

LONG TERM OUTCOMES OF
SURGERY AS EXPERIENCED
BY YOUNG PEOPLE WITH
CEREBRAL PALSY

HEATHER JACKSON

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Abstract

Background: Pathways of care are available for people with cerebral palsy (CP) including various conservative and surgical interventions. A common aim of these interventions is to improve functional ability and prevent or reduce the prevalence of pain. There is currently no research evidence that demonstrates whether a surgical approach is more effective in achieving these aims than conservative treatment. Moreover, there is also no available research that explores the experiences of young people and their satisfaction with life in relation to the clinical management of their CP.

The aim of this research was, retrospectively, to establish whether young people with CP who had experienced surgery as children to their lower extremities had better long term functional outcomes, less pain and a greater satisfaction of life than young people who had not experienced surgery as children. It also aimed to gain an understanding about their lives with CP and about experiences of the pathways of care that they had received.

Method: This research design was mixed methods using a sequential explanatory design with the emphasis on the qualitative element. The research was conducted at two specialist centres for children and adults with CP in Munich, Germany. Sixty two participants aged between 18 and 28 years fulfilled the inclusion criteria and agreed to participate. The participants were initially categorized according to whether they had or had not experienced surgery as a child to the lower extremities. They were subsequently divided into groups of functional ability using the recognized Gross Motor Function Classification System. Three outcome measures were completed together with an evaluation by the participant about the change in their function from childhood to the present day and the actual prevalence of pain. The analysis identified significant relationships between the level of function, satisfaction with life and prevalence of pain between the two groups. These data were used to inform the qualitative phase including participant selection and structure, content and phrasing of the interview questions.

Eighteen of the participants were selected and agreed to take part in the qualitative phase of the study involving semi-structured interviews which were analyzed using Fleming's framework based on Gadamer's philosophy.

Key Findings: The quantitative findings indicated that surgery to the lower extremities of non ambulant young people with cerebral palsy may not be the most effective form of treatment to improve long term functional ability compared to conservative management. In addition, surgical intervention was no more successful than conservative treatment for the long term reduction of pain or improving satisfaction with life. The themes identified from the interviews support these results and also highlighted that in many aspects of their lives young people with CP did not have a voice that was listened to and were not involved in decision making. This has influenced several aspects of their lives including their satisfaction with life.

Conclusion: Health professionals should be aware of these findings when giving advice on the best pathway of care to follow. Young people need to have an informed voice to be able to make decisions and therapists need to be included in decision making. Health care providers may facilitate this by moving away from the currently adopted medical model of health and challenging the medical hierarchy that is in existence in Germany. Additionally therapists need to gain autonomy and improve their status. In time a long term objective is to change aspects of the health insurance system and abolish prescription of therapy to ultimately assist in meeting the social, physical and medical needs of people with CP.

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

A handwritten signature in black ink that reads "Heathw Jacob". The signature is written in a cursive style with a long, sweeping tail on the final letter.

Dated

14.10.2012

Chapter 1: Introduction

1.1 Personal Background

I am a UK trained physiotherapist and have been working in Germany at the 'Integration Centre for Cerebral Palsy' (ICP) for 11 years. The ICP is a centre of excellence which provides a comprehensive package of healthcare, education and work for young people with cerebral palsy (CP). Working as head physiotherapist at ICP for the past 9 years has given me the invaluable experience of being involved with the long term care and treatment of young people with CP. During this time, changes in the care and treatment of people with CP have occurred in the UK (Chartered Society of Physiotherapy 2009) in line with the recommendations made by the World Health Organisation (WHO) (2001), which focuses on empowering people with disabilities and enabling them to participate in society. Germany conversely, has not seen these developments to the same extent. Additionally, physiotherapy in Germany has not developed educationally at the same rate as education in the UK (Neal and Morgan 2000). This in turn this has prolonged a hierarchical system of delivery of care whereby physiotherapists are still under the direction of doctors and therefore perceived more like technicians rather than independent practitioners (Chanou and Sellars 2010). Clinical decisions which frequently result in recommendations for surgery to the lower extremities in young people with CP continue to be made by doctors and consultant medical practitioners in the field of paediatric cerebral palsy.

Young people with CP are usually offered a conservative pathway of care prior to recommendations for surgery to their lower extremities. Such conservative pathways can include physiotherapy approaches which are not always evidence based and are often clinically derived. Such approaches include the Bobath concept (Butler and Darrah 2001) and Vojta Therapy (Feldkamp et al. 1989). Other conservative interventions include Botulinum toxin injections (Graham 2008) and orthotics (Morris 2002). A common aim of both surgical and conservative pathways of care is to improve functional ability and prevent or reduce the prevalence of pain. However, research would indicate that despite implementation of a surgical and/or conservative approach, children with a low level of functional ability are likely to experience a deterioration of functional ability as they reach adolescence and adulthood

(Rosenbaum 2007; Hanna et al. 2009). Many possible explanations have been proposed including pain (Jahnsen et al. 2004), muscle weakness (Ross and Engsborg 2007), changes in body mass index and an increase in height and personal and environmental factors (van Eck et al. 2008).

In light of my clinical experience I have questioned whether a surgical pathway of care is most appropriate and why it is often considered preferential to continuing a conservative pathway of care in improving or maintaining functional ability long term, satisfaction with life and the prevalence of pain of young people with CP. This feeling of professional disquiet has resulted in me undertaking a literature search to explore the evidence underpinning some of the clinical decisions being made by the doctors and consultant medical practitioners and physiotherapists in the field of paediatric cerebral palsy.

My literature search, detailed in Chapter 2.7 and 2.8, suggests that there is no research to date which has investigated whether a conservative or a surgical pathway of care best meets the needs of people with CP into adulthood and assist in improving their satisfaction with life. In order to provide evidence on which to base treatment, it is necessary not only to compare differences in functional outcome in young people who have experienced surgical interventions compared with those who have experienced conservative interventions but also to explore differences in satisfaction of life and prevalence of pain as a result of the different interventions experienced.

This research was carried out in German and was undertaken with German speaking participants. Although I am a UK trained physiotherapist I have been living in Germany for over 15 years and can speak German fluently. I also understand the language nuances and recognise words that do not translate directly. Where this has happened I have given an appropriate interpretation to be as true to the data as possible. Where outcomes were used, translations were additionally validated.

It is important to describe the health care environment in which the research was undertaken and in particular the health care system in Germany and the training of physiotherapists both of which demonstrate many differences to that in the UK.

1.2 Health Service and Health care in Germany

There is a two tiered health system in Germany which consists of both a state and a private health insurance system. State-mandated health insurance began with the Health Insurance Act in Germany in 1883 (Busse and Riesberg 2004). At that time approximately 10% of the population were covered by health insurance (EOHCS). The Private Health Insurance System was officially founded in 1926 and accessible to people only from specified professions. This was modified in 1989 to allow people from all professions who earned over a certain threshold to enter the private health insurance system (Deutsche-Sozialversicherung). This has remained to the present day. All employers contribute to the health insurance of their employees regardless of the type of insurance they may have.

About 90% of Germany's residents have mandatory health insurance (GKV-Spitzenverband). The privately insured are mostly civil servants and self employed people who contribute to 'for-profit' insurance companies. People who are eligible for the private health insurance are also eligible for the state system. However, once in the private system it is only possible to change into the state system through unemployment.

There are definite advantages to private insurance, particularly for single people who pay less than they would for state insurance. Private health schemes provide more extensive cover than that of the state including the option of private/-semi private hospitals, alternative treatment, full dental cover, consultation with a senior consultant with the option of a second/third/fourth opinion, free medication and a greater availability of assistive devices. Some doctors choose to treat private patients in preference to state insured clients because they can charge much higher rates. Private patients can go directly to a specialist whereas state insured clients have to first go to their general practitioner to gain access to a specialist (Versicherung-info).

These are just some of the differences between the two systems which distinctly give the privately insured clients a better and more comprehensive service. It is possible however, at extra cost for those in the mandatory health system to improve their insurance cover. This enables them to access the medical system in a similar way to those who have private insurance.

The consequences of these two systems are apparent in the Integration Centre for Cerebral Palsy (ICP). For example all children have a designated paediatrician who is external to the centre whose role is to undertake the regular developmental checks. In addition, all children are assessed at least twice a year by the consultant in ICP. If there is a conflict in opinion between the external paediatrician and the ICP consultant about prognosis or the management of the child, the parents are likely to seek further advice. In certain cases this can result in conflicting opinions regarding the best pathway of care to follow.

1.2.1 Physiotherapy in Germany

The type of physiotherapeutic intervention for young people with CP in the UK is decided upon by the physiotherapists. In Germany however, although the treatment available is comparable to that offered by physiotherapists in the UK it is prescribed by the consultant who is involved with the management of the young person. Germany and Greece are the only two countries in Europe who are reliant on doctors for the prescription of physiotherapy (Chanou and Sellars 2010).

In addition to a very different health care structure between UK and Germany, there are also differences between the education of physiotherapists and the development of physiotherapy as a profession between the two countries.

1.2.2 A comparison of the development of physiotherapy in Germany and UK

In May 2005 the Canadian Alliance of Physiotherapy Regulators produced a paper 'Towards a Better Understanding of Physiotherapy Education and Practice in Germany' following an evaluation of the training of physiotherapists in Germany.

Physiotherapy in Germany, like other European countries has a long history which has seen many developments over the last 150 years. The early treatments were hydrotherapy, exercise and massage. Dr. C. Neumann brought the 'schwedische Heilgymnastik' to Germany and in 1853 he opened the first 'Gymnastenschule for Damen'. The first official society in the UK, which was the Society of Trained Masseuses, was founded later in 1894, and was also influenced by Sweden. Physiotherapists in Europe had little autonomy and were banned from seeing patients without medical referral and prescription. Although the profession grew in Europe

due to the needs during and following the wars 1870/71, 1914-18 and 1939-45 physiotherapy was still seen as part of the early spa culture and not the scientific medical model.

At this point, physiotherapy in Germany seemed to be developing in line with that of the UK. However in 1920 the Institute of Massage and Remedial Gymnastics in UK merged and in 1944 adopted its present name of Chartered Society of Physiotherapy (CSP). The equivalent in Germany 'Der Zentral Verband für Physiotherapie/Krankengymnasten' (ZVK) was first established in 1949. In 1959 physiotherapy obtained the recognition of an 'ärztliche Hilfsberuf' (assisting the doctor). It was only in 1994 that the term 'Krankengymnast' was replaced with Physiotherapist to come in line with European and international terminology.

