

**Pilot study of parent and child perspectives evaluating the
effect of a 14 week swim programme on quality of life, self esteem
and independence in children with cerebral palsy**

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Abstract

Pilot study of parent and child perspectives evaluating the effect of a 14 week swim programme on quality of life, self esteem and independence in children with cerebral palsy

Background

The properties of water are known to create a supportive environment for physical activity, by reducing joint-loading force, allowing for reduced pain during movement, and providing resistance for strengthening. For those with cerebral palsy (CP), previous literature indicates that aquatic based activity can improve physical endurance, strength, and motor control. Greater freedom of movement experienced in water has been indicated as providing an environment that promotes social interactions and improved self-concept for children with CP. Research is yet to investigate the specific effect of a 14 week, structured learn-to-swim programme on the quality of life, independence, and self esteem in children with CP.

Method

Design: This mixed-method pilot study consisted of a single-group design involving eight families with a child with CP; with pre- and post-intervention measurements of the Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child) and post-intervention semi-structured interviews. The CPQOL-Child included a parent-proxy (children 4-12 years old) and child self-report (9-12 years) version; three of the children in this present study were aged 9-12 and eligible to complete the self-report. The pre-intervention measure was followed by a 14 week water-skill focused swim programme carried out by experienced swim instructors, once per week for 30 minutes, with participants in either small groups or one-on-one sessions, depending on the participant's individual abilities.

Sample: Eight children aged 5-11 with CP, and Gross Motor Function Classification System (GMFCS) levels of motor impairment I to III and their parents. The participant sample included five children with hemiplegia, two with diplegia and one with ataxic CP.

Data analysis: Changes in the CPQOL-Child from pre- to post-intervention were analysed using the Chi-square analysis and the post-intervention interview transcripts were analysed for theme development through a descriptive, exploratory approach.

Results

The mean improvement in CPQOL-Child for all participants was $3.12\% \pm 2.97$ (mean percentage \pm SD), with Chi square analysis demonstrating no significant change ($P=0.23$), and no significant change was shown in the individual seven domains of quality of life within the CPQOL-Child. Thematic analysis demonstrated incidence of improvement as follows: all eight parents reported improvement in the physical domain of quality of life and in the swim programme; seven parents in the quality of life domains of emotional and cognitive, as well as in independence and self esteem. The lowest incidence was in the social domain of quality of life, where six parents reported improvement.

Conclusion

There is a discrepancy between the quantitative and qualitative results in the present research, with the perceived change from parent perspectives demonstrating higher levels of improvement compared to the CPQOL-Child. This difference may be due to the limited sample size in the research and/or a lack of sensitivity of the CPQOL-Child. A controlled experimental design with a larger sample would provide more information regarding the discrepancy, and would also provide more generalisable results for the effect of the swim programme in children with CP.

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List of Abbreviations

CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
GA	Gestational Age
CPQOL-Child	Quality of Life Questionnaire for Children with Cerebral Palsy

Chaper 1: Introduction

The goal of this research was to explore the impact of a swim programme on the constructs of quality of life, self esteem and independence and their association with the physical impairment of cerebral palsy (CP). The research described the effectiveness of an aquatic exercise programme in achieving positive change within these concepts. This chapter provides a brief introduction to CP and the causative factors of inactivity in this population. The physical and social benefits of aquatic based activity are introduced and the aim of the current research is stated in the conclusion of this chapter.

CP has been defined as a common congenital motor disorder that includes a group of non-progressive, conditions disorders affecting motor function and/or posture (Krägeloh-Mann & Cans, 2009). According to the Cerebral Palsy Society of New Zealand, the frequency of CP in New Zealand is two to three cases per 1000 live births, with approximately 150 – 200 new CP cases identified annually. There is an estimated 7000 people in New Zealand with some level of CP, and one third of those are under 21 years of age (CPSNZ, 2007). Diagnosis is made between the ages of several months to five years old as neurological symptoms develop through early childhood and remain non-progressive (Wood, 2006). The diagnosis is separated into descriptive categories, including three different subtypes: spastic, dyskinetic and ataxic, the affected area: diplegia, hemiplegia, tetraplegia or quadriplegia, and through level of severity (O’Shea, 2008). There has been a scale developed and subsequently widely used in research and clinical settings (Palisano, Rosenbaum, & Walter, 1997). The scale is the Gross Motor Function Classification System (GMFCS) which describes the level of severity from I to V (see Appendix A).

It has been established that both children and adults with CP have a reduced level of physical activity relative to their peers without physical impairments. These sedentary lifestyles affect their health and physical fitness (Damiano, 2006). Individuals with CP are also at a greater risk of developing depression, higher anxiety and stress, lower self esteem and motivation, and social withdrawal (Shapiro & Martin, 2010). Exercise interventions have been shown to have a positive effect on social function, self esteem, depression and on the confidence to become involved in physical activities (Shapiro & Martin, 2010). The aquatic environment specifically has been found to promote social interactions and perceived levels of acceptance. Some have attributed this additional benefit in part to the increased

opportunity water provides to initiate multiple social interaction with peers and teachers (Getz, Hutzler, & Vermeer, 2006).

To date, there are no reports of an investigation into the effects of a 14 week water-skill focused swim programme with the goals of improving all aspects of quality of life in addition to independence and self esteem in children with a variety of CP classifications. The objective of this present research was to conduct a 14 week water-skill focused swim programme comprised of one 30-minute session per week. The aim was to explore the relationship of participation in this swim programme to change in quality of life, independence and self esteem in children with CP, and to contribute additional knowledge towards future management programmes for this population. The effect of this programme on objective change in motor abilities is not reported in this research paper.

Within the introduction chapter, the concepts that have influenced the formation of this research have been briefly introduced. These concepts include CP and what the disorder constitutes, inactivity and its affects, and the specific benefits of aquatic activity. Each of these concepts and some closely related topics will be discussed in greater depth in the review of literature. Following the review of literature, the chapters sequentially detail the methodology and method used. The results are then outlined, and interpreted within the discussion, and the resultant conclusions are stated.

Chaper 2: Review of literature

The review of literature outlines relevant topics and previous research which contributed to the formation of this study. The topics covered are cerebral palsy (CP), the benefits of exercise and specifically the benefits of swimming, specifically detailing the benefits in people with CP. Quality of life is defined and discussed; and the available tools for analysing quality of life are outlined in regard to studies involving people with CP. Independence and self esteem are also defined and then discussed in relation to studies involving people with CP.

Cerebral Palsy

Definition:

Several definitions for CP have been developed over time. The Accident Compensation Corporation (ACC) in New Zealand simply defined CP as “a collection of motor disorders that are either a result of a congenital disease or brain damage before the age of two” (Bowens, Scheib, & Larking, 2011, p. 7)

Other organizations and researchers detailed more specifically what is included under the term CP. The Surveillance of Cerebral Palsy in Europe group (SCPE) stated that “CP is a group of permanent but not unchanging, disorders of movement and/or posture and of motor function, due to a non-progressive interference, lesion or abnormality of the developing/immature brain” (Wood, 2006, p. 286). The SCPE definition excluded other disorders from the classification, including progressive motor disorders, spinal, nerve or muscular disease and also brain metabolic disorders.

Others, such as Krägeloh-Mann and Cans (2009) included links to other functional disturbances in the definition. They said CP is essentially an umbrella term for a set of neurological disorders starting in the early stages of development, causing a non-progressive but permanent motor deficit. The degree of motor impairment varies and is often accompanied with disturbances in perception, cognition, sensation, communication, seizures and/or behavioural changes.

Epidemiology

The epidemiology of CP has been based upon the overall frequency in the general population. The overall rate is further divided into frequency within different gestational ages (GA) or birth weights. Epidemiology also includes the percentage of different causes of CP as well as the frequency of co-impairments.

CP has been found to be more common in premature infants and low birth weights, with half of all incidences occurring in infants with a birth weight of less than a kilogram (Tilton, 2006). The SCPE developed a database of children with CP detailing trends over 9 countries in Europe. Of those children, 55% had a GA of more than 37 weeks, 20% were between 32-36 weeks and 25% were below 32 weeks (Krägeloh-Mann & Cans, 2009). Of the same population, one-third were non-ambulatory, one-third had severe intellectual impairment and 12% had a severe visual impairment (Krägeloh-Mann & Cans, 2009). A systematic review of CP prevalence studies found that reports on the rate of CP in very low birth rate children were inconsistent, with some reporting an increase and others reporting a slight decrease (Krägeloh-Mann & Cans, 2009). Based upon the larger, more reliable population-based studies within the review, Krägeloh-Mann and Cans (2009) concluded the rate of CP was unchanging or gradually increasing.

Krägeloh-Mann and Cans (2009) added that “CP is caused in more than 80% of cases by brain lesions or mal-developments to which can be attributed to different timing periods of the developing brain” (p. 538). The extent and location of injury determines which clinical subtype of impairment occurs. A systematic review of studies reporting MRI findings in children with CP reported abnormal findings in 86% of cases, with an indication of the pathogenesis in 83% of those abnormal cases (Krägeloh-Mann & Horber, 2007).

The same review detailed the types of abnormality most commonly found. These abnormalities were mal-developments, periventricular lesions, cortical lesions and deep grey matter lesions. The timing of the injury during fetal development determined the mal-development or location of the lesion (Krägeloh-Mann & Horber, 2007). The location and extent of change decided the subtype of CP and also related to the presence and severity of the associated impairments.

Diagnosis

Diagnosis is difficult to establish early in life due to several factors (Krägeloh-Mann & Cans, 2009). It may take time for the neurological symptoms to develop and become established. Early neurological signs may be transitory or may change over time. Continued observation is needed to help separate CP from progressive disorders. Differentiation from neurodegenerative conditions is difficult before the age of four as these conditions can initially present with a similar clinical picture (Krägeloh-Mann & Cans, 2009).

The difficulty in making a diagnosis is a long established issue as demonstrated by Nelson & Ellenberg (1982) as cited in Wood (2006). They found that following a diagnosis of CP at one year old, over half the children in the study were free of motor impairment at a seven year follow up. Therefore, a more definitive diagnosis is made by the age of four or five once a clear pattern is determined (Wood, 2006).

Common causes include peri-natal hypoxic-ischaemic encephalopathy (HIE), neonatal seizures and cortical arterial infarction (Krägeloh-Mann & Cans, 2009). HIE is assumed in the absence of another apparent cause; it describes a clinical state in the first seven days of life. HIE includes the peri-natal conditions of cerebral dysgenesis, intrauterine infections, and severe metabolic and neuromuscular disorders (Wood, 2006). The clinical features are seizures, poor self-regulation of state, change in tone, decreased reflexes, and decreased level of consciousness/responsiveness.

While the causative factors increase the risk of developing CP, not all infants who have been premature, have had HIE, neonatal seizures or cortical arterial infarctions develop the disorder (Wood, 2006). Even in the highest risk group of infants, almost half do not develop CP (Badawi et al., 2005). Neonatal ultrasounds, EEG's and MRI's have increased prediction, but in spite of technological advancement there is still a significant grey area, which in the current state of diagnostic capability can only be resolved with time (Wood, 2006). This lack of predictive certainty influences what preventative measures can be taken for at risk infants to improve the outcome. The uncertainty also affects how families are counseled and what resources can be allocated to them (Wood, 2006).

Classification

CP is classified according to three criteria that describe the physical state of the person. One criterion is the level and type of spasticity, another is the anatomic location of what has been affected and the third is an assessment of the degree of impairment. The last is assessed on a scale from more to less able which is based on the functional ability of the individual to perform daily tasks.

Classification of spasticity is made through the signs and symptoms in the individual, focused around the level and type of spasticity displayed. O'Shea (2008) described spasticity as "a velocity-dependant increase in muscle tone that can be assessed clinically as the joint angle at which an increased muscle tone (resistance to stretch) is encountered" (p. 36).

Dyskinetic CP can be either choreoathetotic or dystonic. People with dystonia will display hypertonia and reduced activity, while for those with choreoathetosis the limbs and facial muscles show irregular, spasmodic, and involuntary movements. The anatomic distribution of the motor disorder includes spastic diplegia (bilateral disturbance with leg greater than arm involvement), spastic hemiplegia (unilateral involvement), or quadriplegia (bilateral disturbance with arm equal to or greater than leg involvement) (O'Shea, 2008).

A scale has been developed to assess the degree of motor impairment specifically for individuals with CP (Palisano, et al., 1997). This is the Gross Motor Function Classification System (GMFCS) (see Appendix A). It serves two purposes; to follow the natural course of motor development in children with CP and to differentiate this natural course from change achieved through therapeutic intervention (Wood, 2006).

The GMFCS is used internationally and is widely accepted for use in both clinical and research settings (Carnahan, Arner, & Hägglund, 2007). The GMFCS has been found to be a reliable and stable measure over time for the degree of motor impairment (Wood & Rosenbaum, 2000). Since its validation it has been used in a clinical setting as an assessment tool for the physical aspects of CP (Palisano, et al., 1997). In regard to research, the GMFCS has become commonly used to define the research question or inclusion criteria of a study (Carnahan, et al., 2007; Damiano, 2009; Davis, Davies, et al., 2009; Dodd, Taylor, & Damiano, 2002; Krägeloh-Mann & Cans, 2009; Liao, Liu, Liu, & Lin, 2007; Unger, Faure, & Frieg, 2006).

There are five levels of impairment within the system from I (least affected) to V (most affected). This is further divided into age to describe activity based on those periods of development. These groupings are under two, two to four, four to six and six to 12 years old

(O'Shea, 2008). The GMFCS was used in this study as a part of the inclusion criteria, with the involvement of children with impairments level I-III.

Prognosis

Prognosis is primarily focused around the prediction of ambulation, quality of life and life span (O'Shea, 2008). Prognostic studies have primarily focused on ambulation and other aspects of physical function (Watt, Robertson, & Grace, 1989), including the influence of co-impairments which can be significant (Trahan & Marcoux, 1994). It has been reported that 31% of children with CP have severe intellectual impairment, 21% have epilepsy and 11% have severe visual impairment (O'Shea, 2008).

Mortality is closely related to the "overall level of functional impairment" (O'Shea, 2008, p. 38). This involves both the severity of CP and associated morbidities. One study found the strongest predictor of mortality was intellectual impairment (Blair, Watson, Badawi, & Stanley, 2001) and another found that the higher the number of impairments, the higher the mortality rate (Hemming, Hutton, Colver, & Platt, 2005).

Intervention and Treatment

Traditional interventions have largely focused around the management of symptoms of spasticity. The aim is to improve function, prevent joint contractures and hip subluxation, decrease pain, and relieve caregivers (Wood, 2006). Toward this end, a combination of interventions is utilised, including physical therapy (described in greater detail in the following sub-section), surgery, and pharmacology (Tilton, 2006).

The total number of surgeries in children with CP has been reported as decreasing from 40% in children born 1990-1991 to 15% in those born 1994-1995 (Hägglund et al., 2005). For both these time periods, the children in that population-based study were assessed at age eight. Hägglund, et al. (2005) reported that the need for orthopaedic surgery is decreasing as other therapies are developed. When surgery is required, the most commonly used is tendon lengthening which is most frequently required for the Achilles tendon. Another surgery that may be utilized is dorsal rhizotomy, which selectively severs nerve roots to relieve spasticity (Tilton, 2006). McGinley et al. (2012) performed a systematic review of single event, multilevel surgery studies from 1985 to 2010. Single event, multiple level surgeries address several musculoskeletal pathologies in both lower limbs in one operative procedure (McGinley, et al., 2012). They found that there was a "trend towards

favourable outcomes in gait” (p. 117), with an improving quality of research design and reporting of results over time.

Pharmacological interventions in regard to the physical aspects of CP are focused on reducing spasticity (Tilton, 2006). The most effective and commonly used pharmaceutical is botulinum injections (Hägglund, et al., 2005). These injections may be accompanied by oral medications to decrease global muscle tone. The most common of these are the benzodiazepines, baclofen, tizanidine and dantrolene sodium (Tilton, 2006). All these medications have drowsiness and sedation as side effects, which limit the frequency of use with children (Tilton, 2006). Other pharmaceutical interventions are primarily to treat co-impairments. These include anti-epileptic medication such as phenytoin, lamotrigine and gabapentin (Dilorio et al., 2003). Medication may also be useful for improving concentration in cases where Attention Deficit Disorder is present (O’Shea, 2008). The type of medication, dosage and frequency of administration is determined on a case-by-case basis, ideally with the purpose of achieving best possible function (Dilorio, et al., 2003).

Exercise

The exercise section covers the definition of physical activity, levels of inactivity in those with CP, and physical exercise recommendations. The section then goes on to describe the general benefits of exercise, benefits in those with CP and finally movement interventions for people with CP. The main topic which will be explored in detail is how exercise is widely acknowledged as being beneficial to our quality of life (WHOQOL, 1996), with these benefits extending to mental and physical health. These benefits are strongly supported by research in adult and child populations (Trudeau & Shephard, 2010). Exercise has become widely acknowledged as advantageous to the health of the general population, to the extent of being recognised by the New Zealand government in the form of the initiative to ‘push play.’ This initiative encourages physical activity for at least half an hour per day for adults and one hour per day for children (McLean & Watts, 2004). Water-based activity specifically has a wide range of benefits (Timothy, John, & Michael, 2007), which will be explored in the following section.

Physical Activity, Exercise and Fitness

Definition

Movement is accomplished through the combined function of the musculoskeletal system, the central nervous system, and the body’s ability to metabolise sources of energy. The main sub-categories of movement are physical activity, physical exercise and physical fitness, depending on how the movement is performed. Perez (2008) described physical activity as “any body movement produced by the skeletal muscles that results in energy expenditure” (p. 515), whereas physical exercise was “planned, structured and respective, with the intent of improving physical fitness incorporating all body systems” (p. 515). The concept of physical fitness extended to include the factors of cardiovascular fitness, respiratory fitness, body composition, flexibility, and muscle strength and elasticity (Perez, 2008).

Inactivity

Based upon reviews of literature and on survey data, the World Health Organisation (2010) have stated that physical inactivity was identified as the fourth leading risk factor for global mortality, following high blood pressure (13%), tobacco use (9%), and elevated blood glucose (6%). Inactivity (6%) was closely followed by the fifth leading risk factor of being over-weight or obese, which were responsible for 5% mortality. Physical inactivity was estimated as being the primary cause of 21-25% of breast cancer and colon cancer, 27% of diabetes, and an estimated 30% of ischemic heart disease (WHO, 2010). These statistics were based upon a meta-analysis and systematic review performed by Renehan, Tyson, Egger, Heller, and Zwahlen (2008) on the link between increased body mass index and various cancers. The link between physical inactivity and cancer “seems to be mediated by alterations in the metabolism of endogenous hormones” (Bianchini, Kaaks, & Vainio, 2002, p. 5) which included testosterone, oestrogen, insulin and insulin-like growth factor.

The American College of Sports Medicine released recommendations for physical activity which were based upon current exercise literature (Garber et al., 2011). Garber et al. (2011) stated that “reducing total time spent in sedentary pursuits and interspersing short bouts of physical activity and standing between periods of sedentary activity should be a goal for all adults, irrespective of their exercise habits” (p.1334).

Physical Inactivity in Individuals with Cerebral Palsy

The established benefits of exercise have lead to research regarding the extent to which inactivity affects individuals with CP. “Moderate to vigorous activity is an important component in the prevention of disease and promotion of general wellbeing” (Retarekar, Fragala-Pinkham, & Townsend, 2009, p. 342). However, people with CP have been found to be less physically active as a result of impairments such as muscle weakness, spasticity, lack of coordination, difficulty walking and less adequate cardio-respiratory function (Damiano, 2006; Dodd, et al., 2002). Additionally, children with CP spend less time participating in physical activity, such as playground activities with peers, and live a more sedentary life style, which leads to a reduction in energy levels and endurance (Fowler et al., 2007).

Bottos, Feliciangeli, Sciuto, Gericke, and Vianello (2001) conducted a study with 72 individuals with CP to examine the progression of their impairment from childhood to adulthood. It was found that as the participants became adults the use of rehabilitation services reduced, and independent walking reduced in ability and endurance. Bottos et al. (2001) concluded that in order to facilitate function, therapeutic plans should concentrate on

an approach to aid independence.

A cross-sectional study recorded the daily total step count over a five day period of 81 ambulatory children with CP compared to a typically developing control group (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2007). It was found that the children with CP had significantly lower levels on all measured outcomes as compared with the control. Children with a higher level of physical impairment were the least active, while those with the least impairment were as active as those who were typically developing. Bjornson et al. (2007) suggested that differing levels of exercise and walking intensity should be offered in physical therapy interventions to account for the varied level of impairment.

The American Physical Therapy Association undertook a literature review to identify and promote physical fitness interventions for children with CP (Fowler, et al., 2007). A part of their aim was to identify the contributing factors toward the high rate of inactivity in this population. Factors which had been well researched were muscle weakness, lower endurance, muscle spasticity and deficient balance which all contributed to a difficulty in maintaining a high enough intensity of exercise to improve their physical fitness. They concluded that “although many of the factors contributing to physical inactivity in children with CP have been identified, few coordinated investigations have examined how physical fitness programmes can ameliorate their negative effect on these children” (Fowler, et al., 2007, p. 1504).

Physical Exercise Recommendations

There was a joint recommendations issued in 1995 by the Centers of Disease Control and Prevention (CDC) and the American College of Sports Medicine (ACSM) which stated that “every US adult should accumulate 30 minutes or more of moderate intensity physical activity on most, preferably all days of the week” (Haskell & Lee, 2007, p. 1). Subsequently, survey data demonstrated that in 2005 only 49% of US adults met these recommendations (Haskell & Lee, 2007). Active New Zealand Survey data showed a lower status than the US, with 39% of adults performing 30 minutes of physical activity at least five days per week in 1997-2001 (Van Aalst, Kazakov, & McLean, 2003). In the same survey 76% of 9-12 year old children were found to be active. For New Zealand adults there was a rise to 48.2% in the 2007/08 survey, but child data were not included (SPARC, 2008).

General Benefits of Physical Activity and Benefits in Cerebral Palsy

Introduction

Taking part in regular exercise has been found to be essential for the prevention of cardiovascular disease, type 2 diabetes mellitus and obesity (Eyre, Kahn, & Robertson, 2004; Haskell & Lee, 2007; Perez, 2008; Shephard & Balady, 1999). “Regular physical activity has an inverse and generally linear relationship with the rates of all-cause mortality, total cardiovascular disease, and the incidence of type 2 diabetes mellitus” (Eyre, et al., 2004, p. 1999). A part of this disease prevention comes from maintaining healthy blood pressure, respiratory function, immune function, muscle strength, and bone density.

