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CONQUERING THE PHYSICAL CHALLENGES OF RECREATIONAL ACTIVITIES: HOW TO PROVIDE SITTING POSTURAL SUPPORT FOR THE DISABLED

Degree Programme in Physiotherapy
2013

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Degree Programme in Physiotherapy
November 2013
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Number of pages: 43
Appendices: 1

Key words: Accessibility, muscular dystrophy, hemiplegia, spasticity, posture support and sitting position

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The purpose of this thesis was to provide Malike services with information about posture support in the sitting position for individuals with muscular dystrophy, hemiplegia and spasticity. The information was used to help guide facilitators and family members of those with physical challenges when using different types of sports and recreational equipment requiring the participant to be in a sitting position.

The theoretical information studied in this thesis included information about accessibility, adaptive physical activity, muscular dystrophy, hemiplegia, spasticity and sitting posture support. The qualitative method was used to gather the research material from professional in the related field answering the questionnaire.

In conclusion, physiotherapists from 2 different countries answered the questionnaire and provided valuable insights for the sitting position, the seat and posture support. Additional information for facilitators on how to approach the task of positioning individuals having physical challenges was collected.

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1 INTRODUCTION

According to the latest data by the World Report on Disability, the population of the worlds disabled is increasing, leading to greater challenges for every nation. As a result of this increase, legislation has been developed to work at reducing discrimination and supporting advances toward better accessibility for all. (Website of the National Council on Disability 2013.) The European Disability Strategy 2010-2020 is aimed at providing full rights and equality for all individuals and is encouraging the promotion of involving the disabled in every part of life (Website of EU 2010). Each State is responsible not only to provide access and resources, but are required to promote and encourage sports, leisure and recreational activities (Website of the UN 2006). With this demand in place, organizations throughout the world have emerged to help provide these services. As more and more disable individuals become active, the need to improve recreational equipment is required and demands better information for making safe and affective changes. (Website of Malike 2013.) Therefore, this thesis is aimed at gathering information for Malike services to assist them in having reliable and clear instructions to providing individuals with physical challenges with a safe and stable sitting position when participating in recreational activities.

For this study, muscular dystrophy, hemiplegia and spasticity will be the focus groups and the aim will be to gain an understanding of the physical issues and challenges presented by each condition. Another goal is to gain an understanding of what needs to be modified, how to make the modifications and how to properly support those changes to create a safe and enjoyable experience for each participant. Furthermore, the qualitative research method will be used to gather information from professionals who understand the requirements for proper sitting posture and support for individual who have physical challenges. Moreover, the result will help Malike, facilitators and family members who can apply the information in a practical way.

2 PURPOSE AND OBJECTIVE OF THESIS

This bachelor thesis will be prepared for and in cooperation with Malike, a service organization in Finland, which works with the physically challenged. The purpose is to provide information to Malike in what to consider in providing proper sitting postural support for individual with muscular dystrophy, hemiplegia and spasticity when using different types of sports and recreational equipment. The information will help support families and facilitators of recreational activities participated by the target groups and give guidance on how to properly support the posture.

The method used to prepare the thesis will begin by discussing the subjects of accessibility and adapted physical activity in order to understand why and where this information can be used. Secondly, the target groups and the special needs requiring support will be researched to gain an understanding of each condition. Thirdly, the sitting posture and posture support will be discussed to give a basic understanding of the requirements when using the equipment. Last of all, several professionals who understand posture support and the target group's physical issues will answer a questionnaire about the issues of support. The results will provide experiential ideas and practices professionals use to provide the physically challenged participants in recreational activities with an enjoyable and safe experience.

3 MALIKE

Malike is a word made up of three abbreviated words in the Finnish language meaning: traveling, moving, into the middle of life. They are a service-oriented group provided by Kehitysvammaisten Tukiliitto ry, which is the Finnish Association for people with intellectual disabilities. Malike works with families, adults and professionals who have physical challenges or children with challenges in providing a wide variety of helps and services. Their services include organizing events, training courses and activities all geared at promoting, providing and teaching how to use different types of recreational equipment. They also give counselling and ideas for ways individuals

can use those devices in everyday life and recreation. Along with the education, Malike has three locations in Finland where equipment can be rented. Their equipment includes devices for skating, cycling, hiking, boating and skiing. They also have a wide variety of support equipment to help maintain proper positioning and safety with the equipment. (Website of Malike 2013.)

Their aim is to support every individual`s right to have equal opportunities for physical exercise and participation with others in all types of activities. They are supported by Raha-automaattiyhdistys, which is the Finnish slot machine association. Their headquarters is located in Tampere, Finland and their website is www.malike.fi. (Website of Malike 2013.)

4 ACCESS FOR THE PHYSICALLY CHALLENGED

4.1 Accessibility

According to the Convention on the rights of persons with disabilities article 9, accessibility is the promotion of action aimed at enabling the disabled to have full access in all aspects of life in regards to physical environments, transportation and information. This aspect focuses a great deal on the development of buildings and modes of transportation all to be developed with a mind promoting the abilities of all people having access without obstacles. (Website of the UN 2006.)

In 2011, the World Report on Disability estimates that there are more than one billion people having disabilities, meaning 15% of the world`s population. Also due to the aging populations around the world, this number continues to grow. The National Council on Disability currently supports programs aimed at inclusion for all disabled people in order to reduce poverty and support economical developments throughout the world. Their goal is to remove discrimination and support advances in accessibility developments. (Website of the National Council on Disability 2013.)

In Finland, the Finnish Association of People with Physical Disabilities (FPD) have started the Accessibility Project to promote the education of accessibility awareness and act as a coordinator of groups to network together for building a better environment for those with disabilities. They estimate about 10% of the Finnish population suffers from disabilities and see this percentage growing in the future. (Website of the Accessibility Project 2010.)

According to the UN's Convention on the rights of persons with disabilities article 2, all individuals regardless of disabilities have full rights, freedom and equality. The importance of recognition and consideration of the needs of those with disabilities are vital to providing opportunities for each person to participate in every area of life. Along with emphasizing the importance of promoting the equal enjoyments of all people, they define important aspects crucial to creating equality. The term "reasonable accommodation" refers to the necessity of modifying and adjusting elements to enhance the enjoyment of those with disabilities. "Universal design" is another term used to define how the environment and other issues are made in a way to promote use by all people regardless of abilities. (Website of the UN 2006.)

To insure the promotion of equal rights for all people, article 4 states that governments are required to make appropriate legislation and laws to give necessary changes in order to include those with disabilities and give them the opportunities to be active participants in every area of life and society. Then Article 30 expands those rights to include the ability and right to participate in sports, leisure and recreational activities as a responsibility of each State and measures should be taken to promote and encourage individuals with disabilities to have access and resources for active participation. (Website of the UN 2006.)

In 2000, the European Union put together The Charter of Fundamental Rights. This document contains the rights and freedoms each individual has within the EU. In December 2009, the Charter became a legally binding document in the EU and put into force at the Treaty of Lisbon. The Charter contains 54 articles concerning the rights of all citizens with article 21 and 26 promoting full accessibility and ensuring those with disabilities full participation in the life of the community. (Website of EU 2010.)

On the 15th of November 2010, the European Commission adopted the European Disability Strategy 2010-2020, enabling the rights for full and equal participation in society and economy by removing everyday barriers in life for those with disabilities. The objectives are followed by actions aimed at the priority areas affecting accessibility, participation, equality, employment, education and training, social protection, health and external actions. (Website of EU 2010.)