Membership is not mandatory for qualified physiotherapists in Germany and only approximately 31% of qualified physiotherapists are members (ZVK 2012) although the percentage is less in the physiotherapy department at ICP where only 3 physiotherapists out of 24 are members (17%). The ZVK therefore has very little power to influence advancements in physiotherapy as a profession. In comparison the CSP has developed into a very strong membership organization that aims to support physiotherapists and increase the profile of physiotherapy amongst the general public and other health professionals. It also aims to influence decision makers.

Furthermore in 1960 the Council for Professions Supplementary to Medicine (CPSM) was established as a regulator of a number of health professions to protect the public. It established a registry of health professions and their members who met the required standards for the profession. In April 2002 it was replaced by the Health Professions Council (HPC) which has continued and extended the remit of the CPSM.

The HPC approves and controls programmes for physiotherapy training thereby maintaining and improving standards. UK physiotherapists can undertake specialist training to become extended scope practitioners to be able to undertake higher level of independent practice to which GP's and consultants refer. This is not an option

available to German physiotherapists within the German health care system where the state continues to be responsible for the development of physiotherapy as a profession.

In July 2005 the HPC agreed the standards of Continuous Professional Development (Chartered Society of Physiotherapy 2005). In 2008 the first audit of CPD for the health professions occurred. The introduction of mandatory CPD has been identified as a development to professionalization in many professions (Neal and Morgan 2000).

The academic entry requirement for physiotherapy training is the lowest in Europe apart from Croatia. Although many students complete the Abitur, which is equivalent to 'A' levels, it is only compulsory to complete 9 years of primary and secondary school leading to an equivalent of a GCSE qualification.

In comparison the first degree course in Physiotherapy in UK was established in 1976 and in 1992 the profession became an all graduate entry profession whereas the first degree course was established in Germany in 1998 and the exam had to be taken abroad. This situation improved and it has been possible to convert the physiotherapy diploma into a degree after further studies since 2001. The first primary degree courses however were introduced in September 2010 (Elzer and Sciborski 2004). The majority of courses remain at a diploma level and are taught in technical schools which are affiliated to hospitals and clinics. Undertaking research does not form part of the syllabus in the diploma course. It was noted by the Canadian Review Body in 2005 that at this time that there were no physiotherapists who were primary investigators for rehabilitation research and that most research was lead by medical doctors.

The paper concluded that the German physiotherapy training did not 'prepare practitioners to become competent in making a physiotherapy diagnosis reflecting on scientific evidence and critical decision making' (Canadian Alliance of Physiotherapy Regulators 2006 p6). The researcher would endorse this statement having had experience with recruiting and working with newly qualified staff.

It is evident that many physiotherapists in Germany are not equipped with an adequate evidence base of knowledge to challenge decisions made by doctors largely as a result of lack of higher education provision and research skills. The combination of lower academic qualifications and a health system that supports the continuation of a hierarchical system of delivery of care has led to an imbalance of power between the professions. This hierarchical structure is evident to the public and often results in parents seeking advice from doctors rather than physiotherapists. This rather dated approach is contrary to the thinking of Fixsen (1989) who over twenty years ago emphasized the importance of a team approach in the management of CP. The consequences of this imbalance of power are therefore potentially detrimental to the long term care and management of young people with CP.

In summary, three main differences have been identified in the development of physiotherapy as a profession in the UK compared to that in Germany (Chanou and Sellars 2010 and Neal and Morgan 2000). These are the establishment of an influential professional body, introduction of graduate training and continuous professional development. It is possible that these factors have contributed to physiotherapists in UK having greater professional autonomy and status than physiotherapists in Germany (Neal and Morgan 2000).

Autonomy is considered to be a hallmark of professional status (Probert 1989) and is a term used to describe an 'individual's freedom to act and make judgements independently within their professional role' (Swisher and Page 2005). In Germany it can be demonstrated that neither the professional body nor physiotherapy managers nor individual physiotherapists have technical autonomy, which includes having control over decisions, nor procedural autonomy which is related to the professional's ability to allocate and control economic resources within their role (Sandström 2007).

1.3 Attitudes to disability in Germany

Legally, children under 16 years of age have the right to be involved in decision making processes. Article 12 of the United Nations Convention of the Rights of the Child (UNCRC) (1989) is the 'right to the child who is capable of forming his or her own views to express those views freely in all matters affecting the child, the views

of the child being given due weight in accordance with the age and maturity of the child'. This includes matters concerning the child's healthcare.

The United Nations introduced Children's Rights' in 1989 but the German government did not make it 'legally binding' until July 2010. The UNCRC did not define the age at which a child can have his own view or when a child may decide about his own healthcare. Therefore German law allows each case to be considered individually. Children should however be encouraged and given the freedom to participate in decision making and actions that may impact on their lives (Cremer 2011). From many years of experience working with children with cerebral palsy, their parents and health professionals, this freedom does not in fact appear to be enforced in many areas of life but specifically when deciding on the best pathway of care for them.

1.4 Location of study

Young people with CP living in and around Munich may be given the opportunity of attending either the Integration Centre for Cerebral Palsy (ICP) or Münchener Förderzentrum (MFZ). Both are centres of excellence which provide a comprehensive package of healthcare, education and work for young people with CP. The centers are affiliated to each other but have different locations in Munich and have different client groups. ICP was established in 1960 because at that time few centres were available for young people with disabilities who had been born since the end of the war. As its name implies it is a centre which specializes in the care, treatment and schooling for children between 3 and 18 years with CP.

Once the young people have completed their schooling and gained the necessary educational qualifications they have the opportunity to take part in a vocational training programme. They leave the paediatric department and enter 'Berufs Bildungs Werk' (BBW) which is on site where they can gain qualifications in office work, catering, metal work and printing. The qualifications they gain after successfully completing 3 years apprenticeship are in accordance with those from other higher education institutions. Further care, treatment and sheltered work are offered in MFZ for people who do not attain the necessary qualifications to take part in this training programme. ICP and MFZ offer a unique opportunity in Germany in

that they offer education, job training, meaningful work in sheltered workshops, recreation and care for people of all ages (through to retirement) and abilities.

The centres are funded by the government, health system and various sponsors. Parents do not have to pay additional health and education contributions for their children at ICP; however they do have to meet the living costs in MFZ.

ICP and MFZ have a governing body, two managing directors, teachers, therapists, carers and remedial teachers. Physiotherapists, occupational therapists and speech and language therapists report to one of the managing directors who is an orthopaedic consultant and who prescribes the frequency of therapy that a young person should receive.

Chapter 2: Cerebral Palsy

2.1 Definition

The definition of cerebral palsy has developed since the early 1840s as a result of new investigation techniques and a deeper understanding of the effects of the underlying brain injury (Rosenbaum et al. 2006). Originally in the 1840's an English orthopaedic surgeon, Little, placed an emphasis on the effects of spasticity causing joint contractures and deformities and noted that behavioural disorders and epilepsy were a problem but with only occasional complications (Morris 2006). The foundation of the American Academy for Cerebral Palsy and Developmental Medicine in the mid 1940s was important for further development and refining of the definition of CP. In 1959 Mac Keith and Polani acknowledged that disorder of movement and posture due to a non- progressive disorder of the brain was not unchanging (Rosenbaum et al. 2006). Later definitions including those by Bax in 1964 and Mutch in 1992 also emphasised motor aspects of CP (Morris 2006). The most recent definition has arisen from the work of an international group of selected leaders in the preclinical and clinical sciences in 2004. The work was later finalised by panels organised by the same group in 2006. The definition emphasised the importance of secondary problems including sensory, cognitive, behavioural and other associated impairments that can arise from disturbances to the developing foetal or infant brain (Rosenbaum et al. 2006). It was the first time that the secondary problems had been acknowledged.

The current accepted definition is:

‘Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems’ (Rosenbaum et al. 2006, p 9).

2.2 Aetiology

The disorders that have been identified and associated with CP are due to lesions or abnormality of the developing brain (Krägeloh-Mann and Horber 2007). The developing foetal or infant brain is considered to include infants up to 2 or 3 years of age (Rosenbaum et al. 2006).

There are multiple risk factors that could be responsible for the damage to the developing brain which results in CP (Reddihough and Collins 2003). These have been identified to be present or occurring in the preconceptual, antenatal, perinatal or postnatal periods (Rosenbaum and Rosenbloom 2012). In the preconceptual period factors such as prior maternal diagnoses e.g seizures, intellectual disability or thyroid disease may be indirect causes of CP (McIntyre et al. 2012). In the early antenatal period congenital infections and cerebral malformation syndromes have been identified as possible causes. The periventricular white matter may be affected in the early 3rd trimester and in the preterm infant by a variety of causative pathologies. These can include ischaemia as a result of hypoxia or other circulatory disturbances or maternal infection. Preterm infants are also at risk of sustaining an intraventricular haemorrhage (Rosenbaum and Rosenbloom 2012).

Hypoxic- ischemic mechanisms and perinatal stroke are the main causes of disturbances to brain development in the perinatal period and bacterial infections, inflammatory disorders and trauma are considered to be the main causes of CP in the postnatal period (Rosenbaum and Rosenbloom 2012).

A systematic review of studies using MRI in children with CP was done by Krägeloh-Mann and Horber (2007). Twenty one papers were included in the review which had a total of 388 MRI reports. It was found that brain lesions could be found in 75% of pre term infants with CP and mal-developments in about 10% of infants with CP. Periventricular leukomalacia (PVL) were the most frequently occurring lesions (56%) resulting in CP and occurred significantly more often in pre term infants than infants born at term. Cortical and deep grey matter lesions accounted for 18% of infants with CP.

Children with PVL most frequently present with a bilateral spastic CP with a predominance of lower limb involvement whereas children who have PVL and cortico-subcortical lesions present with a more severe bilateral spastic CP and upper limb involvement. The basal ganglia are most likely to be affected in children with dyskinesia (Bax et al. 2006).

2.3 Prevalence and Incidence

The Surveillance of Cerebral Palsy (SCPE) was set up in 1998. It includes 14 centres in 8 countries in Europe and collects statistics on the prevalence and other information of CP through surveys and registers. The statistics collected in 1998 showed a prevalence of 1.5 to 3 children per 1000 live births in the participating countries (Cans 2000). More recent statistics including those from third world countries where the prevalence is higher shows an incidence of CP of between 0.6 and 5.9 children per 1000 live births (Paul et al. 2007). It has been reported that almost 50% of all cases of CP are associated with pre term births (Zerhouni 2008).