Paffenbarger, Hyde, Wing, & Hsieh (1986) as cited in Shephard & Balady, (1999) undertook research on the relationship between mortality and physical fitness. They reported that “when habitual physical activity levels are increased, subsequent mortality is decreased relative to those who remain physically inactive” (p. 963). These authors concluded that the data supported the need to increase levels of physical activity among both women and men. The greatest decrease of mortality rates developed among those who initially were the least fit.

Exercise and Cognitive Function

Cognitive function has been shown to influence the quality of life in individuals with CP. This relationship has become integrated into quality of life outcome measures for this population (Waters et al., 2009). The link to the outcomes of interest in this present study led to further investigation into the influence of exercise on cognitive function. The interaction between exercise and cognitive function is a growing area of research. Recent research results indicated a positive relationship between the two factors in a range of populations (Abbott et al., 2004; Ekeland, Heian, Hagen, & Coren, 2005; Heyn, Abreu, & Ottenbacher, 2004; Ide, Horn, & Secher, 1999; Larson et al., 2006; Rovio et al., 2005; Santos et al., 2003; J. Stevens & Killeen, 2006; Trudeau & Shephard, 2010). The literature which has been systematically reviewed largely displays good sensitivity and strength (Ekeland, et al., 2005; Trudeau & Shephard, 2010).

The evidence suggested that physical activity in older individuals can decrease the risk of developing varying forms of dementia, including Alzheimers Disease (AD) (Abbott, et al., 2004; Larson, et al., 2006; Rovio, et al., 2005). It has been indicated that exercise may be a powerful protection from the occurrence of neurodegenerative decline. In addition, exercise

has been shown to slow the progression of the cognitive symptoms of dementia in those who already have the condition (Heyn, et al., 2004; J. Stevens & Killeen, 2006). These benefits demonstrate the potential for change in populations with neurological compromise, which was previously thought to be irreversible. For individuals with CP this area of research shows promising conclusions which may provide avenues for improvements in quality of life.

Pérez and Cancela Carral (2008) investigated studies the effect of exercise for individuals with AD. They found that exercise had the beneficial effects of decreasing depression and increasing overall health. They also found improvement in cognitive function in the participants. The process of AD involves the formation of amyloid plaques leading to the congestion of normal neurological function and to atrophy of the brain (Rovio, et al., 2005). Pérez and Cancela Carral (2008) stated that regular exercise can modify some metabolic and neuropathic changes associated with AD, as well as some of the psychological and organic abnormalities that accompany AD.

An aerobic exercise programme was designed for adults with AD, and a feasibility trial was undertaken with two participants (Yu & Kolanowski, 2009). The training resulted in improved physical function, therefore the authors stated that aerobic exercise was important for these adults with AD and had the potential to alleviate their symptoms. They concluded that their programme was safe, feasible and easy to implement. However further research was required to examine the cognitive, functional and behavioural outcomes of aerobic exercise on adults with AD.

Tanaka et al. (2009) investigated the effect of a six-month exercise programme on adults with Parkinson's disease. They concluded the exercise programme benefited executive function in their participants. This benefit was expected to facilitate independence, autonomy and quality of life, although these factors were not explored in that study.

Demaille-Wlodyka, Donze, Givron, and Gallien (2011) described how patients with multiple sclerosis were less motivated to participate in physical activity because of severe fatigue and fear of symptom development. This activity restriction was greater than other comparable chronic diseases such as chronic fatigue, cerebral paralysis and COPD. Studies have shown that in rehabilitation settings, involvement in a physical aerobic exercise programme had the outcome of improving the quality of walking and walking endurance without worsening the neurological status or the participants overall feeling of fatigue (Demaille-Wlodyka, et al., 2011).

In younger populations, it has been found that there may be enhanced cognitive function from participating in physical activity. A study explored the effect of high impact

running on vocabulary learning in 30 adult males (Winter et al., 2007). The result was a 20% improvement in speed of learning immediately post-intervention with good vocabulary retention found on an eight month follow-up. Griffin et al. (2011) found that 5 weeks of high intensity cycling training improved function of the hippocampus in young adult males as measured immediately post-intervention.

A randomized controlled trial performed with children and adolescents with CP evaluated an eight month training programme involving 45 minute training sessions of aerobic and anaerobic exercise (Verschuren et al., 2007). Results included a statistically significant improvement in the cognitive domain additional to improvements in physical function.

These studies in younger populations all used acute exercise sessions as a part of their protocol, whereas Grego et al. (2005) performed cognitive measures at 20 minutes and 120 minutes of running, and found the cognitive benefits declined after 120 minutes as exercise-induced fatigue occurred. A meta-analysis on this topic concluded that the enhancement or impairment of cognitive function depended on when it was measured relative to the exercise intervention, the type of cognitive task used as the measurement and the exercise type performed (Lambourne & Tomporowski, 2010).

Benefits of Physical Activity in People with Cerebral Palsy

Damiano (2006) stated that based on historical practice, it was believed that in order to improve functionality in people with CP, a high quality of movement needed to be encouraged over a high quantity. It is now thought to be more beneficial to encourage movement quantity. “Current thinking is shifting toward a view that children need to be as mobile as possible, regardless to some extent of the manner chosen by them or for them” (Damiano, 2006, p. 1534). Providing an assistive mobility device to children with more severe impairments was shown to increase their quality of social life and independence, but providing such devices did not have the same effect as voluntarily choosing an activity (Damiano, 2009, p. 1201).

Van den Berg-Emons, Van Baak, Speth, and Saris (1998) investigated an aerobic sports programme with 20 children with spastic CP. They assessed the effect on the factors of daily physical activity, fat mass and physical fitness in an intervention and control group. Results showed an increase in aerobic power and isokinetic muscle strength in the intervention group. In regard to fat mass, there was no change in the intervention group versus an increase in the control group. These authors subsequently suggested that physical

training may help prevent deterioration of muscle strength and body composition. There was no change in daily physical activity, although the researchers reasoned this may have reflected the small population. They concluded that four sessions of 45 minutes per week may increase the overall level of daily physical activity in the long term, although there was no statistically significant change during the nine month period of the intervention (Van den Berg-Emons, Van Baak, Speth, & Saris, 1998). The interventions used by Van den Berg-Emons et al. (1998) were validated, although not all were validated in a CP population. They do discuss how this factor may have influenced the results. The measures were reliable and answered the aims of the study, however, the researchers excused one outcome (no change in physical activity) based on a small population size, which did not change their emphasis on the positive outcomes in other areas. There was no critique of the positive outcomes or mention of the need to perform a larger scale study to validate these results.

Research was undertaken to assess the influence of age on step activity behaviour (Stevens, Holbrook, Fuller, & Morgan, 2010). The participants were 27 children with CP with a GMFCS of I-II, as compared to 27 age-matched children without physical impairments. Each group was divided into two age groups for data analysis. The older youth with CP had lower levels of step activity as a result of less physical activity when compared to younger children with CP and typically developing children. The conclusion emphasised the need for children with CP to be given the opportunity and encouragement to become involved in physical activity (Stevens, et al., 2010). The main limitation of this study was only six children with GMFCS II were included. This low number limits the generalisability of conclusions regarding comparisons between GMFCS I and II. This limitation was not discussed at any point in the article. One other limitation which was discussed was the lack of information regarding sport or activity involvement of any of the participants. Whilst this would clearly impact step activity, no conclusions could be drawn without this information. Stevens et al. (2010) otherwise performed a well structured study with validated measures and reasonable conclusions.

Movement time and the kinematic properties of unilateral and bilateral reaching movements in adults with CP were investigated by Langan, Doyle, Hurvitz, and Brown (2010). The study focused on the effect that simultaneous or sequential bilateral movements had on inter-limb coordination. These authors concluded that training which involved bilateral sequential movement may prove more beneficial for upper limb coordination. While the population size of this study was small (N=11), the method was otherwise well designed and the implications and limitations of the study were thoroughly discussed.

Movement Interventions for People with Cerebral Palsy

With the increasing understanding that movement and physical activity is beneficial for people with CP, there have been a number of therapies which have become common within this population. These therapies include the Bobath technique, conductive education, hippotherapy and strength training programmes.

The Bobath Technique and Conductive Education

The Bobath Technique and Conductive Education (CE) are therapeutic interventions that aim to encourage movement and functionality in people with CP. Part of the goals in treating children with CP with either of these rehabilitation programmes is to increase their functional capabilities and maximise independence in order to acquire the necessary skills to facilitate daily living (Dalvand, Dehghan, Feizy, Amirjalali, & Bagheri, 2009).

The Bobath Technique was developed in the 1950's as a therapy which aimed to observe how abnormal tone affected the child's ability to function (Barber, 2008). The purpose of this intervention was to analyse a child's performance, determine their potential abilities, correct abnormal postural tone, and subsequently facilitate normal movement patterns (Dalvand, et al., 2009).

Conductive Education (CE) was developed by Andreas Peto in the 1940's in Hungary. The main principle was to promote independent social participation and function in children with motor impairments (Darrah, Watkins, Chen, & Bonin, 2004b). "One of its ideals was to avoid learned helplessness by having students identify new achievable goals" (Liptak, 2005, p. 158). The CE therapists also adopted the role of teacher by facilitating independent function of the child via repetition and verbalisation. In contrast to most other rehabilitative programmes, supportive equipment such as splints, walkers and wheelchairs were discouraged during the therapy sessions (Liptak, 2005). Group settings have frequently been utilised CE programmes, where the children worked collectively to monitor and encourage each other. Interactive activities were used to achieve the educational goals, and the group goals were determined by the general abilities of the group (Darrah, et al., 2004b).

Darrah et al. (2004) presented a systematic review of 15 studies performed between 1966 and 2001, which found a varying degree of evidence for CE with only one study rated at the highest level of evidence according to the credibility assessment scale they were using. They concluded that "the present literature base does not provide conclusive evidence either in support of or against CE as an intervention strategy. The limited number of studies and their weak quality makes it impossible for the literature alone to guide decision-making

regarding CE” (Darrah, Watkins, Chen, & Bonin, 2004a, p. 202). They stated that this conclusion served the purpose of helping families make an informed choice of therapy based upon other factors such as cost, accessibility and how it serves the needs of the family. The review also highlighted the need for future research to display a higher credibility of evidence.

The effects of the Bobath Technique, CE, and parent education in activities of daily living were compared by Dalvand et al. (2009). The study consisted of 45 children with CP aged four to eight years old, equally divided into the intervention groups. They concluded that all three interventions produced statistically significant improvement in the abilities of the children to carry out activities of daily living, with the CE group performing better in the area of social interaction. It was reasoned that the group interaction in CE provided a more encouraging and socialising environment which could translate into other social interaction. Other factors which may have influenced change in any of the groups were not discussed; however, prior studies were mentioned whose findings correlated with this change in the CE group, which provided some validation of the results at least within the CE group.

Hippotherapy

Horseback riding as a therapeutic intervention (hippotherapy) has now become a common therapy for children with CP, but from the 1950’s it was used for children with polio (Liptak, 2005). “Horseback riding therapy is directed towards improving the riders’ ability to receive and process body wide sensory information from the smooth, rhythmical movements made by the horse” (Spink, 1993, p. 6). In theory, horseback riding can improve posture, balance and function. This improvement is achieved through mobilising the pelvis, lumbar spine and hip joints, decreasing muscle tone, improving head and trunk posture, and developing equilibrium reactions in the trunk (Sterba, Rogers, France, & Vokes, 2002).

Sterba et al. (2002) investigated how an 18 week hippotherapy programme affected the gross motor function of 17 children with spastic CP. Results from the Gross Motor Function Measure (GMFM) showed an overall increase in function of 7.6% directly post-intervention. This measure returned to pre-intervention levels six weeks post-intervention, with only the sub-category of walking, running and jumping maintaining an increase at 1.8%. The authors concluded that their results showed that hippotherapy may improve gross motor function in children with CP, and should be considered as an option for therapy with people with CP.

Casady and Nichols-Larsen (2004) undertook research to establish the effect of

hippotherapy on the functional ability in 10 children with CP. Their results were statistically significant in all but the dimension of lying and rolling. These authors suggested that hippotherapy was a feasible treatment option which was capable of improving the functional abilities of children with CP. “The evidence suggests that HBRT” (horseback riding therapy) “and hippotherapy are individually efficacious, and are both medically indicated as therapy for gross motor rehabilitation in children with CP” (Sterba, 2007, p. 68).

Given the growing body of literature advocating hippotherapy as beneficial for motor function, Debuse, Gibb, and Chandler (2009) performed a qualitative study to explore the influence of the intervention from the user’s perspectives. The 17 participants, aged 4-63 years, found hippotherapy to be more beneficial than traditional physiotherapy. Hippotherapy had improved participation and activity levels over all ages, and the improved physical function led to an enhanced self esteem, self efficacy and quality of life (Debuse, et al., 2009). The authors concluded that the physical benefits confirmed what had been previously reported, while their qualitative data provided new insights into the effect on the participants’ wider context.

Strength Training in People with CP

Strength training has become an extensively researched therapy for the CP population (Dodd, et al., 2002; Dodd, Taylor, & Graham, 2003; Liao, et al., 2007; Scianni, Butler, Ada, & Teixeira-Salmela, 2009; Unger, et al., 2006). Strengthening has been defined as “repetitive, effortful contractions of any muscle” (Scianni, et al., 2009, p. 81) and this broad definition addresses programmes involving progressive resistance exercise, electrical stimulation and biofeedback.

Damiano and Abel (1998) conducted strength-training programme over a six week period to analyse its effectiveness in 11 children with spastic CP. Results showed a significant increase in strength, gait speed and cadence. “This study reinforced the relationship of strength to motor function in CP, and further demonstrated the effectiveness of strengthening in this population” (Damiano & Abel, 1998, p. 119).

Dodd (2002) carried out a review which focused on the effectiveness of strength-training interventions in people with CP. Eight of the 10 articles reviewed found a significant increase in strength. Two of the studies performed additional measures of spasticity and reported no change or a decrease thereof.

McBurney, Taylor, Dodd, and Graham (2003) conducted a qualitative study which explored the effect of a home-based strength-training programme in 11 youth with CP aged

eight to 18 years old, with GMFCS scores of I to III. The six week programme consisted of three sessions per week, containing bilateral half squats, heel raises and step-ups. Semi-structured interviews were conducted three months post-intervention. The results described an improvement in strength, flexibility, posture, walking and step negotiation, and an increase in energy levels. There were additional benefits described in the psychological domain, with an improved sense of well being, and increased participation in school and leisure activities. The effect of strength training on psychological outcomes has been less frequently researched, and McBurney et al. (2003) suggested it may be an area for future quantitative research.

Scianni et al. (2009) undertook a systematic review of randomized controlled trials which considered the effects of strengthening interventions. The aim of the review was to assess if strength could be increased and activity levels improved without increasing spasticity. After a review of five studies, they stated that strengthening interventions were not effective in children with CP who were ambulatory. However, the studies demonstrated no harm or increase in spasticity. These authors suggested that future studies of strengthening interventions could focus on including higher intensity exercise and increased frequency of the sessions, to the level of the American College of Sports Medicine recommendations.

In the same year, Damiano (2009) performed a review on a similar topic, and stated “the general consensus across studies is that strength can be predictably increased through a properly designed short-term programme” (p. 1201). Damiano (2009) concluded that some, but not all of the studies showed measurable functional improvements and that longer strength-training programmes might be required to demonstrate more definitive results.

Scianni et al. (2009) were more stringent on their inclusion criteria than Damiano (2009), with only randomised controlled trials included, with a resultant limited sample of five trials being included. Their subsequent conclusion that strength-training was not effective was based upon a small but credible sample. Damiano (2009) summarised the results of several recent systematic reviews, with varied conclusions. They concur with Scianni et al. (2009) that more intensive and longer trials needed to be researched, and added that functional movements may have provided a greater translation into other motor tasks outside the strength-training programmes. The literature concluded that strength-training interventions do not appear to increase levels of spasticity, and are therefore safe (Damiano, 2009; Dodd, et al., 2002; Scianni, et al., 2009). Future programmes were encouraged to focus on frequency and duration of the programmes.

As detailed earlier, physical inactivity has been found to be prevalent in individuals

with CP (Damiano, 2006, 2009; Fowler, et al., 2007; Retarekar, et al., 2009). However, the literature showed a positive change in function for those with CP who participated in functional movement education and physical activity. Results have indicated improvement in motor function, strength, social abilities and participation. Collectively, these findings may further the need to promote greater involvement in physical activity with both children and adults, and for therapists to increase suitable exercise prescription for those with CP.

Swimming

Effects of Hydrodynamic Properties

Introduction

The benefits of aquatic exercise extend over several physiological systems and are especially evident in several populations. The use of aquatic exercise in people with musculoskeletal conditions such as CP is beneficial as it “is a form of low-impact exercise in which joint loading forces are greatly reduced compared with land-based exercises” (Fragala-Pinkham, Haley, & O’Neil, 2008, p. 822). “Water-based exercise is used in the treatment of a wide variety of health conditions and has been recognized as a beneficial therapy for, among others, osteoarthritis, rheumatoid arthritis and stroke” (McNamara, Alison, & McKeough, 2011, p. 25). Water has also been used for strengthening and relaxation, in addition to being used for healing and pain relief (Timothy, et al., 2007). The hydrodynamic properties of warmth and buoyancy can block nociception by acting on the thermal and mechanoreceptors, influencing spinal segmental mechanisms (Hall, Swinkels, Briddon, & McCabe, 2008). In addition, “the warmth of the water may enhance blood flow, which is thought to help in dissipating algogenic chemicals, and it may facilitate muscle relaxation” (Hall, et al., 2008, p. 873). The properties of density, hydrostatic pressure, buoyancy, viscosity and thermodynamics facilitate such physiological changes (Becker, 2009) and provide an ideal therapeutic environment for individuals with CP.

Research into a range of populations is discussed below in order to demonstrate the degree of change possible within different physiological systems. Information on these different populations has been included as these systems have not all been specifically researched within the CP population.

Cardiovascular System

As an individual is immersed in water, the external water pressure exceeds venous pressure, which creates a gradient (Becker, 2009). This pressure gradient displaces blood from the lower peripheral venous system towards the heart and pulmonary vessels. With immersion up to the neck, the central blood volume increases by approximately 60%. According to Arborelius (1972), as cited by Becker (2009), the heart takes up one-third of this additional volume, while the great vessels of the lungs take up the remainder. With the

same level of immersion, cardiac volume increases to 27-30% (Risch, Koubenec, Gauer, & Lange, 1978). Some researchers have stated that cardiac volume is increased by 50% and others by 34% (Hall, Bisson, & O'Hare, 1990). Central venous pressure has been found to rise with immersion to the xyphoid and increase as the body was completely immersed. According to Brody and Geigle (2009), the effect on the heart rate was controversial. However, the main theory was that the heart rate decreased due to stroke volume increasing, with subsequent stimulation of baroreceptors in the arch of the aorta. When participants were immersed to the xyphoid, cardiac filling and stroke volume increased, and the heart rate generally dropped at average pool temperatures by 12-15% (Brody & Geigle, 2009). However it has been found that in warm water the heart rate rose significantly (Becker, 2009).

A study was undertaken to determine how the resting blood pressure in 18 hypertensive adults was affected by regular swimming (H. Tanaka et al., 1997). Their results demonstrated a decreased heart rate and seated systolic pressure. Farahani et al. (2010) explored the effect of a water aerobic exercise programme of 10 weeks duration. Results illustrated that in 40 hypertensive men there was a decrease in systolic pressure of 11.71 mmHg and mean arterial pressure of 5.90 mmHg. Both these studies measured their results 24-48 hours after the last intervention in order to avoid the immediate effects of an exercise session, but neither performed long term, follow up measurements to assess whether the results were sustained. They both concluded that their swim programmes had been effective in decreasing arterial pressure, and may prove beneficial for obese and elderly persons, in addition to those with orthopaedic injuries and exercise-induced asthma.

Respiratory and Pulmonary Systems

The pulmonary system has been shown to be significantly affected by immersion to the level of the thorax. Becker (2009) stated that at that level of submersion, the total work of breathing at rest increases by 60% for a tidal volume of one litre. Hydrostatic pressure was suggested as a contributor to a reduction in lung volume through creating an external pressure on the thoracic cage, resulting in an increased resistance on the diaphragm (McNamara, et al., 2011). The additional resistance can create an increase in the vital capacity, breathing expansion and control (Anstey & Roskell, 2000). "Neck-depth immersion in water places the diaphragm at an increased length, which allows the diaphragm to work through its entire length, resulting in an improvement of fatigue tolerance" (Hildenbrand, Nordio, Freson, & Becker, 2010, p. 279). Physical activity in water may improve exercise tolerance by allowing

people with asthma to breathe more easily. A proposed reason for this exercise tolerance was that it may be due in part to the warm, humid pollen-free air over the water (Hildenbrand, et al., 2010).

McNamara et al. (2011) carried out a review to determine the safety of swimming for those with chronic obstructive pulmonary disease (COPD). The participants performed head out of water immersion (HOWI) water-based exercise. From their results, the authors concluded that HOWI water exercises appeared to be safe even when taking into account the pathological lung changes, which included increased functional residual capacity and volume. Breathing function was not affected by increased resistance on lung function from hydrostatic pressure.

Musculoskeletal System

Prins and Cutner (1999) stated that the hydrodynamic properties of buoyancy and viscosity have benefits for healing and strengthening. These properties create joint and muscle decompression and produce resistance for improving muscle strength. “The concept of underwater therapy offers many possibilities to develop and specify the rehabilitation of injuries” (Wicker, 2007, p. 257). Having an environment which controls “joint compressive forces by varying the degrees of immersion is of primary benefit in the design and prescription of therapeutic exercise” (Prins & Cutner, 1999, p. 447). Wicker (2011) described how water reduced body weight by allowing sport-specific movements with an injured body structure. Having the supportive environment of the water was also found to reduce an injured individual’s fear of motion.

In addition to decreasing the weight on tissues, it has been suggested that muscle blood flow is significantly influenced by immersion. Epstein and Wei (1992) stated that it was probable that a large proportion of the increased cardiac output was redistributed to the skin and muscle. Balldin, Lundgren, Lundvall, and Mellander (1971) supported this statement when they found that muscle blood flow increased with immersion by 225% compared to that of land-based blood flow. “It is therefore reasonable to conclude that oxygen availability to muscles is significantly increased during immersion at rest” (Balldin, et al., 1971, p. 491).