4.2 Inclusion

The term ‘inclusion’ refers to the practice of including or attempting to include people regardless of their abilities, age, gender, race or culture. The term is normally used in reference to those having some disadvantage or disability and is often used by those who advocate the rights for those individuals. The idea is that people with disabilities can participate freely and without pity or restrictions. (Website of the Inclusion club 2013.) Inclusion also involves a number of issues beginning with the valuing of each individual and allowing for equal participation. The focus is on reducing barriers that inhibit individuals due to their differences and learning to see those issues as a positive point rather than a problem. (Website of the Centre for Studies in Inclusive Education 2013.)

When it comes to applying the ideas of inclusion in sports and activities, models have been developed to help adapt and modify activities to include everyone. In order to make these models easy to remember, acronyms have been used. In the mid-1990`s the Youth Sport Trust in the UK began using the STEP model. This model brought attention to the space used, the task performed, ways to adjust or change the equipment and how to adjust the people involved. A similar model was developed in the Australian Sports Commission (ASC) in their Disability Education Program called TREE. This model focused on the teaching style, the adjustment of rules and regulations, the environment or area used for the activity and the equipment modifications. More recently the ASC introduced the ‘Change it’ program to promote the inclusion of all abilities. The same ideas were promoted in this model along with adding more specific changes to activities. In 2005, Kasser and Lytle formulated an-

other model called FAMME. This model follows a four-step process of understanding the activity and the components required to perform the action. Next the abilities and skill level of the participant was considered for the activity. While the activity is performed, modifications would be made to support inclusion. The last step is to evaluate the modifications effectiveness to assure the adjustments are contributing to the participant's skill development. One of the latest inclusive designs developed was in the USA at the Perkins School for the Blind called FAIER. The focus is on ensuring inclusion of all participants and relies mostly on the creativity of the coach or teacher to find solutions to the activities. The model begins with setting goals for the activity and each participant, which is the foundation of the plan. Being aware of each individual participant and their abilities leads to the implementation step. As the activity is performed, evaluation leads to changes or modification of equipment or techniques. The last step involves the refinement of the activity in order to meet the goals and lead to better skills development. (Website of the Inclusion club 2013.)

Overall these ideas are formulated to enable tasks to be planned, adapted and supported in order to meet the needs of every participant. The flexibility in these models helps provide a wide range of possibilities and removes the limits once believed to exist. With these approaches to activities the participants are the focus of the activity and the opportunities for everyone to be involved is enabled. (Website of the Inclusion club 2013.)

4.3 Design for all

The phrases such as "Universal Design" and "Design for All" have guided our way of thinking into a different approach to bring better education, understanding and equipment that can improve normal daily activities. Through the research of systematic reviews, studying human factors, surveys, focus groups and related field and laboratory studies, new develops are being made to increase social participation. Along with these important issues, education is vital to communicating the possible ways of initiating change in product and architectural design, information technology and organizational developments. (Website of IDeA 2013.)

Design for all involves an innovative and holistic approach to create and design the society, environment, services, culture, information and objects for human diversity. The aim is for everything made by people and for people to be accessible and convenient for everyone in the society. This results in a consciousness geared on end users and involves a more creative way at looking at the process of design according to human needs. (Website of Design for all Europe 2008.)

When it comes to improving the potential to develop a better quality of life for a wider range of people, universal design introduces the idea that creates products, place and systems that meet the needs of a larger volume of the population. As a result of adopting these standards, the stigma attached to the disabled is reduced and in most cases the society as a whole is benefited by the changes. It also results in people being more involved socially, self-reliant and the assistive devices work easier. The economy is improved by reducing the needs for special programs and services due to improved accessibility by more of the population. After considering all the ways universal design has been defined, the most improved definition leads to the point of making life easier, healthier and friendlier, with the ultimate goal being full inclusion. Along with the idea, constant improvements are required to improve the quality of life for everyone. (Steinfeld & Maisel 2012, 28-29.)

5 ACTIVITY FOR THE PHYSICALLY CHALLENGED

5.1 Adapted Physical Activity

Adapted physical activity (APA) is a term used to describe the services used to promote and facilitate an active lifestyle for those with special needs. The aim is to enable individuals to participate in physical activity through the means of modifying known activities or to create new activities. The focus is centred on the individual and the surrounding environment by adapting equipment and actions that encourage every individual in physical activity throughout life. In order to fulfil this strategy the idea is to create activities that work for all ages, can be performed in all settings, meet a large variety of purposes, involve all types of sports activities and is able to

adapt to all individuals regardless of disabilities or differences. While most sport contain a set standard based on rules and culture requiring all participants to conform, APA works with individuals who are not able to comply due to their physical challenges. Therefore APA's important factor is that the activity is adapted, not the individual. (Valkova & Moriskbak 2006, 19-20.)

The components of organizing an APA event is based on a person`s abilities to be creative, have knowledge of the activity and ideas of possible adaptation strategies. It is not necessary to create a new game, but simply modify known games such as basketball, football or freeze-tag. The main idea is to adapt the game to those playing and make adjustment such as the number of participants, the equipment, the physical space or how to score. The objective is to enable the participants the opportunity to activate muscles through movement and interact with others. (Valkova & Moriskbak 2006, 21.) APA also enables individuals to have the opportunity to participate on all levels such as special education and inclusive programs, leisure and recreational activities, competitive sports and rehabilitation programs (Website of International Federation of Adapted Physical Activity 2013).

5.2 Sports and Recreational Equipment

The equipment used for each activity depends on the sport or type of recreation, the physical challenges and the environment. When a sport already uses a particular type of equipment, the device is either used as it is or is modified in some way to provide adequate support and safety. For instance, a sailboat can be modified by adding a chair fastened to the floor to support individuals who cannot hold themselves in a proper position in the boat. When taking a trip through the woods, a variety of devices have been designed to travel outdoors in rough terrain and can either be rented or bought. While these devices have a general design, modifications can be made to suit each need. Therefore different types of equipment for physical activity is either designed or modified such as; prosthesis, sleds, wheelchairs or boats. (Website of International Federation of Adapted Physical Activity 2013.)

6 UNDERSTANDING THE PHYSICAL CHALLENGES

6.1 Muscular Dystrophy

Muscular Dystrophy (MD) is a genetic disease that damages muscle fibres resulting in muscle weakness and atrophy. There are different types of the disease and the symptoms can begin in early childhood while other types only surface in adulthood. While the disease can be found in both sexes, males account for a larger percentage of the disease. The symptoms not only affect muscle strength, but can also cause problems with breathing, swallowing, the heart and other organs. The disease is normally progressive, leading to the use of a wheelchair. (Website of Mayoclinic 2012.) As an inherited disorder, MD results in a defect in one or more genes responsible for normal muscle function. Dystrophinopathies as a muscle disease are the most common and a third of those diagnosed do not have any family history. (Tawil & Venance 2011, 51.) The progressive nature results in muscles gradually weakening causing the size of the muscle to decrease. While muscle weakness is the primary symptom, MD can also affect mental abilities as well as heart and respiratory functions. (Website of Uptodate 2013.)

