $\alpha = 0.73$, emotional functioning reliability of $\alpha = 0.87$, social functioning

reliability of $\alpha = 0.86$, and cognitive functioning reliability of $\alpha = 0.88$. The PedsQL™ Infant Scales internal consistency reliabilities exceeded the recommended minimum alpha coefficient standard ($\alpha = 0.70$) for all group comparisons. The infant scales total scale score is suitable for a summary score, while the individual scales may be utilized for specific domains and subgroup differences (Varni et al., 2011).

This study utilized the PedsQL™ Infant Scales chronically-ill module and will not use the PedsQL™ CP module or the generic scales PedsQL™ due to the child being diagnosed with a chronic illness (CP) and the age of the child being younger than 2 years old. Both the CP module and generic scales are validated for ages 2 to 18 years old, and the child was an infant under 24 months of age, therefore the infant scales must be utilized (Varni et al., 2011). The KIDSCREEN, LAQ-CP, and CP QOL were not utilized for this study either due to the validated age range of the assessments and/or no proxy-report validated (Arnaud et al., 2008; Dobha et al., 2014; Laporta-Hoyos et al., 2017).

When scoring the infant scales the emotional, social and cognitive functioning dimensions are added together for the psychosocial health summary score and physical functioning and physical symptoms dimensions are added together for the physical health summary score, and the sum of all the items leads to a total score divided by the number of items answered (Varni et al., 1999). While the PedsQL™ Infant Scales were utilized for this study, the parent was also be given the opportunity to voice any comments about their child to allow for possible comparison of themes discussed to numerical data collected.

Theoretical Perspective: Social Learning Theory

There have been many theories and concepts when it comes to learning, a key aspect initially of learning was that it was done through direct experience, but learning can occur by observing others' behaviors (Bandura, 1971). In Bandura's Social Learning Theory (SLT) the main principle is that learning can occur by observing others or observing a model exhibit behaviors or skills. There are four steps in the process of SLT: attention, retention, reproduction and motivation (reinforcement) (Bandura, 1971).

The attention of the observer must be focused on the modeled behavior for observational learning to start. If a behavior is not exposed to a person enough or if the behavior goes unnoticed, then the behavior may not be imitated by the observer. After the behavior is noticed retention, remembering the behavior, is the next important step of SLT. If a behavior is not remembered by the observer than it cannot be imitated. Reproduction is the third piece of SLT that pertains to performing the modeled behavior after initially noticing and remembering the modeled behavior. The final piece of SLT is motivation to perform the modeled behavior. How the observer is motivated by rewards, punishments, perceived rewards and perceived costs of the modeled behavior, which influences the likelihood that the modeled behavior will or will not be performed by the observer. The observer considers what benefits and consequences come from the behavior that was modeled and weighs these possible outcomes into their motivation to imitate the modeled behavior (Bandura, 1971).

SLT explains how people can learn behaviors from observing others perform the behavior and their subsequent consequences from performing the behavior. When discussing how parents learn to make medical decisions for their children SLT can be

applied. Parents learn how to parent and make decisions, medical or otherwise, from observing other parents (Bandura, 1971). There is a cycle of parents learning from other parents, and parents understanding the benefits or consequences of their parenting behaviors. Making medical decisions for their child is a behavior that can have profound impacts on their child. It is important to understand how parents make medically related decisions for their child and how their decisions could be influenced by other parents' behaviors (i.e. choosing for their child to participate in various therapy types) (Bandura, 1971).

For example, a child is diagnosed with a chronic illness and through various means (i.e. parenting groups, support groups, meetings while waiting for doctor's appointments, etc.), their parent observes another parent come to the decision to start their child with the same diagnosis in a specific treatment. Over time the parent observes the child and parent benefit from the treatment. The parent is likely to follow the example of decision-making behavior and start their own child in that treatment as well (Bandura, 1971). If the parent perceives the treatment of the observed family as beneficial or negligible, then the parent's perception of the observed family's treatment outcomes will influence the treatment they do or do not seek for their own child. RT can easily be placed in this example as the treatment and benefits of RT leading to improved HRQOL and improved HRQOL leading to improve overall QOL. Understanding the way parents learn to make medical decisions for their child helps in understanding how parents perceive their child's HRQOL and QOL.

CHAPTER III

METHODOLOGY

Introduction

This section will outline the following: research design, participants, data collection, instrument, and data analysis.