The presentation of the secondary problems following the disturbance to the developing or foetal brain is varied but similarities can be identified. Many different classifications of cerebral palsy have been postulated over the years.

2.4 Classification of Cerebral Palsy

Classifications of CP have been developed over many years as a result of the continuing refinement of the definition of CP and also the development of International Classification of Function, Disability and Health (ICF). This was developed by the World Health Organisation (2001) which preceded the International Classification of Diseases (ICD) (WHO 1980). The ICF gives a framework for measuring health and disability based on body functions and structures, individual and societal perspectives.

In 1990 classification was limited to the type of abnormal muscle tone or involuntary movements. These were related to a specific underlying pathophysiology and divided into spasticity, dyskinesia and ataxia. Further subdivisions included the anatomical distribution of the involvement including hemiplegia, tetraplegia or diplegia.

Dyskinesia was further classified into choreoathetotic or dystonia types. (Morris 2006).

The classification of cerebral palsy that has been recommended by SCPE (2000) has been developed with 4 dimensions which are:-

1. motor abnormality
2. impairment
3. anatomical position of lesions
4. prenatal adverse events.

The first is motor abnormality and is subdivided to include the nature and typology of the motor disorder as in 1990 (spasticity, dyskinesia and ataxia) but with an addition of functional motor abilities to fulfil the requirements for ICF. Functional motor abilities are assessed and classified using the Gross Motor Function Classification System (GMFCS) (Appendix 1) which was developed by Palisano et al. and published in 1997. It was revised in 2006 to include children between 12 and 18 years. It is a recognized standardized system to classify gross motor function in children and young adults (1 -18 years). It has separate descriptions for the age ranges:- before 2 years, 2-4 years, 4-6 years, 6-12 years and 12-18 years. Within these age ranges there are five levels:- I is for those without motor limitations to V who have severe limitations.

It is widely used in research (Kim and Park 2011; Knox and Evans 2002; van Eck et al. 2008) and in clinical practice. The GMFCS is not only useful for classification purposes but it can also provide information regarding development of children with CP with varying levels of functional ability (Palisano et al. 1997).

There are also other classification systems which are similar to the GMFCS including the Manual Ability Classification System (Eliasson et al. 2006) or the Bimanual Fine Motor Function Scale (BFMF) (Himmelman et al. 2006). These however, assess function of the upper extremities.

The second dimension considers what impairments and how these impairments interfere with participation in everyday life. These include measuring IQ, vision and

hearing acknowledging seizure disorders, emotional and behavioral issues and developing musculoskeletal problems.

The underlying neuropathology of CP is non progressive but it is widely accepted that the clinical manifestations will change over time (Hanna et al. 2009). This can result in a deterioration of function (Bottos et al. 2001b) particularly for people classified in GMFCS level III, IV and V (Hanna et al. 2009 and Day et al. 2007).

Many factors have been suggested to contribute to the deterioration in ability. These include impairments such as pain (Jahnsen et al. 2004), length of the spastic muscle which does not keep up with the changes in bone length (Johnson et al. 1997), muscle strength (Ross and Engsborg 2007) and hip displacement (Dobson et al. 2002). Changes in body mass index and an increase in height and personal and environmental factors (van Eck et al. 2008) have also been identified as possible causes for deterioration in functional ability.

Some of the impairments that have been identified as possible reasons for deterioration in function and are the main focus of conservative and surgical treatment will be described in the following section (Chapter 2.5).

The third dimension of anatomical distribution has been updated to include unilateral and bilateral motor involvement. It is recommended that neurological imaging findings are included in the classification (Rosenbaum et al. 2006).

The fourth dimension is cause and timing although adverse events in the prenatal, perinatal and postnatal periods do not lead exclusively to CP (Rosenbaum et al. 2006).

This current classification of cerebral palsy (SCPE 2000) provides a comprehensive picture of the person with CP. This is demonstrated with an example of a person with spastic bilateral cerebral palsy with a GMFCS level II and a MACS level II. A shortcoming of this classification however, is that it does not explore individual needs and goals.

2.5 Development of secondary problems

The current classification of CP identifies that secondary problems can develop as a result of the underlying pathology. Some of these, which health professionals consider to contribute to deterioration of functional ability and on which they focus their treatment interventions, will be discussed.

2.5.1 Impairments

Abnormal movements in people with CP are due to defective coordination of movement and /or regulation of muscle tone (Bax et al. 2005). Spasticity and muscle weakness are primary impairments that are directly related to a lesion in the central nervous system. It is generally accepted that in addition to reflex hyper excitability, changes occur in the biomechanical properties of the muscle which can be clinically assessed as an increase in resistance to movement which is similar to that of spasticity (Poon and Hui-Chan 2009). Changes to the biomechanical properties of the muscles occur when muscle is not moved through its normal range of movement as is seen in children with CP who are not developing normally or when the muscle is immobilized. Both neural (spasticity) and muscular factors are considered to contribute to muscle stiffness and the development of contractures (Barrett and Lichtwark 2010). However, there is little consensus about the actual morphological changes that occur in spastic muscle and the mechanism for the development of contractures and muscle weakness (Smith et al. 2011). There is however, consensus that muscle volume, muscle thickness and cross sectional area and muscle belly length are reduced in people with cerebral palsy. The impact of this is to reduce muscle force, production capacity and muscle strength (Wiley and Damiano 1998; Stackhouse et al. 2005) and therefore function (Barrett and Lichtwark 2010).

Muscle strength in the lower extremities of 21 children with spastic diplegia and hemiplegia was found to be significantly weaker compared to a control group of normally developing children. Moreover, children with spastic CP who are ambulant produce 52% of the force of normally developing children during maximum voluntary contractions as measured by a hand held dynamometer (Wiley and Damiano 1998).

Reducing spasticity and improving muscle strength are the focus of many treatment interventions for people with CP. Recent research has shown that there is a significant relationship between spasticity and gross motor function but that no significant relationship was found between spasticity and functional ability (Kim and Park 2011). Earlier work by Ross and Engsberg (2007) however, had contradictory results and did not show a significant relationship between spasticity and gross motor function. Both studies used the same outcome measures for spasticity and gross motor function namely the Ashworth Scale and Gross Motor Function Measure, the sample sizes were similar but the severity of CP varied between the two samples. Kim and Park (2011) had a mixed sample representative from all levels of GMFCS I-V whereas Ross and Engsberg (2007) included only ambulant children with GMFCS levels I-III. This was the main difference between the two groups indicating that the level of mobility of the participants might have influenced the findings.

There is more agreement regarding the relationship between muscle strength and gross motor function and functional ability. Damiano et al. (2001), Kim and Park (2011) and Ross and Engsberg (2007) all identified the importance of muscle strength in positively affecting the level of gross motor function and functional ability. Surgery to the lower extremities can contribute to increase muscle weakness post operatively which based on research and clinical experience, can fail to improve long term (Seniorou et al. 2007). The current muscle strength available and the ability of a young person to participate adequately with a post operative physiotherapy programme to increase muscle strength should therefore be indicators when recommending surgery to the lower extremities.

Muscle weakness contributes to an inefficient gait pattern requiring greater oxygen consumption and a higher heart rate which in turn makes walking more strenuous than for children developing normally (Perry, 1992). The clinical significance of this can be seen in the ability of many young people with CP who can only walk short distances and therefore prefer to use a wheelchair. Wheelchairs not only make it possible to move greater distances but they also offer speed and promote independence which can improve quality of life (Bottos et al. 2001a). However, it should be considered that functional ability has been found to deteriorate at a

younger age if a wheelchair becomes the chosen mode of mobility together with a further reduction in general physical fitness (Verschuren et al. 2009).

This also highlights the importance of maintaining and improving muscle strength and identifying the most effective pathway of care when the young person's aim is to remain ambulant for as long as possible.

2.5.2 Hip Development

At birth the hips of children with CP are usually not affected and classified as normal (Flynn and Miller 2002). However, spasticity and contractures of the hip adductors, hip flexors and the medial hamstrings and lack of weight bearing can contribute to muscle imbalance, osseous deformity including an increase in femoral anteversion and acetabular dysplasia (Bagg et al. 1993). In turn these have the effect of altering the biomechanics of the hip joint which can lead to the posterolateral migration of the femoral head and subsequent hip subluxation and possibly hip dislocation (Stott and Piedrahita 2004).

In turn hip dislocation and subluxation can cause deterioration in sitting balance, increase the incidence of pressure sores and result in difficulty with personal care. Early work has also been reported that hip dislocation can increase the rate of femoral fractures (Pritchett 1990), cause pelvic obliquity and scoliosis (Letts et al. 1984), and may also be a cause of hip pain (Noonan et al. 2004). The aim of management is therefore to prevent dislocation occurring.

The severity of hip displacement which includes hip subluxation and dislocation can be measured using different lines of reference from the radiograph. Reimers migration percentage (MP) is a standardised measure and is frequently used when reporting the status of hips (Stott and Piedrahita 2004; Scrutton et al. 2001). A hip is considered to be subluxed if the MP is >33% (Reimers 1980) although others have taken values >30% (Soo et al. 2006). A MP of 100% defines a dislocated hip (Soo et al. 2006). Miller and Bagg (1995) however divided MP into 4 groups. Normal hips were classed as having a MP of <30%, subluxed hip 30-60%, severely subluxed 60-90% and dislocated hips with a MP of >90%.

Reports of the prevalence of hip displacement are difficult to compare due to the difference in severity of CP between the samples, surgery that has been performed, the length of time and the age at follow up. In addition there are differences in terminology. Soo et al. (2006) reports of hip displacement, to include all levels of hip migration, whereas Morton et al. (2006) reports of hip dislocation, to be hip migration of > 90%.

In a sample of 323 children with CP who were studied for a mean of 11 years and 8 months, 35.3% were reported to have hip displacement and 6.5% of these children had dislocation of one or both hips (Soo et al. 2006). Morton et al. (2006) in comparison reported that 27% of a sample of 110 subjects with CP had one or both hips that were dislocated at 15 years of age. Hägglund et al. (2005) however, found from the results of a 10 year programme of hip surveillance that it was possible to significantly reduce the occurrence of hip dislocation ($p < 0.001$). None of the 206 children who participated developed a dislocated hip.

Despite the lack of conclusive evidence about the prevalence of hip displacement there is agreement that the incidence of hip dislocation increases in people who have more severe spastic involvement and less functional ability (Scrutton et al. 2001; Soo et al. 2006; Morton et al. 2006). Both Morton et al (2006) and Soo et al. (2006) classified their sample population using the GMFCS. Morton, et al. (2006) reported that 50% of the sample in GMFCS level V had hip dislocation by the age of 15, 30% with GMFCS level IV, and 11% in GMFCS level III and none in GMFCS levels I and II. The trend was similar for hip displacement as reported by Soo et al. (2006). In GMFCS levels V, 89% had hip displacement, GMFCS level IV 70%, GMFCS level III 41% and GMFCS level II 15%.