Symptoms in general begin with weakness, fatigue, muscle atrophy and intolerance to exercise. When the legs are affected with these symptoms, the person will have difficulties in going up and down stairs, rising from a sitting position, unable to squat and have a tendency of dragging feet or tripping. When the arms are affected, the person will have difficulties lifting objects, gripping items and using the fingers effectively. When the facial muscles are affected, the person may find it difficult to swallow, drink or blow. Plus the persons speech may be slurred and have double vision or drooping eyelids. (Tawil & Venance 2011, 9.)

Duchenne Muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) are both progressive muscle weakening and wasting disorders caused by a mutation in the dystrophin gene. DMD presents itself with delayed milestones in the gross motor skills resulting in difficulties running and falling to the ground. The calf muscles can be enlarged and muscle weakness in the hip girdle can cause a waddling gait and dif-

ficulties in getting up from the ground. Cognitive dysfunction has also been noted with this diagnosis. The progression of the symptoms quickly leads to loss of walking ability by 12 years of age. Once transition to wheelchair is made, kyphoscoliosis worsens leading to a decrease in respiratory functions. Surgical interventions to the spinal cord may be required to help maintain better respiratory functions since chronic respiratory failure is the primary cause of death. From the age of 10 and beyond, regular electrocardiograms are recommended to track cardiac problems and medication is normally given to treat interval problems. (Tawil & Venance 2011, 51-52.)

DMD is the most common form of MD and occurs in about 1 in 3500 of males. Females having DMD normally have few or no symptoms of muscle weakness, but tend to only carry the abnormal gene. The symptoms normally appear between the ages of two and three with weakness beginning in the trunk area and afterwards spreading to the extremities affecting the lower limbs before the upper limbs. As a result of the muscle weakness, children will have difficulties in walking, running, climbing stairs, sitting and squatting. Heart problems may also develop causing irregular heartbeats or enlargement issues. Fractures of the arms and legs are also common due to falls. (Website of Uptodate 2013.)

Becker muscular dystrophy (BMD) can present itself at any age and is commonly noticed with a symmetrical limb-girdle muscle weakness. The disease takes a milder path of progress when the onset of the symptoms presents themselves later in life. Learning difficulties and behaviour problems can be found in adolescents in men with BMD. Patients who remain ambulatory over the age of 16 are said to have BMD, while those losing the ability to walk between the age of 12 to 16 are classified with an intermediate type. Individuals with BMD should have biannual examination of pulmonary and cardiac functions because these symptoms are more common due to the more dynamic activities and increased demands on the heart. (Tawil & Venance 2011, 52-53.) BMD is similar to DMD also occurring mostly in boys. The appearance of symptoms is usually later and milder in comparison with DMD. The child is able to walk until the age of 16 and in some cases into adulthood. The occurrence of mental impairments and heart problems are less, but if heart problems do occur, then they are normally more severe. (Website of Uptodate 2013.)

Emery-Dreifuss muscular dystrophy (EDMD) is also know as humeroperoneal MD affecting both boys and girls with muscle weakness and atrophy beginning in the arms between the age of 10 to 20. Legs and facial muscle weakness can follow later at a slower rate of progress. Often the first sign of the disease is noticed by contractures in the elbow and neck. The heart is also affected with this type of MD leading to serious problems requiring treatment to control the regularity. (Website of Uptodate 2013.)

Myotonic dystrophy type 1 (DM1) is the most common form among adults, affecting 5 to 20 per 100,000, while type 2's (DM2) prevalence is unknown and more frequently misdiagnosed, yet this type is linked with those having northern European ancestry. The most common feature of type 1 is myotonia (muscle relaxation impairment following contraction) and cataracts before the age of 50. Other characteristics that aid in making a diagnosis are atrophy of forearm flexor muscles, male pattern baldness and some prominent facial features due to muscle weakness. The onset of the symptoms can range from the 20's to 50's, with the earlier ages experiencing sleeping disorders, fatigue, cognitive issues, hypotension, dysarthria, dysphagia, cardiac disturbances and general weakness. When DM1 occurs at birth, the symptoms are more severe and life threatening. (Tawil & Venance 2011, 80.) DM2 presents itself between the ages of 20 to 75 with similar symptoms at the onset as DM1. Many of the symptoms are the same as in DM1, but the level of muscle weakness and atrophy are much less with fewer systemic complications. DM2 patients experience more pain in the extremities and muscle stiffness than those with DM1. (Tawil & Venance 2011, 82.)

Limb-girdle muscular dystrophy (LGMD) is a relatively rare form occurring in 1 in 100,000 and recognizes 22 different forms. Diagnosing the forms of LGMD is difficult due to the variable presentations, progressions of symptoms and other scientific factors used to identify the precise type. (Tawil & Venance 2011, 57.) The age of onset is between the early teens and adulthood with the dominant form presenting itself in the 20's and usually progresses slowly. Age of onset, speed of progress and muscle strength assessments is used to clarify which type of LGMD is present. Intellectual impairments are not seen in LGMD's suggesting a significant difference with other dystrophinopathies. (Tawil & Venance 2011, 60-61.) LGMD is a group of dis-

orders affecting the shoulder and pelvic girdle area. Lower back pain is the most common symptom along with the muscle weakness in specific areas. (Website of Uptodate.com.)

Facioscapulohumeral dystrophy (FSHD) is the third most common form of MD and affects about 1 in 20,000. FSHD onset can range from infancy to late adulthood and has a specific distribution of muscle weakness that allows for an accurate diagnosis. The facial muscle weakness is the common presentation resulting in an asymmetrical appearance followed by the scapula muscle weakness making lifting the arms above shoulder level difficult. The humeral component of FSHD is reflected in the weakness of the biceps and triceps while the deltoid muscles continue to function normally. (Tawil & Venance 2011, 74.) FSHD affects both males and females usually progressing slowly. When symptoms appear in an infant, the child is usually in a wheelchair by 9 or 10 years of age. When the facial muscles are affected, facial expressions and the ability to close eyes when sleeping are reduced. As the weaknesses progress, shoulders, hips, wrist and ankles are affected. Children may also experience epilepsy, hearing loss and some reduced mental abilities. If the onset is later in life, usually the symptoms begin in the 20's and 30's. The progress is slow and life span is near normal. The weakness in the facial muscles affects the ability to whistle, close eyes tightly making the normal facial expressions difficult. The shoulders and upper limbs are also affected some. In some cases problems with vision, hearing and heart rhythm are presented. Also if the disease progresses quickly, some significant disabilities are normally experienced. (Website of Uptodate 2013.)

Congenital Myopathies (CMD) consist of a group of genetic muscle disorders defined by abnormal structural muscle biopsies and account for 2% of the genetic muscle conditions. There are four broad pathological patterns each relating to distinctive internal and external abnormal features of the muscle fibre resulting in changes in the normal architecture of the muscle. The common clinical features presented at birth or soon after are muscle weakness, difficulty in sucking and required respiratory support. Diagnosis can also be recognized in childhood or later for those with milder symptoms. Weakness affects swallowing, respiratory, and facial muscles, leading to respiratory problems and feeding difficulties. Also dislocation of the hips can be seen in several forms of congenital myopathies. Scoliosis and proximal or distal joint con-

tractures are common when there are higher levels of muscle weakness. The rate of progression can be static or relatively slow and the cognitive functions remain normal. (Tawil & Venance 2011, 103–104.)