Research Design

The design for this case report study was quantitative in nature and utilized a pretest-posttest design of a standardized assessment survey for data collection. Data collection and analysis was conducted by trained members of the research team to ensure questions were interpreted correctly by participants and correct calculation of scores from surveys for analysis.

A case report was utilized for this study due to case reports consisting of typically a single patient/participant (however can have up to three) and due to case reports highlighting the practice of medicine that occurred with the specific patient/participant chosen, while a case study consists of multiple patients/participants and an in-depth analysis of a specific research question. Case reports help practitioners report their findings in interesting or unique cases of care to help provide possible insight for similar cases of care (Porcino, 2016; Sayre, Toklu, Ye, Mazza, & Yale, 2017). The utilization of a case report for this study was necessary to help build the initial insight and knowledge of parent's perceptions of QOL of their child with CP while focusing on the impact that

RT has on the child's perceived QOL. It was important to examine perceptions of QOL of a child from the parent's perspective due to the minimal research on the subject. The participant also provided a unique perspective of examining QOL of a child with CP, specifically an infant aged child. As established previously, there is minimal research pertaining to perceptions of a child's QOL and even less pertaining to an infant child or a child with CP.

Participant

This case report study consisted of one participant who met the criteria listed below.

Population. Included in the study population were parents of a child that had a diagnosis of CP, who lived in the state of Oklahoma and had received RT treatment.

Sample. The sample of this study was one parent of a child under the age of 2 years-old, who lived in the state of Oklahoma, whose child was diagnosed with spastic CP, and had received RT treatment. The participant of this study was a mother of a child under the age of 2 years old, whose child had a diagnosis of spastic CP. The child had received RT treatment for 8 months by the end of the study, with sessions twice per week for 30-minutes each, at Stillwater Medical Aquatics and Fitness in Stillwater, Oklahoma from a dual credentialed and licensed Certified Therapeutic Recreational Therapists (CTRS/L), who was also certified as an Aquatic Exercise Therapist (ATRIC).

Data Collection

The pretest survey was scheduled with the help of the child's Recreational Therapist to be completed during the child's 30-minute session. The participant and her

child arrived to the RT service center and was introduced to the researcher by the Recreational Therapist. After the child began their session with the Recreational Therapist the researcher explained the survey process to the participant. After informed consent was obtained from the participant, the survey was completed by the participant. The survey was completed in less than 5-minutes. After completion of the survey the researcher obtained demographic information, discussed posttest procedures that would be happening in the future and thanked the participant.

The posttest survey was completed 8-months after the pretest, in the same manner as the pretest. The participant and child arrived to the RT service center and the child began their session with the Recreational Therapist. The researcher again explained the survey process and while the child was participating in RT interventions the participant completed the posttest survey. The posttest survey was completed in less than 10-minutes. After the posttest survey was completed the participant was given the opportunity to voice qualitative comments related to the child's QOL and RT treatment. The qualitative comments were completed within 5-minutes. After the completion of the posttest survey and qualitative comments, the researcher thanked the participant for their time and participation.

Instrument

The instrument utilized in this study was the Pediatric Quality of Life Infant Scales (PedsQL™ Infant Scales). The PedsQL™ Infant Scales was utilized twice per participant in pretest-posttest design.

Data Analysis

The analysis for this study was descriptive statistic. Descriptive statistics was utilized to compare the pretest and posttest scores of the PedsQL™ Infant Scales, comparing both pre- and post-test for total scales scores, and each subscale (physical functioning, physical symptoms, emotional functioning, social functioning and cognitive functioning), as well as comparison of pre- and post-test comparison for physical health summary and psychosocial health summary scores.

CHAPTER IV

FINDINGS

Introduction

The purpose of the study was to examine a parent's perception of the impact of RT interventions related to their child's QOL with CP. The data was analyzed using descriptive statistics comparing pretest and posttest data. This case report involved one parent of a child diagnosed with CP, who utilized RT treatment provided in an aquatic environment.

Demographics

The participant of this study was a mother of a child under the age of 2 years old, who had a diagnosis of spastic CP. At the time of completion of the study the participant was 34 years-old and the participant's child was 15 months-old (7 months-old at start of pretest). The participant reported her race and ethnicity as Caucasian, being married, having a college degree and working as a stay-at-home mom. The parent reported that their child was receiving RT treatment completing 30-minute sessions each, on average twice per week and that the parent had heard about RT services from a friend, whose child had received RT services related to their diagnosis.