Munguía-Izquierdo and Legaz-Arrese (2008) conducted a randomised controlled trial of a 16 week, three times per week aquatic training programme in a warm, chest-high pool. Their purpose was to demonstrate change in global symptomatology in 60 women with fibromyalgia. Results showed decreases in the tender point count, improved sleep, and cognitive and physical function directly post-intervention, with a high exercise adherence rate

found in the exercise group on a 12 month follow-up. Munguía-Izquierdo & Legaz-Arrese (2008) concluded that their aquatic exercise therapy programme had improved most fibromyalgia symptoms and resulted in a high rate of exercise adherence.

Sensory and Neuromuscular Systems

Proprioception and sensory input has been shown to play a significant role in maintaining balance and controlling posture. Sherrington (1906) as cited by Lephart and Jari (2002) defined the proprioceptive system as “afferent information from proprioceptors located in the proprioceptive field that contributed to conscious sensations (muscle sense), total postural (postural equilibrium) and segmental posture (joint stability)” (p. 2). The hydrodynamic properties of hydrostatic pressure, thermal influence, viscosity, drag and turbulence have been implicated as have an influence on the sensory nervous system. “The touch sensory receptors, mechanoreceptors and cutaneous skin receptors respond to the constant hydrostatic pressure and intermittent pressure provided by jets or turbulence, drag and viscosity” (Brody & Geigle, 2009, p. 41). Geigle et al. (2001) as cited by Brody and Geigle (2009) explored the effect of an aquatic therapy programme in participants with an inversion ankle sprain, which has been shown to reduce proprioception at the ankle joint. Their results demonstrated a positive change in the participants’ ability to perform a unilateral test of balance.

Kaneda, Sato, Wakabayashi, Hanai, and Nomura (2008) found that a water exercise programme decreased postural sway and tandem-walking times in elderly persons. They concluded that the water exercise programme, which included deep water running, improved dynamic balance ability.

Kesiktas et al. (2004), as cited by Brody and Geigle (2009, p. 199-200), studied the how hydrotherapy effected spasticity and functional independence measures (FIM) in people with spinal cord injury. The study involved two intervention groups, one receiving daily passive ranges of motion, oral doses of baclofen, and 20 minutes of aquatic exercise, and the other group received the same, but without the aquatic exercise. Their results showed that both groups had significant increases in FIM scores and reduced spasticity. The aquatic therapy group further demonstrated a decreased intake of daily oral baclofen.

Aquatic-Based Studies with Cerebral Palsy

Physical Outcome Measures

Various aspects of motor control and coordination have been investigated in people with CP through land-based studies (Anttila, Suoranta, Malmivaara, Makela, & Autti-Ramo, 2008; Charles & Gordon, 2006; Dalvand, et al., 2009; Damiano & Abel, 1998; Damiano, Vaughan, & Abel, 1995; Darrah, et al., 2004b; Dodd, et al., 2002; Dodd, et al., 2003; Langan, et al., 2010; MacPhail & Kramer, 1995; McBurney, et al., 2003; Scianni, et al., 2009; Stevens, et al., 2010; Unger, et al., 2006; Van den Berg-Emons, et al., 1998). However it has been stated that most of these studies involve ambulatory children (Thorpe, Reilly, & Case, 2005), and that a greater impairment in motor function, motor deficits, abnormal tone and joint contractures with CP can make it difficult to participate.

The hydrodynamic properties of water have been described as providing a more stable and supportive environment than land, which allows individuals with CP to move with greater ease. The buoyancy of the water can provide postural support and “reduced levels of joint loading and impact” to allow people with CP to move in the water with increased freedom (Kelly & Darrah, 2005, p. 840).

Hutzler, Chacham, Bergman, and Szeinberg (1998) performed a six-month intervention combining land-based movement and a swim programme with 40 children with CP. They investigated the effects on respiratory function and water-based competency skills. Each session was 30 minutes in length, with swimming sessions twice weekly and sessions of group physical activity in a gym once per week. Children were divided into the movement-swim group and a control group of Bobath therapy. Results demonstrated that the intervention programme improved baseline vital capacity results by 65%, whereas the control group improved by 23%.

Fragala-Pinkham et al. (2008) conducted a 14 week aquatic aerobic exercise programme to establish its effect on the cardiorespiratory endurance of 16 children with impairments. The impairments included autism spectrum disorder, myelomeningocele, CP and other developmental disorders. The children swam laps and participated in aquatic relay races and games while maintaining a target heart rate zone. From pre- to post-intervention measurements, there was a significant reduction in the time the children took to complete a half-mile walk/run. The children who had improved in their swimming abilities also had

improved swimming endurance. However, no improvements were observed for strength or motor skills outside of the aquatic exercise programme. The researchers concluded that the lack of change in strength and motor skills may have been because the aquatic programme did not include task-specific situational skills compared to other land-based studies.

Chrysagis, Douka, Nikopoulos, Apostolopoulou, and Koutsouki (2009) undertook to evaluate a 10 week aquatic programme in relation to its effect on gross motor function, range of motion, and spasticity in 12 adolescents with CP. Results demonstrated increased active shoulder range of motion, passive hip abduction, knee extension, and in the mean walking scores. Additionally, hip flexor and knee extensor muscles showed a decrease in spasticity.

A 12 week aquatic aerobic exercise intervention was performed with a five year old girl with spastic diplegia CP (Retarekar, et al., 2009). Post-intervention, there was a statistically significant improvement in participation, activity and walking speed. Retarekar et al. (2009) concluded that their aquatic aerobic exercise programme was effective. They stated that the intervention provided preliminary evidence which supported the effectiveness of aquatic programmes for children with spastic CP.

Ballaz, Plamondon, and Lemay (2011) carried out a 10 week aquatic exercise programme for the purpose of evaluating its feasibility and the effect on gait efficiency in 12 ambulatory adolescents with CP. An additional assessment of training intensity was measured using heart rate monitors. Their results demonstrated that those who were more physically able, with a lower GMFCS level, were able to train at an increased heart rate for a longer duration in comparison to those with a higher GMFCS level. However, all participants except for one improved to some degree. They concluded that the aquatic programme was feasible and had demonstrated improved gait efficiency. The authors stated that there may have been a significant impact on autonomy and quality of life, although these last factors were not assessed.

Social Outcome Measures

The effects of an aquatic programme on social function, behaviour and body awareness have been the focus of other research (Aidar et al., 2008; Getz, et al., 2006; Özer et al., 2007). Getz et al. (2006) contrasted an aquatic exercise programme with a land-based exercise programme. Their purpose was to assess the effect on social function, perceived competence and social acceptance in 22 children with CP. Twelve of the children participated in the aquatic programme and 10 in the land-based programme. Social function was measured using the the Peadiatric Evaluation Disability Inventory (PEDI). Perceived

competency and social function were measured using a Pictorial scale developed for use with children with CP. Their results showed increased social function and acceptance in the aquatic group, with no significant difference between the intervention groups in the area of physical competence. “The aquatic environment, and particularly buoyancy, enables children to be more active and to initiate multiple social interactions with their instructors and other children” (Getz, et al., 2006, p. 226).

A 14 week swimming programme was conducted by Özer et al. (2007) to explore its effects on social competence, problem behaviour and body awareness in 13 children with CP, aged five to 10 years. They found that the swim programme improved their body awareness but had no significant effect on their behaviour or social competence. A further study on the effect of aquatic activities on social function was performed by Aidar et al. (2008), with 21 children with CP. Social function was evaluated by PEDI and the Manual Abilities Scale and the results demonstrated a positive change in motor and social function.

All these studies have incorporated variations on aquatic therapy, whereby such activities as relay races, play and some specific rehabilitation or aerobic activities have been used to structure the sessions. None of the above had focused specifically on improving swimming skills. Collectively, there seemed to be a strong indication in the literature that aquatic exercise had a beneficial effect on aspects of physical function, including cardiorespiratory function, walking speed and endurance, and joint range of motion. There was also an indication that participating in an aquatic-based programme improved social function and perceived acceptance. This present study intended to explore the effect of a structured swim programme which aimed to improve basic swimming skills. The structured swim programme was evaluated in regards to how the improvement of a physical skill interacts with the general quality of life and independence of the child, expanding upon the research performed in the areas of social function and acceptance.

Quality of Life

Definition

Quality of life was defined by the World Health Organisation Quality of Life Group 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” (WHOQOL, 1996, p. 5). Shelley et al. (2008) stated that it is a multidimensional construct which assesses an individual’s sense of wellbeing across several domains of their life. When placed in the context of research, it became an outcome variable which added an element other than physical function variables. In research performed with child participants, the purpose of quality of life questionnaires was to assess how a child felt about various aspects of their lives, rather than their ability to perform tasks or achieve goals (Davis, Shelly, Waters, & Davern, 2010).

Quality of life and function have become conceptually separated; a task which was in part performed by the World Health Organisation (WHOQOL, 1996) and other researchers in the early 1990’s, who called quality of life “the missing measurement in health care” (Fallowfield, 1990, p. 2). The purpose of defining quality of life as separate was in part to be able to use it as an outcome measure in research. From a wider perspective, it was to broaden the way in which health was measured beyond the traditional indicators such as mortality and morbidity. Quality of life goes beyond the scientifically objective purpose of eradicating disease to a more balanced and humanistic approach to the individual’s wellbeing (WHOQOL, 1996).

Health related quality of life (HRQOL) measures the health related aspects of life satisfaction including self care, communication and mobility (O’Shea, 2008). HRQOL is a subsection of quality of life. This is influenced by the level of impairment, and in research with people with CP, HRQL measures have been found to worsen in correlation with increasing functional impairment (P. Rosenbaum et al., 2007).

However, it has been found that an increasing level of functional impairment does not necessarily worsen the experience of quality of life (Davis, Shelly, et al., 2009; Dickinson et al., 2007). This separation of function and the individual’s perspective is especially true of the psychosocial domain, which has shown the most significant difference in reporting (Shelly, et al., 2008). Domains such as feelings about physical health and pain were more

closely associated with the level of function, which reflects research performed with HRQOL.

Tools of assessment

There are many tools which have been developed for assessing quality of life. There are general, condition specific, and age specific versions available. Most take the form of questionnaires. The condition and age specific questionnaires have been developed as general versions have failed to query areas of life relevant to specific populations in an appropriate manner (Davis, et al., 2010). For example, for individuals with CP, part of assessing the physical domain of quality of life is querying their feelings about their ability to perform daily tasks, which may be affected by hemiplegia, quadriplegia or ataxia. Questioning more specifically means a greater relevance to the individual and more reliable results (Davis, et al., 2010).

Tools of assessment which have been more recently developed and validated have given the opportunity to explore quality of life in children with CP (Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007). In the realm of quality of life questionnaires, there are several which are used in the population of children with cerebral palsy.

Vargus-Adams and Martin (2009) described domains of importance for evaluating therapeutic effects and the best tools for evaluating these domains from the perspectives of youth with CP, their parents and health professionals. They used five surveys to explore these topics and found eight domains of importance, which were impairment, general health, self care/fine motor skills, integration/participation, quality of life, gross motor skills, speech/communication and caregiver issues (Vargus-Adams & Martin, 2009). Of these domains, quality of life was found to be the most important. On evaluation of available tools for assessing quality of life, there were four identified as being relevant to children with CP. These were KIDSCREEN, Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child), Pediatric Quality of Life Inventory, and Caregiver Priorities and Child Health Index of Life with Disabilities. Of these the CPQOL-Child was perceived as the most appropriate in the present research for assessing quality of life due to being condition-specific and having a strong basis in qualitative research (Vargus-Adams & Martin, 2009).

Development of Quality of Life Child Questionnaire for Children with Cerebral Palsy (CPQOL-Child)

The CPQOL-Child questionnaire has been developed to be used as a condition-specific tool of assessment. In the initial stages, qualitative interviews with both parents and children were used to establish what comprised quality of life from their perspectives (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). This, along with the body of literature available, helped establish the content.

The subsequent content included social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being, access to services, pain and impact of impairment, and family health (see Appendix B). There was a parent-proxy version in which the parents report on the quality of life of the child, which was validated for an age range of 4-12 years old (Davis, et al., 2010). There was also a self report version for children aged 9-12 years. The information from the child perspective was beneficial due to quality of life being largely an individual's perception of their own state (Waters, et al., 2009). Therefore, the use of both versions is preferable if possible for a greater depth of information.

Validity

There has been one direct validation study done with the CPQOL-Child, comparing it with two other well used and validated tools; the Child Health Questionnaire (CHQ) and a generic health related quality of life questionnaire KIDSCREEN-10 (Davis, et al., 2010). The CPQOL-Child was found to be as valid and internally consistent as KIDSCREEN and performed more strongly than CHQ.

The self-report version has been validated for use with children aged 9-12. This age group was used to create the questionnaire through interviews and trial administration (Waters et al., 2006). As the questions were directed at the level of understanding of the 9-12 year old age group, this was the group used to fill in the self-report version in the present study.

Sensitivity

One of the purposes of the CPQOL-Child, as stated by the accompanying manual, is in "conducting research to determine whether an intervention has increased a child's quality of life" (Waters, et al., 2006, p. 9).

One study which has been done so far with this purpose was a land based intervention of horse riding over a 10-week period (Davis, Davies, et al., 2009). They found there to be no statistically significant change in quality of life. The sensitivity of the CPQOL-Child to change had yet to be established and this point was raised as a potential contributing reason for the lack of change. Whilst the test-retest reliability of this questionnaire had been established (Davis, et al., 2010; Wang et al., 2010), the sensitivity to change over an intervention had yet to be thoroughly investigated.

In discussion of the limitations of the study, Davis, Davies et al. (2009) included the potential influence of not having qualitative interviews as a part of the method and a lack of consistency in the structure of the riding sessions. Also, they had used a control group in comparison with the intervention group, which may have presented difficulties in this population with assessing quality of life, due to the variation in both levels of disability and in the subjective nature of quality of life.

Research with Cerebral Palsy

It has been found that participation in daily activities improved quality of life in children with CP in the age range 8 – 12 years old (Mc Manus, Corcoran, & Perry, 2008). This improvement was regardless of age, sex or grade of impairment. The domains which showed the most improvement were Physical well-being, Social support and peers and Moods and emotions.

An area which had lacked clarity in the past was the extent of which a parent or guardian could report accurately on their child's quality of life. Results in recent research have shown that there was a difference in the level of reporting, with children reporting their own quality of life at a higher level than the parent (Davis, et al., 2010). This discrepancy came about as more tools provided a child-report version so there was comparative information available.

Independence

One of the aims of rehabilitation exercise is to enhance independence in as many aspects of life as possible (O'Shea, 2008). Independence has been defined as "not depending on another for livelihood or subsistence...capable of thinking or acting for oneself" ("Concise Oxford English Dictionary ", 2008, p. 723). While complete independence may not always be fully achievable for people with CP, especially those with a higher scoring on the GMFCS

scale (level IV-V), previous studies have demonstrated that aquatic therapy can positively influence their independence.

Dorval, Tetreault, and Caron (1996) found that functional independence improved following an aquatic therapy intervention. Functional independence was defined as the burden of care required by the level of physical and cognitive impairment (Dorval, et al., 1996). Getz, Hutzler and Vermeer (2007) explored competence within the context of an aquatic intervention and found a measurable improvement, primarily in relation to physical independence.

Within the concept of independence, there also exists a close association with the motivation to think for oneself and try new activities (Pomeroy, 2007). This has yet to be explored as an outcome measure in a study with children with CP, although it has been reported anecdotally in several articles' discussions (Aidar, et al., 2008; Ballaz, et al., 2011; Özer, et al., 2007; Retarekar, et al., 2009). Aider et al. (2008) extrapolated that aquatic physical exercise and increased motor function improved physical function which improved social function, inferring an increase in a wider experience of independence.

Self Esteem

Self esteem has been defined as the feelings of satisfaction a person has regarding themselves, which reflects on the relationship between their self image and their ideal self image, or more simply "how people evaluate themselves" (Baumeister, 2005, p. 35).

Varsamis and Agaliotis (2011) explored self concept and goal orientation in 75 adolescents with mental and physical impairments, finding that those with physical impairments had significantly lower scores for both measures than those with mental impairments. For those with physical impairments, the authors recommended programmes which supported the adolescents' self concept, and the development of activities which were adapted to facilitate their learning and enhance their chance of succeeding. Russo et al.(2008) found that 86 children with CP experienced lower self esteem and quality of life in comparison to age matched, typically developing children.

In research performed with adult male basketball players, those participants with physical impairments (N=64) were found to have a lower self esteem and self perception than able bodied participants (N=69). In the same study, it was found those with physical impairments were more at risk for developing depression, anxiety, stress, frustration and lack of motivation (Ferreira & Fox, 2008).

McClung (1997), as cited in Shapiro and Martin, (2010), found that in adults with physical impairments participation in recreational activities enhanced their self perception, and their confidence to pursue physical activities. Youth with physical impairments have been found to gain psychosocial benefits from physical activity, including the areas of improved social support, friendship, enjoyment, empowerment and a decrease in depression (Shapiro & Martin, 2010).

Dorval et al. (1996) evaluated the effect of a swim programme on self esteem and functional independence in 20 adolescents with CP, and found both factors had statistically significant improvement directly post-intervention and on a nine month follow-up assessment. Aidar et al. (2008) inferred an improvement in self esteem from the improvement they had found in functional independence.

Conclusion

Given the inactivity reported in individuals with CP, it has been concluded that it was important to promote physical activity for all ages within this population (Fowler, et al., 2007). Physical activity has been discussed as being especially important in children with CP as it can establish proactive patterns of behaviour (Damiano, 2006). This pro-activity can help mitigate the decline of activity levels into adulthood. Any type of physical activity has been found to be advantageous for promoting improvement in aspects of physical function (Damiano, 2006). The aquatic environment had the additional benefit of reducing joint-loading forces and providing resistance for strengthening (Fragala-Pinkham, Haley, & O'Neil, 2008). For individuals with CP, these features of the aquatic environment were significant as land-based activities often do not allow for them to reach the level of effort required to improve physical fitness (Damiano, 2009).

Those with CP were also found to be at greater risk for reporting lower levels of self esteem, and higher levels of depression and social withdrawal (Dorval, et al., 1996). Investigating an activity which may promote higher self esteem and social function would benefit this population. A positive relationship has been reported between the factors of functional independence, social function and perceived acceptance in relation to aquatic-based activity, therefore was an area which warranted further exploration (Getz, et al., 2006; Özer, et al., 2007).

In order to assess these aspects of social function and expand upon the available information, the CPQOL-Child questionnaire was considered a useful measure. The CPQOL-Child was a condition specific, quality of life measure which had been developed for children

with CP. It had demonstrated good validity and test-retest reliability (Waters et al., 2007). While it had yet to show sensitivity to change, there was no comparable measure readily available which had demonstrated greater strength in this area (Davis, Davies, et al., 2009). The present research into change over a swimming intervention has further contributed to the body of literature available on the area of sensitivity of the CPQOL-Child. The previous study which utilised the CPQOL-Child to assess an intervention used a control group and found no significant change (Davis, Davies, et al., 2009). In the present research, an inclusion of analysis of pre- and post-measures for each individual, using them as their own control, had the potential to demonstrate greater change.

One goal in the present research was to expand on what had been explored in previous research. Part of the intention was to further develop the information available on the impact of the aquatic environment on independence both in and outside the swim programme. This intention was fulfilled through evaluating not only if functional independence was affected, but also the wider aspect of the children's motivation to think for themselves and try new activities.

Baumeister (2005) stated that one of the benefits of improved self esteem was enhanced initiative. This opinion can be seen to show the interrelationship of self esteem with independence, and the benefit of encouraging children with CP to become proactive both inside a swim programme and in other areas of life. Neither the factor of independence or self esteem has been queried in children with CP through a qualitative, semi-structured interview approach within a swim programme intervention. A qualitative perspective may provide a greater depth of knowledge in the relationship between these two concepts for the participants involved. As Dorval et al. (1996) was the only study to directly include self esteem within their measures of a swim programme. The inclusion of self esteem as a measure in this present study may be seen to have facilitated the knowledge available.

The semi-structured interviews also partly countered the lack of established sensitivity of the CPQOL-Child questionnaire. However, the interviews primarily allowed for a greater exploration of the depth of information available on the effect of the swim programme on quality of life, independence and self esteem. The interrelationship of these factors with each other had been described by previous authors, and the interviews provided the opportunity to explore this possibility further (Baumeister, 2005).

Chapter 3: Methodology and Method

Methodology

The Methodology and Method sections contain the justification and description for the use of the theoretical perspective and the research tools employed in this present research. The purpose of the present research was to evaluate the effect of a swim programme on the quality of life, independence and self esteem of children with CP. To fulfill this aim, it was necessary to come from a theoretical perspective and methodology which would provide a framework to work within. Another basis for the methodology and method lies in the body of literature available, which has informed the present research topic. An interpretive, mixed-method approach was chosen to answer these aims, employing the methods of a pre- and post-intervention questionnaire and a post-intervention semi-structured interview.

Theoretical Perspective

The theoretical perspective is “the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria” (Crotty, 1998, p. 3). The research methodology used in this study was Evaluation Research, which as a mixed-method approach had been informed by both the paradigm of interpretism and positivism. Interpretism is a worldview involving the philosophical stance that human action is inherently meaningful, and that we understand through interpretation (Crotty, 1998). This worldview informs qualitative research. Positivism is a worldview which states that objective meaning can be discovered regarding the object under consideration (Crotty, 1998). The research methodology termed Evaluation Research is influenced by both of the paradigms that inform it, and these paradigms are discussed in the following sections within the context of the methods employed.

One purpose of Evaluation Research is to determine whether an intervention is producing the results it intends to (Babbie, 2007). For the intention of this present research, Evaluation was a useful perspective as the intervention was the swim programme and the intended result was determining if a change occurred in quality of life, independence and self-esteem. Evaluation Research is an area of social research which can utilise scientific methods for the purpose of the “collection and analysis of information about the content, structure and outcomes of programmes, projects and planned interventions” (Clarke &

Dawson, 1999, p. 1). Evaluation can be used, as in this case, to assess practical and applicable measures, including those affecting beliefs and values (Babbie, 2007).