CMD is normally recognized at birth and includes several types such as; Fukuyama type (primarily in Japan), Ullrich congenital MD, Merosin-deficient or merosin-positive CMD, Walker-Warburg syndrome, and muscle-eye-brain disease. The symptoms are normally recognized at birth as low muscle strength and multiple contractures of joints. (Website of Uptodate 2013.) The main complications resulting from MD affects mobility due to muscle weakness leading to contractures and the development of scoliosis. Also the muscle weakness can affect the heart, lungs and swallowing efficiency requiring special attention to these issues. (Website of the Mayoclinic 2012.) In table 1 a summary of the types of muscular dystrophy are listed, pointing out the general symptoms of each disease (Website of Uptodate 2013 & Website of Mayoclinic 2012).

Table 1. Types of Muscular Dystrophy (Website of Uptodate 2013 & Website of Mayoclinic 2012)

Duchenne MD (DMD)	Most common form Symptoms appear between 2 and 3 years of age Beginning weakness in trunk area Muscle atrophy in limbs Difficulty walking, running, climbing stairs, sitting and squatting Heart problems Curvature of spine causing breathing difficulties Fractures in extremities due to falls Require wheelchair by age 12 to 13 Large cafe muscles
Becker MD (BMD)	Occurring mostly in boys

	Symptoms appear later and are milder Able to walk until age of 16 or adulthood Heart problems can be severe Mental impairments are less
Emery-Dreifuss MD (EDMD)	Affects boys and girls between the age of 10 to 20 Beginning in arms, later spreading to legs and face Contractures in elbows and neck Heart problems can be serious
Myotonic Dystrophy	Affects males and females Occurring in adolescence and adulthood Two genetic types (1 and 2) Muscle weakness in arms, legs and face Heart problems, cataracts, glandular problems and intellectual issues Difficulty swallowing and joint problems Daytime sleepiness problem Delayed muscle relaxation after contraction
Limb-girdle MD (LGMD)	Affects shoulder and pelvic girdle area Slow progress Onset from childhood to adulthood Lower back pain Muscle weakness
Facioscapulohumeral MD (FSHD)	Affect male and female Progresses slowly Wheelchair by age 9 or 10 if symptoms appear at childhood Facial muscles affected reducing expressions and ability to close eyes

	Affects shoulders, hips, wrist and ankles Epilepsy, hearing loss and reduced mental abilities Onset in 20's, progress is slow and near normal life span Vision, hearing and heart rhythm problems
Congenital MD (CMD)	Recognized at birth Muscle weakness and multiple contractures of joints Development of scoliosis Affects heart, lungs and swallowing

6.2 Hemiplegia

Hemiplegia simply defined relates to muscle over activation or reduction on one side of the body, increasing muscle weakness, reflexes and tightness and loss of selective motor control. Hemiparesis is also another term used to describe the partial paralysis on one side of the body with incomplete loss of muscle power. Regardless of the term used, they both describe movement disabilities affecting one half of the body. Also it is common that the other side of the body will experience some physical difficulties as well. (Barnes & Fairhurst 2011, 17.) The symptoms normally occur on the half of the body opposite to the part of the brain that is damaged (Website of Chase 2013).

There are normally two patterns recognized in the movement disorders of hemiplegia. First is spasticity or hypertonia, which is associated with a movement disorder, caused by damage to the adaptive motor system. This results in an increased muscle tone and reflex due to the abnormal motor controls affecting muscles. Secondly is dyskinesia or dystonia, which is due to a failure of the basal ganglia to work properly with the central nervous system causing movements to lose their smooth action.

Muscles either being too tight or too loose due to the physical condition of the individual characterize this condition. Normally both of the patterns operate in those who have movement disorders, yet generally one of the patterns will dominate depending on the basis of the problem. (Barnes & Fairhurst 2011, 17.)

The symptoms experienced are different for each person and they can change over time. As stated before, the affects are on one side of the body, although there can be some slight abnormal activities on the opposite side. Muscles are normally stiff or weak and the strong side is favored in performing all tasks. Walking and balance are difficult, as well as other motor skills with the upper limb. (Website of Chase 2013.)

Because hemiplegia is commonly a result of a brain injury, cognitive and a variety of physical challenges can be presented. The following issues are possible with individuals suffering from a brain injury. Memory and attention problems can exist causing the person to have difficulties concentrating on what is said and remembering what to do. They can also have difficulties accomplishing task and executing functions can be slow. Speech and social skills can be lacking or slow to execute on a timely basis, making communication challenging. Behavior can be unstable resulting in a variety of outcomes due to the brain injury. The person may have various sensory impairments affecting the sight and hearing. Also seizures are possible and can be controlled with proper medication. (Website of Chase 2013.)

Hemiplegia is not a disease; therefore it does not have the capacity to progress. Although due to the nature of the injury and the parts affected, growth of the body or changes in the body can occur causing some problems to the affected limbs. For instance, as a child grows, the affected side will become more noticeable in size and structure. Bone length and muscle tone will all develop differently due to the initial injury to the brain. For an adult who has suffered an injury, these changes will seem less noticeable. (Website of Chase 2013.)

When the brain is damaged due to a stroke, the body can be affected in different ways depending on which side is damaged. The right side of the brain controls the left side movements of the body resulting in either an inability to move (hemiplegia) or weakness in the arm or leg (hemiparesis). Because the right side of the brain con-

trols positioning and judging distances, a person will have difficulties knowing the distance of object, which can lead to falls. This can also affect their abilities of picking up objects and gauging the size or position of objects. Neglect of the left side is also common and can lead to an individual not seeing things to the left and even ignoring the left side of their own body. Decision-making can also be difficult, resulting in safety issues and impulsive behaviors. Also the short-term memory can be affected as well as the learning speed and attention span. Another affect is the person's inability to recognize the physical changes and disabilities; therefore they believe they can continue doing what they have always done and don't understand they have a problem. The right side of the brain also controls facial muscles leading to weakness in the facial muscles, problems swallowing and their speech can be difficult to understand. (Website of UWHealth 2012.)

The left side of the brain controls the movement of the right side of the body, therefore when damage has occurred the right side is affected. Not only is it possible for hemiplegia or hemiparesis, but other symptoms can also occur. Speech and understanding written or spoken languages may be difficult from the left brain damage. They can also have aphasia, causing an individual not to understand or speak their known language. Their movement often becomes slow and giving directions to them can take extra time. Plus they will have difficulties remembering and learning. They too will not be able to visualize things on the right side of their body and even neglect their own right side. Facial muscles can be weakened causing difficulties in swallowing and speech can be unclear. (Website of UWHealth 2012.)

Hemiplegia can occur at different times giving specific terms and definitions to explain how the disorder began. The term Congenital means the disorder was present at, before or soon after birth although the signs can appear later. Acquired hemiplegia means that the effects of the disorder occurred later in life, but not at birth. Next is the term Cerebral palsy which accounts for a group of disorders of movement, posture and motor function. This impairment of the brain is caused by a non-progressive injury or abnormality in a developing brain. Although the damage to the brain remains static, the fact that our bodies continue to grow can cause problems experienced to change over time. (Barnes & Fairhurst 2011, 16.) One form of cerebral palsy is called hemiplegia where the arm and leg on one side of the body is affected.

Most of these individuals have normal mental abilities, they can attend school and grow up living a fairly normal life except for the experience of the physical challenges. Normally the arm has more disabilities than the leg and the end of the limbs are usually affected more. Growth of the affected limbs will have less range of motion and movement due to the shortness and stiffness of the muscles. (Miller & Bachrach 2006, 123.) Hemiplegia can also be caused by a large number of injuries or diseases affecting the human body. Infection, stroke, hemorrhages, thrombosis, migraines, head trauma, brain tumor, hereditary disease, various syndromes and ischemia can all result in damages to the brain leading to hemiplegia. (Website of Chase 2013.)