Findings

Due to the natural progression of the child growing and aging, both the PedsQL™ 1-12 months version and 13-24 months version were utilized for this study. The PedsQL™ 1-12 months version is comprised of 36-items and the 13-24 months version is comprised of the same 36-items with the addition of 9-items to account for normal, expected development as the child ages totaling 45-items (Varni et al., 2011). Both of the 1-12 months and 13-24 months versions were utilized for this study. Utilization of both versions of the PedsQL™ meant that the data was analyzed in two parts due to the 13-24 months version having additional items. The data was first analyzed with only the same items (36-items total) and labeled as the “pretest” and “Same Items Posttest”, and then all items present were analyzed and labeled as “All Items Posttest” (36-items for 1-12 months pre-test and 45-items for 13-24 months post-test). The two-part data analysis was necessary to compare and distinguish possible differences between the pretest and posttest that were unrelated to the child aging and growing specifically.

The pretest total score was 34.722 points; this score did not change between "same items" or "all items". Given that it was a pretest, the score would be the same pretest score utilized for comparison for both the Same Items Posttest and All Items Posttest analysis, and the pretest was completed once only giving one score. The Same Items Posttest total score (36-items) was 52.778 points, which increased 18.056 points from the pretest total score. The All Items Posttest total score (36-item pretest and 45-item post-test) was 46.111 points, which increased 11.388 points from the pretest total score (see figure 1). As with the overall total scores of the PedsQL™ Infant Scales increasing, the physical health summary and psychosocial health summary scores, and

scores of all subscales increased, regardless of if examining only the same items or all items from the pre- and post-test (see figure 2).