Evaluation Research can investigate the participant's point of view and draw out tacit knowledge which may otherwise be overlooked (Patton, 2002). One study of the effectiveness of a health care programme stated that evaluation was necessary "to assess the validity and reliability of any effect of the interventions" (Jansen, De Bont, Foets, Bruijnzeels, & Bal, 2007, p. 3). The addition of a qualitative element to the research process facilitated the aim of exploring the participant's point of view. The broad perspective of the mixed-method approach is described in the following section, and the individual topics of the quantitative and qualitative elements are subsequently explored.

Mixed-Method Approach

The mixed-method approach involves the triangulation of data sources, which can occur at the level of methodology or at the level of the research method; it can also be sequential or simultaneous in nature (Tashakkori & Teddlie, 2003). A simultaneous, methodological triangulation was chosen in this instance and involved "combining data sources to study the same social phenomenon" (Tashakkori & Teddlie, 2003, p. 7). This form of triangulation provided the opportunity to define relationships between variables of interest with greater accuracy by studying it from more than one perspective.

In the present research this approach involved the collection of both quantitative and qualitative data. The aim was to expand the depth of enquiry through the complementary nature of the results (Schneider, Elliott, & Whitehead, 2007). The positivist contribution to the present Evaluation process was the addition of "the capacity to examine the strength of association between variables of interest" (Castro, Kellison, Boyd, & Kopak, 2010, p. 342). The interpretive approach placed those variables within the environmental context of the participants, providing rich, detailed accounts of their experiences (Castro, et al., 2010).

The advantage of using mixed-methods was that the strengths of each offset the weakness of the other. Both quantitative and qualitative are required to "generate and test theory, improve understanding over time of how the world operates, and support informed policy making and social program decision making" (Patton, 2002, p. 92) .

From the theoretical perspective, the mixed-method approach is often either more qualitative or quantitative in the inferences from the research topic. This is in spite of the integrative nature of the data collection and analysis, (Tashakkori & Teddlie, 2003). In the present research there was a greater emphasis on the quantitative element due to the

hypothesis-driven method, the evaluative nature of the research, and the interviews were structured to allow for deliberate exploration of the outcome variables. These factors placed an overlying quantitative emphasis on the study which aligned with the intent of gaining knowledge of specific outcomes involving the participants' quality of life.

A potential limitation within mixed-methods may be the difficulty in effectively integrating the two elements of "quantitative and qualitative approaches under a unified and fully integrated research design and data analytic plan" (Castro, et al., 2010, p. 344). In a description of how to integrate the two methods, Castro et al. (2010) placed the main points of integration at the stages of data analysis and at interpretation of results, where each data set informs the conclusions from the other.

Castro et al. (2010) goes on to discuss another issue, which was collecting effective and informative interview data which can offer adequate thematic comparison to the quantitative data. If the questioning in the interviews is too shallow, the data will not be able to generate reasonable thematic categories. Additionally, interview data can be sub-categorised into themes which are too narrow, with a high occurrence of 'not mentioned.' Narrow sub-categorising can result in a skew of data with weak thematic variables, which may yield non-significant results when compared to quantitative data.

In the present research, the intended goal of including the interviews was to ensure the depth of information regarding the primary outcome measures. The semi-structured interviews were ordered around topics to ensure that all domains of quality of life, self esteem and independence were discussed. If the topics were not raised through the natural course of the conversation, the interviewer prompted the participant with pre-established questions.

Ensuring the theme categories were broad enough came at the data analysis stage and at the interpretation stage. At these stages the themes were assessed for the incidence of being mentioned and the relevance to the outcome measures of the present research. Through this process the thematic variables were strengthened, which subsequently increased the likelihood of significant results when compared to quantitative data.

The Quantitative Element - Questionnaires

In order to conduct Evaluation Research, it must be possible to “operationalise, observe and recognize the presence or absence of what is under study” (Babbie, 2007, p. 366). This structured framework of Evaluation lent itself to the use of a quantifiable tool, such as the CPQOL-Child questionnaire, which was used in this present research, using pre- and post-intervention assessments.

The CP QOL-Child questionnaire was a condition-specific questionnaire that queried aspects of quality of life in children with CP (see Appendix B). In this present research it provided a tool which had a parent-proxy and child self-report version which expanded the data availability. It had been validated both by its original developers and by subsequent separate researchers and it explored most of the key areas within the aims of the study.

Quality of life has been closely related to physical function in both children and adults with CP, an association which was inferred from parent and child interviews performed by Waters, Maher, Salmon, Reddihough, and Boyd (2005) and further established through a large scale study with questionnaires (Shelly, et al., 2008). The perceived relationship between quality of life and function lent itself to further exploration into whether an intervention introducing physical activity could improve quality of life. As far as was known, the CPQOL-Child questionnaire had yet to be used in a New Zealand setting; therefore the present pilot study provided the opportunity to explore its use within this setting.

An aim of this study which was not within the scope of the CQOL-Child questionnaire was providing an in-depth exploration into the constructs of independence and self esteem. In order to gain a greater depth of information in these areas, they were further queried in semi-structured interviews.

The Qualitative Element - Interviews

The Evaluation approach is well used within the qualitative framework. It has been stated that utilising the Evaluation methodology can convey knowledge of both facts and feelings, as it has both factual and “artistic” elements within its scope (Patton, 2002, p. 173). These elements were reflected in this study with the use of semi-structured interviews that lent a greater experiential element to the data collected. The qualitative method allowed for an opportunity to explore the perceived impact of the programme on the constructs of interest from the perspectives of the participating parents of children with CP.

As a research tool, interviews allowed for a depth of data which quantitative methods did not have the scope to address. This scope was the exploration of thematic development

and the ability to draw out more information from participants which might otherwise have been easily overlooked (McBurney, et al., 2003).

An example of this was the development of the CPQOL-Child questionnaire, which started with interviews involving parents and children with CP (Waters, et al., 2005). The themes from those interviews became questions, which were taken back to participants to check how comprehensible the questions were (Waters, et al., 2007). The questionnaire was then tested on a larger group in order to establish validity (Waters, et al., 2009). The circular approach from qualitative to quantitative and back displayed the fluid and interactive nature of research design. As one informed another there was a more thorough understanding of what was important to query and how best to gain that information.

Once the validity of the CPQOL-Child questionnaire had been established, it was then possible to utilise it as a tool to assess change in quality of life. The CPQOL-Child was used in conjunction with two other measures to assess the effect of hippotherapy on quality of life in children with CP. There was no significant change in quality of life, and the authors reasoned this may be due to a lack of sensitivity to change of the instruments (Davis, Davies, et al., 2009).

Given this potential lack in sensitivity, for this present research it was considered reasonable to return to qualitative data as a means of assessing the questionnaire against comparative data. Using interviews over the swim programme intervention in conjunction with the CPQOL-Child allowed for a return to rich data, and provided greater detail from the participants as to whether change had occurred. This return to qualitative data further illustrated the continuing circular process of research.

McBurney, et al. (2003) stated that “qualitative research is still relatively uncommon in the field of physical rehabilitation” (p. 662). Given the growing evidence that physical activity influences areas of life other than physical function, the addition of qualitative inquiry may have given a more complete picture of what was occurring (McBurney, et al., 2003). Areas such as a change in quality of life, self concept, and acceptance have become recognised as important outcomes for those with physical impairments, and qualitative methods allow for a comprehensive evaluation of these effects. The aim of this present study in assessing self esteem and independence consequently lent itself to the use of qualitative methods to explore potential changes in these areas.

When considering interviews as a research tool, there are several approaches which can be taken. In this instance semi-structured interviews were chosen to explore the outcome measures. It was established that semi-structured interviews would give the participants the

opportunity to express their opinions freely in as much depth as was required. Some structure was needed in order to maintain a focus on answering the research question, which was specific to certain aspects of their child's life (McBurney, et al., 2003). An unstructured interview may have given too much freedom resulting in a lack of specific information about this research (McBurney, et al., 2003). Semi-structured interviews provided a balanced approach gaining a greater depth of information whilst maintaining focus.

The interviews were also included due to the small sample size available. With less statistical data available from the questionnaires due to the low number of participants, other sources of data were necessary. One option would have been to include more questionnaires around quality of life. This would have provided more quantitative data, but not necessarily a greater depth of information on quality of life. The CPQOL-Child questionnaire had performed well against comparable questionnaires, therefore it was deemed unnecessary to provide more statistics on the same topic (Davis, et al., 2010). Choosing other quantitative data sources which explored related topics would have increased the quantity of data, but may not have addressed the specific the aims of the present research. Given the limited sample size and the subsequent limited statistical data, interviews were considered a better option for increasing the depth of information (McBurney, et al., 2003).

In summary, this study was performed using the mixed-method approach of Evaluation; with post intervention semi-structured interviews, accompanied by the pre- and post-intervention questionnaires, which both informed the interview process and were analysed through statistical tests. The two forms of data became integrated at the point of data analysis and in the interpretation of results.

Method

Design:

The study was performed using a one-group, pre-test and post-test quasi-experimental design, with no control group and no randomisation involved. “This design, however, does allow the evaluator to measure change objectively by taking measurements from the same group both before and after their involvement in the programme” (Clarke & Dawson, 1999, p. 49). Quasi-experimental designs are useful in situations where it is necessary to adapt to a real world setting as “they are practical, feasible and generalisable” (Schneider, Elliott, LoBiondo-Wood, & Haber, 2003, p. 327). The use of the one-group, pre-test and post-test design suited the nature of the research question, which was to evaluate an existent programme. Due to the small sample size available, it was considered impractical to include a control group. The involvement of child participants provided the added ethical consideration that withholding a potentially beneficial programme from a control group would potentially cause harm. Withholding a potentially therapeutic intervention goes against the guidelines for health research involving children in New Zealand (Peart & Holdaway, 2000).

The main drawback of this design was it did not give an idea of what results may have occurred in the absence of the programme (Clarke & Dawson, 1999). This drawback limits the ability to make a clear cause and effect inference (Schneider, et al., 2003). In order to minimise potential other explanations for a causal relationship, the inclusion criteria was limited to a specific population. Additionally, this research question built on previous research, which has shown a positive causal effect between this population and swimming (Kelly & Darrah, 2005; Özer, et al., 2007; Retarekar, et al., 2009). The combination of results from experimental and quasi-experimental studies can meet the criteria for the justification of finding a causal relationship (Schneider, et al., 2003). However, the primary focus of this pilot study was to explore a potential trend within the data through relating this intervention to the outcomes of interest. Establishing effectiveness would require a further definitive trial.

The tools used for testing were pre- and post- test administration of the CPQOL-Child questionnaire for both children and parents (see Appendix B) and post- test interviews with the parents (see Appendix C). The CPQOL-Child, both parent-proxy and self-report versions, was freely available within the framework of normal copyright conditions of the developers (Waters, et al., 2006). Notification of the use of the questionnaire was optional as long as no

element of it was altered. For this present research the developers were notified through their website, www.cpqol.org.au, and consent was given for its use.

Recruitment:

The sampling strategy was convenience sampling as it was the most ideal for this population. It suited the purpose of this study, in spite of being a self-selective, volunteer process for participants. As a purposive sampling method, there is “an underlying focus on selecting specific cases that will provide the most information for the question under study”, seeking to “focus and where practical, minimise the sample size, generally in non-random ways, so as to select only those cases that might best illuminate and test the hypothesis” (Tashakkori & Teddlie, 2003, p. 279) . This convenience sample was drawn from organisations that would most likely have access to the desired population. The desired population criterion included geographical location (within reasonable distance of the swim complex), on top of the inclusion criteria into the study.

Northern Arena was the swim complex at which the swim programme took place. This swim programme was structured by M.S., who was the programme director and primary swim instructor for this research. Recruitment was a part of the Northern Arena’s advertising of their learn-to-swim lessons. Their advertising included additional information for children with CP and their families on the opportunity to participate in this study. Further notification went out to nearby schools on the North Shore, the Wilson Home and the Halberg Trust, which are charitable organisations within New Zealand who provide support and opportunities for those with physical and mental impairments.

On signing up to the swim programme M.S. reminded families of the opportunity to be involved in the study. Of those who were interested, their contact details were passed on to the researcher and an information sheet sent out via email.

The swim programme included children aged 5-11, with a mean age of 8.1 years old. Only the 9-12 year olds were able to complete the self report questionnaire. It was decided to recruit children younger than 9 years old on discussion with the swim instructor, as 5-12 is the age range which is normally involved in the swim programme. There was a limited population available for this study, and too many limitations would have made finding participants difficult. Due to these reasons this study did not have the scope to exclude younger children. This limitation contributed to the study’s status as a pilot study.

Information sheets:

The parents who expressed interest were given information sheets describing this study (see Appendix F) and had the option of participation. They contacted the researcher via email to communicate their interest.

Inclusion assessment:

The researcher clarified with potential participants whether they fit the inclusion criteria.

Swim programme participants:

Inclusion:

- 5 to 12 years of age
- Diagnosis of CP
- Classification of I to III on the GMFCS
- Must display water confidence
 - Able to have feet off bottom of the pool
 - Able to put head under water on their own
- Willing and able to be taught

A part of inclusion in the swim programme was having a diagnosis of CP and being within level I-III on the GMFCS scale (see Appendix A). If the level of impairment was unknown prior to the study, this was assessed for eligibility by a paediatric physiotherapist, Kate Hedges, who has worked with children with impairments for 35 years and has experience with this measurement tool

Questionnaire participants:

- Parents of children (5-12 years) with CP. One parent per child who participated in the swim programme completed the questionnaire.
- Children also filled out the CPQOL-Child self-report if they fit the criteria of being between the ages of 9-12 years old, as that was the age group the self-report questionnaire was validated for.

Interview participants:

- Parents of children (5-12 years) with CP. One parent per child who participated in the swim programme was interviewed, apart from one family (Sam, Sarah and Shelley) in which the father chose to participate in the interview in addition to the mother.

If the child participant had dropped out of the swim programme, the parents still had the option of completing the interview process. If that was the case, the reasons for withdrawing were also to be queried. However, this situation did not arise as all participants remained in the study.

Consent:

Those who wished to participate were met in a setting with which they were comfortable, such as their home or the swimming complex. Any questions regarding the study were explored and written consent was obtained (see Appendix G). The consent form was signed by the parent who was most involved in the study through completing the questionnaire and interview process.

The initial assessment of the child's ability and willingness to participate was assessed by the parents. From there, the assent of each child was gained by the researcher for participation in each element of the research. Consent and assent are further discussed in the section titled Ethics. The study was described at the initial meeting with appropriate terms for the age of the child and they were given time to understand and then verbally assent. If a child had expressed reluctance at any point, this would have been explored by the researcher and they could have chosen not to participate without consequence. The time frame for withdrawal was any time up to two weeks after the last data collection session.

Sample size:

According to the Cerebral Palsy Society of New Zealand (2007) the prevalence of cerebral palsy has remained relatively stable at 2.0 to 2.5 per 1,000 live births. Approximately 7,000 people in New Zealand have some degree of cerebral palsy, with one-third being under 21 years of age. Recruitment for this study predominantly took place in Auckland's North Shore area, and the participants were of a small age bracket. Therefore the swim instructor and researcher agreed that a sample size of 5-10 participating families was practical and realistic.

Another factor which might have affected sample size was the classifications of CP, which are spastic, dyskinetic and ataxic. Due to having a limited specific population, this study's participant group was not limited to a single classification. Therefore children of all CP classes had the opportunity to participate.

The resultant participant group was eight participants of age range 5–11 years old (mean age of 8.1). There were two male and six female children, including GMFCS levels I-

III over all sub-types of CP. There were two with left hemiplegia, three with right hemiplegia, two with diplegia and one with ataxic CP. This range over such a small group did decrease the specificity of the results, but increased the generalisability.

Week 0: Pre- intervention questionnaires

The CPQOL-Child questionnaire (see Appendix B) was administered one week prior to the intervention in person at the swim complex. Meeting at the swim complex was more convenient for the participants.

The parents were initially to assess the child's capacity to answer the self-report questionnaire. The CPQOL-Child could be filled in without help, with the help of the parent or, if desired, the researcher. As stated earlier the self-report questionnaire was to be completed by 9-12 year old participants, and of the children in this research there were three who fit these criteria. Hannah (pseudonym) filled it in without help, Pippa with the help of her parent and Andrew completed the questionnaire with the help of the researcher. Both Pippa and Andrew had additional mental impairments which required that the questions be rephrased and explained in order to be comprehended.

The parent-proxy CPQOL-Child could be used with the younger population and provided quantitative data on the 5-8 year olds. This also allowed for the parents of the younger population to be included in the interview process. The inclusion of the 5-8 year olds means that the results of the study were applicable for a wider population.

Week 1 – 14: Swim programme

The intervention was a 14 week swim programme with weekly sessions carried out by an experienced instructor. Each swim session was 30 minutes in length, in groups or individually depending on the needs and availability of the child. If a session was missed, there was an allowance for one free make-up session per child. This followed the terms and conditions of the swim programme.

The swim instructor was M.S., whose qualifications were a Diploma in Physical Education and a Diploma in Teaching. He had 22 years of experience coaching and teaching swimmers with physical and mental impairments. The focus in these sessions was to improve swimming skills, water confidence and functional independence (see Appendix D).

The swim programme was a part of the normal structure which was already being taught by M.S. The families were paying for the swim programme, as it was considered a part

of their normal choice of activities, and the reasoning for this choice of structure is further discussed in the Ethics section below.

Structure of the swim programme:

1. Teach kicking and swimming with fins – even though most children with CP have limited kicking action the fins introduce slight buoyancy and balance.
2. Teach arm action - slow movements, large straight arm movement
 - Arm action with full support from teacher
 - Arm action with limited support from teacher
 - Arm action removing support from teacher
3. Kick on back
4. Backstroke arms
 - Teacher supports head
 - Slowly remove support
5. Introduce freestyle breathing
 - Teach rotation of body
 - Practice arms and breathing with teacher support
 - Teach shoulder roll
 - Teach breathing to side – with teacher support

Week 15: Post- intervention questionnaires

The post-intervention questionnaires (see Appendix B) were administered within one week following the swim programme via mail-out or email. The method of administration depended on the convenience of the participant.

Week 16 – 17: Interviews

Semi-structured interviews took place within two weeks of completing the post-intervention questionnaire. These interviews predominantly followed the same structure, with some variation to allow for exploration of each individual's responses (see Appendix C).

Some of the questions were based topics from the questionnaire. Other aspects not covered by the questionnaire were also explored, such as experience of the child's independence, self esteem and opinions on swimming. These were queried post-intervention to allow parents to reflect on any change in opinion and experience they may have had over the 14 weeks. These parent interviews were to be done either face-to-face or via Skype (T),

depending on the convenience of the participant. All participants chose to be interviewed in their homes. Verbal consent was gained at the start of each interview additional to the written consent which was gained at the beginning of the study. The interviews were recorded and later transcribed by the researcher.

Data Analysis

The analysis was done in three parts:

- Comparison of pre and post-intervention CPQOL-Child responses using Chi square analysis.
- Comparison of parent and child responses from the quality of life questionnaires using Chi square analysis of parent-proxy and child self-report data.
- Part three was thematic analysis through analysis of data from the interviews.

Thematic analysis was performed by the researcher following transcription of the interviews by an external individual. The transcriptions were reviewed and reflected upon for theme development. According to Schneider et al. (2007) “themes can only be ascertained or constructed appropriately (through thematic analysis), by having a ‘feel’ for the overall meaning of the whole set of data” (p. 146). Within this style, it was necessary to review and reflect upon the data until the meaning has been satisfactorily understood. The process of thematic analysis is described in greater detail the Data chapter.

For the qualitative data, the rigour and credibility of the analysis process were taken into consideration. An external researcher performing a separate analysis of the transcripts would have provided a check against bias. The inclusion of another individual was not considered practical due to the time constraints of the project and access to potential resources within the time available. This limitation on the reliability was acknowledged during the data analysis process and care was taken to limit its effect as much as possible.

Rigour in the data analysis was maintained through external transcription which was checked for accuracy by the researcher against the original interview recordings. Thematic categories were then tabulated to assess for rate of occurrence and if the occurrence indicated a positive or negative change or if there was no effect noticed. Any observed trends were recorded and the process was reflected upon throughout the analysis. The ongoing documentation and reflection was to maintain the intended context of the participant responses, maintain the integrity of the data, and reduce the researcher bias in the resultant conclusions.

Ethics

A complete ethics proposal was submitted to and approved by the Unitec Research Ethics Committee (see Appendix E). Ethical issues that may have arisen in the recruitment and interviews included anonymity, confidentiality and the right to withhold any information the participant did not wish to divulge.

Pseudonyms were used instead of the actual participant names in order to maximise anonymity, and the participants were given the option of nominating a name. Any details which could identify them were altered or omitted. This applied to both interview and questionnaire data. Full consent was gained from the adult participants prior to starting each interview in the form of written consent at the start of the research process (see Appendix G) and verbal consent before each interview commenced (see Appendix C).

If the participant did not wish to continue the interview at any stage they had the option of concluding the interview and any data gained would not have been used in the study, unless the participant provided consent for its use. This option was clearly outlined before each interview began, but no participant chose to terminate the interview. It was possible the discussion may have raised questions or doubts in the mind of the participant; therefore each participant had the right to withdraw data gained from the interview up two weeks after the interview. All participants chose to remain in the study.

In regards to the questionnaires and the swim programme, written consent was obtained from the parent who was most involved in the study. All child participants had signed parental/ guardian consent sheets. Parents were recommended to be present during all stages of their child's participation. The children who participated had the study explained in person using language and terms which they could understand. Each child provided assent to their own inclusion in the study, in accordance with the New Zealand Guidelines for Health Research with Children (HRC), as outlined by Peart and Holdaway (2000). In following these same guidelines, if the children had displayed reluctance at all this would have been explored by the researcher and they could have withdrawn without consequence.

The families paid for the swim programme and as such it could be considered a part of their normal choice of activities. The researcher did not wish to be providing inducement to participate, which may have compromised the freedom with which both parents and children consented and assented, respectively.

Funding was to provide travel compensation in the form of petrol vouchers, which were to be applied for through the Departmental Research Budget at Unitec. These would

have been for the participants to cover the extra trips involving data collection, as this was an additional expense directly related to participating in the study. However all participants chose to be interviewed in their homes and there were no additional travel costs.

Once data were collected the questionnaire data was transferred to a data analysis program and the electronic transcripts of the interviews to a password protected file, with hard copies of the data filed in a locked filing cabinet and kept until the completion of the study. Data were only accessible to the researcher and the supervisor.