6.3 Spasticity

Spasticity is a muscle disorder causing muscles to be tight and stiff resulting in an inability for muscle control. If the reflexes persist for longer periods of time, the hyperactivity can lead to permanent physical changes. The main cause is found to be an imbalance between the central nervous system and the muscles. Cerebral palsy, stroke, spinal cord injury, traumatic brain injury and multiple sclerosis are all possible causes of spasticity. (Website of Webmd 2013.) While spasticity is the most common phrase used to define overactive muscles, it is important to understand that spasticity is one part of the Upper Motor Neuron Syndrome (Brashear & Elovic 2011, preface).

Healthcare professionals use the term spasticity in describing an increase in muscle tone. To define the term in a simple form, spasticity occurs when muscles stiffen as the stretch reflexes are activated through movement. EU-SPASM, a European working group has found other components also contributing to the stiffness and define spasticity differently. They find that disorders in the sensorimotor control, as a result of an upper motor neuron lesion, causes intermittent or sustained involuntary action in the muscles. This allows other symptoms like spasms and clonus to be included in the term of spasticity. (Johnson, Jarrett & Porter 2004, 146.)

The symptoms of spasticity include increased muscle tone, involuntary movements, pain, decreased or delayed functional abilities, abnormal posture, contractures and

bone and joint deformities. Pain is a common symptom for those who suffer from spasticity and the level of pain can range from a mild feeling of muscle tightness to as severe as resulting in spasms in the extremities, especially the legs. Low back pain and pain around the joints is also associated with spasticity. (Website of Webmd 2013.)

Spasticity is a common symptom for those suffering from multiple sclerosis. In 2004 a survey showed that 84% of those with MS experience spasticity that affects their daily life. Spasticity can range from a minimal level up to a stage that prevents participation in daily activities. However it must be understood that spasticity can often be managed in a way to minimize its effects. In order to manage spasticity properly, a person must know how it develops and how it affects the person. Understanding how it develops is often times based on each individual, but can vary over time and be unpredictable. (Johnson, Jarrett & Porter 2004, 145.)

Spasticity not only involves dealing with muscle stiffness, but other potential symptoms can occur. Weakness is often experienced even though the muscles are stiff and appear to be strong. Also the common feature of pain is experienced with those having spasticity. Understanding the different features helps identify the proper treatments involving drugs, stretching and exercise or repositioning the posture and sitting position. Normally a combination of these treatments is used to relieve the pain. It is also important to understand that spasticity is not always a negative factor. Spasticity has been found to improve vascular flow, help maintain an upright posture and help bring stability for walking or standing. Hence it is important to understand these issues in the decision making process when managing an appropriate plan of treatment. Because of the complex nature of spasticity, the goal of treating the problems is directed toward improving function, preventing complications and reducing pain in order to improve the quality of life (Johnson, Jarrett & Porter 2004, 149). Therefore treatment should be given when spasticity is harmful, interferes with function or is causing pain (Walton 2003, 345).

When working with individuals with spasticity, the terminology normally used should be understood. Muscle stiffness can result from a number of issues ranging from neural components to disuse of the muscle. When moving a limb of an individ-

ual, the resistance felt is referred to as tone, ranging from low (hypotonia) to high (hypertonia). Spasm is a term used to define the involuntary sudden movements resulting in flexed, extended or adducted actions. The limbs move upward toward the body when there is a flexor spasm, move away from the body in an extensor spasm and move across the body in an adductor spasm. A person can also experience trunk muscle spasms resulting in bending backwards in an arched position or falling quickly in a crunched position from a chair. Another term used for repetitive involuntary actions is clonus, such as tapping of the foot. (Johnson, Jarrett & Porter 2004, 148.)

In order to manage spasticity correctly, positioning is important. Part of the plan is to help maintain proper lengthening of vulnerable soft tissue, correct asymmetry and support the body in a position to allow relaxation and comfort. Also positioning a person in a position contrary to the normal spasm position can reduce problems for instance; if the extensor position causes spasms then place the limb in a flexed position. The appropriate sitting position is important in producing functional independence and reducing secondary complications. The general aim is to support the individual in order to maintain symmetry, balance and a stable posture with hips, knees and ankles at 90-degree angles. Additionally, maintaining proper stability and support for the trunk can also reduce an over use of the upper and lower limbs. Using a variety of adjustments and supports, these requirements can be met to help alleviate factors leading to spasms. (Johnson, Jarrett & Porter 2004, 154-155.) In table 2, a list of possible causes that can trigger an increase in spasticity and spasms are shown (Walton 2003, 345).

Table 2. Possible causes of spasms (Walton 2003, 345)

Anxiety	Stress from the event Traveling or transportation timings Delayed use of toilet
Discomfort	Using a new chair or functional device Size of device is longer or shorter than normal Bladder is full Poor bowel management

	Pressure sores Inadequate support
Poor posture	Poor positioning increases spasticity Sitting in wheelchair or functional device too long Lack of support for trunk control leading to lower limb spasms
Poor positioning	Lying position can increase spasticity and spasms Functional device is inappropriate
Quick movements	Travel to place not smooth Un-level terrain causing quick stops or motions Poor handling techniques or experience with functional devices

7 SITTING POSITION FOR THE PHYSICALLY CHALLENGED

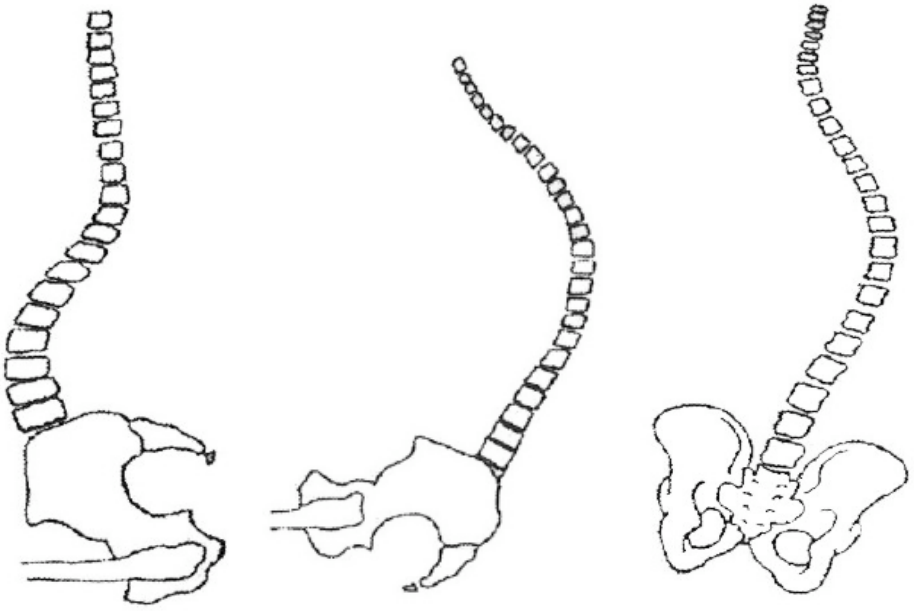
7.1 Sitting position

There is a basic philosophy for the sitting position that works for all. The elements include a balanced body that is stable and symmetrical in posture resulting in comfort and the maximum level of function. (Kirkwood & Bardsley 2001, 124.) The posture is one important element when talking about the sitting position. A good posture is one that has the weight evenly distributed and enables you to perform the required task without muscles over working. The normal sitting position is sitting upright with hips and knees at 90-degree angles and feet flat on the floor with the trunk relatively vertical. Depending on the task required to perform while sitting, a forward leaning posture is favoured for writing or working at a desk, whereas a reclined position is preferred for relaxing. (Pain, McLellan & Gore 2002, 52.)