Scrutton et al. (2001) however, used walking ability as an indicator of how a hip would develop. They found that the ability to walk by 5 years strongly influenced how the hip would develop. In his study none of the children who walked by the age of 30 months had hip problems and only 2 out of 52 who walked by 5 years developed hip problems. Scrutton et al. (2001) reported that the severity of involvement only became significant at 5 years. Between the ages of 18 and 48 months there was no significant difference in migration values between the children

of varying severity of motor involvement. Similar conclusions can be drawn from these two studies that both indicate that a greater functional ability reduces the possibility of hip displacement.

2.5.3 Pain

Pain in and around the hip appears to be a significant problem in adults (Hodgkinson et al. 2001) and children (Lipak et al. 2001; Young et al. 2007) with CP which will affect quality of life (Schwartz et al. 1999; Jahnsen et al. 2004).

This will be discussed in relation to preventative and reconstructive surgery for the hip (Chapter 2.8.4 and 2.8.5).

Possible factors that are considered responsible for changes in functional ability over time have been discussed. Available evidence that has focused on the changes in functional ability of people with cerebral palsy over time will be presented.

2.5.4 Changes in functional ability over time

There is little research that maps changes in functional ability of people with CP into adulthood and longer term. There is research that indicates that children are unlikely to experience a change in functional ability as measured by the GMFCS (Palisano et al. 2006). They found that 73% of the 610 children with a mean age of 6 years and 9 months who were tested and retested over a 4 year period using the GMFCS remained in the same classification level. The remaining 27% who were reclassified in an either lower or higher GMFCS level were distributed over all levels of functional ability. These results only indicate that young children are likely to maintain their functional ability and cannot support clinical experience that people with CP are likely to experience long term deterioration in functional ability.

Some research however, is available that investigates long term changes of function of children and adults (Day et al. 2007). They used a retrospective method to collect data over 15 years from a very large sample of 13,371 children and adults with CP. Using assessments that had been carried out over the years they were able to report on the functional development of children into adulthood between the ages of 10 and 25 years and from adults between the ages of 25 and 40 years. The participants of the two samples had varying levels of functional ability which ranged from GMFCS

level I to V. The results showed that people who were ambulant but required assistance and who started using a wheelchair at the age of 10 years had a 34% chance of losing their ambulatory ability at 25 years of age compared to those who did not use a wheelchair at 10 years who had a 11% chance of losing their ambulatory ability at 25 years of age. The level of mobility at the age of 25 years is likely to remain the same up to the age of 40 years which was the maximum age of the participants in the sample.

The results support more recent research by Hanna et al. (2009), who in a prospective study performed a mean of 5 assessments on 657 children and young adults (from 16 months to 21 years) with CP. Hanna et al. (2009) classified the participants according to GMFCS and reported that ambulant children (GMFCS I and II) are likely to retain their mobility up to the age of 21 years compared to children who are dependent on assistance for their mobility (GMFCS level III-V) who can expect a deterioration of mobility into early adulthood.

None of the studies reported however, give details of the type of treatment that children had experienced and whether it was possible to establish whether this could affect the GMFCS outcome in adulthood. Moreover there is also a lack of research that follows up the functional status of people with CP over 20 years.

Bottos et al. (2001b) performed a retrospective study of the functional status of 70 adults with CP with a mean age of 33 years ranging from 19 to 65 who were born between 1934 and 1980. They were not classified according to the GMFCS but from the description of the functional capabilities given of the sample, it suggests that the sample was from mixed abilities. The percentage of the sample with dyskinesia was high (33.8%) although this was likely to have been representative of the people with CP at that time where the incidence was higher due to the higher rate of asphyxia in babies following neonatal accidents in term babies (Hagberg and Hagberg 1996). Bottos et al. (2001b) found that 29 participants from a total sample of 72 were independently mobile at the age of 18 years. At a mean age of 33 years however, only 16 out of 29 people (55%) had maintained this level of function. Moreover, only 5 out of 12 people (41%) who had been classified as having limited mobility using a walking device had maintained this ability.

It is very difficult to compare results of the studies (Bottos et al. 2001b and Day et al. 2007) that have reported changes in functional outcome into adulthood because they use different methodological approaches. In addition, retrospective studies collect data over a long period of time that can give long term outcomes but because classification and outcome measures of CP have changed, comparison of the results with prospective research designs should be treated with caution. Variables such as cognitive level of ability and the type and frequency of surgery are not mentioned but confirm that children who are not independently mobile are likely to deteriorate long term into adulthood and especially over 25 years.

Palisano et al. (2006) identified the need to investigate the reasons for a change in functional ability long term, but to date no research is available that focuses on this.

The studies by Palisano et al. (2006), Bottos et al. (2001b) and Day et al. (2007) evaluated change of functional ability of people with cerebral palsy. Others (Molenaers et al. 2006; Stout et al. 2008) have evaluated changes in gait pattern that people with cerebral palsy might experience.

2.5.5 Gait patterns

The effects of shortened, weak and spastic muscles can manifest themselves in a typical gait pattern, hip deformities, pain, developmental delay and later a possible deterioration in function (Molenaers et al. 2006).

Typical gait patterns can develop depending on the severity of CP. People with spastic bilateral involvement and who have a GMFCS level II-III, previously classified as diplegic can develop typical gait patterns which are toe walking, crouch gait, scissoring and stiff knee gait and can be the cause of many surgical procedures. The possible effects of corrective surgery will be discussed in Chapter 2.8.3.

Specific muscle contractures and muscle weakness are considered to be mainly responsible for the different gait patterns. Contracture of the gastrocnemius complex can result in 'true equinus' or toe walking (Jahn et al. 2009). It can cause hyperextension of the knee in mid to late stance phase. This is usually combined with a shortening of the hip flexors and adductors. Hyperextension of the knee can also be

as a result of over corrected surgical hamstring lengthening (Chambers 2001). An ‘apparent equinus’ is when toe contact occurs first because of a dynamic or fixed knee flexion and not due to excessive plantar flexion at the ankle (Chambers 2001). Contractures or tightness in the hamstrings and/ or of the psoas muscle in addition to an increase in plantar flexion and a reduction of knee extension due to quadriceps insufficiency can also contribute to a crouch gait (Stout et al. 2008).

The hip adductors are likely to be shortened in a scissoring gait (Zorer et al. 2004). Rectus femorus spasticity is considered to be the main cause for a stiff knee gait (Zorer et al. 2004). It is most evident during the swing phase where the foot is unable to clear the floor due to inadequate knee flexion at the appropriate time. Over activity of rectus femorus is considered to be the primary cause of the inadequate knee flexion (Reinbolt et al. 2009). This results in compensatory mechanisms to clear the foot from the floor including ipsilateral circumduction at the hip and external rotation of the lower extremity (Chambers 2001).

Bell et al. (2002) investigated changes in gait in children with diplegia who had not had surgery. They found that children, who had a mean age of 7.8 years at the start of the study, experienced deterioration in gait over a 4.4 year period (mean value). More specifically elements of the gait cycle e.g. stride measures, passive range of motion and kinematic parameters had deteriorated. There was however, no comparison between those who had and those who had not had surgery.

Johnson et al. (1997) also found deterioration in gait of children with diplegia. Their study was conducted over a period of 32 months with children with a mean age of 8 years. Although children were excluded from the study if they had experienced surgery within the first year preceding the first gait analysis or between the two assessments, there were 9 of 18 children who had had previous surgery. These results do not therefore compare the long term results of gait in people who have never had surgery to their lower extremities.

2.5.6 Sleep

Sleep disorder is an additional secondary problem for many young people with CP (Newman et al. 2006). It is known that 22.5% of children with CP are likely to have

a sleep disorder compared to 5% of children in a normal population. A number of factors have been considered to affect sleep including cortical visual impairment and the severity of CP (Mol et al. 2012). One of the most common causes of sleep disturbances in young people with CP has been reported to be epilepsy (Newman et al. 2006).

2.5.7 Summary

Research that has been presented has identified that people with CP who as children have limited mobility, can expect to experience a deterioration of mobility into adulthood. There is no conclusive evidence available to account for this.

There is agreement that CP leads to disability of varying severity and appearances. There are many different pathways of care available to people with cerebral palsy which will be discussed in Chapter 2.7 and 2.8. The model of disability that a health professional follows will influence their approach to the care and management for people with CP. The main models of disability will be discussed and later followed by an explanation of the different pathways of care that are most frequently offered to people with cerebral palsy in Germany.

2.6 Classification of disability

There are several models of disability including the medical, social and bio psychosocial models. The medical model regards the underlying cause of a disability including the physical, mental or sensory impairments, to be responsible for limiting independence and participation in society. The focus of medical care is therefore to cure the condition or the impairments that have developed. For example this could be to lengthen shortened muscles. This focus of care can lead to a culture of dependency and may not address the needs or wishes of the people it is trying to help (Action for Inclusion 2001).

Alternatively there is the social model that recognises that disability can affect anyone and it shifts the focus from the cause of the disability to the impact that it has on the individual and also on the social implications. It does not deny the existence of impairments that may affect a person's life but it emphasizes that the real barriers that prevent individuals being included and participating in society are as a result of

environmental and attitudinal factors rather than the individuals' condition or illness. It also recognizes that people with disabilities are part of the economic, environmental and cultural society (Lang 2007). However, although removing physical barriers and including people with disabilities in society gives them the opportunity to take an active part in society, it does not necessarily empower people to manage and have control over their own situation. The bio psychosocial model addresses this issue and combines the social model with a psychological element (Suls and Rothman 2004). The change in emphasis in understanding disability has brought about a shift from segregating people with disabilities to integrating and including them.

The International Classification of Functioning, Disability and Health (ICF) provides a framework to explore the issues addressed by the social model of disability, namely body structure and function, activity, participation and environmental factors (World Health Organisation 2001) (WHO). This has been implemented at ICF but physiotherapists continue to be challenged by the dominance of the medical model used by other health professionals for the care and treatment of people with CP. Doctors continue to be responsible for decision making regarding pathways of care and hold the resources and power to implement these decisions. In contrast the bio psychosocial model underpins the work of physiotherapists in UK (Chartered Society of Physiotherapy 2009).