First contact for recruitment was advertising through the swim instructor, after which volunteers could register their interest through phone or email contact. This was followed by an information sheet from the researchers (see Appendix F). The information sheet gave a comprehensible outline of the protocols of the study and the option of withdrawing from the study at any time with no consequence. It informed that data collected was as anonymous as possible and that the information obtained was relevant to understanding the aims of the study. It further outlined that the data would be accessible only to the researcher and the supervisors, with quantitative data, transcribed documents and audio recordings being transferred into a statistical programme and raw data sheets being kept in a locked cabinet. According to the HRC guidelines (Peart & Holdaway, 2000), these records will be destroyed after a period of 10 years.

In conclusion, before commencing this present research the requirements of the Unitec Research Ethics Committee were met, in addition to the New Zealand HRC guidelines. The ongoing ethical commitments will continue to be met through the secure preservation of the research data collected, for the appropriate length of time.

Chapter 4: Results

Tashakkori and Teddlie (2003) described a like-to-like technique of analysing mixed-method data, where the qualitative and quantitative data were analysed separately; “that is, qualitative techniques are used to analyze qualitative data...and quantitative techniques are used to analyze quantitative data.” (p. 327). Any inferences which incorporated both sets of findings were made once this parallel analysis had taken place. In the interpretation of the results, the findings of each set of data can be verified against the other, with the goal of “establishing convergent validity” (Tashakkori & Teddlie, 2003, p. 328). Therefore, in this chapter the two sets of data will be viewed separately.

The results chapter contains the relevant participant characteristics, provides a statistical analysis of the data collected from the pre- and post-intervention measurements of the Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child). The seven individual domains of quality of life were analysed to identify the presence or absence of statistical change in the participants. A thematic analysis was performed with the semi-structured interview transcriptions to identify patterns of change in the participating children from the parent perspectives. The two data sets are compared in the following Discussion chapter for their ability to adequately reflect the opinions of the participants.

Participant Characteristics

Eight children with CP, ranging in age from 5 to 11 years (8.1 ± 2.5 years, mean \pm SD) took part in this study. Their characteristics are shown below in Table 1.

Table 1. *Characteristics of Study Participants (N=8)*

Pseudonym Parent/Child	Sex	Age	GMFCS	CP Type	Aids
Amy/Andrew	M	11	1	Left Hemi	splints, medication
Beth/Becky	F	6	1	Right Hemi	splints, medication
Cathy/Caleb	M	7	3	Left Hemi	splints, walker
Hannah/Helen	F	11	3	Diplegia	splints, walker
Liz/Lacy	F	5	3	Diplegia	splints, walker
Nel/Naomi	F	8	1	Right Hemi	none
Penny/Pippa	F	11	2	Ataxic	splints
Sam & Sarah/Shelley	F	6	2	Right Hemi	splints, medication

Quality of Life Questionnaire for Children with Cerebral Palsy

The quality of life questionnaire for children with CP (CPQOL-Child) used in this present study contained seven domains: social wellbeing and acceptance, participation and physical health, emotional wellbeing and self esteem, functioning, access to services, family health, and pain and impact of disability. The mean improvement as a percentage for all domains of the pre- to post-intervention quality of life questionnaire was $3.12\% \pm 2.97$ (mean percentage \pm SD), with Chi square analysis demonstrating no significant difference ($P = 0.23$). Table 2 shows the mean percentage change for the individual domains of the quality of life questionnaire from pre- to post-intervention measures. Although the mean of each domain varied between pre- and post-intervention, the magnitude of variation was not sufficient to reach a significance of $P \leq 0.05$.

Table 2. *Percentage Change (Mean \pm SD) for the Individual Domains of the Quality of Life Questionnaire for Children with Cerebral Palsy*

Individual Questionnaire Domain	Mean Change \pm SD (%)
Social wellbeing and acceptance	+2.2 \pm 4.1
Functioning	+3.2 \pm 6.5
Participation and Physical Health	+1.7 \pm 4.4
Emotional wellbeing and Self esteem	+3.6 \pm 5.2
Pain and Impact of disability	- 2.0 \pm 9.3
Access to Services - Parent report	+7.2 \pm 10.4
Family Health - Parent report	+5.9 \pm 5.3

Comparison of Parent-Proxy to Child Self-Report from Quality of Life Questionnaire

A comparison of parent-proxy to child self-report responses was performed with the three parent-child pairs over the five applicable domains, as these domains were completed by both parent and child participants. The domains of access to services and family health were only included in the parent-report questionnaires, thus they were excluded from the comparison to the child responses. Three of the eight children in this present study fit the age criteria of 9-12 years required for the CPQOL-Child questionnaire. A comparison of the parent to child responses over the five applicable domains demonstrated a mean percentage change for the parents of $-4.0 \pm 3.9\%$ compared to the child self report at $+2.2 \pm 1.3\%$. Chi square analysis showed the magnitude of variation was not significant ($P \geq 0.05$) for all the parent to child comparisons. Table 3 shows the comparison of parent-proxy response to child self-report response for the five individual domains.

Table 3. *Comparison of Parent-Proxy and Child Self-Report Quality of Life Questionnaire Responses as Mean Percentage Change*

Individual Parent and Child Self Report Domains	Parent Mean Change (%)	Child Mean Change (%)
Social wellbeing and acceptance	-2.0	+3.3
Functioning	-3.3	+2.0
Participation and Physical Health	+0.7	+3.7
Emotional wellbeing and Self esteem	-5.7	+1.0
Pain and Impact of disability	-9.7	+1.0

Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) is a measure of motor impairment severity; level I representing the least affected, and level V representing the most affected. This study included eight participants from levels I to III, of which three participants were GMFCS level I, two level II, and three level III. Due to a limited participant sample size, statistical analysis of the effect of the intervention on quality of life within the GMFCS sub-groups was not performed. The difference between the three GMFCS levels was very minimal when the mean percentage changes were compared within the sub-groups, from the parent perspectives: with level I having a change of $4.2 \pm 3.0\%$, level II changing by $-2.3 \pm 0.1\%$ and level III showing a change of $5.8 \pm 6.4\%$.

Summarised Interview Responses – A Precursor to Theme Analysis

The summarised interview responses have been included here to illustrate the individual changes which have occurred. The purpose was also to demonstrate the variation and depth of information acquired, as well as placing the themes within the context of each participant.

Amy and Andrew

Amy described how the main physical improvement she had noticed in 11 year old Andrew was in swimming technique, endurance and water confidence. Specific technique benefits were correct strokes and breathing bilaterally. Exercise benefits in general life included an improved focus and increased appetite on the day of exercise. He gained a sense of accomplishment regarding his achievement and experienced enjoyment during the lesson. Amy described him as a generally happy child who was not bothered by what he could or could not do in comparison to others.

Andrew's general social attitude was described as reluctant to participate in team sports due to an inability to comprehend the rules, but he was happy to participate in one on one activity. Andrew required a lot of encouragement to take on new activities and did not like to think for himself, which continued through the swim programme. A social area which changed was home life and interaction with his mother. After being prescribed medication half-way through the year he was able to listen and follow instructions, which relieved the stress on the relationship and calmed Andrew. While she solely put this change down to the medication, she had mentioned that on the same day as exercise he had displayed improved focus and more settled behaviour.

Amy described his mental age as about five years old, with significantly decreased concentration. Andrew had a marked improvement in his ability to focus during the year, which she ascribed to the medication, but she did not feel there was a change in his learning at school as a result of this improved concentration.

Beth and Becky

Beth described six year old Becky as a physically active child who loved participation but struggled with team sports. With her right hemiplegia, Becky found it difficult to maintain her balance, to perform bilateral activities, and she had a general decrease in motor perception. For the first 12 weeks of the swim programme, Becky struggled to comprehend

the physical requirements of swimming in regards to lifting her feet off the bottom, having her body in a horizontal position, putting her face in the water and using her arms. Beth described how all these factors came together in the last two weeks, with coordinating movement between strokes and kicking with her legs, and she displayed improved endurance. Outside the swim programme Beth said that Becky had improved in balance, strength and endurance with bike riding, ball skills in throwing accuracy, and speed and ability in running. Beth described Becky as calmer and more peaceful following an active day. As Becky had a mental impairment additional to her CP, everyday activities required a large degree of mental concentration and energy. From Beth's perspective, matching Becky's mental exertion with physical exertion gave Becky a greater feeling of satisfaction and prevented her from displaying behavioural issues at the end of the day.

Having after-school activities was very important to Becky as it provided a feeling of inclusion. She had previously experienced frustration at not having an activity of her own. The swim programme (in addition to the soccer she started) provided her with a routine to match her siblings and school peers, which made her "extremely happy" and "normalised" life for her. Other activities also contributed to this normalisation, including soccer, keeping a lamb to show at Agricultural Day and being included in classroom responsibilities. In regards to how other children viewed Becky, Beth says that her peer group was already positive, but seeing her swimming and doing the same activities as them improved their acceptance of her. Beth said that Becky loved being included in community activities and being able to do so through swimming improved her confidence. Improving Becky's confidence was very important to Beth, as she wished to provide her with tools for later in life, when Becky becomes more socially aware.

Becky had previously struggled at school in her ability to concentrate, her behaviour and her comprehension of reading and writing. She was previously unable to comprehend words and was holding a pencil in a fist grip for drawing. During the swim programme she was a lot more settled, which allowed her to concentrate and learn. She went without a teacher aid two days per week, her reading ability advanced one level and she was able to write. In the home environment she was now able to concentrate, sit, and watch a movie.

Beth expressed how Becky had improved physical and social confidence during the swim programme. Beth described this improvement as the "best part" of the benefits of the swim programme. She felt providing Becky with a confidence in her ability to accomplish activities and a history of achievement to draw on later in life would prove a preventative measure for Becky. Beth believed that achieving the swimming, being involved in normal

activities and having improved confidence has had the combined effect of improving her self esteem. She hoped that the improved self esteem gave Becky the confidence to integrate further into social activities.

Cathy and Caleb

During the swim programme, Cathy reported that seven year old Caleb improved in swimming skills, strength, endurance, posture, and sleep pattern. He was confident to put his head under the water and swim for a greater distance, and Cathy reported he felt a great sense of achievement on accomplishing these skills. Outside of the pool, Caleb displayed increased strength in being able to step up into a car. When cycling he displayed greater strength and endurance with having the added weight of his younger sister on the back. Cathy described how Caleb was standing straighter through the year, which she attributed to improved core strength from swimming. Cathy said any additional activity exhausted Caleb on the same day, but having regular swimming improved his energy levels in general.

Cathy described how Caleb had an improvement in his emotional response in regard to swimming as well as his general attitude. This swim programme was the first Caleb had participated in and he was initially reluctant, which was demonstrated through tantrums. However, even at the start of the programme his tantrums stopped when he got in the water, which was an environment he loved. His pre-swimming tantrums subsided towards the end of the programme as his skills improved. This improvement was when he started to feel a sense of accomplishment over and above his enjoyment of the water. His change in attitude was such that he was eagerly looking forward to participating in his school swimming and showing others his achievement.

The main cognitive area of improvement during the swim programme was in Caleb's reading, which advanced from the bottom third to the top third of the class from the beginning to the end of the year. Each achievement improved his self esteem, and gave him greater confidence to try other activities in the future, such as swimming with his class.

Caleb's temperament in general had improved over the year, with fewer tantrums. Cathy ascribed this change in part to maturing and reaching an age where he was able to reason in a more logical manner. During the swim programme, he also displayed a greater ability to cope with his physical impairment, which could cause him to fall. His past response would be anger, whereas he was more capable of responding in a calm manner.

Cathy expressed how the swimming had been good for their family as it gave them time together when they took both the children to Northern Arena. For Caleb, being able to

participate in a sport was something he had wanted to be able to do, but team sports had proved difficult. Swimming provided a sport environment and a sense of inclusion without a dependence on the inclusive attitude of a team. For Cathy, that sense of inclusion was very important and it had been the focus of her and her husband's decisions regarding school, sports, and social activities for Caleb. Due to Cathy and her husband's efforts, his social acceptance at school was already positive and that continued through the swim programme. Cathy described how Caleb had not interacted with children with CP previously and there was a twofold benefit. He formed a friendship with another boy in the swim programme, and he was able to place his physical impairment in perspective and realise his CP was not as limiting as some others'.

Hannah and Helen

Eleven year old Helen's swimming technique and her endurance in the water improved markedly during the swim programme, with a rapid increase in number of lengths in the pool and in her swimming strokes. She responded well to the goal setting in each swim session. These swim programme goals were primarily technique focused, but independently getting in and out of the water was also emphasised for those with physical impairments, which Helen achieved with difficulty. Helen became more physically able with her use of her walking frame: going to the bathroom without assistance, improved dexterity in moving around home and getting up and down from chairs. In regards to endurance, she had been able to walk out of school some days instead of using her wheelchair and had enough energy to do her homework, which demonstrated a change from previous years. Hannah reasoned that these improvements outside the swim programme were due to a decrease in fatigue levels and a motivation to be independent.

Helen had previously been in swim programmes and stopped due to embarrassment as she felt watched by her peers. On entering this swim programme she experienced enjoyment of the water and a sense of achievement with the swimming goals, as well as feeling accepted in the swim programme environment. Socially, Helen participated in school activities such as school camps and athletics day, but in these activities she required encouragement to participate. Her reluctance stemmed from the difficulty involved as she could not join in most physical activities. However, Hannah expressed that the environment of social acceptance at Northern Arena was a very positive experience for Helen, and swimming with other children with CP provided an equal comparison of ability which was less discouraging than swimming with able-bodied children. Hannah also expressed how accomplishing skills and activities had

given Helen a sense of being more like her able bodied peers, which increased her feeling of acceptance and independence.

Hannah described how when swimming, the motivation to achieve goals and to be accepted was as important to Helen as the physical gains. Helen's academic learning had always been very good in the past and continued to improve through the year, in spite of changing schooling environments part way through the year.

Hannah described how Helen was becoming more motivated to be independent during the swim programme, and this was gradually translating into becoming more physically independent. Hannah ascribed this to her age; as she was getting older she did not want to have to rely on others for support and was motivated to do things for herself. Her low energy levels could sometimes prevent her from achieving this goal; therefore as she maintained a physical activity like swimming which provides her with higher energy levels, she was more able to maintain her independence.

Helen expressed pride in her achievement in the swim programme and this sense of accomplishment had had followed through into how she viewed herself. Hannah explained that Helen had always had good self-esteem, but involvement in the swim programme had improved it as she achieved, participated and had a reasonable comparison to measure herself in the other children with CP.

Liz and Lacy

Five year old Lacy had improved in her co-ordination within the swim programme, which Liz attributed partly to performing a functional, bilateral activity. Lacy had responded well to having goals to achieve, as she had previously enjoyed the water but not attempted to improve her skills. Liz also describes how Lacy's motor planning had improved in the last four to six weeks of the swim programme, which was important for her as she daily had to organise movement between performing tasks and balancing with her walker. Her energy levels and endurance also improved, which had expressed itself in other areas of life as she took on more physical activities and coped.

Lacy was described as generally happy, but accomplishing new tasks and being praised for them improved her attitude and enjoyment of life. In the middle of the intervention Lacy had surgery, which made her temporarily anxious about activity, but on recovering she was happy to continue with her usual activities.

Liz described Lacy as responding well to both peer and adult interactions and this had continued through the swim programme. Lacy had only just started at school six months

before the swim programme began, but during the swim programme Liz expressed that Lacy had improved in learning, concentration, and memory. Lacy had been much more motivated to try to perform tasks without assistance, including going to the toilet independently, playing at the park, using her walker around school more and carrying things for herself.

Liz described how she had become more confident to speak out in the class room. Liz reported Lacy had experienced a great feeling of satisfaction and pride in herself in being able to put together the movements required for swimming. The improvement in self esteem had fed into her motivation for independence.

Nell and Naomi

Nell found that 8 year old Naomi's upper body strength and co-ordination improved within the swim programme. She also improved in concentration in the swim programme as she found she was able to reach achievable goals. Naomi felt excitement and a sense of achievement in gaining swimming technique. Nell reported that while Naomi was normally a happy child, she experienced less embarrassment, frustration, and anger in performing a sport which was within her capabilities, as opposed to trying netball the previous year which she did not enjoy due to reduced co-ordination causing her embarrassment. Outside the swim programme, Naomi improved in her posture while walking, sitting at school, and in her endurance playing hockey.

Nell reported that previously, Naomi has been reticent to participate in her peer group at school. During the swim programme, she developed a close friendship with another child at school, which improved her sense of social acceptance and confidence in participating.

Nell described the most academic progress at school as any of her time there to date. This improvement was most pronounced in the area of reading skills, but she also had improvement in maths. Naomi had always been motivated to try new activities, in spite of lacking some confidence in her physical capability. As Naomi had become involved in activities over the last several years, Nell had seen an improvement in her confidence that continued to improve over the swim programme. Naomi felt a great sense of pride in herself as she achieved goals throughout the swim programme.

Penny and Pippa

During the swim programme, eleven year old Pippa had improved from only being able to swim with a floatation device to being able to swim three to four metres consecutively without support. In the water she had an enhanced kicking ability and she also expressed a

great enjoyment of the freedom of movement that water allowed. In other areas of physical function Pippa experienced improved standing co-ordination and motor planning, which was shown in her newfound ability to run, walk over uneven ground, and balance. Penny had noticed she was able to shift her weight from foot to foot while standing still. Pippa's endurance improved during the swim programme, as shown by being able to walk to the park without assistance. Pippa learnt to walk two and a half years prior to the study but improved at a faster rate over the 18 months prior, including the time period of the swim programme.

Penny reported Pippa was happy when she was able to have a sense of self sufficiency from taking control of her social life and make decisions for herself. During the swim programme, Penny believed Pippa was more willing to try new activities in the physical area in spite of her awareness of her own limitations. She was also thinking for herself in the social arena, with a greater confidence to take the initiative to create social situations. Pippa had been more confident to have attention on herself, which was shown in her newfound readiness to stand in front of a group and perform. Penny described Pippa as already having high self-esteem, but it had improved markedly during the swim programme, with pride in her achievement in swimming and greater confidence in the social domain.

As she matured in age, she had become more aware of the comparison between herself and her peers in the area of physical capability. The swim programme provided an active environment without the element of comparison, so she found she could improve at a rate suitable for her and still feel a sense of accomplishment and progress.

During the time period of the swim programme, Pippa made a best friend, and gained confidence in approaching other children to form friendships. This change in attitude had improved her sense of self efficacy and wellbeing. Pippa had improved in her ability to concentrate and hear instructions, interpret them cognitively and translate those instructions into the correct movement. In regards to learning, she had improved in the areas of maths and reading, and Penny believed the physical activity influenced her learning capacity.

Sam, Sarah and Shelley

Six year old Shelley had improved in swimming technique with improved strokes as her shoulder improved in mobility and strength, and her endurance also improved. Beyond the swim programme these factors had been displayed in her ability to bilaterally hang from monkey bars and transfer weight from one hand to the other, and increased speed and endurance in running. She had improved in her ability to dress herself without assistance, eat, and pick up small items with her affected hand, which Sarah believed to be due to an

improvement in fine motor skills. Both Sam and Sarah described an improvement in her balance during the swim programme. One negative physical change was decreased appetite, which was a side effect of a new medication. The decrease in appetite had resulted in weight loss, although her parents had been exploring options to counter this side effect.

Shelley was described as a usually motivated person who was willing to take on new challenges. Her confidence in herself had generally increased during the swim programme, and she responded well to the encouragement of the swim instructor as it increased her motivation to improve. Her ability to cope with stressors had been negatively impacted by her decreased food intake, which mostly developed into behavioural issues at school.

Sarah and Sam reported that Shelley was generally very social and she had a good level of peer participation, perceived acceptance and motivation to join new groups or new activities at the time of the swim programme. As she matured, it had recently become more important for her to be perceived as 'normal', which was shown in her desire to have neutral toned splints instead of bright, noticeable colours. Her desire to be treated equally was also shown in team sports, and she worked hard through the year to achieve a level of function which allowed her to participate at the same level as typically developing children.

Several months before the swim programme began; Shelly was diagnosed with Attention Deficit Disorder and prescribed a medication to improve her concentration. The medication had helped significantly as she had been able to follow instruction both at home and at school. Shelly had improved further in her cognitive function over the 14 weeks of the swim programme. She received more academic achievement certificates than previously and had improved in her story writing.

While she was already an independent child, during the swim programme Sarah and Sam reported that Shelly gained further independence both in the water and outside, with a greater willingness to try new activities. Her independence had been shown in her desire to swim further on her own. Shelly had become more confident in physical activities, both in regards to trying new sport activities and specifically around the use of her affected arm. This physical confidence had improved her confidence in general life, in the social and cognitive areas.

Sarah and Sam reported that Shelly gained a sense of achievement and pride in her swimming ability and an improvement in her confidence in herself. Shelly's improved confidence made her more secure in drawing attention to her affected arm at home as she achieved greater function with that arm, and Sarah expressed that Shelly did not doubt herself as much as previously.

Interview interpretation

Before performing thematic analysis it was necessary to acknowledge the lens through which the researcher was viewing the interview respondents. For this process, it was useful to query the purpose of the analysis process: to describe the interviewees' responses on the topic of the beliefs, feelings, and experiences of their children.

It was felt the best fit for serving this process was to take a descriptive, exploratory approach to the interview data, taking the interview responses as an account which represented the experiences the participants had throughout the swim programme. A constructionist approach would have involved paying more attention to each participant's context; however this may have clouded the issue of discovering the response to the given topics. It was desired in this present research to place a greater focus on the information rather than the context of the interview itself (Silverman, 2006).

While this perspective served the purpose of the present study, it was acknowledged that the participating families had an experience which was "embedded in a social web of interpretation and re-interpretation" (Kitzinger, 2004, p. 128). The influences on the participants' responses included family dynamics, their social, physical and economic environments both current and historic, and the wider social construct of what was involved in being a family with a child with a physical impairment. While it was recognized that each of these factors influenced responses to varying degrees, the primary focus of this present analysis process called for a greater emphasis on the response rather than the context. Any focus on the contextual nature of the data will take place in the Discussion chapter, as any potential reasons for interview themes will be further discussed at that point.

Thematic analysis

Following transcription of the interviews, the complete transcriptions were reviewed while listening to the interview recordings. This process allowed for gaining a better understanding of the meaning behind the participant's responses before commencing a formal data analysis. The transcriptions were reflected upon for theme development with this perspective in mind to allow for better understanding of the intended meaning.