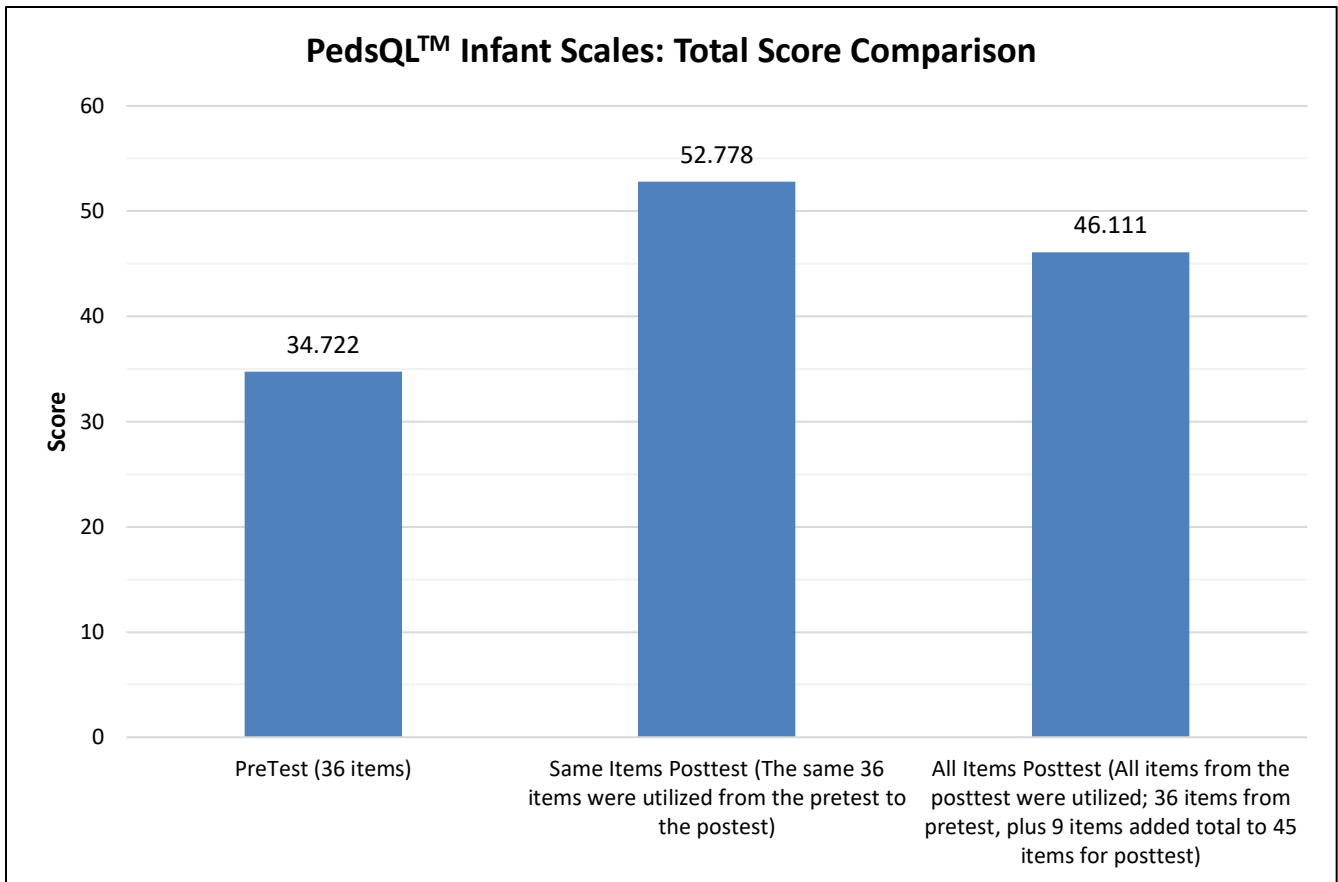


Figure 1. Comparison of PedsQL™ Infant Scales Total Scores of Pretest and Posttest

The total score was comprised of the physical functioning, physical symptoms, emotional functioning, social functioning and cognitive functioning subscales. There was two health summary scales with the psychosocial health summary comprised of the emotional, social and cognitive functioning subscales, and the physical health summary comprised of the physical functioning and physical symptoms subscales. The two health summary scales and five individual subscales was utilized as tools to further analyze specific aspects of the child's QOL.

The physical functioning subscale pretest score was 12.5 points, and the Same Items Posttest score was 50 points, while the All Items Posttest score was 38.889 points. The physical symptoms subscale pretest score was 42.5 points, and the Same Items Posttest and All Items Posttest scores was the same at 55 points. The posttest score was the same between the Same Items Posttest and All Items Posttest analysis due to the physical symptoms subscale having no addition of items between the pretest and posttest (the same 10-items were present for both the pretest and posttest, thus there was no difference in the Same Items Posttest versus All Items Posttest).

The emotional functioning subscale pretest score was 54.167 points, and the Same Items Posttest and All Items Posttest scores were the same at 66.667 points. The posttest score was the same between the Same Items Posttest and All Items Posttest analysis due to the emotional functioning subscale having no addition of items between the pretest and posttest (the same 12-items being present for both the pretest and posttest, thus there was no difference in the Same Items Posttest versus All Items Posttest). The social functioning subscale pretest score was 18.75 points, and the All Items Posttest score was 43.75 points, while All Items Posttest score was 50 points. The cognitive functioning scale pretest score was 6.25 points, and the Same Items Posttest score was 18.750 points, while the All Items Posttest score was 13.889 points.

The psychosocial health summary pretest score was 37.5 points, and the Same Items Posttest score was 52.500 points, while the Same Items Posttest score was 45.192 points. The physical health summary pretest score was 31.25 points, and the Same Items Posttest score was 53.125 points, while the All Items Posttest score was 47.368 points.