In Germany a young person with CP will typically be prescribed physiotherapy as soon as developmental delay has been identified. Physiotherapy practices that have qualified Bobath or Vojta trained physiotherapists are available to parents and their children. Schools for children with special needs usually continue to care for children with cerebral palsy once they reach school age.

Young people with CP are likely to have experienced conservative and surgical treatment by the time they reach adulthood. Conservative treatment most commonly includes physiotherapy, occupational, speech and language therapy, botulinum toxin injections and orthotics.

The pathways of care that the participants are most likely to have experienced will be described and the evidence that supports their use will be evaluated.

2.7 Conservative management and treatment interventions

There are many different conceptual approaches used by therapists to treat young people with CP but the Bobath Concept (Butler and Darrah 2001) or Neurodevelopmental (ND) and Vojta therapy (Feldkamp et al. 1989) are the only ones recognised by the German Health Insurance. Therefore young people at ICP are most likely to have experienced either of these or possibly both by the time they leave school. Many other treatment concepts are available but they are provided on a private and self financing basis.

The evidence base of these concepts is inconclusive although they all have the same aim which is to maximize motor development, improve function and posture. There is however, evidence to support other forms of physiotherapeutic interventions including postural management (Pountney et al. 2000) and muscle strengthening (Bryant et al. 2012) in the management of people with CP.

Other approaches that many young people are likely to have experienced include botulinum toxin injections, orthotics and orthopaedic surgery but evidence for these and other interventions is also inconclusive and this impedes the provision of evidence based guidance to the most appropriate pathway of care (Paul et al. 2007).

2.7.1 Neurodevelopmental/ Bobath Therapy

Neurodevelopmental therapy or the ‘Bobath Concept’ is probably the most widely used and best known form of treatment for children and adults with CP in Germany. The Bobath concept is well known by health professionals and by parents with children with cerebral palsy. It is considered to be an important treatment approach for children with CP (Tsorlakis et al. 2004) yet there appears to be confusion among therapists, doctors, researchers and parents as to what the concept actually is (Mayston 2008). It is practiced differently throughout the world and also nationally.

Mayston (2008) suggested that the confusion and differences of teaching are due to modifications and changes to the concept facilitated by the development of new

understanding of motor control and Central Nervous System diseases which are not necessarily interpreted in the same way amongst Bobath tutors and clinical physiotherapists. A brief explanation of the initial Bobath concept will be given followed by the changes that have occurred and the concept as it is considered today.

The Bobath concept was developed during the 1940s by Berta and Karel Bobath, a physiotherapist and neuropsychiatrist. It was developed on the understanding that the dysfunction of the Central Nervous System in children with CP resulted in abnormal motor development and function. Their goal was to achieve normal motor development and function and the prevention of contractures and deformities. The treatment approach 'focused on sensorimotor components of muscle tone, reflexes, and abnormal movement patterns, postural control, sensation, perception and memory' (Butler and Darrah 2001). Children were treated by inhibiting their spasticity and abnormal reflexes thereby preventing abnormal movement patterns and facilitating normal development.

Mayston (2008) has summarised and interpreted the concept as it is widely used today. Two important elements are that the Central Nervous System is only one system of many that influence motor control (Butler and Darrah 2001) and that a person should be actively involved with their management and achieve participation in everyday life. The level of participation and independence will vary for different people with their individual wishes and abilities.

Treatment to achieve the aims includes suppressing abnormal and atypical patterns of coordination and movement and normalising or improving muscle activity. In addition it is also widely agreed that other types of intervention including muscle strengthening (McNee et al. 2009), fitness (Fowler et al. 2007) and postural management (Pountney et al. 2000) are necessary to achieve the aims of treatment. Postural management uses specialised postural management equipment to provide adequate support in lying, sitting and standing to achieve active movement, function and participation, maintain muscle length and thereby preventing or reducing the incidence of contractures and deformities (Gericke 2006).

Despite the widespread use of the Bobath Concept, Butler and Darrah (2001) were unable to find conclusive evidence of the effectiveness of this treatment approach in literature reported between the periods 1956 to 2001. The research during this period was criticised for small sample sizes and that the participant characteristics were not comparable between studies. The validity and sensitivity of the outcome measures used to detect change was also questioned. Since then there have been many studies looking into the efficacy of the Bobath Concept. These range from the effects of intensive Bobath treatment (Tsorlakis et al. 2004; Knox and Evans 2002; Trahan and Malouin 2002) to a comparison between Bobath and Adeli Suit, which is another form of treatment for CP (Bar-Haim et al. 2006).

Intensive Bobath treatment has been shown to be more effective than non intensive Bobath treatment in a number of studies (Tsorlakis et al. 2004; Knox and Evans 2002) but the use of different method designs, outcome measures and small sample sizes make comparisons and conclusions difficult. It also does not report on the efficacy of Bobath over other treatment concepts. While the study comparing Adeli Suit treatment to Bobath treatment (Bar-Haim et al. 2006) produced inconclusive results, many of the treatment ideas of Bobath and Adeli are similar which might have influenced the outcomes.

There is evidence in non core elements of Bobath that postural management can reduce hip deformity (Pountney et al. 2009) and muscle strengthening programmes can improve gross motor function (Bryant et al. 2012). However, to date there has not been any qualitative research regarding the effectiveness of the Bobath concept although from the researcher's clinical experience, participants report that their therapy is important and deterioration in mobility is reported after long holiday breaks.

Quantitative research may not be the most appropriate method to measure the effectiveness of physiotherapy treatments. Rosenbaum (2007) commented on the results of a randomised controlled trial which looked at the impact of therapeutic horse riding on the quality of life, health, and function on people with CP. The results did not show a significant benefit but Rosenbaum questioned whether it was necessary to always have statistical evidence of benefit for an activity that people

want to do. He suggested that it would be useful to find out the experiences of the riders and their parents through qualitative research. This approach would also be relevant to evaluate the Bobath approach in more detail.

2.7.2 Vojta Therapy

Another form of therapy was developed in the 1950's by Prof. Dr. V. Vojta. The principles of Vojta therapy are to facilitate the automatic regulation or control of the body's position, to facilitate the active maintenance of the support function of the extremities and to stimulate coordinated muscle activity (International Vojta Gesellschaft e.V). This is achieved by eliciting reflexes (Reflexlocomotion) from the child or adult in specific positions. Pressure is applied to local body points to achieve a movement. This is considered to be same as the physiological movement seen in children developing normally (von Aufschnaiter 1989). For example, eliciting hip and knee flexion in a prone position can be the focus of treatment to achieve the prerequisites for crawling. Parents are expected to carry out the therapy several times a day although many parents find this intensity of treatment difficult to sustain and later change to another form of therapy. In addition young children frequently cry during treatment which is difficult for parents to experience unless they are convinced by the treatment concept.

The Vojta concept is well known in Germany and many physiotherapists choose to gain training and expertise in this. However, there do not appear to be any published studies on children or adults with CP looking at the efficacy of this treatment.

2.7.3 Botulinum toxin

Botulinum toxin (Botox) was first used in humans in 1980 and its use has since been expanded and is now used as an adjunct to physiotherapeutic treatment for people with CP. The use of Botox aims to reduce spasticity and thereby assist with the effectiveness of muscle strengthening regimes, reduce contractures, hip deformities and pain and improve function (Simpson et al. 2008).

Botulinum toxins are proteins from bacterium. There are 7 different types (A-G) of which A is the most potent and most frequently used in the treatment of spastic muscles of people with CP (Forsberg and Tedroff 1997). The action of Botox is to

cause a selective and temporary chemical denervation of the muscle (Molenaers et al. 2006) by preventing the release of acetylcholine vesicles at the neuromuscular junction (Forsberg and Tedroff 1997).

A review of the available literature investigating the effectiveness of Botox for the treatment of children and adults with CP between 1993 and 1997 found only 7 articles and a large number of abstracts (Forsberg and Tedroff 1997). An evaluation of the articles suggests that research was not well designed or conducted and as such the results could not advocate its use for this client group. One of the main criticisms was that the studies failed to assess the effect of Botox on muscle tone using valid methods. Recommendations were that gait analysis and Gross Motor Function Measure and a precise measurement of range of movement should be used to measure outcome.

A more recent review of the literature for exploring the use of Botox A for adult spasticity and spasticity in paediatric CP suggested that a reduction in muscle tone was demonstrated in some cases but it was not always measured with the use of gait analysis or other valid functional measures (Simpson 2008). However, the statistical results were not identified as being significant. An improvement in gait was observed after injections into gastrocnemius for spastic equines, however no details of which elements of gait had improved were included.

Other studies have explored different uses of Botox in the treatment and management of CP. Graham et al. (2008) reported that although Botox to the hip adductors and hamstrings at 6 month intervals for a period of 3 years and abduction hip bracing showed some reduction in the rate of hip displacement in children with CP the results were not significant. Barwood et al. (2000) looked at the analgesic effects of Botox and reported encouraging findings. They found in a sample of 16 children with spastic CP with a mean age of 4.7 that there was 74% reduction in post operative pain following adductor lengthening ($p < 0.003$) if they had received Botox preoperatively. In these cases 50 % less analgesic was used ($p < 0.005$) compared to a placebo group.

Lundy et al. (2009) also found that Botox could be effective in the treatment of pain. A sample of 26 children between 2 and 19 years (mean 11y 6m) with severe spastic CP (GMFCS V) was taken to evaluate the use of Botox in reducing pain. All of the participants had hip pain and 13 had either a subluxed or dislocated hip. At 3 months after Botox injections into the adductor magnus, medial hamstrings and iliopsoas muscle groups there was a significant improvement in pain ($p < 0.001$). Pain was measured by the Paediatric Pain Profile which was developed for assessing pain in children with more severe involvement.

Following the literature review, Simpson et al. (2008) recommended that Botox be used for equinus varus deformity, for treating adductor spasticity and for post operative pain following adductor lengthening surgery. The significant results in the study by Lundy et al. (2009) indicated that Botox should also be considered for children with hip pain.

If Botox is used on carefully selected children with CP it can play a significant role in the reduction of pain and spasticity. As with many other interventions there are no long term studies that evaluate this intervention in relation to function. Tedroff et al. (2009) reported that muscle tone could be reduced long term, although the longest follow up time was just 3 years and 7 months, but that it did not improve range of movement. They expressed concerns about the effect of Botox on muscle morphology and that it might in fact have an adverse effect on muscle growth in children with CP.