A list of concepts was derived from the transcripts and descriptively grouped into thematic categories according to similarity. These themes were developed based upon the intended topics covered in the interview. As the number of responses to each topic was accounted for, the themes were initially narrower. 'Confidence' was initially assessed as a separate theme, as it had a high incidence of being mentioned, but its similarity to the concept

of 'independence' led to a merging of these categories. The efficacy of the questionnaire was discussed in several interviews, but was excluded due to the lack of relevance to the research aims. The final theme categories were directly related to the research topic, being the four domains of quality of life: physical, emotional, cognitive and social, as well as self esteem and independence.

Any resultant themes were applicable to the time frame of the intervention, as the interviews were performed directly post-intervention. The comments some parents have made regarding future changes in their child's quality of life are mentioned where applicable. However these future changes have not been established through follow-up interviews, therefore they are not considered to have as great an influence on the primary outcomes.

Relevant quotes have been used from the participants through the results section. At the points they are used, it has been for the purpose of offering "evidence for a conclusion or claim; to illustrate an interpretive point; to represent, and facilitate understanding of, the thoughts and feelings of the persons studied" (Tashakkori & Teddlie, 2003, p. 344). The verbal quotes may be edited for clarity and comprehension.

Thematic Results:

The description of the themes are structured here as the title and key terms, an introduction, which is followed by an account of the theme within and then beyond the swim programme. The themes were separated into impact within and beyond the swim programme because of the variation in the incidence of being mentioned. The sub-division of the themes was also influenced by the participants placing a distinction on whether there had been any impact in one and/or both of these two areas of life. Participant quotes have been inserted in each theme as examples of the responses. These quotes are followed by an exploration of the key terms which have developed within each theme. The thematic results section is concluded with a summary of the main points derived from the various themes.

Quality of Life Domains

Physical Domain: *improved endurance, strength, coordination and confidence in the water*

All participants in this sample reported improvement in the physical domain of quality of life during the swim programme, which was described as occurring both in and outside the intervention. Factors of physical function which were reported on included strength, endurance, motor planning and balance.

Physical Domain - Within the swim programme

All the children were described by their parents as improving physically within the swim programme, with a progression of swimming skills leading towards increased upper and/or lower body strength and endurance in distance of swimming. For some children, there was an improvement in coordination, and the parents who expressed this found this to be a noteworthy change, as a lack of coordination and balance are frequently a part of the presentation of CP.

Amy: He swims actual strokes now and he can swim a few lengths without putting his feet down which he couldn't do before and he's also now learning the breathing technique for swimming and moving your head to the side and that. And he can do it a little bit but I think the more he swims the better he will get at it.

Liz: She's just started putting it all together with arms, legs and face in the water... she did this length where she was putting her face in, kicking and paddling all

at the same. And she comes up to me at the other end and says, ‘Look at me Mum I can multi-task.’... It’s not quite correct swimming, it’s more like dog paddle and a push kick but I can see that she’s moving actually towards swimming.

Through the experiences related by the parents several elements of physical ability were explored. All parents spoke in detail on this topic, using examples of improved strength, endurance and coordination. Opinions about the potential causes of this change were discussed in the interviews, with some parents commenting on a change in motor planning and fine motor skills.

The quality of the swim programme was reflected in the parents’ description of how their children loved participating in it, and several parents reported their children had expressed enjoyment of the general environment at Northern Arena and the freedom they experienced in the water. Three parents expressed their relief knowing their child was made safer in the water through attending a swim programme, which not only gave them water confidence but competence as well. This attitude was described within the context of beach visits, pools at home or swimming on holiday which occurred within the time period of the swim programme. Amy expressed her comfort in being able to take her eyes off Andrew for a moment without worrying to the extent she had previously.

One parent mentioned she would like to see more specialised swim teachers involved in swim programmes for students with physical and mental impairments, as she had seen the benefits of the swim teacher having a thorough knowledge of the condition. Overall, the experience was a positive one for both parents and children from the perspective of the physical domain.

Physical Domain - Beyond the swim programme

Seven of the parents described how during the swim programme, the changes in physical function had carried over into daily activities such as play, self-care, balance, strength, energy and endurance. The improvement in play was described in the context of such apparatus as monkey bars, trampolines and swings, while endurance was discussed in regards to walking distance, running speed and distance, and cycling. Self-care was described as being able to perform tasks with reduced or no assistance, which included tasks such as dressing and going to the bathroom. The parents who reported improvement in physical competency in these areas described how it gave their children a sense of accomplishment

and some reported that it motivated their children to further increase their physical independence.

Cathy: In his legs I've noticed a big difference. He's started to get himself in and out of ...the van, which is quite a big step up; which he always used to fall about an inch short of in lifting his leg up. And now he does. He pulls himself up into his car seat now which a lot of is coming from his bottom and his sides, his hamstrings and quads. So that's new and that's really exciting...We took him cycling in the weekend and for a while it takes him to get into the rhythm but when he did, boy he powered through it this time and he was actually driving with his sister in the back of it.

Sarah: She started wanting to sit at the table and put some attention or focus back on herself and she'd call out, 'Look Mum I can eat with my right hand.' Well she's never ever done that before... She was able to hand me clips for her hair in the morning with her right hand, which is her fine motor [skills]. Just putting that hand out, without being prompted to use it... She's had cross country at school during that [swimming] period and she came 11th out of 22 able bodied athletes, and that was two laps around a reasonably tough course... That's a big improvement on last year.

Several parents explored aspects of their child's daily life which had experienced improved in physical function during the swim programme. The greatest focus in this area was on performing self-care tasks, play, and aspects of physical function which influenced the children's ability to participate in daily activities. These daily activities included getting in and out of a car, balance, running, sitting and standing, and for two of the children, manoeuvring their walker around a house. This improved physical function allowed for a greater ability to experience life from a more physically independent context where they could function without assistance. Some parents described their own positive attitude about this improvement, as any opportunity for their children to live a more physically independent life was important to them.

The change in physical function in aspects of general life was explored in a manner which demonstrated its importance to those parents expressing their thoughts. From their perspective improved physical independence and experiencing an accompanying sense of wellbeing in this area was a worthwhile outcome.

Emotional/Behavioural Domain: *happy and confident in the water, lower frustration levels, excitement and pride over the achievement of swimming, anticipation of future swimming activities*

All parents reported a positive emotional experience for their children within the swim programme. Beyond the swim programme fewer parents had noted a change, but for those who did, they identified aspects such as being ‘calmer’ and ‘happier’ with reduced ‘frustration’.

Emotional/Behavioural Domain - Inside the swim programme

All eight parents described how the swimming inspired emotions of excitement and happiness, and all children enjoyed the experience of being in water. In contrast with other sporting activities, participating in the swimming provided an environment which reduced embarrassment and gave a sense of acceptance. The goal-setting within the sessions also motivated the children to achieve further swimming skills. There was anticipation of future swimming opportunities with their peers, which some children had previously not enjoyed or avoided.

Hannah: She didn’t like to get in the pool and was embarrassed. But we’ve really worked through that which has been fantastic and she really enjoys coming which is great... Getting Helen back into the water has been a huge milestone to overcome because she used to swim a long time ago and the thing is she went off it because she felt everybody was looking at her.”

Beth: We talk about our week [as a family]... Becky would always be, What about me? What am I doing? She’d get quite fixated on it whereas now because she’s got swimming and also because she’s got soccer now as well, when she starts talking about the things she can’t do like netball for example, you switch the conversation to, ‘Ah but you’ve got swimming on Wednesday.’ And that completely placates the whole frustration because she has her thing... she goes swimming with [M.S.] on a Wednesday and that’s her routine and she loves it... I think she’s extremely happy to be included in some sort of after school activity and to be learning to swim.

From the parent perspectives, their children’s involvement in the swim programme resulted in a positive emotional and behavioural experience. Aspects of emotional impact in

the swim programme included the freedom experienced in the water, the enjoyment and ownership involved in having a routine activity, and reduced embarrassment due to the accepting environment. One child was initially reluctant to participate due to past experiences and one was reluctant due to a lack of familiarity, but both were described as coming to thoroughly enjoy this swim programme. The emotional aspect of quality of life as it was explored in the interviews was descriptive of an experience which presented an enjoyable, encouraging atmosphere of learning.

Emotional/Behavioural Domain - Beyond the swim programme

Five parents expressed how physical activity has the influence of calming their child, reducing frustration levels and improves the child's attitude in general. These emotions were described in the context of experiences had within the duration of the swim programme.

Nell: She's always been a happy child. But I suppose embarrassment, she played netball last year and she stopped that because she got a bit embarrassed, because of the poor co-ordination, frustration, anger.

Penny: I have noticed in dancing this year she suddenly has been aware that she just can't do things like the other girls and keep up with the dancing. So there's more of an awareness of what she can and can't do. But she's also happier because she makes sure she does the things she loves to do... I think dancing she does find a bit stressful at times. Whereas swimming she doesn't at all because there isn't that competition factor. She's just doing her best and feeling like she's doing really well instead of feeling like she's way behind and can't do it like everyone else.

Of those parents who described experiences of change in the emotional/behavioural domain, the emotions included calmness, an increased ability to cope with life experiences and a generally improved attitude. For some, there was a reduced level of frustration, anger and embarrassment than in previous years. This change was attributed by one parent to the use of excess physical energy, and by two other parents as a consequence of improved physical fitness. The impact of the swim programme through an improvement in coping provided a valuable life skill for these children. Having a permanent physical impairment can be interpreted as a situation which will continue to require methods of coping from these children. A programme which provides improvement in the emotional domain is therefore a

valuable tool to utilise. Whether these coping skills are maintained beyond the swim programme is, however, not within the scope of this present research.

Social Domain: *sense of inclusion, being normal, difficulty in team sports*

Within the social domain, the sense of inclusion was mentioned by some parents and building a repertoire of normal activities was also mentioned. Some parents discussed the effort they had previously made to create an environment of inclusion and normalcy for their child through the choice of activities, schools and social environments. The difficulty in participating in team sports became a recurring theme which was not originally an area this research intended to explore.

Social Domain – Within the swim programme

Five participants discussed how the environment at the swim programme promoted a sense of inclusion, acceptance, and motivation to learn, regardless of whether the child was in a group or one-on-one lesson structure.

Cathy: He's bonded really well with another boy in the group. That's really nice and he's formed a friendship outside of it and I think he has realised that his cerebral palsy isn't as bad as some of the other children he's met, which is quite a significant thing for a seven year old to realise.

Hannah: I think just having them there and having them in the pool and the fact that they've all got the same disability is huge because you're not always comparing against able bodied and can swim miles faster than you. So that's good...Her social acceptance just being - I think, interestingly, that hasn't been an issue this time. Whereas a few years ago it was and I think maybe because of [M.S.] and the whole atmosphere there at Northern Arena and I think swimming with the other kids has also really helped with that... The more she can do, then she's like other children and the more able bodied that she feels and the more independence that gives her...just the motivation and the atmosphere of swimming with other children, with other young teenagers and it's also about that normality. The fact is the whole atmosphere and culture in the place, [M.S.] just treats them like able bodied students, which is awesome.

An exploration of the social domain in the context of the swim programme yielded several descriptions of the community atmosphere at the complex. There was a focus within the comments on the inclusiveness the children enjoyed through being a part of that community and experiencing a sense of acceptance. Three parents commented on the influence of interacting with other children with CP, which had a positive influence on the children's experience of perceived social acceptance.

The environment was also described as motivating, with the children responding positively to the opportunity to work to a set of goals aimed specifically at their individual abilities and having other children with physical impairments to compare themselves. For some, previous experiences of sporting environments had promoted a sense of exclusion, frustration and embarrassment. For those who described the accepting environment of the swim programme, it was clearly an important feature when compared to other sporting environments. There was an association with the promotion of such an environment and the children expressing the desire to continue to attend.

From the parents' perspective, there were positive comments on the level of discipline, the balance between play and structured learning and the competency of the swim instructors. Several parents related instances of these features, such as describing the short sessions of play at the end of the lessons. One parent was impressed by the discipline displayed in one particular instance, where a child spat into the water and was immediately instructed to treat the swimming complex with respect, before the lesson continued without belabouring the point. The parents all stayed and observed most of the swim sessions and therefore gained a thorough impression of the overall structure and all found it to be an excellent environment for their children.

Social Domain - Beyond the swim programme

Changes in the social domain were noticed outside of the swim programme by five parents, with most children already having a positive experience of their peer group and their own sense of acceptance. However, the difficulty in team sports was an experience which several children had before or during the swim programme with activities such as rugby, netball and soccer.

Sarah: Now that she seems to have got a lot more sturdier on her feet, a lot better balance, her muscles seem to have stretched a smidgeon I guess or loosened up... I think that has helped her with her social acceptance, she feels less likely for

people to go, 'Oh you can't do that because there's something wrong with you'... She's got a lovely group of friends and an awesome, awesome surrounding of parents around which are very encouraging and accommodating for her to join in... I think it [the swim programme] has given her a lot more confidence, just in that area of doubt that she's had over balance and stability, not having the full extension in the arm. Those sorts of things, now she's like, 'No I want to play that.' I'm like 'Are you sure you want to give it a go?' 'I'll give it a go.' 'OK we'll give it a go.'

Nell: Her confidence socially, I think she's developed a lot last year to this year. She's got a good friend at school... Her confidence has improved because she has a really good friend; it's very social at school so she automatically includes Naomi.

During the swim programme, some parents described an improvement in social confidence and in making friends. In comparison to this programme, some parents had found other sports to be more difficult for their children. The parents' responses to this situation varied, with some choosing to stop certain activities and some found methods of getting around the issues by finding accepting teams, or through coaching their child to be physically ready to participate. The response depended somewhat on the level of physical impairment as to whether participation was possible. However, swimming was an activity in which all children could participate without the issue of negative comparison or competition, which most parents found to be a more positive environment.

There were two children who developed significantly greater social confidence and made good friends in the time of the swim programme, and two other parents noted an improvement in general social confidence. These changes were described through instances where a new confidence developed to draw attention to themselves in social environments, such as in family interactions or in performing in front of an audience. All parents who explored change in the social domain wanted their children to be motivated to participate. Ferreira and Fox, (2008) found that adults with physical impairments are more at risk for social withdrawal and depression. Therefore, it can be seen to be a rational desire to provide children with the motivation to participate and create positive behaviour patterns which may carry on through to adulthood, although this present research does not comment directly on this potential influence.

Cognitive Domain: *improved reading skills, math skills and general concentration*

Several of the participants improved in their ability and desire to concentrate during the swim programme. Additionally, some children were described as improving at school in concentration and academic achievement and at home in displaying the ability to complete assigned tasks.

Cognitive Domain - Within the swim programme

Five parents saw an improved concentration within the swim programme. They ascribed the improvement to the process of the children seeing their own improvement in skill, wanting to improve further, and therefore displaying greater focus.

Hannah: She'll get out in comparison with to one of the other girls who swims with her and, 'Oh I was able to keep up with her today.' So a lot of it is actually with Helen is also psychological.

Penny: [While swimming, she was] enjoying herself and probably the things she finds the most difficult, concentrating and listening, following the instructions and getting her body to follow the instructions. She often finds it hard to get her body to do what her brain says it should do... The concentration, and hearing the instruction and putting it into her brain and getting her body to do it, that's improved a lot.

Five parents gave a description of the meaning of the psychological aspect of the swim programme to their children. The goal-setting helped the children focus, and as they improved in skill level and realised they could accomplish these goals, their desire to remain focused increased. For some children, the concentration required for this was tiring, and the cognitive processing needed to translate instruction into motor planning was difficult, but as they worked toward achievable goals they were motivated to continue. The overall experience in the cognitive domain may be described as taxing, but rewarding toward the end of the swim programme. It can be concluded from this description that in the approach to performing a swim programme with children with CP, it was beneficial to be mindful of the physical and sometimes mental limitations which were involved, and set realistic goals accordingly.

Cognitive Domain – beyond the swim programme

The main improvement reported in six children appeared to be primarily in reading comprehension, with some parents describing improvement in maths and writing skills. Two parents partly ascribed this improvement to a recent change in medication, which improved their respective children's concentration levels. For other children who showed improvement in cognition, there were no other significant lifestyle changes.

Beth: Probably the main one is that she's starting to learn to read... She has two days at school now without a teacher aid. She's able at home to sit and watch a movie - simple things like that. Now she can sit and concentrate, even not for a long period of time and certainly not like another seven year old, but she can do it and last year she wasn't really doing anything at school. It was kind of, 'What's a word?' And she wouldn't even have that concept of what a word is and now she can sit and read 'the cat sat on the mat' and she would sit and follow, track and actually read it. That's been the biggest thing I think, this year...Its massive, you know, for a little girl last year who showed no signs of reading or writing and not holding a pencil - still holding in a fist grip and just scribbling, but not even knowing where the page ended, just keep going. But now we're sitting and she can hold and she can write and, yea all with a lot of help, but still she can do it.

Sarah: She's come home with quite a lot more certificates from school for academic just in the last sort of 14 weeks. They did a production, she got a story published by the Principal that she dictated to her teacher aid and the teacher aid typed it out.

The improvement in the academic domain was not an expected outcome of the swim programme, as it was not reported by previous research involving swim programmes. However, there is some evidence with other land-based exercise interventions that show an improvement in cognitive function (Griffin, et al., 2011; Verschuren, et al., 2007; Winter, et al., 2007). In the present research, the primary improvement was in reading comprehension, with some children improving in maths and writing skills. An improvement in concentration was also described by some, with an ability to follow instructions at home and school, or as Beth described, to sit down and watch a movie. The cognitive improvement explored with these six parents was felt to be more rapid than in previous years, while the other two parents felt their children's learning had continued at the same rate as previously.

Independence: *confidence, motivation*

There was an improvement described in the area of independence in seven of the eight interviews. In the interviews, independence was defined as the ability to think for yourself and the desire to try new activities. All seven who expressed improvement described an improvement in the water, while outside the swim programme five expressed that their children had a greater desire to think for themselves and five in trying new activities.

Independence – Within the swim programme

Seven of the children were described as having greater water confidence with a desire to try new activities such as exploring play and performing tasks they would not do at the start of the 14 weeks, such as putting their head under water.

Sam: She's probably a bit over confident in the water now... [On holiday] we never put any floating devices on her because we thought it might make her go backwards in her swim programme so that was it. If she wanted to swim she had to swim unaided. And she did.

Hannah: It might not even be the swim distance, what she's been able to achieve is actually getting in and out of...not so much into the pool from the ladder, but she's been able to achieve getting out of the pool on the ladder, which is an awesome achievement.

The main area which has improved in regards to independence in the swim programme is in water confidence. While most of the parents did not explore this change in detail, one described their child's confidence in swimming independently on holiday. Another parent described her son's willingness to be thrown in the air, as he now felt it was safe environment. There were two examples of a greater degree of thinking for themselves, one was in feeling secure enough to start making suggestions for activities, and the other was gaining the physical independence to get out of the pool by herself. Getting out without assistance was a difficult but important achievement, as the implication was that she would be safe and physically independent in the water if assistance was not immediately available. Gaining water confidence in conjunction with improving in skills was generally felt by the

parents to be a positive aspect of the swim programme and was related by several parents to an improved self esteem, which is discussed in greater detail below, within that theme.

Independence – Beyond the swim programme

Six parents described a general improvement in the children's ability to think for themselves and try new activities. Several children were motivated to perform tasks for themselves without assistance, such as using the bathroom, dressing and negotiating the use of their walker without help.

Penny: This year, she organises things for herself a lot. Every holiday this year, she's organised a 'girls' day' she calls it and has emailed all her friends that are girls and invited them over and planned what they'll do...I think she's a lot happier because she's finding, she's able to make things happen. The things she wants to do in life she makes them happen with friends and things.

Liz: Her physical ability and her drive to do things on her own has increased quite a lot as well. In the last couple of weeks of the last school term, they said she was just using her walker a lot more and she was wanting to carry things around and do things. She was just wanting to be a lot more independent... I think trying new things physically she's definitely wanting to do a little bit more and she'll quite often say, 'I want to do it by myself.' A lot of her personal cares, like go to the toilet and things like that she's stopped asking for as much help and she's says, 'Oh I'll do it by myself Mum'. So she's definitely wanting to be more independent in her daily living. For instance if we go to the park or something like that she's definitely showing an interest to want to do more on her own there.

For those parents who described a greater level of independence in their children, most related it to an increase in self-confidence leading to a desire to think for themselves and/or try new activities. In the area of thinking for oneself there were two examples given, one of proactively searching out new physical activities and one of organising her own social activities.

Some responses in the area of independence related to the desire to try new activities, which included performing daily tasks without assistance and taking up new physical activities. As physical function in the area of swimming improved, it was thought by the parents to increase the feasibility in the children's minds of achieving other activities. The

value in this change in attitude was potentially a long term benefit to their sense of independence, as it would be beneficial in adulthood to maintain a greater sense of self-efficacy.

Self esteem: *pride, satisfaction*

Self esteem was defined in the interviews as the feeling of satisfaction a person has regarding themselves. All eight parents described the sense of achievement their children felt within the swim programme as they accomplished goals and improved in swimming technique. A further improvement outside the swim programme was described by four parents.

Self esteem – Within the swim programme

The sense of achievement all the children gained in the swim programme was expressed through such actions as drawing their parents' attention during the swimming to demonstrate their skills and in reporting on their improvement later to family members and friends.

Cathy: And to see his own face shine when he's done something and he sees that we're really proud of him is really nice as well...he's really proud of himself and he comes home and tells Nanna word for word what he did or if Dad's taken him he'll come back and tell me. So he is really proud of himself.

Nel: She just gets excited about it, 'Mum, look what I've done'... I think throughout this whole swimming programme, she was very proud she could do it. And every time she could do stuff or swim longer, she'd get so excited about it, you could see that she was proud and she wanted to tell me... Absolutely, I think she got a lot of satisfaction out of what's she achieved, because she was in the smaller pool and she went into the bigger one and she just loved it. She made progress.

All parents described their children's great sense of achievement and pride in themselves in accomplishing goals within the swim programme. They demonstrated their pride through drawing attention from their parents or the swim instructor, telling others of their experiences later and in their general attitude of satisfaction after a swim session. Some parents also described how their children were excited to display their new skills in future

school swim programmes, which they had previously been reluctant to participate in. Within these descriptive explorations from the parents, it can be seen the swim programme has a positive impact on this aspect of quality of life in these participants.