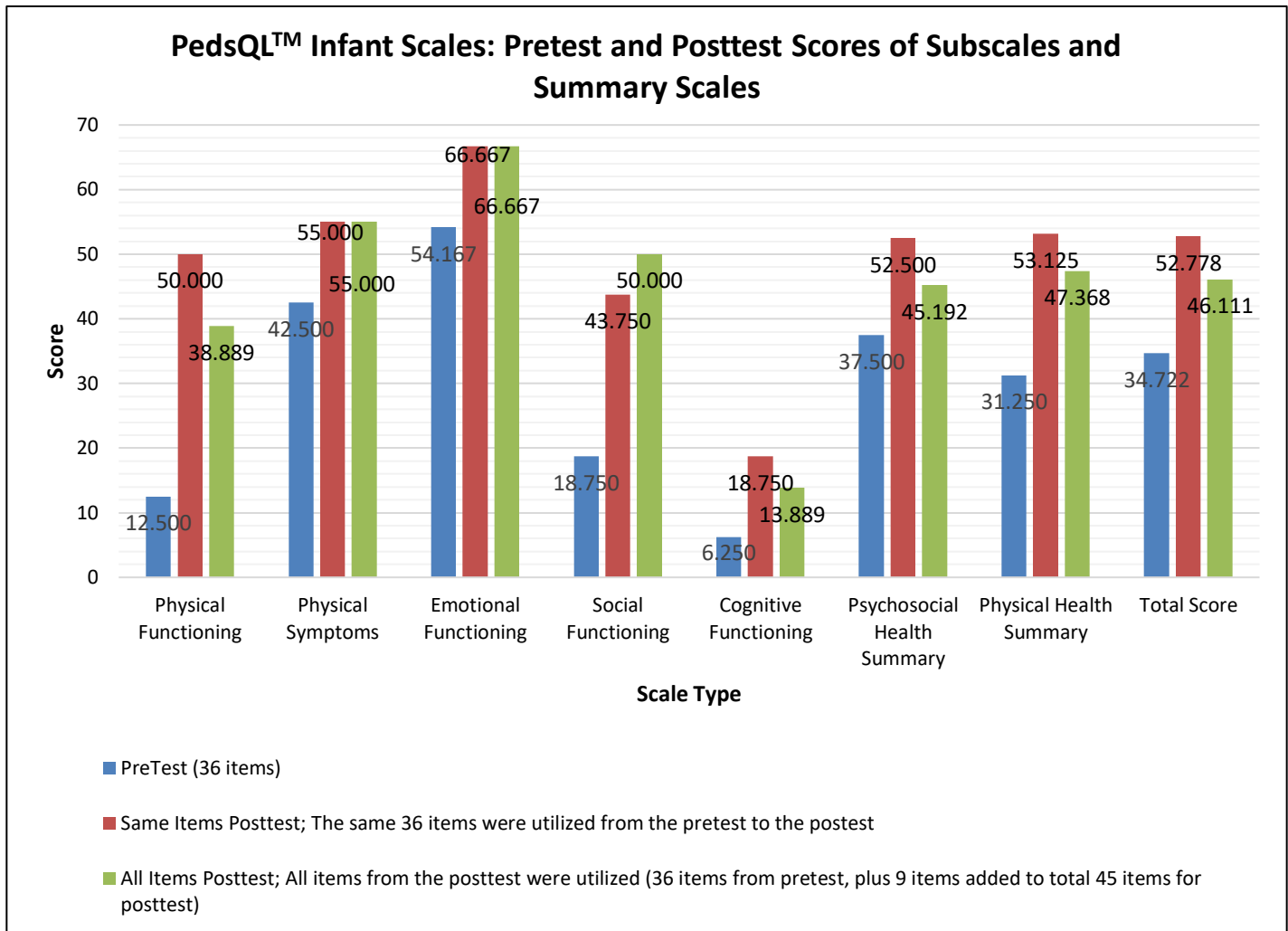


Figure 2. Comparison of PedsQL™ Pretest and Posttest Scores of All Scales

The participant was given the opportunity to voice any qualitative comments related to their child’s QOL and RT treatment. The participant stated that her daughter “had the most improvement from RT than in any other therapy and she does PT, SLP, OT, and vision therapy.” The participant stated that the RT treatment her daughter had received was “the most beneficial treatment she does,” having a “large impact” on her child’s life and their life as a family. These positive comments align with the positive improvement of the PedsQL™ scores.

Hypothesis I

The hypothesis for this study was to understand a parent's perception of the impact of RT interventions related to their child's QOL with CP. The null hypothesis for the study was the parent of the child with CP will not perceive improvement in QOL of their child after RT treatment, while the alternative hypothesis for the study was the parent of the child with CP will perceive improvement in QOL of their child after RT treatment. As discussed previously when comparing overall the total score for pretest and posttest, there was an increase in PedsQL™ Infant Scales scoring. The post-test of same item comparison increased 18.01 points from the pretest, and post-test score of all items comparison increased 11.4 points from the pretest.

CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to gain understanding into how a parent of a child with CP perceives the impact of RT treatment on their child's QOL. The parent did perceive improvement in QOL of their child after receiving RT treatment as evidenced by the outcome of the study.

Significance of the Study and Practical Implications

The implications of this study improves the understanding of perceived QOL, specifically in this case a parent's perceptions of their child's QOL and how RT treatments may help to continually improve their child's QOL. The data collected indicates that the parent did perceive an improvement in their child's QOL from RT treatment.