When setting a person with physical challenges in a sitting position, the starting point is to make the pelvis level, straight and upright. Once the pelvis is supported, the remainder of the body can be properly positioned. The goals for the sitting position are safety, comfort, functionality, decrease abnormal muscle tone, improved head movement and increased independence. Proper positioning is important for those with disabilities. Without adequate support physical and functional abilities are reduced and can lead to other problems. (Pain, McLellan & Gore 2002, 66.)

Part of establishing the goals for positioning an individual begins with making a proper assessment. The first step is to evaluate the individuals sitting needs. Any abnormal posture issues that require special attention have to be evaluated. Can those abnormalities be corrected or are they fixed? What kind of support is required to maintain stability while giving the best opportunity for mobility? Other factors are required depending on the activity and the abilities of the individual. (Sherman 2011.)

Some of the functional problems for the sitting posture result from the pelvic being in the wrong position. The ideal sitting position has the anterior superior iliac spine (ASIS) equal to or slightly above the level of the posterior superior iliac spine (PSIS). A posterior pelvic tilt occurs when the PSIS are lower than the ASIS (Figure 1), causing an increase in kyphosis. The ischia's move forward making new pressure points on the sacrum and spine. In an anterior pelvic tilt, the ASIS are lower than the PSIS (Figure 1), causing the lumbar spine lordosis to increase and the hip angle decreases. In some cases the ASIS is positioned more forward than the other ASIS causing a rotation in the pelvic. Many times an asymmetrical muscle tone can cause this condition. Last of all is the pelvic obliquity where the one side of the ASIS is lower than the other side (Figure 1) causing the pelvis to tilt to the side and creating a compensating scoliosis in the spine. As stated before with all these positions, if the posture is flexible and the individual can tolerate the correction, the posture should be corrected and stabilized in a proper sitting position. Otherwise the sitting position should accommodate the posture with adequate support if it is fixed. (Sherman 2011.)



Anterior pelvic tilt Posterior pelvic tilt Lateral pelvic tilt

Figure 1. Pelvic position and spine reaction (Jalovaara 2013)

7.2 Seat

The purpose of a seat is to provide support for the body's posture while performing the appropriate activity with comfort. The comfort experienced is different for each person and depends on the interaction between the seat, the user and the task. Table 3 list the characteristics important that affect the level of comfort. (Pheasant S. 1996. 68.) Measuring the comfort level of a chair is difficult to determine and is mostly based on feedback from the user. Most studies show that it can take 20 to 30 minutes for an accurate judgement to be made about the level of comfort. (Pain, McLellan & Gore 2002, 54.)

Table 3. Characteristics that affect comfort (Pheasant 1996, 68.)

Seat	User	Task
Size	Body size	Time of event
Angles	Aches and pains	Visual requirements
Material	Circulation	Physical requirements
Design	Mental state	Mental requirements
	Physical challenge	

7.3 Posture support

When working with low muscle tone, the muscles are normally weak and unable to hold the weight of the body. Therefore more support is required to maintain the pelvis in the proper position. The type of pelvic strap depends on the level of weakness, but either a two-point or four-point attachment is used to keep the pelvis from moving. Also it is good to have the seat tilting upward to prevent slipping, but not too high which could cause an incorrect tilting of the pelvis. A good backrest and lumbar support is also necessary to help maintain the proper pelvic position. The individual with low muscle tone will also be affected by gravity and the pressure can affect the joints negatively. Therefore it is important to position a person with this condition in a way to ensure the pressure is working directly through the joint in a correct way to avoid damage or pain. The same is true for those with high muscle tone in keeping the joints in the right direction. (Pain, McLellan & Gore 2002, 68.)

When working with high muscle tone the aim is to position the individual in a way to reduce muscle tightness. Therefore by positioning the hip and knee joints at a 90-degree position, the muscle contraction is reduced. Using a pelvic strap and a seat that has a ramp is also beneficial in reducing slipping. Stabilizing the ankles and knees has also been found to help muscles relax and reduce unwanted contractions. (Pain, McLellan & Gore 2002, 70.)

8 RESEARCH AND RESULTS

8.1 Research method

A questionnaire was used for this research to gather qualitative information to find solutions to support the sitting position and posture of the different types of physical challenges. Experts in the field were chosen to provide information from their own experiences and gained understanding about the different challenges and issues presented in each case.

In qualitative research the researcher seeks to explore the experiences and opinions of the participants allowing them the opportunity to explain and give understanding to the researched topic. The participants are able to express real life experiences and give realistic insights they have gain from practical actions. It involves a subjective view of the topic while relying on the participant's own character to shape the information gained through his or her own knowledge of the issues. (Carey 2009, 4.) Using a questionnaire is one method used to gather data for qualitative research. The questions can be open and/or closed and participants can complete and return the answers themselves. Using open-ended questions allows for participants to explain their views with more detail and depth. (Carey 2009, 124-125.)

8.2 Questions and answers

The questionnaire was sent to physiotherapists in four different countries. The selected participants were familiar with the different physical challenges and the sitting requirements. Below are the consolidated answers received from the participants. Each question was aimed at learning about the sitting requirements and issues that should be considered for the best outcome. The complete questionnaire is found in Appendix 1.

The first set of three questions was aimed at learning what a facilitator should consider when placing a person with physical disabilities into a functional device. Muscular dystrophy is the first area to consider, requiring a greater amount of support because of the lack of muscular strength. The positioning requires good sitting angles, proper pelvis positioning and taking the necessary time to get every part in the right place. Once the participant has been placed in the seat, the facilitator should make sure the pelvis is in the right position and supported well enough not to move. Afterwards, the remainder of the body can be positioned and supported until the entire body is comfortable, safe and positioned for optimal functionality. The seat should be wide enough to make the necessary adjustments and enable the facilitator adequate room for transfers and repositioning. The support factor is also very important for safety and maintaining a proper position. The seat cushion should be the

kind to alleviate pressure and reduce shear, friction, moisture and temperature. Using proper pelvic straps keeps the pelvis fixed in the right position and reduces the risk of fractures. Using lateral and postural supports help maintain the trunk in the midline position. Some individual require head support, adequate armrest with good padding and special wheels if the person is able to mobilize himself.

Some additional advice from the professionals is the importance of listening to the participant and using reason when positioning the individual for the best functional capacity. Make sure the individual is comfortable and has a feeling of safety because the support is adequate and does not cause pain. Also be ready and willing to make adjustments and be prepared to make transfers when needed. Table 4 provides a simple checklist of each area mentioned above.