Self esteem – Beyond the swim programme

The improved self esteem of six children outside the swim programme was described as occurring when other tasks and activities became achievable, and these new skills became a source of satisfaction for the child. The importance of the interaction between accomplishing physical activities and the sense of self became evident over the process of theme analysis.

Beth: Yea, I'd say she's really, really happy about it, and it's feeling confident and happy about herself... I think it's definitely improved her self esteem. It has, hand in hand with lots of other things this year - I think it's been a crucial part... I don't want her ever to be, 'I can't do that - I have cerebral palsy'. I think that doing these activities, the swimming and soccer, helps that aspect of her, 'Oh I can't do that,' life. And although I haven't seen much of it at the moment, I believe, in the future it'll stop that coming up, because it's a case of, 'You can, you do it differently but you can, of course you can – look, you do swimming you do all sorts of things at school.' I think it's not so much now that I see a big result, but I'm hoping it will pay off in the future.

Sarah: I think it's given her more confidence. She's not doubting herself nearly as much.

Self esteem outside of the swim programme was explored as an area of change with six of the parents. They described how improved physical or social function had an impact on their children's self esteem, with a close inter-relationship between the two factors. The process of impact was described as: an improved function leading to an improved self image and confidence, leading to a willingness to try new activities, the more functions which were achieved, the greater the build up of self esteem, and vice-versa.

The benefit in this process was recognised by some parents who aimed to improve their children's confidence as much as possible during childhood in order to give them greater potential to achieve later in life. This process has been addressed in research previously, in which physical activity has been found to counteract low self-esteem and

depression in those with physical impairments (Varsamis & Agalotis, 2011). Within the context of this swim programme, there were immediate benefits demonstrated within the area of self esteem for the participants involved, although the future impact some parents described was not substantiated through a longitudinal investigation.

Summary

In this research, the results gained through parent interviews indicated the swim programme performed well when evaluated against aspects of quality of life, self esteem and independence in children with CP. The parents described their children's love of the freedom in the water, their improvement in swimming skills and their enjoyment of the accepting environment. The experiential descriptions of beyond the swim programme also portrayed improvements. These included enhanced abilities to be involved in play and to perform self care tasks, greater confidence in physical activities and social interactions, and gaining a sense of satisfaction in their achievements. Not all participating children gained improvement in all areas, but all children were described by their parents as gaining improvement in at least four of the six themes.

Regarding their future plans, all parents intended to continue attending due to the manifold benefits they perceived and some mentioned they had also referred others to the swim programme. The only negative point which arose in several interviews was the expense of attending the swim programme. All parents who expressed this point said it would not prevent them from attending as the benefits outweighed the expense, but they stated that financial assistance from the Cerebral Palsy Society or the Halberg Trust had helped considerably. One parent stated that from her perspective, full (possibly government) coverage of the cost of swim programmes would be beneficial for all children in New Zealand in order to ensure their safety around water.

Chapter 5: Discussion

The discussion chapter interprets the data generated from the quantitative and a qualitative measure carried out before and after the swim programme, and discusses the implications of those results. The interpretation of results leads to an exploration of the importance of physical function, an accepting environment, a 'normal' routine, and having challenging but achievable goals in the swim programme. Comparison is made to relevant literature regarding aquatic exercise and land-based exercise. The observed limitations of the study are discussed, along with the opportunities for future research to continue investigating the effect of swim programmes on quality of life, independence and self esteem in children with CP.

Interpretation of Results

Quantitative: Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child)

Before and after the intervention all eight parents in this research completed the parent-proxy version and the three children aged 9-12 years old filled in the additional self-report versions of the CPQOL-Child questionnaire. Results demonstrated the mean improvement for all domains of the pre- to post-intervention quality of life questionnaire was $3.12\% \pm 2.97$ (mean percentage \pm SD), with Chi square analysis demonstrating no significant difference ($P=0.23$). The questionnaire was divided into seven domains of quality of life. No significant ($P \leq 0.05$) change was found in any of these individual domains, nor was there significant comparative change between the levels of motor impairment, represented by the Gross Motor Function Classification System (GMFCS) levels I-III.

The lack of significance in the CPQOL-Child questionnaire results may be related to the swim programme not producing a meaningful change in quality of life. This conclusion would partly be based upon the factor that the intervention primarily focused on improving swimming skills, not on improving quality of life. If the questionnaire represented an accurate picture of the effect of the swim programme on quality of life, then it was an appropriate tool to measure this relationship.

However, the lack of significant measureable change may also have been the consequence of the small number of participants. A larger sample size might have shown a greater level of significance, with a more reliable representation of the population of children with CP.

Another potential reason for this result may be the lack of sensitivity of the measure. Although it was designed partly for the purpose of assessing change, it has yet to be established in related research as being sensitive to change. For use in the present research, there were no comparable condition-specific tools available with a validated responsiveness to change. The lack of an ideal instrument was one reason that this measure was initially chosen, and why it was supplemented with an additional qualitative measure. Previous aquatic interventions have been shown to provide statistically significant change in physical function. The latter may be a more likely reason for this result as there was no significant change found within the physical domain of the CPQOL-Child questionnaire in this present research.

Qualitative: Semi-Structured Interviews

The thematic data described in the Results section are discussed in relation to topics which appeared throughout the domains of quality of life. These aspects developed as being areas worth noting for the participants and for the aims of this research. The topics are: the importance of physical function, an accepting environment, goal-setting, normalcy and normalisation, cognitive function and family life.

Importance of Physical Function

Through their exploratory interviews all of the parents described aspects of improved physical fitness related to the swim programme, and most described similar improvements in the environment beyond the swim programme. From their description, the implications of these general improvements had a greater significance to the parents and their children more than the pure appreciation of the improved fitness. This could be seen in the examples given in the Results, which described an improved ability to engage in activities which required fine motor skills, endurance and strength; such as picking up small objects with the affected hand or walking to the playground.

The different stories demonstrated how the impact of physical function had a different meaning for each person, which influenced their lives in a variety of ways. What was illustrated was the meaning of physical function in the context of their family dynamics, in

their children's social environment, and the children's perception of themselves within these contexts. The descriptions portrayed a picture of how enhancing physical function allowed the children to interact with their environs in a more integrated manner. For example, Becky was able to feel she was on equal terms with her sister in her placing within the family's weekly activities, and Shelley felt confident to challenge herself in front of her peers in what playground apparatus she could attempt to achieve. Each participating parent described different situations in which improved physical function benefited the lives of their children, and in some cases the health of family interactions. For Pippa, there was a significant benefit in that she was able to walk and play without assistance. To her this meant greater independence, confidence to try new activities, and the development of a sense of self efficacy.

Most of the families involved found the changes that had occurred had had a profound effect on physical function beyond the swim programme. This improvement had enhanced the children's self esteem, motivation to be independent, and their ability to cope with stressors. Overall, from the enhanced physical function all reported an improved general sense of wellbeing in the children during the programme. This result was also found by Debusse, et al. (2009), with an improved physical function from hippotherapy leading to improved self esteem, self efficacy and quality of life.

Wood (2006) stated that CP is "a group of permanent but not unchanging, disorders of movement and/or posture and of motor function" (p. 286). Therefore, if one views these physical changes from a wider perspective and in relation to this definition of CP, it may be seen that finding activities which promoted change was of primary importance, in order that all potential change was allowed to occur to the full extent possible. Investigating activities which benefit individuals' sense of physical well-being has been an ongoing process within the clinical and research fields (Damiano, 2009; Getz, et al., 2006; Retarekar, et al., 2009). The subjective descriptions in the present research have contributed to the existent knowledge in this area. These descriptions have demonstrated that it was possible to improve upon these children's sense of physical well-being and their overall physical function.

Another benefit of promoting physical function in individuals with CP is preventing the development or slowing the progress of secondary conditions which affect the musculoskeletal and cardiorespiratory systems (Damiano, 2006). The possibility for neural adaptation was also a potential benefit noted in previous research, as "the developing brain is more malleable and may respond to interventions that could redirect this process" (Damiano, 2006, p. 1537). It has been acknowledged that in CP, the development of new movement

options may be limited by the early developmental redirecting of motor pathways to more frequently used pathways. These pathways may be difficult to reverse once established (Damiano, 2006). Therefore, this author rationalised that it was important to reinforce functional movement through activity early in the development process to attempt to repair existent damage and prevent further damage occurring. In the present research, swimming represented this kind of functional, full-body movement, and the parents' descriptions of the improvement in coordination and balance indicated that this activity positively influenced the neural function of these children.

Accepting Environment

Several participants described the accepting and supportive aspects of the swim programme environment and the consequent effects it had on their children's quality of life. The parents described the effect on the children's perceived social acceptance, with a consequential improvement in confidence and self esteem. An example of this acceptance included one girl not feeling embarrassed or that she was being watched, as she had felt in other swimming environments which had caused her to stop swimming at the time. The importance of acceptance was illustrated in the objective of the parents to have their children involved in a physical activity and to keep them participating.

Another example of the environment of acceptance was for the children to have had the opportunity to compare themselves against others with CP. Most children had generally had positive social experiences prior to this research; however some negative experiences were described within the area of sporting and physical achievements. Some parents felt that their children had struggled to integrate into able bodied groups as they could not physically keep up. The swim programme provided an environment in which they participated on equal terms, which motivated some of the children and the parents to want to continue swimming in preference to other activities.

Some research had found that children's desire to participate in an activity was related to their level of acceptance. As stated by Imms (2008) "development of participation is driven as much by the social and environmental context in which activity takes place as it is by the maturation and development of skills within the child" (p. 1868). Maintaining participation is key to the improvement in quality of life of children with CP. Participation both improves their ability to interact socially and it directly relates to physical activity and all the benefits that physical activity brings, as detailed in the preceding section.

Goal-setting within the Swim Programme

Several parents found the structure of providing realistic, but challenging goals to be a positive experience for their children. Some parents contrasted it positively to the structure they had found in other programmes. The goals were primarily related to swimming technique, with some additional goals related to achieve physical independence in the water. This goal-setting motivated the children to achieve a greater level of skill. The improved skill provided further motivation to concentrate in the sessions, and as greater skill was achieved, the children experienced improved self esteem and emotional wellbeing through the swim programme. Without having a goal oriented approach, the children might not have achieved the level of physical improvement they did, which would have had a direct effect on the sense of satisfaction they experienced as a result of their physical improvement.

As previous research has found that children with physical impairments experience reduced levels of goal orientation (Varsamis & Agaliotis, 2011), an activity which promotes achievable goal-setting can be seen to be an important addition to the quality of life of children with CP. As described above, in the present research goal-setting impacted the physical and emotional domains of quality of life in addition to their self esteem and independence. The improvement in goal orientation which they had experienced were important factors in task participation and for implementing tasks in an effective manner (Varsamis & Agaliotis, 2011).

For some of the children, the reduced concentration capability was a part of their CP, and for those children this may always influence their ability to plan and achieve goals. However all participants showed improvement in their goal-setting within the swim programme, which demonstrates that for these participants, some level of improvement was possible regardless of their co-impairments.

Normalcy and Normalisation

Before detailing the development of the theme of ‘normal’, it is acknowledged that the term is a social construct based upon the messages received by the children on what level of ‘difference’ is tolerated. The construct of ‘normal’ is formed by the social world in which they live, and the individuals desire for normalcy is the result of a “developmental and social phenomena” (Elliott, Lach, & Smith, 2005, p. 675).

The descriptive term ‘normal’ was mentioned by several parents in relation to situations such as having an activity like their peer group or siblings, or feeling normal in

comparison to the other children with CP in the swim programme. This sense of being the same as others was important to the children as it related back to their sense of perceived social acceptance.

Having a routine was described as important to the child in some of the interviews. Routine activities were perceived as being a part of normal life by the children, as their friends and siblings presented a comparative reality that demonstrated this to be true. Consequently, the children had found that having their own routine activities provided a match to this comparative reality, which feed into their sense of normalcy and subsequent perceived social acceptance.

Normalcy has been explored through qualitative methods in youth with epilepsy (Elliott, et al., 2005). These authors found that the seizures experienced by their participants acted as a barrier to normalcy, with an accompanying feeling of alienation. The experience of feeling 'different' was described as impacting all domains of quality of life; the physical, emotional, social and cognitive.

A similar conclusion could be stated about the participating children in the present research. Several parents described that prior to the intervention their children had a growing awareness of being 'different', with accompanying emotions of embarrassment or frustration. The parents who described this process were the parents of the older participants. The younger children were described as not being entirely aware of how they felt about their own experiences, although having had a normal routine was described as giving them a sense of happiness or satisfaction. This was significant as it emphasized that for the children, viewing themselves as 'normal' was a part of their evaluation of their own sense of wellbeing.

In contrast to the research by Elliott et al. (2005), the present research explored the impact of an intervention on aspects of quality of life. Thus, this research was able to demonstrate a growing sense of normalcy in all domains. In the physical domain, increased endurance, strength and balance were described. In the emotional domain the children had reduced levels of frustration and embarrassment. The social domain was described as having had an increase in the ability to play and participate in activities. The cognitive domain had improved in the ability to focus, with an increase in reading and maths levels. An improved cognitive function had allowed some of the children to have a more integrated experience in the classroom, with more tasks delegated to them and fewer days with teacher aids.

All these factors indicated a decrease in the sense of the abnormal self as a positive reflection on the swim programme. While their CP could not be removed from their lives, it was a positive result to see that a process of normalisation was possible to a certain extent.

Knafel and Deatrick (2002) described the importance of normalisation to the families of children with chronic conditions. They described normalisation as a process of viewing their family and their child as “unchanging in the important ways”, while also recognizing the seriousness of the illness (p. 49). Any management of the condition was undertaken through this ‘normal’ lens, by adapting to management regimes in a flexible manner and incorporating them into the family routine. These authors emphasized the importance of clinicians supporting and promoting the families’ efforts in this direction.

The experience had by the families in this research reflected the process of normalisation. The families were able to experience an activity which accounted for the symptoms of the children’s condition and contributed to its management, while concurrently providing an environment which added to their sense of normalcy. In this manner, the swim programme had contributed to the families’ process of normalisation and the children’s sense of normalcy.

Cognitive function and Swimming

Most parents described the experience during the swim programme as including a gradual improvement in the capacity of their children to concentrate. The increasing concentration was described as resulting from improved physical skills, and acted as a motivator for the children to achieve further goals. These improved skills then related back into self esteem. Several parents described the cognitive area of motivation as a very important outcome of the swim programme.

Motor planning capabilities and its effect on coordination were also influenced through the swim programme. Three parents described the moment at which their child ‘got’ the concept of swimming; where they linked together the instructions, mentally processed what was required, and translated that into the coordinated movement of swimming. In each of these experiences, the child expressed a great satisfaction in their achievement, and improved more rapidly from that point in the swim programme.

Beyond the swim programme, there was a marked improvement in some children’s academic achievements; along with the additional improvement in their general concentration capabilities. The improved academic achievement was described in the context of more certificates achieved, or more advanced books being brought home from school, the improved ability to grasp concepts in reading comprehension and maths, and in two instances an improvement in writing.

Some of these children had a mental impairment as a co-impairment with their CP, and it may be that an activity which promoted cognitive function would prove advantageous to them if it was maintained through their lives. The ability to grasp concepts with greater ease could realistically provide additional benefits for other domains of their quality of life, as it may permit them to interact with their peers to a greater degree, or to facilitate achievement of life goals as adults. The improvement in cognition is reflected in some literature involving land-based physical activity (Griffin, et al., 2011; Verschuren, et al., 2007; Winter, et al., 2007), but the continued impact of this into adulthood has yet to be explored in populations with CP.

Family Life

The impact of the programme on family life and parent perspective arose in some form in all the interviews, although this topic was not the primary focus of this research. For most of the parents, they simply expressed their own pride and pleasure at watching their child achieve a new skill and participate in an accepting environment. Some parents went further into detail regarding their concerns, changes in their opinions, the impact on family dynamics, or the development of new goals for their child.

All of the parents had described the positive experience of watching their child improve and their child's pride in achievement within and beyond the swim programme. All of the parents came to the conclusion, from the observations they had made, that the programme was an experience worth investing into further through time and finances, as they all intended to re-enrol their children. Cathy described how she now had the goal of involving Caleb in the Special Olympics squad, which she had not previously considered. Four parents expressed a decrease in their worries over the safety of their child in the water. These four parents described this in the context of holidays, putting in a pool at home or going to the beach. One parent described how the whole family had gone to Northern Arena each week, which had allowed them to have time together as a family. This additional benefit of the programme had become a valued experience. Embedded in all these descriptions was the implicit feeling of greater freedom for the whole family to undertake family activities with a decreased focus on the impairment of the child with CP.

Previous research has explored the effect of CP on family participation. Rentinck, Gorter, Ketelaar, Lindeman, and Jongmans (2009) found that the parents in their study felt restricted in their ability to participate in family activities when their children were 18 months old. This feeling of restriction had increased at a two year follow-up interview.

From the interviews in the current study, these participants felt there had been change within the area of family participation; it had occurred as they adopted an activity which promoted family involvement, although this was not a direct goal, but a by-product of the swim programme.

Knafl and Deatrick (2002) described that the families of children with chronic conditions usually adopt a flexible approach to management of the condition, with an emphasis on incorporating the condition as a part of the usual routine of the family. These authors also described how many families choose to focus on the normal aspects of their child and on the family dynamics. For several of the parents in this present research, having their child in the swim programme facilitated both the sense of focussing on the normal aspects of what their child could achieve, while making allowance for the limitations of CP.

Two parents described the impact of the swim programme on their own relationship with their child. The stress on the relationship had decreased as their child had demonstrated an increase in focus and in coping with instructions. There was a subsequent decrease in arguments and in the frequency of the child's tantrums. Following these changes, the parents found they had been able to bond with their children to a greater extent. Raina et al.(2005) found that behaviour in children with CP was a predictor of the parents well-being. However, a change in relationship through any kind of exercise programme has not been explored in previous research.

The overall altered attitude of the parents as a result of their positive experience of the swim programme increased the range of activity options available to the children. Imms (2008) described how a part of the child's choice of activity comes from their exposure to the opportunity. In this present research it was observed that the control the parents had over their child's exposure to activities was a vital part of the child's decision to become involved. The parents' attitude subsequently increased the child's quality of life through the continued positive impact of the swim programme.

Comparison of Measures

What was desired in this research was to assess what the parents thought in comparison to the questionnaire results. The concept was to verify what the parents said with quantitative results. This process didn't achieve the aim of substantiating qualitative results.

While the themes from the research demonstrated positive change in the domains of quality of life, self esteem and independence, the Chi-square analysis showed a lack of significance in the results from the CPQOL-Child questionnaire. There was a trend towards change in the mean percentages for the different domains of quality of life. However the opinions expressed through the interviews demonstrated a greater change over the same domains. The difference between these two data sources was a matter of note as the participants completed the final questionnaire and the interview within two weeks of each other and, theoretically, the one should have reflected the opinion given in the other.

The discrepancy illustrated between the two sources of information and the cause for this lack of agreement may lie within several areas. The CPQOL-Child questionnaire may have lacked adequate sensitivity to change for this intervention, or the sample may have been too small to have demonstrated statistically significant change. If that was the case then the qualitative results were a more representative measure in this present research and the conclusion is weighted towards the experiential descriptions, demonstrating that there was a positive impact on quality of life, independence and self-esteem.

However, the CPQOL-Child questionnaire was a validated measure of quality of life, and the statistical results may be accounted for as having some potential influence on the combined results. The inferred conclusion is that there are positive results for the individuals in the present research, but improvement was from the qualitative perspective only, with relatively small improvement in quantitative measureable terms.

The nature of this research as a pilot study was to explore trends, instead of statistical significance, within the relationship between a swim programme and the outcomes of interest. The minor trend toward positive change on all quality of life domains and the strong interview themes indicate this relationship would be worth testing through a more appropriately powered definitive randomised controlled trial.

Evaluation of the Swim Programme

From the experiential descriptive data, the evaluation of the swim programme was almost entirely positive. Based upon the descriptive data from the parents, the structure of the programme with its approach to goal-setting, focus on swimming skills, and the general environment of acceptance promoted improvement in physical function. The improvement in physical function had follow-on effects into the social domain, the emotional/behavioural domain, the cognitive domain, self esteem and independence.

From some of the parents' descriptions, this swim programme had a better influence on their children's quality of life than other swimming programmes or other land-based activities they had experienced. This comparative advantage was primarily attributed to the greater degree of perceived social acceptance at this swim programme. The swim-skill focus was also described by some as being an advantage over other swim programmes, as they wanted their children to gain competence in swimming. One parent noted the benefit of having swim instructors who understood the children's physical impairments, which allowed the instructors to set realistic goals that also challenged the children within their limits.

One negative point was raised in several interviews, which was the expense of attending the programme. The parents who discussed this also described strategies they had found for dealing with it through utilising funding which was available through charitable organizations within New Zealand, such as the Halberg Trust or through the Cerebral Palsy Society of New Zealand. All these parents also stated that their children would still attend the swim programme if funding was not available, as the benefits outweighed the cost. All families who participated in the present research expressed their intention to continue with the swim programme. Therefore, it can be concluded the swim programme was successful according to its original goals and intentions, and the outcomes achieved.

Comparison to Previous Research

Participant sample

Although the present study was small, it had certain advantages compared to the four previous studies that assessed the effect of aquatic activities on social function. The present research included children aged 5-11 years, compared to Getz et al. (2006), who used a younger sample of three to six years old to assess social function and perceived competence, and Retarekar et al. (2009) which included one five year old with CP. Those studies with a more comparable age range had larger samples of 13 and 21 participants, but limited their inclusion of CP subtypes to spastic CP (Aidar, et al., 2008; Özer, et al., 2007). The present research had eight participating children with CP and their parents. This included one child with ataxic CP, providing an indication of the effect of this swim programme in most subtypes of CP.

The levels of GMFCS used in previous research and in this present research were I, II and III, with a greater focus in those with spastic CP. Research which focused on more severely physically impaired people with CP, and in the subtypes dyskinetic and ataxic, would provide more information for management and recommendations for these individuals.