The subscales with the largest improvements include physical functioning (pretest score at 12.5 points, Same Items Posttest score at 50 points, and All Items Posttest score at 38.889 points) and social functioning (pretest score at 18.75 points, Same Items Posttest score at 43.75 points, and All Items Posttest score at 50 points). The physical functioning score from pretest to Same Items Posttest score increased fourfold and tripled from pretest to All Items Posttest scores. These increases could indicate that there was likely large improvements in physical functioning resulting from RT treatment that the

participant could have perceived as improving QOL in physical functioning. The social functioning score more than doubled from pretest to Same Items Posttest score and pretest to All Items Posttest score. This was not as large of an improvement compared to physical functioning, however there was large increases in social functioning scores. This could indicate that the child has increased social interactions with the participant and other family members, thus an increase of QOL in the social domain could have occurred as a result of RT treatment.

The subscales with the smallest improvements include physical symptoms (pretest score at 42.5 points and 55.0 points both Same Items Posttest score and All Items Posttest score), emotional functioning (pretest score at 54.167 points and 66.667 points posttest for both Same Items Posttest score and All Items Posttest score), and cognitive functioning, which had the smallest improvement (pretest score at 6.25 points pretest, Same Items Posttest score at 18.750, and All Items Posttest score at 13.889 posttest). Cognitive functioning had the smallest improvement of all the subscales, however this could be due to cognitive age-related growth being slower than physical functioning improvements and that the RT treatment focused on physical improvements rather than cognitive improvements. This could also be an indicator that there needs to be more emphasis on cognitive functioning within RT treatment sessions. Emotional functioning and physical symptoms had lower ratings than physical functioning or social functioning but rated higher than cognitive functioning. Emotional functioning and physical symptoms both increased by 12.5 points from pretest to posttest scores. This may indicate that child's emotional functioning and physical symptoms were perceived as being closely related by the participant.

The psychosocial health summary had the lowest improvement of the two health summary scores (pretest score at 37.5 points, Same Items Posttest score at 52.5 points, and All Items Posttest score at 45.192 points), while the physical health summary score had the largest improvement of the two (pretest score at 31.25 points, Same Items Posttest score at 52.778 points, and All Items Posttest score at 46.111 points).

This appears to align with the RT treatment the child received being more focused on the physical domain rather than cognitive domain due to the child's diagnosis of CP, a disorder that impacts physical functioning. It seems logical that there should be larger improvements in physical functioning resulting from treatment rather than larger cognitive functioning improvements for a physical disability. The physical symptoms scale was one of the scales with the least improvement in perceived QOL by the participant, however this could be due to participant's own perception of her child's physical symptoms. It is possible that a different caregiver (father, grandparents, etc.) might have perceived a larger improvement in the child's physical symptoms than the participant.

The subscale scores can give indications of areas of life that need continued improvement to increase QOL. The treatment can be further tailored to the specific areas of needed improvement to increase QOL. The participant in this study perceiving the lowest improvement in cognitive functioning of their child may help the Recreational Therapist in planning interventions that tie in cognitive functioning along with physical functioning for continual improvement.

Future Directions

This study's case report design reported outcomes of one unique individual's parent's perceptions of the impact RT had on the QOL of their child diagnosed with CP and this could lead to a possible limited view of child's QOL from one perspective (the parent). Future studies centered around RT and young children with physical disabilities should aim to increase the total number of participants in the study to gain more understanding in how multiple parents perceive their children's QOL and possibly add to the generalizability of parent's perceptions of the child's QOL. There is also the possibility of including multiple caregivers (such as parents, grandparents, therapists) of each child to rate a child's QOL. This can lead to examining how different parents and/or caregivers perceive the child's QOL differently, as well as allowing for perceived QOL of multiple children receiving RT treatment in the same facility or within the same RT treatment program.

Future studies have the potential to utilize specific subscales and health summary scores to hone in on certain domains of life and perceptions of QOL of specific domains. Further analysis into specific areas of QOL is necessary to be able to fully understand QOL as a whole. There is also the possibility of including specific CP types and other therapy services, such as physical therapy and occupational therapy, in the study with RT to compare how parents perceive the impact of each therapy service on their child's QOL and/or how different CP types are perceived to impact QOL. The instrument used in this study was quantitative in nature and specifically related to HRQOL given the nature of RT treatment being in healthcare. There is the potential to use more generalized QOL instruments not specifically relating to HRQOL to assess QOL outside of the context of

health, as well as conducting qualitative studies to gain deeper understanding into parent's perceptions of their child's QOL.