2.7.4 Orthotics

The International Society of Prosthetics and Orthotics has identified aims of lower limb orthotic management of CP (Morris 2002). The first aim is related to the impairment level or body structures and is to correct or prevent deformity. The other aim is to improve functional ability by providing a stable base of support, facilitating training skills and improving the efficiency of gait. It is recommended that the level of GMFCS is considered to provide the most appropriate orthotic management. This recognizes that children at different levels have different requirements to be able to reach their goals.

The results of a meta-analysis of spatiotemporal measures to evaluate interventions to improve gait in cerebral palsy concluded that orthotics may result in a small increase in range of movement and thereby increasing gait velocity (Paul et al. 2007). There is however, no evidence to support the use of orthotics to improve function or participation and none of the studies included the opinions from the users. Although there are guidelines to assist in choosing the most appropriate orthoses, Morris et al. (2002) identified that the types of orthoses prescribed for children with CP varied across health districts. Clinicians reported confusion when prescribing orthoses and in particular ankle foot orthoses. Confusion as to the most appropriate orthotic for a child has also been identified at the centre of this research. The lack of evidence based research comparing the short and long term outcomes of various orthoses for a homogeneous group of children with CP and the different products available perpetuate this problem. Research therefore needs to be undertaken to assess whether the orthoses meet the aims that they are meant to fulfill.

The development of contractures in the lower extremities of children with CP is a common problem which can affect function. This has been discussed in Chapter 2.5.1. The use of splints and passive and active stretching have been shown to play an important role in neuro rehabilitation. A questionnaire sent out and completed by 26 Canadian rehabilitation centres who treat children with CP established that 25% of the physiotherapists time was spent stretching and teaching others how to stretch (Newman et al. 2006). Stretching in particular in the form of night splints plays an important role at the centre of research and has been used for over 50 years as an adjunct to physiotherapy and surgery. The aim of night splints is to produce a long sustained passive stretch primarily to reduce spasticity and thereby prevent, correct or reduce the risk of contractures (Stotz and Müller, 1973).

There are a number of reviews investigating the effectiveness of stretching in people with neurological conditions (Katalinic, et al. 2011; Teplicky, et al. 2002) and more specifically children with cerebral palsy (Pin, et al. 2006; Wiart, et al. 2008). Evidence of the efficacy of hand and foot splints worn during the night was included but there appears to be no research investigating full leg night splints. This indicates that this form of management of young people with cerebral palsy is probably not

common practice. This is confirmed by colleagues working with children and young adults with cerebral palsy in the UK.

The only research that was found which investigated the effects of night splints in the management of children with cerebral palsy was that published by Stotz and Müller (1973). The electromyography (EMG) of triceps surae and tibialis anterior was measured and it was demonstrated that spasticity could be reduced significantly over a period of 40 minutes with night splints and continued to show a reduced level of EMG for a 40 minute period after the splints had been removed. This sample however, was small with 15 children with cerebral palsy of varying levels of spasticity and functional ability. In addition the measures were made over a 120 minute period of which only 40 minutes were wearing the night splints which does not resemble practice. The aim is usually for the children to wear the splints for a large part of the night. A reduction in spasticity was assumed by Stotz and Müller (1973) to reduce muscle stiffness and prevent contractures. However, this was not evaluated. This assumption has provided the basis for the use of night splints at the centre of research.

A systematic review on the effectiveness of passive stretching in children with cerebral palsy (Pin et al 2006) found evidence that supports the work by Stotz and Müller (1973). All of the 4 studies that were included in the review that investigated the change in spasticity following stretch showed a reduction in spasticity. The interventions were however, all different and ranged from passive stretch to the use of a tilt table and the effect sizes were small. There was no evidence of carry over into functional activities.

A more recent systematic review by Katalinic (2011) included research that evaluated the use of casts to stretch muscles and prevent contractures in people with neurological conditions. Out of all the methods of stretching the use of casts most closely represent night splints. There were two studies (Ackman et al. 2005; McNee et al. 2009) that used casts for children with cerebral palsy. Ackman et al. (2005) compared treatment of two sample groups using either Botox or Botox and casts to the lower extremities. They showed that the combination of casts and Botox was effective in increasing the muscle length of gastrocnemius for up to 3 months

following treatment and that there was a reduction in spasticity in gastrocnemius for up to 12 months. McNee et al. (2009) who aimed to improve an equines gait pattern using serial casting found that the small increases in range of movement were short term and are not enough to improve function. They did not however test for a change in spasticity. Casting however, does not represent present practice in Germany where long leg night splints are frequently prescribed for children who are at risk of contractures.

2.7.5 Summary

Critical evaluation of the three physiotherapeutic concepts and other conservative approaches that are used to treat children and adults with CP highlights that there is very little significant evidence that supports these treatment approaches. There is also a dearth of qualitative literature and research designs in this field.

2.8 Surgical procedures

Surgery to the lower extremities is usually performed to improve gait and function (Abel et al. 2003) or to prevent or restore hip dislocation (Scrutton et al. 2001). This represents past and current practice. It is either performed at single level which is generally to lengthen shortened muscles or single event multi level surgery where the muscles over more than one level are lengthened and if necessary the bones are realigned to enable the muscles to work more efficiently (Abel et al. 1999). Multi level surgery can reduce the number of separate surgical procedures that are required and minimize the post operative rehabilitation (Seniorou et al. 2007).

Fixsen (1989) divided possible surgical procedures into those performed at hip, knee and foot level and recommended that the surgery performed at these levels should be influenced by the functional ability of the subject.

However, evidence supporting the most effective procedure is equivocal. Fixsen (1989) and other authors (Chambers 2001; Lofterod et al. 2008 and Zwick et al. 2001) stress the importance of gait analysis and that patients, parents, therapists and surgeons all work together to identify realistic goals. In clinical practice, this is not always achieved.

2.8.1 Multi level surgery

Evans (2004) reviewed the available research involving single-event multi level surgery for people with CP and concluded that there is little evidence to prove its short or long term efficacy. More recently McGinley et al (2012), in a systematic review, identified some research which reported on short term benefits of multi level surgery (Gough et al. 2008; Schwartz et al. 2004; Saraph et al. 2002) but emphasized the necessity of evaluating outcomes to include global changes such as happiness and well-being.

Included in the systematic review (McGinley et al. 2012) was a study by Gough et al. (2008) who compared children who had multi level surgery and those who did not have surgery. The sample size of 24 was small and all the children were under 7 years of age. Thirteen children had multi level surgery and they had 2 follow up gait analyses at yearly intervals. The 11 who had not had surgery but had been recommended for surgery had a follow up gait analysis at a mean of 1.5 years. It was found that elements of gait had improved in the surgical group but had deteriorated in the non surgical group. Other research by Schwartz et al. (2004), who followed 135 children for between 8 and 24 months, also demonstrated short term benefits of multi level surgery on gait patterns. A general improvement in gait velocity, stride length and decrease in cadence was found in a study by Saraph et al. (2005). They followed up 32 children with diplegia with a mean age of 11 years for a mean period of 4.4 years, after multi level surgery.

Research demonstrates that some short term improvements in gait may be expected in children who have multi level surgery. However, it does not show whether this is maintained as they mature into adolescence and adulthood.

Recently Gannotti et al. (2010) looked at changes in walking abilities of 11 young adults and adolescents with CP after multilevel surgery. This was a long term study with the follow up between 11 and 15 years after surgery (mean 13 years). The participants had a mean age of 25 years at the last follow up. The results showed that there was an initial improvement in gait in 6/11 participants, no change in 4/11 and a deterioration in 1/11. Long term however, 4/11 maintained the improvement, 6/11 had returned to the preoperative status and 1/11 was worse than the pre operative

level. This was a very small study but it suggests that multilevel surgery was only successful in terms of an improvement in gait in 36% of the sample.

Dreher et al. (2012) also identified that surgery can have poor long term outcomes as measured by various gait parameters. A 10 year retrospective study of ambulant children with cerebral palsy who had undergone single event multilevel surgery that related specifically to hamstring lengthening, found that there was a significant deterioration in a number of gait parameters long term. Short term findings showed significant improvements in gait parameters. This is consistent with other research investigating short term outcomes (Schwartz et al. 2004).

Muscle weakness has been suggested as a reason for deterioration in gait (Ross and Engsborg 2007) but it is also known that muscles weaken following surgery (Seniorou et al. 2007). Seniorou et al. (2007) found that there was a significant reduction in muscle strength ($p < 0.05$) in all muscle groups of 20 ambulant children (mean age 12.5 years) with CP 6 months after multi level surgery. The 12 month post surgery measure suggested that intensive physiotherapy helped improve strength. However, the pre operative values for the hip and knee flexors and the hip extensors were not achieved. Moreover, the pre operative level of motor function was also not achieved. To date there are no studies that have evaluated the long term effects of surgery on muscle strength or to evaluate long term changes in muscle strength following surgery in non ambulant children with CP.

Gait analysis is most frequently chosen to evaluate outcome. It provides objective results but improvements to some elements of gait do not necessarily correlate to an improvement in function (Bjornson 2007; Abel et al. 2003), participation or quality of life (Rosenbaum et al. 2007; McGinley et al. 2012). Indeed Rosenbaum et al. (2007) found that youths and their parents did not primarily correlate quality of life with functional abilities. In addition, from clinical experience children who are non ambulant also experience multi level surgery to improve function. There are no studies that evaluate functional outcome of young people who had multi level surgery as children and who were non ambulant.

2.8.2 Single level surgery

Surgery that is most frequently considered to improve ‘stiff knee gait’ is either distal release or distal transfer of rectus femorus (Öunpuu et al. 1993). Transfer to the distal medial hamstrings reduces the extensor activity during the swing phase of gait and allows it to act as a knee flexor (Hemo et al. 2007). The outcomes of various studies have been reported to be inconsistent and difficult to compare due to the different outcome measures used, different sample sizes and different sample populations between groups under investigation (Reinbolt et al. 2009). In a small study with 13 children one group had 6/7 who had a spastic diplegia and 1/7 with quadriplegia whereas in the comparison group 4/6 had quadriplegia and 2/6 diplegia (Hemo et al. 2007). In addition they all had experienced other surgical interventions previously which could also affect the results. Öunpuu et al. (1993) found in a study of 98 children with CP that a transfer was preferable over distal release if the available motion at the knee is less than 80%. The long term results of these procedures are not yet known.

Crouch gait which has been described in Chapter 2.5.5, can be treated surgically by a distal release of the hamstrings using a release of the gracilis and semitendinosus and lengthening of the semimembranosus on the medial side and if necessary a lengthening of biceps femoris on the lateral side (Fixsen 1989). Evidence evaluating this procedure is limited (Chambers et al. 2001).