Swim Programme Intervention

When compared to aquatic programmes in previous research, this programme included a standard learn-to-swim focus which was similar in structure to several other interventions (Ballaz, et al., 2011; Chrysagis, et al., 2009; Getz, et al., 2006; Özer, et al., 2007). Some studies included such equipment as an underwater treadmill in order to maintain a high heart rate and facilitate evaluating physical measures (Fragala-Pinkham, Haley, & O'Neil, 2008; Retarekar, et al., 2009). For the purpose of the present research, it was more useful to evaluate a programme which provided a realistic representation of a learn-to-swim programme. The structure of this swim programme could provide practically applicable tools to a participating child with CP. If repeated in other locations, a degree of the improvements seen could be achieved in the application of a similar process. Limitations may exist in other facilities for replicating this process, but the application of the same principles and structure would prove beneficial for other individuals with CP.

Measures

The four studies which assessed aspects of function other than physical change used multiple quantitative measures that primarily focused on social function and perceived acceptance (Aidar, et al., 2008; Getz, et al., 2006; Özer, et al., 2007; Retarekar, et al., 2009). The present study provided a different approach to exploring these aspects of function. Fewer measures were used, but this research explored in greater depth than other studies the areas of quality of life domains, independence and self esteem. These comparative studies included measures which related closely to physical function and did not explore most domains of quality of life. Having a larger number of domains in this present study might have provided more information on the breadth of the influence of the swim programme, rather than what could have been yielded by employing more measures within one domain.

Limitations of Present Study

Sample Population

The small sample size of eight participants possibly contributed to the CPQOL-Child questionnaire showing no significant change. The sample included seven children with spastic CP and one with ataxic CP, with three children having GMFCS level I and III, and two were level II. A larger sample size that included even numbers of CP classifications and GMFCS levels may provide more accurate results within a quantifiable tool such as the CPQOL-Child questionnaire over a swim programme intervention. It might also be better to recruit a sample that is more homogenous with less variation of types of impairment.

Intervention

The swim programme in this present research included one 30 minute session per week over 14 consecutive weeks, which proved to be a sufficient and practically feasible structure for the families involved. However, a longer programme would allow for more familiarisation and would potentially show greater benefits within a quantifiable measure. Several parents described how their children had just started improving in swimming skills towards the end of the swim programme, and they anticipated a continued more rapid improvement on enrolling in further swim programmes at Northern Arena.

Quantitative Measure

On completion of the data analysis process, it was clear that the CPQOL-Child questionnaire did not provide satisfactory sensitivity to change. There was no way of knowing this until after the post-intervention data had been collected, but retrospectively it would have proved useful to have employed a comparable quantifiable tool. Although there is no known condition-specific quality of life tool which has a higher sensitivity, a measure of the social domain which had demonstrated change might have been explored as an option for including in this research.

Qualitative Measure

The interviews proved to be a valuable source of rich data within this research. As a novice interviewer, the ability to draw out descriptive detail improved through the process of data collection. There was a greater amount of detail in the later interviews than in the initial ones. While it is not felt that this minor difference in interview style would have altered the participant responses as to whether there was change or not, the richness of data was partly influenced in those initial stages of interview data collection. While this could be viewed as a minor limitation, all topics were discussed and therefore this difference in data does not majorly affect the ability to compare the relevant participant descriptions.

Opportunities for Future Research

The following observations are based upon both the quality of the results and on issues identified by this study.

Future aquatic exercise studies could include: a larger population size, additional age groups, CP classification ataxic and dyskinetic, and a greater impairment severity (GMFCS IV and V). The quantity of previous research which involved those with GMFCS level IV and V is more limited. However, those with greater physical impairments likely require more management of their symptoms than those with lower levels of impairment, and may gain a greater benefit from programmes which could potentially improve their self care, social acceptance and self esteem.

The CPQOL-Child questionnaire could be further explored to establish its responsiveness to change over a longer period of time or over an intervention. It may also be beneficial to explore research investigating the expected duration of the positive changes described in the interviews through a longitudinal study. Another useful perspective may be gained from performing a multi-site study, to assess whether the change described in these

thematic results is unique to Northern Arena, or whether the same principles of teaching will produce the same results, which would increase the transferability of the results to non-research settings.

Cerebral Palsy Aquatic Exercise Programme

Northern Arena is currently unique in New Zealand as it is a facility especially designed to maximize accessibility for those with impairments. It provides specific learn-to-swim programmes for children with CP and other neuromotor and developmental conditions. Expansion of aquatic exercise programmes in New Zealand would require funding for staff training and professional development, programme development and expansion, new facilities and/or modification of current facilities.

Attendance

Overall attendance of the scheduled swim sessions was 99.3 percent, and seven of the eight participants completed their full 14-scheduled swim sessions. Five participants required a catch-up session in the same week. No injuries or health issues as a result of the programme were reported.

Chapter 6: Conclusion

Within the CP population there is a low level of physical activity, which has been associated with decreased social participation and acceptance (Varsamis & Agaliotis, 2011). Lower levels of self esteem and higher levels of depression, anxiety and stress are also reported in those with CP (Ferreira & Fox, 2008). Activities and treatment programmes are promoted not only to improve physical function, but to influence these areas of social and cognitive function as well (Damiano, 2006).

The aim of the present study was to evaluate the effect of a structured 14 week, water-skill focused swim programme on quality of life, self esteem and independence in children with CP. This mixed method study included the measurements of the Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child) and semi-structured interviews. Statistical analysis demonstrated no significant change in the CPQOL-Child, possibly due to the small sample size and/or a lack of responsiveness to change, however thematic analysis from the interviews showed a description of change.

The thematic analysis explored the positive impact the swim programme had to varying degrees on all aspects of quality of life, and on independence and self esteem. The theme of improved physical function and an improved sense of physical wellbeing were advantageous for these participants. From this result, it may be theorised that a change in motor function could potentially have preserved or improved neural pathways which promoted greater functional movement. The themes of improved goal-setting, acceptance, and that of normalcy were a consequence of the improved physical function and of the swim programme environment. The latter themes demonstrated the variety of benefits the children gained from participating in the intervention.

It is postulated that the improvements in quality of life, independence and self esteem were due to the structured water-skill focused swim programme. The intervention encouraged an improvement in physical function, and fostered an environment of goal-setting, motivation, and acceptance.

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Appendices

Appendix A: Gross Motor Function Classification System

Extracts from Palisano, Rosenbaum, Bartlett, and Livingston (2007, pp. 2-4) who have described the levels of impairment:

LEVEL I - Walks without Limitations

LEVEL II - Walks with Limitations

LEVEL III - Walks Using a Hand-Held Mobility Device

LEVEL IV - Self-Mobility with Limitations; May Use Powered Mobility

LEVEL V - Transported in a Manual Wheelchair

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when travelling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device.

Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

Between 6th and 12th Birthdays:

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when travelling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface.

When travelling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance.

Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Appendix B: Quality of Life Questionnaire for Children with Cerebral Palsy (CPQOL-Child)

Extracts from the manual for the CPQOL-Child outlining the questions used in both the parent-proxy and child self-report questionnaires (Waters, et al., 2006, pp. 22-26).

Domains and Items for the Parent-Proxy version of the CP QOL-Child

* Indicates items that begin with ‘How do you think your child feels about...’

Domains	Items:
Social wellbeing and acceptance	the way they get along with people, generally?* the way they get along with other children at preschool or school?* the way they get along with other children outside of preschool or school?* the way they get along with adults?* the way they get along with their teachers and/or carers?* going out on trips with the family?* the way they get along with their brothers and sisters?* how they are accepted by their family?* how they are accepted by other children at preschool or school?* how they are accepted by other children outside of preschool or school?* how they are accepted by adults?* how they are accepted by people in general?*
Functioning	their ability to play on their own?* the way they communicate with people they know well?* the way they communicate with people they don't know well?* the way other people communicate with them?* how they sleep?* the way they use their arms?* the way they use their hands?* their ability to keep up academically with their peers?* their opportunities in life?* their ability to dress themselves?* their ability to eat or drink independently?* their ability to use the toilet by themselves?*
Participation and physical health	their ability to play with friends?* their ability to participate at preschool or school?* their ability to participate in recreational activities?*

	<p>their ability to participate in sporting activities?*</p> <p>their ability to participate in social events outside of preschool or school?*</p> <p>their ability to participate in their community?*</p> <p>their physical health?*</p> <p>the way they get around?*</p> <p>the way they use their legs?*</p> <p>being able to do the things they want to do?*</p> <p>their ability to keep up physically with their peers?*</p>
Emotional wellbeing and self esteem	<p>the way they get along with you?*</p> <p>the way they look?*</p> <p>their life in general?*</p> <p>themselves?*</p> <p>their future?*</p> <p>How happy is your child?</p>
Access to Services	<p>your child's access to treatment?*</p> <p>your child's access to therapy?*</p> <p>your child's access to specialised medical or surgical care?*</p> <p>your ability to get advice from a paediatrician?*</p> <p>your child's access to extra help with learning at preschool or school?*</p> <p>the special equipment they have at home?*</p> <p>the special equipment they have at their school?*</p> <p>the special equipment that is available in the community?*</p> <p>your access to respite care?*</p> <p>the amount of respite care you receive?*</p> <p>how easy it is to get respite?*</p> <p>your child's access to community services and facilities?*</p>
Pain and impact of disability	<p>Is your child bothered by hospital visits?</p> <p>Is your child bothered when they miss school for health reasons?</p> <p>Is your child bothered by being handled by other people?</p> <p>Does your child worry about who will take care of them in the future?</p> <p>Is your child concerned about having cerebral palsy?</p> <p>How much pain does your child have?</p> <p>How does your child feel about the amount of pain they have?</p> <p>How much discomfort does your child experience?</p>
Family Health	<p>your physical health?</p> <p>your work situation?</p> <p>your family's financial situation?</p>

	how happy are you?
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Domains and Items for the Child Self-Report version of the CP QOL-Child

* Indicates items that begin with 'How do you think your child feels about...'

Domains	Items:
Social wellbeing and acceptance	<p>the way you get along with people, generally? the way you get along with other children at preschool or school? the way you get along with other children outside of preschool or school?*</p> <p>the way you get along with adults?*</p> <p>the way you get along with their teachers and/or carers?*</p> <p>going out on trips with your family?*</p> <p>the way you get along with their brothers and sisters?*</p> <p>how you are accepted by your family?*</p> <p>how you are accepted by other children at school?*</p> <p>how you are accepted by other children outside of school?*</p> <p>how you are accepted by adults?*</p> <p>how you are accepted by people in general?*</p>
Functioning	<p>your ability to play on their own?*</p> <p>the way you communicate with people you know well?*</p> <p>the way you communicate with people you don't know well?*</p> <p>the way other people communicate with you?*</p> <p>how you sleep?*</p> <p>the way you use your arms?*</p> <p>the way you use your hands?*</p> <p>your ability to keep up academically with your peers?*</p> <p>your opportunities in life?*</p> <p>your ability to dress yourself?*</p> <p>your ability to eat or drink independently?*</p> <p>your ability to use the toilet by yourself?*</p>
Participation and physical health	<p>your ability to play with friends?*</p> <p>your ability to participate at preschool or school?*</p> <p>your ability to participate in recreational activities?*</p> <p>your ability to participate in sporting activities?*</p> <p>your ability to participate in social events outside of school?*</p> <p>your ability to participate in your community?*</p> <p>your physical health?*</p> <p>the way you get around?*</p>

	<p>the way you use your legs?*</p> <p>being able to do the things you want to do?*</p> <p>your ability to keep up physically with your peers?*</p>
Emotional wellbeing and self esteem	<p>the way your get along with your parents?*</p> <p>the way you look?*</p> <p>your life in general?*</p> <p>yourself?*</p> <p>your future?*</p> <p>How happy are you?</p>
Pain and impact of disability	<p>Are you bothered by hospital visits?</p> <p>Are you bothered when you miss school for health reasons?</p> <p>Are you bothered by being handled by other people?</p> <p>Do you worry about who will take care of you in the future?</p> <p>Are you concerned about having cerebral palsy?</p> <p>How much pain do you have?</p> <p>How do you feel about the amount of pain you have?</p> <p>How much discomfort do you experience?</p>

Appendix C: Interview Structure

Review of information:

We are here to talk about what effect the swim program has had on your child's quality of life, self esteem and independence. We will be covering, in your own words, some of what was in the questionnaire as well as some extra questions in the same area.

Consent:

Spoken-Do you agree to this interview and to its recording? You are free to stop the interview at any time and the information will not be used in the research, unless you consent to its use. You can also reconsider your participation up to two weeks after this interview and the information will be withdrawn.

Pseudonym for mother and child chosen

Explanations:

Do you have any queries about the process?

Opening: Your child has been in the swim programme for 14 weeks now... tell me about how this has been for them?

Would you talk about whether participation in the programme was worthwhile?

Would you describe any outcomes you noticed?

Have you noticed any changes in their affected side?

Experience: If I had been in the program, what experience would I have seen your child having?

If you think back to the first session, what was it like? And later?

I would like to ask you about your child and their independence. If you think about independence as motivation to think for yourself and try new activities, what do you think about the effect of the swim programme on their independence?

Now I would like to ask about self esteem. If you think of self esteem as the feeling of satisfaction a person has regarding themselves (how people evaluate themselves), what is your opinion of the effect of the swim program on your child's self esteem?

What was your opinion of the questionnaire?

What would you like to see happen with the swim program?

Domains of QOL checklist:

Physical- energy levels, sleep, endurance, use of affected limbs

Emotional- experience of happiness, embarrassment, frustration/anger

Social- acceptance (how widely and genuinely), self-confidence

Cognitive- learning, concentration, memory

What do I need to know that I haven't covered?

Summarising:

That was everything we needed to cover today; the questionnaire and other quality of life factors, was there any questions you have about the interview?

Appendix D: Teaching Swimmers with an Impairment

Philosophy of Northern Arena:

When teaching children with an impairment, the teacher has to make the tasks achievable, fun and challenging.

As a life skill, children with an impairment have to become independent. Sometimes this requires extending the child to the limit. The teacher is required to understand where this limit is and make sure the child does not go beyond the limit.

The teacher's motivation and enthusiasm can inspire children to try new activities.

The level of achievement can vary for every child. Some will make large improvements some will be small. All must be given the opportunity.

Aim

To improve the swimming ability of children with Cerebral Palsy.

Method

1. Teach kicking and swimming with fins – even though most (children with Cerebral Palsy) CWCP have limited kicking action the fins introduce slight buoyancy and balance.
2. Teach arm action - slow movements, large straight arm movement
 - a. Arm action with full support from teacher
 - b. Arm action with limited support from teacher
 - c. Arm action removing support from teacher
3. Kick on back
4. Backstroke arms
 - a. Teacher supports head
 - b. Slowly remove support
5. Introduce freestyle breathing
 - a. Teach rotation of body
 - b. Practice arms and breathing with teacher support
 - c. Teach shoulder roll
 - d. Teach breathing to side – with teacher support

Mark Saunders 2011-03-16

Appendix E: Letter of Ethics Approval

Faith Crawford
20 Raleigh Rd
Northcote
Auckland

20.7.2011

Dear Faith,

Your file number for this application: 2011-1189

Title: Pilot study of parent and child perspectives on the effect of a 14 week swim program on quality of life and independence in children with cerebral palsy.

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been approved for the following period:

Start date: 20.7.2011

Finish date: 20.7.2012

Please note that:

1. **The above dates must be referred to on the information AND consent forms given to all participants.**
2. **You must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.**

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

Yours sincerely,

P.P.
Scott Wilson

Scott Wilson
Deputy Chair, UREC

cc: Elizabeth Niven
Cynthia Almeida



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Appendix F: Information Sheet



Information Sheet

Pilot study of parent and child perspectives evaluating the effect of a 14 week swim program on quality of life and independence in children with cerebral palsy

About This Research

The aim of this study is to investigate how a structured 14 week swim program that is aimed at improving water skills, affects the quality of life of children with cerebral palsy (CP).

Swimming, Quality of life, and Cerebral Palsy

Land based activities can sometimes be difficult for children with CP. Studies have shown that water is a beneficial environment as it allows greater freedom of movement, while the resistance promotes strengthening, and the warmth of the water increases muscle blood flow.

Quality of life is how a person feels about various aspects of their life. Quality of life has been found to be important for improving general function and function is influenced by physical activity. Self esteem, independence and quality of life have been reported as being positively influenced by swimming. A questionnaire has been developed to assess change in quality of life in children with CP. However, self esteem and independence are not included in the questionnaire, so these will be looked into with parent interviews at the end of the study,

Your child's involvement in this study will help provide further knowledge on how an aquatic environment influences a child with CP.

What Does Your Participation Involve?

In this study, the term 'parent' represents a primary caregiver. This is an individual who has day to day care of the child and wishes to be a part of the study.

This study will involve your child participating in a half an hour, once a week swimming lesson over a 14 week period. These lessons will be taught by Mark Saunders, who has 22 years experience in teaching swimming to children with impairments including CP. These will be held at Northern Arena, Silverdale, North Auckland.

Your child needs to complete a minimum of 12 of the 14 sessions to continue participation in this study. If your child is absent for a session, optional catch up sessions within the same week can be organised through Northern Arena.

There will be a questionnaire for both parents and children to fill in one week before and one week after the swim program. There will be interviews with the parents after the swim program as well.

The cost of the swim program is the responsibility of the families who are participating. This is because the swim program is a choice you are making separate from this research. If you withdraw from the research at any time, your child can continue swimming. However, petrol vouchers will be supplied for any extra trips involving the study which would lie outside the swim program, such as meeting for an interview.

To be involved in this study your child will need:

- To be 5 to 12 years of age
- To have a diagnosis of cerebral palsy
- A classification of I to III on the GMFCS (see explanation below)
- To be water confidence (able to have feet off bottom of the pool, able to put head under water on their own)
- A willingness to be taught
- To have a pair of fins (flippers)

Interview/questionnaire participants:

- Parents of children (5-12 years) with CP, one parent per child who is participating in the swim program- to fill in the questionnaire and be interviewed.
- Children will also fill out the questionnaire if they are between the ages of 9-12 years old.
- If your child withdraws from the study, you (the parent) still have the option of completing the interview process.

The Gross Motor Function Classification System (GMFCS) is the most widely used measure of function for children with CP. If your child has not been classified, they will need to be classified to ensure participation. This will be performed by Kate Hedges, paediatric physiotherapist, who has worked with children with CP for 35 years.

Teaching Swimmers with Cerebral Palsy

Aim

To improve the swimming ability of children with Cerebral Palsy

Method

1. Teach kicking and swimming with fins – even though most children with CP have limited kicking action the fins introduce slight buoyancy and balance.
2. Teach arm action - slow movements, large straight arm movement
 - Arm action with full support from teacher
 - Arm action with limited support from teacher
 - Arm action removing support from teacher
3. Kick on back
4. Backstroke arms
 - Teacher supports head
 - Slowly remove support

5. Introduce freestyle breathing

- Teach rotation of body
- Practice arms and breathing with teacher support
- Teach shoulder roll
- Teach breathing to side – with teacher support

Research Data Collection

The Cerebral Palsy Quality of Life Child questionnaire (CPQOL-Child) is used to assess a variety of aspects of quality of life specifically in children with CP. There is a parent report version (covering 5-12 years) for one parent per child who is in the swim program. There is also a self report version for the children 9-12 years old. Both versions involve answering questions on a scale of 1 (very unhappy) to 5 (very happy) about how the child feels about what they can do. Each participating parent and child will fill this in one week before and one week after the swim program. This aims to provide information on any change in quality of life.

The other assessment is an interview with one parent per child. This will follow the swim program and give the parent an opportunity to discuss any change to quality of life in more depth, and give their perspective on the swim program and its effect on the child and their interaction in general life.

Potential Risks to Research Participants

The swim program will be carried out by experienced instructors and the research will not alter the usual swim sessions protocol in any way. The data collection that you and your child will perform is answering a series of questions regarding normal everyday activities and interactions. These questions do not intend to cause any emotional distress. The researcher can be present if you or your child wishes for assistance with the questionnaire.

There are no known published data that suggest any risk associated with this research. However, the researcher accepts that it is possible that there may be some undetermined risks involved in the research process. In the event that any potential risk or harm is identified, for any of the research participants, the research process will be suspended immediately.

Confidentiality

Please be advised that since your child maybe participating in a group swim lesson, complete anonymity around participation in this study cannot be guaranteed. However, confidentiality and anonymity regarding your child's results will be protected in the following ways:

- All consent forms and results will be seen only by the researchers.
- All hard copies and information will be stored in a locked file in a secured room. Only the researchers will have access to this file.
- Only anonymous data will be presented in reports related to this research.

You have the right to decline participation, or to withdraw your data from this research project within two weeks of your final data collection. This can be done by contacting Faith Crawford or Elizabeth Niven by telephone or email, or by verbally informing either person that you no longer wish to participate.

A final report containing the information from this study will be available at the Unitec Main Library upon completion.

Information and Concerns

For further information or concerns please contact the researchers by phone, email, or fax:

Faith Crawford
School of Health and Community Studies
Unitec New Zealand
Telephone: 021 127 5087
Email: faithcrawford85@gmail.com

Or

Elizabeth Niven (Research Supervisor)
Unitec Institute of Technology
Email: eniven@unitec.ac.nz

Appendix G: Participant Consent Form



Participant consent form

Pilot study of parent and child perspectives evaluating the effect of a 14 week swim program on quality of life and independence in children with cerebral palsy

My child and I understand what is expected with involvement in this research project. My child and I have had the research project explained to us in a way that we understand, and we have read and understand the information sheet given to us.

My child and I understand that we do not have to be part of this if we do not want to, and that we may withdraw at any time prior to the completion of the research project up to two weeks after the final data collection.

I understand that my child must participate in a minimum of 12 of the 14-scheduled swim session to continue participation in this study. I understand that optional catch up session will be organised through Northern Arena. My child and I understand that any questions or concerns that we have disclosed to the researcher are confidential and that none of these will identify us.

I understand that as my child may be participating in group swim sessions, complete anonymity about participating in this study cannot be guaranteed. However, I understand that all collected data is confidential and none of the data will identify any participant, and that the only persons who will know my child's results will be the researcher and their supervisor.

I understand that all the collected data will be stored securely on a computer at Unitec for a period of 5 years. I understand that we can view the finished research document. We have had time to consider everything and I give my proxy consent for my child to be a part of this project.

Child's Name.....*Child Signature (optional)*

Printed Name of Parent/Guardian.....

Parent/Guardian Signature..... *Date*.....

Project Researcher: *Date:*

UREC REGISTRATION NUMBER: 2011 – 1189

This study has been approved by the Unitec Research Ethics Committee from 23/06/2011 to 23/06/2012. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 6162). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.