Conclusion

Cerebral palsy, like many disorders, is complicated and multidimensional, and requires extensive investigation to be able to begin to understand the complexities. This study focused specifically on one parent's perception of QOL of their child with spastic CP who received RT treatment. The findings of this study are important for multiple reasons. This study adds to the limited number of studies related to CP, QOL, and RT, giving additional data, analysis, and discussion to an important topic that needs more and continued research. The study is important for not only understanding the perceptions of QOL, but also improving treatment services of children with physical disabilities, specifically CP, and improving their QOL. The study found that a parent of a child with CP did perceive an increase in QOL after their child received RT treatment and this is an important piece to continuing research of perceived QOL of young children with physical disabilities.

REFERENCES

- Alghamdi, M., Chiarello, L., Palisano, R., & McCoy, S. (2017). Understanding participation of children with cerebral palsy in family and recreational activities. *Research in Developmental Disabilities, 69* (Supplement C), 96-104.
doi:<https://doi.org/10.1016/j.ridd.2017.07.006>
- American Therapeutic Recreation Association. (n.d.). *What is RT/TR?* Retrieved October 8, 2017, from <https://www.atra-online.com/page/AboutRecTherapy>
- Arnaud, C., White-Koning, M., Michelsen, S., Parkes, J., Parkinson, K., Thyen, U., Beckung, E., Dickinson, H., Fauconnier, J., Marcello, M., Mcmanus, V., Colver, A. (2008). Parent-reported quality of life of children with cerebral palsy in Europe. *Pediatrics, 121*(1), 54-64.
- Austin, D., Crawford, M., McCormick, B., & Van Puymbroeck, M. (2015). *Recreational therapy: An introduction* (4th ed.). Urbana, IL: Sagamore Publishing.
- Bandura, A. (1971). *Social learning theory*. New York, NY: General Learning Press.
- Becker, B. (2009). Aquatic therapy: Scientific foundations and clinical rehabilitation applications. *Journal of Physical Medicine & Rehabilitation, 1*(9), 859-872.
- Becker, B., & Cole, A. (2011). *Comprehensive aquatic therapy* (3rd ed.). Pullman, WA: Washington State University.

- Burton, L. & Brigham, H. (2013). Proprioceptive neuromuscular facilitation: The foundational of functional training. Retrieved from https://www.functionalmovement.com/Articles/127/proprioceptive_neuromuscular_facilitation_the_foundation_of_functional_training
- Centers for Disease Control and Prevention. (2018). *Health-related quality of life*. Retrieved from <https://www.cdc.gov/hrqol/concept.htm>
- Centers for Disease Control and Prevention. (2019). *Cerebral palsy*. Retrieved from <https://www.cdc.gov/ncbddd/cp/index.html>
- Delaney, B., Crandell, D., & Barfield, J. (2014). Sport-based therapeutic recreation: Perceived outcomes and implications for research. *Palaestra*, 28(3), 12-16.
- Dobhal, M., Juneja, M., Jain, R., Sairam, S., & Thiagarajan, D. (2014). Health-related quality of life in children with cerebral palsy and their families. *Indian Pediatrics*, 51(5), 385-387.
- Gilson, K., Davis, E., Reddihough, D., Graham, K., & Waters, E. (2014). Quality of life in children with cerebral palsy: Implications for practice. *Journal of Child Neurology*, 29(8), 1134-1140. doi:10.1177/0883073814535502
- Kim, E., Lee, D., & Kim, Y. (2015). Effects of aquatic PNF lower extremity patterns on balance and ADL of stroke patients. *Journal of Physical Therapy Science*, 27(1), 213–215. doi:10.1589/jpts.27.213
- Kolman, S., Glanzman, A., Prosser, L., Spiegel, D., & Baldwin, K. (2018). Factors that predict overall health and quality of life in non-ambulatory individuals with cerebral palsy. *The Iowa Orthopedic Journal*. 38.