Stout et al. (2008) evaluated a different surgical procedure which involved distal femoral extension and or patellar tendon advancement to reduce knee flexion contracture and improve quadriceps sufficiency in a sample of 73 ambulant people with cerebral palsy. 16/73 had undergone distal femoral extension osteotomy only, 33/73 had distal femoral extension osteotomy and patellar advancement and 24/73 patellar tendon advancement only. Subjects had pre and post operative gait analysis. The subjects were followed up to 36 months after surgery making it a short term study. 93% of the sample had had previous surgery which confirms Chambers (2001) observation that crouch gait is mainly a result of previous surgery. The results showed that the combination of distal femoral extension osteotomy and patellar advancement is necessary to improve the static knee flexion contracture and improve dynamic quadriceps sufficiency.

An 'apparent' equinus deformity refers to a gait pattern where toe contact precedes heel contact due to either a dynamic or fixed knee flexion. It is common in ambulant children with spastic bilateral CP but should not be treated by surgically lengthening tendo achilles as this procedure can result in over lengthened tendo achilles which can result in a typical 'crouch gait' (Fixsen 1989; Chambers 2001). For a true equinus deformity however, tendo achilles lengthening is recommended (Chambers 2001). There is no long term evidence available to support this procedure.

The evidence for single and multi level surgery is limited to evaluations of the pre and post operative assessments for a specific procedure and not on comparisons between the effectiveness of single surgery on one sample of participants and multi-level surgery on a comparable sample. However work by Damiano et al. (1999) looked at muscle strength and gait following single level surgery (hamstring lengthening) and more recent work by Seniorou et al. (2007) who also reported on muscle strength following multi-level surgery.

Damiano et al. (1999) and Seniorou et al. (2007) both recruited 20 children with diplegia who had a mean age of 8.51 and 12.5 years respectively. The final follow up reported by Damiano et al. (1999) was 9 months post surgery and the results indicated that gait and hamstring strength deteriorated post operatively but by 9 months the values had reached the pre operative values. The study by Seniorou et al. (2007) which followed the sample up to 12 months following surgery reported that muscles remained weak up to a year post multi-level surgery indicating that the level of recovery was quicker following single level surgery. However, long term results and larger sample sizes are needed to be able to compare the efficacy of the two procedures.

There is insufficient evidence on which to base surgery to the lower extremities for long term improvement of walking ability. Surgery to improve gait most frequently involves lengthening shortened muscle. The resulting short term gait pattern improvements may however not be advantageous in improving gait patterns long term (McGinley et al. 2012). Physiotherapists therefore need to be aware of the different surgical procedures and how they might influence the gait pattern post operatively to be able to make an informed decision when discussing the possible

longer term pathways of care with the young person, his parents and other health professionals.

2.8.3 Possible effects of surgery on gait patterns

In Chapter 2.5.5 typical gait patterns that people with cerebral palsy may develop were described. The possible effects of surgery that is frequently performed to correct this will be analyzed.

As described in Chapter 2.5.5 over activity and contracture of the hamstrings is a frequent presentation of people with spastic bilateral cerebral palsy. It is likely to result in a 'crouch gait'. The effect of this on the specific phases of the gait cycle has been identified (Perry 1992). Due to excessive knee flexion initial contact is made with the forefoot and the heel is raised although there is minimal plantar flexion. The excessive knee flexion remains during loading response. There is a premature rise of the heel during mid stance. Stability is lost in terminal stance as the body moves ahead of the forefoot support. Excessive heel rise, plantar flexion, increased knee flexion and a posterior-lateral pelvic drop is evident. 60 degrees knee flexion is required at initial swing but this tends to remain throughout mid swing where only 25 degrees is required. Thus by terminal swing there is inadequate knee extension.

Lengthening of the hamstrings continues to be a standard surgical procedure to reduce excessive knee flexion (Dreher et al. 2012). However, this can also reduce the strength of the knee flexors and for the lengthening to have a positive effect on the gait pattern quadriceps must be strong enough to produce adequate knee extension and stability. Inadequate flexion due to muscle weakness or an inability passively to flex the knee due to spasticity in the quadriceps can affect the loading response, pre swing, initial and mid swing phases of gait. Normally forty degrees of passive knee flexion is required in the pre swing phase. However, in people with CP this may be prevented by spasticity in the knee extensors which can have the effect that the ankle is dorsiflexed instead of achieving 15 degrees plantarflexion. Heel contact is prolonged into initial swing and a lack of knee flexion, which in a normal gait pattern reaches 60 degrees, can contribute to toe drag. This must then be compensated by increasing active hip flexion if possible or laterally tilting the pelvis and circumducting the hip. This gait pattern that might be adopted as a result of surgery

to lengthen the hamstrings may not be preferable to the crouch gait and indeed may be the cause for a scoliosis developing as a result of the compensatory mechanisms. Muscle weakness is a well known impairment in people with CP (Seniorou et al. 2007). Lengthening the hamstrings would give the knee extensors the prerequisite to function but they may have insufficient strength to improve gait and may in fact result in another compensatory mechanism which may not necessarily be more efficient than the pre operative gait pattern. The quadriceps is active during the phase of initial contact, loading response and terminal swing. In terminal swing they work to produce full knee extension. In the other phases there is some degree of knee flexion and the main role of quadriceps is to give stability around the knee. Therefore weakness can cause excessive knee flexion or hyperextension of the knee joint which is commonly seen in people with cerebral palsy. The effect that this has on the complete gait pattern has already been discussed.

In addition to excessive knee flexion, a common characteristic of a crouch gait is excessive hip flexion, medial rotation and adduction (Chambers 2001). This can be due to either an over activity of the hip flexors as a result of spasticity, contracture of the hip flexors, muscle weakness of the hip extensors, pain and hip arthrodesis (Perry 1992). From clinical experience it is frequently a combination of spasticity, contractures and muscle weakness that result in excessive hip flexion or lack of hip extension. The main hip flexors are psoas major, and iliacus with rectus femoris, tensor faciae latae, sartorius and pectineus. The hip extensors in the mid range of movement are largely the hamstrings with activity from gluteus maximus at the extremes of movement. Semimembranosus and semitendinosus are largely responsible for medial rotation at the hip.

Hip extension is required mostly in the phases mid stance and terminal stance. If this is inadequate the centre of gravity moves forward resulting in postural instability. Compensatory mechanisms to realign the body segments result in a lumbar lordosis which is especially seen in children (Dreher et al. 2012). If this is not adequate to provide sufficient stability greater extensor muscle activity is required. This is usually not available and realignment can be achieved by flexing the knees although this in turn requires an increase in quadriceps activity. Compensation is also seen with excessive ankle dorsiflexion or a raise of the heel. All of these elements

contribute to the development of a crouch position. On examination knee flexion might be identified as the main problem with a recommendation for lengthening the hamstrings (Chambers 2001).

Lengthening the hip flexors and hamstrings would bring about a realignment of the body segments. However, this would necessitate greater activity of the hip extensors which are the hamstrings together with gluteus maximus. Surgery could therefore result in achieving straight limbs but due to the possible weakness of the hamstrings it could also have a negative impact on postural stability and result in a further increase in knee flexion. At this stage an orthosis is most likely required to support the tibia to prevent forward collapse (Perry 1992).

Lengthening the hamstrings would also reduce medial rotation. However, in addition to being medial rotators as has been mentioned they are also flexors at the knee and extensors at the hip when the knee is extended while walking. Lengthening, and most probably thereby weakening the medial rotators of the hip, would also have the consequence of weakening the extensors of the hip.

Active excessive hip flexion is a compensatory mechanism in order to clear the foot with inadequate dorsiflexion. Other compensatory gait patterns can develop in people with cerebral palsy and surgery is frequently suggested and performed to endeavor to rectify the abnormality. However, by taking 'crouch' gait as an example and examining in detail not only the deviations from the normal but also the possible effects of trying to rectify it, it can be seen that surgery might not be the best intervention to improve gait. Altering one part of the gait cycle will alter the whole gait pattern. It is unrealistic therefore that surgery can restore balance to the complete gait cycle.

Single level surgery is not performed exclusively to improve gait and function but also for preventing or reducing hip displacement. The procedures for single level surgery for hip displacement are dependent on the severity of the displacement. Surgery can be considered as preventative, reconstructive or salvage. Hip surveillance clinics have been set up with the aim to prevent hip dislocation through preventative surgery (Hägglund et al. 2005; Dobson et al. 2002). In surveillance

reports (Hägglund et al. 2005; Dobson et al; 2002) three different levels of hip surgery were recommended. Preventative surgery is performed with a migration of > 40 %, an increase of migration of >10% in one year or an acetabular index of 27°. Reconstructive surgery was indicated with a migration of >50 % and increasing and salvage surgery is performed when other treatment fails.

2.8.4 Preventative (soft tissue) surgery

There are a number of different possible preventative surgical procedures which include Adductor Longus, Gracilis and Adductor brevis releases, Iliopsoas lengthening and Obturator neurectomy of the anterior branch (Dobson et al. 2002).

Whilst it is generally agreed that surgery is required for treating painful hip subluxation or dislocation (Cooperman et al. 1987) there is less agreement about the treatment of painless hip dislocation or progressive subluxation (Noonan et al. 2004). Preventing hip dislocation through surveillance, postural management and surgery has reduced the number of incidences of hip dislocation short term. It is however disputed whether soft tissue surgery, which is performed in preventative management, can reduce the incidence of subluxation and dislocation of hips long term and thereby reduce the prevalence of pain.

An evaluation of 10 years hip surveillance (Hägglund et al. 2005) has shown that the occurrence of hip dislocation dramatically reduces when preventative surgery is performed early. Hägglund et al. (2005) found that none of the children (206) who were in the hip surveillance clinic developed a dislocated hip compared to 8 of 103 children in the control group with comparable level of involvement. The reduction of incidence of dislocation was significant at $p < 0.001$. Dobson et al. (2002) reported their outcomes in relation to the number and type of surgical procedures that were necessary over the study period of 3 years. They found that the number of preventative procedures rose from 36 to 61, the number of reconstructive procedures reduced by 1 from 26 to 25 and salvage operations reduced from 8 to 0. Neither study however, gives long term results of the preventative surgery and whether hip surveillance prevents hip dislocation long term into adulthood. Hägglund et al. (2005) had a maximum follow up of 7 years and to age 11 years and Dobson et al. (2002) followed his sample for 3 years and up to age 7 years. It would also be

important to know how often surgery needs to be performed to prevent hip dislocation in adults as surgery itself can bring disruption to family life (Pountney and Green 2006), pain (Dobson et al. 2002), muscle weakness (Seniorou et al. 2007) and loss of function. It should also be noted that the reports from the surveillance clinics however, did not include the prevalence of pain.