Table 4. Muscular dystrophy

Positioning	Proper sitting angle Pelvis position most important Weight on the back wheels Everything affects everything Take one part at a time; pelvis, legs, arms, back part, head support and sometimes when correcting one part, another part changes Patience to fine-tune the position Small changes affect functionality
Seat	Extra space in the seat width
Support	Important factor Adequate pelvic strap Lateral support for trunk position Postural supports for the midline Chest harness Head support from headrest Specialized seat cushion Proper armrest with padding

	Padded wheels for weak fingers
Additional advice	Use reason and listen to participant Safety for movements and angle changes Comfort by giving a feeling of support and safety without pain Provide independent movement Provide easy transfers

Hemiplegia is the second area to consider with individuals experiencing a variety of symptoms affecting one side of the physical body. When positioning an individual with hemiplegia, body symmetry is important, so the position is in an upright direction and not leaning to one side. Also positioning the pelvis in a proper fixed position is important due to the obliquity issues presented with the muscle imbalance. The seat should not be too broad in order to help alleviate the asymmetric position and a high back is recommended because of an inability to perceive ones own body and control balance. Side supports are also recommended to help support the positioning. The sitting pillow is important and needs to be comfortable and sturdy enough to support a symmetric position and guide the hemi-side leg straight. If you are using a kicking chair, the chair should be in a straight sitting angle with the back upright in order to support the activation of the upper body for kicking. Also the foot bar should be close to the ground to help with the sitting height. When supporting a proper trunk and upper body position, lateral chest supports or an "H" chest harness can be used. The hemi-side arm will also need support because the spasticity and positioning can affect the whole sitting symmetry position. Also the hemi-side shoulder should be supported with a shoulder support and either a table bar or special armrest to prevent the arm from hanging down and getting sore. Some additional advice places safety as an important factor and recommends attention to pressure and sensations felt by the participants. Table 5 is a simple checklist for hemiplegia considerations for sitting postural support.

Table 5. Hemiplegia

Positioning	Symmetry Pelvic positioning to correct obliquity

Seat	Width of seat not too broad High back height Side supports Comfortable and sturdy sitting pillow Kicking chair in a straight sitting angle and back upright and foot bar close to the ground Kicking chair - detached foot support, armrest with elbow support, proper tire placement for kicking
Support	Lateral chest support Shoulder support "H" chest harness Table bar or special armrest
Additional advice	Safety Focus on sensation and pressure

The last area to consider in the first set of three questions pertains to spasticity. When positioning someone with spasticity in a sitting position, understanding the type of spasticity is important in selecting the best position. If spasticity is in the lower torso, bending knees to a 90-degree position breaks the spasticity or in some cases the opposite is true. People with CP (tetraplegia spasticity), who have stretching spasticity in the whole body or ligaments, require a straight sitting angle with knees bent at 90 degrees, proper support at the bottom of their feet and a high back support. This will break the stretching that comes with spasticity when the person hears loud noises. Depending on the type of spasticity, positioning the chair at different angles can help reduce muscle tone therefore the seat should have this capacity. To support individuals with spasticity it is important to maintain symmetry with a four-point pelvic belt to keep the hip and posture stable. Also the use of lateral chest supports, shoulder support or an "H" chest harness can be used to support the trunk and upper body. Other cases require the legs, arms, head and neck to be supported. Some additional advice from the professionals suggests the facilitator gets to know the individual and clarifies what kind of spasticity and what part of the body is affected. If there is a lot

of spasticity in the upper torso, transitions and control of sitting is more difficult. Also if spasticity is on one side, it is very demanding to obtain a good sitting position, causing asymmetric problems in the whole body. There is no common position that works for everyone, so each individual requires a proper assessment. In some cases spasticity gives an advantage to functionality and creates a type of self-support. Medication is also a factor for those with spasticity and can have a positive benefit when taken on time. Last of all is the importance of safety and being prepared in advance for quick transitions in case of sudden spastic movements in the body and ligaments that can cause a dangerous situation. Prevention is the best choice to reduce injuries from increased tone or movements, so be mindful of the individuals condition all the time. Table 6 is a short checklist of the information mentioned above.

Table 6. Spasticity

Positioning	Bending knees to 90-degree angle Positioning legs at other angles
Seat	Angle adjustments High back Proper foot rest
Support	Four-point pelvic belt Lateral chest support Shoulder support “H” chest harness Legs, arms, head and neck support
Additional advice	Clarify spasticity type and where Get to know the person Medication Spasticity negative or positive No common position Consider transitions and be prepared Safety - prevent injury from increased tone or movements

The next set of two questions deal with the issue of muscle tone and the best way to support them in a sitting position. When supporting an individual with high muscle tone in a sitting position, it is important to give proper support to the head, hips and lower limbs. The sitting device should have some flexibility rather than being completely rigid. In order to reduce muscle tone, the chair should have an ability to tilt more or less than 90 degrees and then remain in the selected position. Also the seat should have femoral curves to promote femoral abduction along with the use of a 90-degree footplate.

When supporting low muscle tone, it is important to provide support for the head and thoracic spine. Laterals and mild hip support can be accomplished with supportive cushions to alleviate pressure and it is important to ensure feet are located on footplates with the knees apart. Also femoral curves can be used to promote femoral abduction. To promote the support for the most symmetrical position possible, a four-point pelvic belt, an "H" chest harness and laterals at chest and shoulder levels are the most effective choice. The use of wide armrest will promote propping and help support the trunk. Last of all is the head pod, which can promote proper head control and support.

The sixth question looks at the idea of placing a person in a sitting position, but because of the type of sitting device they will be required to keep the legs in a straight position. The answers suggested that cushions should be used to manage the prolonged pressure in sitting and reduce shear, friction, moisture and temperature. Armrest at the appropriate heights will allow for individuals to do lifts from the seat. Consideration should be made for the angle of the chair and a need for the seat back to move to an open angle or lay flat to relieve pressure on the knees. Footplates should be properly located and positioned to give support. Some other considerations deal with the range of motion of the hips, knees and ankles. Also pain, spasms, contractures, neural tension, previous surgeries/injuries, length of time in the position, spine/scoliosis and safety are factors that should be considered when placing an individual in this type of sitting position.

The seventh question is similar to the one before, this time the person is sitting with knees bent. The focus is on pressure relief, reduction of pain in lower back, back po-

sition, trunk support, foot support, and the angles of the knees and hip. If the client is self-propelling, the position of the footrest plates and seat back height will be important. The upper body gets more stability and functionality depending on the height and angle of the foot support when knees are bent; therefore the support angle cannot be too steep. Support that is too low does not support the sitting position and lets the pelvic tilt backwards and the person slides down from the seat. If the support is too high, the thighs are not supported and the seat pressure becomes strong on the surface of the sitting bumps and cause flexion of the pelvic to increase. Also femoral curves should be in the seat as a means to promote femoral abduction. Last of all, when working with people who have lower limb paralysis, it is important for them to see their legs and know where and how they are.

The eight question addresses the issue of how to support the position when the individual has some type of deformity. First of all, this requires individual solutions. If a person has contractures, deformities or is asymmetrical, investigate the problem and either fix the position or give adequate support. Support the posture or modify the sitting equipment so the user can function or sit as well as possible. Lateral support, backrest, headrest, and supportive cushion should be used to resolve any issue. Try to get an equal pelvic position as a basis for symmetrical posture. Also consider the need for specialized individual contoured seat back or seating cushion to manage prolonged pressure in sitting to reduce shear, friction, moisture and temperature.