- Kruijssen-Terpstra, A., Ketelaar, M., Verschuren, O., Gorter, J., Vos, R., Verheijden, J., Marian, J., & Visser-Meily, A. (2016). Efficacy of three therapy approaches in preschool children with cerebral palsy: a randomized controlled trial. *Developmental Medicine & Child Neurology*, *58*(7), 758-766.
doi:10.1111/dmcn.12966
- Laporta-Hoyos, O., Ballester-Plané, J., Póo, P., Macaya, A., Meléndez-Plumed, M., Vázquez, E., Delgado, I., Zubiaurre-Elorza, L., Botellero, V., Narberbaus, A., Toro-Tamargo, E., Segarra, D., & Pueyo, R. (2017). Proxy-reported quality of life in adolescents and adults with dyskinetic cerebral palsy is associated with executive functions and cortical thickness. *Quality of Life Research*, *26*(5), 1209-1222.
- Maher, C., Williams, M., Olds, T., & Lane, A. (2007). Physical and sedentary activity in adolescents with cerebral palsy. *Developmental Medicine And Child Neurology*, *49*(6), 450-457.
- Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2008). Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. *Quality of Life Research*, *17*(9), 1163-1171.
- Majnemer, A., Shikako-Thomas, K., Schmitz, N., Shevell, M., & Lach, L. (2015). Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy. *Research in Developmental Disabilities*, *47*, 73-79.
doi:10.1016/j.ridd.2015.08.009

- National Institute of Neurological Disorders and Stroke. (2013). Cerebral palsy: Hope through research. (NIH Publication No. 13-159). Bethesda, Maryland: U.S. Government Printing Office.
- Palisano, R., Chiarello, L., Orlin, M., Oeffinger, D., Polansky, M., Maggs, J., . . . Gorton, G. (2011). Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy. *Developmental Medicine And Child Neurology*, 53(2), 142-149. doi:10.1111/j.1469-8749.2010.03819.x
- Passmore, T., Gbur, T., Lindenmeier, D., Price, T., & Passmore, J. (2018). Warm-water—A recreational therapy intervention: A case report. *American Journal of Recreation Therapy*, 17(1), 21. doi: 10.5055/ajrt.2018.0151
- Porcino, A. (2016). Not birds of a feather: Case reports, case studies, and single-subject research. *International Journal of Therapeutic Massage & Bodywork*, 9(3), 1-2.
- Radsel, A., Osredkar, D., & Neubauer, D. (2017). Health-related quality of life in children and adolescents with cerebral palsy. *Slovenian Journal of Public Health*, 56(1), 1-10.
- Reedman, S., Boyd, R., & Sakzewski, L. (2017). The efficacy of interventions to increase physical activity participation of children with cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 59(10), 1011-1018. doi:10.1111/dmcn.13413
- Robinson, N., Lorenc, A., & Liao, X. (2011). The evidence for Shiatsu: A systematic review of Shiatsu and acupuncture. *BioMed Central Complementary Alternative Medicine*, 11(1), 88.

- Salzman, A. (2007). How to define aquatic specialty techniques: Operational definitions. Retrieved from <http://www.aquaticnet.com/Article%20-%20How%20to%20define%20aquatic%20specially%20techniques.htm>
- Sayre, J., Toklu, H., Ye, F., Mazza, J., & Yale, S. (2017). Case reports, case series - from clinical practice to evidence-based medicine in graduate medical education. *Cureus*, 9(8), E1546.
- Sevick, M., Eklund, E., Mensch, A., Foreman, M., Standeven, J., & Engsborg, J. (2016). Using Free Internet Videogames in Upper Extremity Motor Training for Children with Cerebral Palsy. *Behavioral Sciences*, 6(2), 1-14. doi:10.3390/bs6020010
- Varni, J. (2019). The PedsQL. Retrieved September 1, 2019, from <https://www.pedsql.org/index.html>
- Varni, J., Limbers, C., Neighbors, K., Schulz, K., Lieu, J., Heffer, R., . . . Alonso, E. (2011). The PedsQL infant scales: Feasibility, internal consistency reliability, and validity in healthy and ill infants. *Qual Life Res*, 20(1), 45-55. doi:10.1007/s11136-010-9730-5
- Varni, J., Seid, M., & Rode, C. (1999). The PedsQL: Measurement model for the pediatric quality of life inventory. *Med Care*, 37(2), 126-39. doi:10.1097/00005650-199902000-00003
- Velasco, M., Raya, R., Muzzioli, L., Morelli, D., Otero, A., Iosa, M., Cincotti, F., Rocon, E. (2017). Evaluation of cervical posture improvement of children with cerebral palsy after physical therapy based on head movements and serious games. *BioMedical Engineering OnLine*, 16, 1-13. doi:10.1186/s12938-017-0364-5

World Health Organization. (1997). *WHOQOL: Measuring quality of life*. Geneva,
Switzerland: WHO

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