The ninth and last question asked the professionals for any special advice to give to facilitators working with individuals having muscular dystrophy, hemiplegia or spasticity. The professionals suggest to always get to know the individual and their needs first. Working with a team including the parent/care givers to understand all the issues is recommended as well as using a systematic process when assessing the individual from either head to toe or in reverse so that nothing is missed. Also a facilitator should not be afraid to try several combinations of elements to achieve the best possible outcome. Last of all, everyone is different so working out the safest, most comfortable and supportive position is necessary. It is also important not to forget to ask the individual how they feel.

8.3 Conclusion

The final results of the questionnaire yielded a variety of solutions for each physical challenge and clearly showed a significant difference in relationship to the diseases and symptoms. The participants shared similar underlying issues that must be considered when fixing the sitting posture in the proper position and explained what affects those changes can make for better functionality and stability. Every individual is unique and special requiring his own assessment in order to fit the position properly. The importance of care plays a role in assessing, positioning and correcting the individual, requiring patience and a willingness to take the necessary time to perform the task properly. Listening to the participant and observing him helps the facilitator with valuable insights in making sure the position is the best possible. The end result is aimed at providing a comfortable, safe and secure sitting environment for the participant in order to have sustainable enjoyment throughout the activity.

9 DISCUSSION

9.1 Process of the thesis

The idea for the thesis originated during a functional device course in the spring semester of 2012. During the practical application part of the course, I practiced the activity of facilitating the positioning and support work for physically challenged clients by placing them in a winter sled. Afterwards I spoke with the instructor about the support issues and it was mentioned that this subject would make a good thesis. On 14.5.2012 the instructor and I met with Malike in Tampere, Finland to discuss some possible ideas for research. At that time, the aims for the thesis and target groups were selected and an agreement was made with Malike. Due to the busy school schedule, I was unable to begin work on the thesis until December of 2012.

On 17.12.2012 I began researching the topics and reading about making a thesis. This work lasted less than a month because I was too busy in school to continue the

thesis work. In June of 2013, I restarted the work of gathering information for the theory and was assigned an additional teacher as my supervisor. After several meetings with my supervisors a plan was made for the thesis. Over the next few weeks I struggled with getting started and was finding it hard to write. I continued searching for information, but the overwhelming feeling of the slow progress made writing a thesis very difficult. I discovered the importance of taking notes and placing them in the thesis form, and through this activity I was able to make progress and my attitude improved concerning the thesis.

The original plan for gathering the research information was by interviewing professional in the field who were familiar with the physical challenges and understood the issue of the sitting position and posture support. On the 31st of July 2013, I sent interview request to three professionals in three different countries and after three weeks I had received no responses. On the 21st of August, I changed the interview into a questionnaire hoping this would give responders an easier way to provide information and I also added an additional professional to the list. On 3.9.2013 I received my first returned questionnaire and had received an email from one of the original recipients stating that they would reply soon. On 11.9.2013 I had received a new contact for a physiotherapist in another country and immediately sent the questionnaire. This contact opened a door for many possibilities with professionals seemingly excited about the research and willing to participate. By the 24th of October, I had received two more returned questionnaires and sent a final notice to the other recipients giving a deadline for returning the answers. Unfortunately the three original professionals never returned the questionnaire, therefore I was glad I found new participants. Throughout this time I have continued to research the different topics, take notes and meet with my supervisors.

All of the research has been done via my home computer and through the Internet. While I was able to find many resources from our school library, other sources were difficult to acquire. Many books and articles containing pertinent information were either not in our library or the access to those sources cost money through the Internet. Regardless of the limitations, I feel that the resources used in this thesis are accurate and reliable.

The strengths of this thesis exist in the theory part, defining the main issues presented throughout the thesis and the connecting factors leading to the questions. The sources for accessibility, muscular dystrophy, hemiplegia, spasticity and the sitting position were easy to locate and showed a consistency that provides accurate information. Arriving at a point of understanding the issues makes the thesis useful for those wanting to gain a simple understanding of the elements used to develop the idea. Also the connectivity of the thesis is easy to follow as it moves from one point to the next leading to the area of research. Therefore constructing the basis of the thesis is its strength.

The weakness of this thesis is based on the difficulty that can sometimes be experience when using qualitative methods to gain information. While the information gained is reliable because those providing the information answered from their own experiences, the lack of information leaves more questions to be answered rather than the answers leaving the issue fully resolved. The insights gained from the professionals are valuable, but due to the inability to follow through with an interview, limitations leave the information provided less than what I would have hoped. Through the use of an interview, rather than a questionnaire, I would have been able to immediately follow up answers with additional question to gain more clarity and information. Regardless of the weakness, the information is still useful and reliable.

By working on this thesis I gained a great deal of information about the three different physical challenges and feel more confident in identifying the symptoms and common traits. My understanding has been opened to the area of accessibility and all the relating factors that influence our world, governments, societies and profession. Also the information received from the physiotherapist has given me valuable tools for my own practice in the future. I have always had an interest in this area of neurological physiotherapy; therefore I believe the basis of this thesis will assist me in the future by what I have learned.

9.2 Research evaluation

I chose the qualitative research method for the thesis because I felt it was important to obtain information from professionals working in the field who could give ideas based on experience. As mentioned before, the plan was to interview the professionals, but unfortunately that did not work. The information I received is useful and I believe will assist those who read and apply what is suggested. If I could have interviewed the professionals, I believe I would have obtain more information as I could have asked clarifying questions to obtain clearer ideas and practices. Also after receiving the returned questionnaires, I soon realized that most of the professionals interpreted functional device as a wheelchair rather than a type of device used in recreational activity. This misunderstanding could have quickly been corrected during an interview.

9.3 Further research suggestions

Some ideas for further research could be other types of diseases or physical challenging issues not covered in this thesis. Although my plan to interview professionals did not work, another thesis could be done with interviews. Also interviewing those with physical challenges could be another idea. Clarification issues of a functional device could be studied since I found the use of the word misunderstood. Another idea would be to look into ways to motivate those with physical challenges to be more active and participate in outdoor recreational activities or to discover what barriers exist that keeps them from being active.

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APPENDICES 1

Questionnaire

Introduction information: My thesis is being prepared for an organization in Finland that provides functional devices for people with physical challenges. Facilitators and family members will place the physically challenged people in the device and the organization will provide them with information about proper posture support in the sitting position. The target groups selected for the study are those with Muscular dystrophy, spasticity and hemiplegia. I'm using the qualitative approach in my thesis by asking professionals who have an understanding of proper sitting position, posture support and knowledge of the target groups to provide experiential information. This information will be collected and used in preparing the instructions for the facilitators of functional devices.

Therefore I would appreciate your participation in this questionnaire and would ask you to answer the questions below with the knowledge you have gain through your professional experiences. If a question is not in your field of experience, then please only answer the questions that you feel would benefit the information of the thesis.

Thank you.

Questionnaire

What should be considered when placing a person with Muscular Dystrophy in a sitting position in a functional device?

What should be considered when placing a person with spasticity in a sitting position in a functional device?

What should be considered when placing a person with hemiplegia in a sitting position in a functional device?

What is the best way to support high muscle tone in a sitting position?

What is the best way to support low muscle tone?

What are the vital elements to consider in a sitting position posture with the legs in a straight position?

What are the vital elements to consider in a sitting position posture with the legs in a bent position?

When the persons posture is deformed due to their disease, how do you support their position?

Any special or related advice you would give for people facilitating the work of positioning a person with (MD, Spasticity or Hemiplegia) and using supportive equipment?