Other studies have reported on the efficacy of soft tissue or preventative surgery. Stott and Piedrahita (2004) wrote an evidence report about the effects of surgical releases for hip subluxation in CP. They found that although almost all studies showed successful outcomes following adductor releases if they were performed with a migration of 30-40% there was a low body of evidence, the samples were small, the results were short term, and there were different sample groups and different procedures that made comparisons difficult. There were no control groups which Stott and Piedrahita (2004) suggested were necessary because subluxed hips do not necessarily lead to dislocation.

A more recent retrospective long term study by Morton et al. (2006) of 110 participants over 10 years followed the progression of hip dislocation in relation to treatment. From their sample, of those who had preventative surgery, 21% proceeded to dislocation. In a very recent retrospective study (Shore et al. 2012) of 330 children with cerebral palsy, of whom 73% were non ambulatory with GMFCS levels of IV-V, it was found that the results for these non ambulatory children were poor. After a mean of 7.1 years post surgery 27% of children with a GMFCS level IV had not had subsequent surgery and the hips had a migration of < 50%. This was considered to be a successful outcome. For children with a GMFCS V the success was less, with only 14% meeting this criterion.

Additional long term results are necessary to evaluate whether the increase of preventative surgery (Dobson et al. 2002) is justified to reduce the incidence of hip dislocation and subsequent salvage operations. The inconclusive results from the evidence report and short term results from the surveillance clinics suggest that although the incidence of hip dislocation appears to reduce with preventative surgery there is no conclusive evidence whether adductor releases do prevent hip subluxation. Indeed recent research (Shore et al. 2012) indicates adductor surgery for

non ambulant children does not prevent dislocation and further surgery long term. Moreover, in the effort to reduce hip dislocation it is possible that a child will have a number of hip operations and it is not clear whether the results are better than carefully managed non operated hips.

Pountney et al. (2009) in a prospective study followed 39 children with CP who were 18 months or less at the beginning of the study. These children received postural management in lying, sitting and standing (Pountney et al. 2000) and were reviewed on a three monthly basis until they were five years old. The control group were children taken from the research by Scrutton et al. (2001) who recruited and reported on the development of the hips of 202 children with CP between 18 months and 5 years. The results showed significant differences in outcome of hip problems between those who had received postural management and the control group. The intervention group had significantly less surgery, botulinum toxin or orthotics ($p= 0.001$) than the control group. These results suggest that children who are at risk of hip displacement should receive postural management which may improve long term outcomes of hips in adults with a reduced need for surgery.

2.8.5 Reconstructive Surgery

Procedures for reconstructive surgery include femoral varus derotation osteotomy, pelvis and a combined femoral and pelvis osteotomy (Dobson et al. 2002). These procedures will be considered if preventative surgery has failed or if hip displacement has been overseen and has subsequently progressed to >50%.

Preventing further deterioration of hip migration is considered important as this can be a cause of hip pain, a deterioration of sitting balance and other functional abilities and difficulty of access for personal care (Dobson et al. 2002). There is however limited agreement in the prevalence of hip pain in people with CP. It is difficult to compare the available research due to different research designs, different sample sizes and the method of collecting information about pain. This has ranged from interviews (Cooperman et al. 1987) and questionnaires (Boldingh et al. 2005) with the participants to questionnaires with the carers (Hodgkinson 2001 and Noonan et al. 2004).

Cooperman et al. (1987) reported that untreated hip dislocation is a source of pain and disability in about 50% of patients. This finding was later endorsed by Hodgkinson et al. (2001) from a sample of 234. They suggested that the prevalence of hip pain in non ambulatory adults (mean age 27 years and 10 months) with CP was high (47.2%). Hip dislocation was found however, to be not the only reason for hip pain. 22% of the sample reported pain but had a hip migration of $<30^\circ$. Hip pain was reported for example during physiotherapy or specific movements or if the position had not been changed for a period of time. It was not reported whether the participants who complained of pain had experienced surgery to their hips or whether they were untreated hips. In an earlier study Bagg et al. (1993) reported from the results of a retrospective study of 45 participants (mean age 26 years) with a hip migration index of between 33% and 75% that participants with dislocated hips had significantly ($p < 0.005$) more pain than people with either subluxed or reduced hips.

Noonan et al. (2004) however reported that the prevalence of hip pain is low. Reporting from the results of a sample of 77 adults (mean age 40 years) with severe CP they found that only 18% of hips were definitely painful and that pain was not directly associated with hip displacement. Despite this, these results should be treated with caution because the results were obtained from interviews with the primary caregivers who might not give an accurate estimate of the true level of pain experienced by people with severe CP.

Although studies reporting hip pain do not agree on its prevalence the results do suggest that hip pain can result following hip subluxation or dislocation and is a frequently occurring secondary problem for people with CP. Preventing hip pain through hip surveillance clinics is considered preferential over reconstructive or salvage surgery (Hägglund et al. 2005). There are however studies that report that both soft tissue (preventative) and bony surgery (reconstructive/ salvage) can reduce the prevalence of hip pain.

Boldingh et al. (2005) reported on the outcomes of a sample of 160 adults (mean 36 years) with severe CP. Of the 160 participants 53 (33%) had surgery due to pain with 24 having soft tissue and 29 having bone surgery. The results of soft tissue surgery were comparable to bone surgery. Pain was reduced in 13/24 (54%) of those who had

soft tissue surgery and in 16/29 (55%) following bone surgery. This resulted in 24/160 (15%) who were left with residual hip pain. Surgery appears to have reduced pain in 33% of the participants to 15%. The results were supported by Owers et al. (2001) who reported that reconstructive surgery resulted in a reduction of pain by 85% for people with severe CP where their hips had a migration of >33%. All participants had bilateral simultaneous combined soft tissue and bony surgery. The sample consisted of 21 children with a mean age of 7.7 years who had a mean follow up of 3 years. Although 8 hips were subluxed or dislocated 85% of the people who reported pain preoperatively were free of pain. Only 2/13 participants reported pain which indicates a successful outcome of surgery.

There are no available studies that report on long term improvement in function or an improvement in maintaining personal hygiene following hip surgery. However, Noonan et al. (2001) reported on the success of reconstructive surgery in relation to the pre and post operative migration values. In a retrospective review of 65 participants (mean age 7.6 years) and a follow up after a mean of 5.2 years 79 hips had undergone varus osteotomies. Complete statistics were collected from 73 hips. Pre operatively 30 hips were dislocated (migration index greater than 90%) and 43 were subluxed (migration index of 35-89%). At follow up, 3 hips were dislocated, 18 were subluxed and 52 had a migration index of less than 35%. There were significantly less subluxed or dislocated hips ($p=0.002$) in the children who had surgery younger than 6 years compared to those older than 6 years.

Reconstructive surgery has been shown to improve hip pain and reduce the incidence of hip subluxation and hip dislocation at least short term.

2.8.6 Salvage Surgery

Unsuccessful preventative or reconstructive surgery where there are persistent problems with pain, seating and maintaining hygiene are likely to be reasons to do salvage surgery. Procedures for this include excision of the proximal femur, valgus osteotomy, interposition and replacement arthroplasty and arthrodesis (Dobson et al. 2002).

2.9 Summary

The secondary problems that frequently develop in young people with CP have been explained and the interventions that have been used and are presently available for people with CP have been critically reviewed. Evidence based research of the efficacy of surgical and conservative intervention is mainly inconclusive. Clinical experience in this field confirms these findings and it has identified that long term functional ability may be best achieved by following a conservative pathway of care.

Clinical experience also confirms evidence that people who have surgery may experience complications including pain, muscle weakness and a disruption to family life. These reasons, together with an absence of research which defines the requirements of people with cerebral palsy, have led me to pursue this research question.

2.10 Aims of research

The aims of this research were to develop an understanding of the experience of life of young people with cerebral palsy and also to map, describe and evaluate the type of treatment and management they had experienced. Additionally their current functional status, satisfaction with life, the prevalence of pain and long term functional changes was recorded. This enabled a comparison between those who had and those who had not experienced surgery to their lower extremities as children to be undertaken.

In order to be able to compare functional outcomes and also ‘personal experience’ the use of a mixed methodological approach was necessary. Whilst the quantitative outcome measures were sourced from notes and reviewing the participants, the ‘personal experiences’ data were sourced through in depth interviewing. This methodological design was a deliberate choice in order to be able completely to answer the research question under investigation.

2.11 Objectives of research

The objectives of this study were to identify any differences in long term functional ability, satisfaction of life, prevalence of pain and long term changes in function between young people who had experienced surgery to their lower limbs as children

and those who had not. In addition, with the use of semi structured interviews, the objectives were to gain an understanding from young people about their experiences of everyday life with cerebral palsy and their experiences and opinions about the different pathways of care that they had followed. The understanding gained from the participants by the researcher and the analyzed statistics will be used to provide young people, parents and health professionals information on which to base decisions regarding the most appropriate pathway of care.

2.12 Research question

The research questions were:-

1. Do young people with cerebral palsy who had experienced lower limb surgical intervention as part of their management have different long term functional outcomes and prevalence of pain to those young people who had experienced non-surgical interventions?
2. What impact did the different management approaches have on the satisfaction of life of the young people?

Chapter 3: Methodology

This chapter aims to provide the philosophical and practical reasoning behind the use of mixed methods that was chosen for this research. Whilst it is understood that research is usually reported in the third person it was decided that for this chapter on methodology and in particular when explaining personal standpoints that the use of the first person was more appropriate.

3.1 Introduction

This research follows a mixed method sequential explanatory design with the emphasis on the qualitative element. It is based on pragmatic philosophical assumptions and methods of inquiry.

There is literature that argues that the research question and the chosen method and analysis techniques are decided upon largely depending on the personal world perspective (Guba and Lincoln 1994). There is also literature which argues that the research question develops from the gap in knowledge in the area to be studied and that the methods and analysis chosen are the ones considered to be most suited to the question and the research design (Fidel 2008). I believe that both of these perspectives influence the question and research design. This will be discussed in more detail when I explain my worldviews and the influence this has had on my methodology and the chosen research design.

3.2 Worldviews

Worldviews (paradigm) contain a set of beliefs or assumptions that guide research which may change as a result of different life experiences (Guba and Lincoln 2005). My worldviews have shaped this research from defining the question through to the identification of the methods used and the analysis and interpretation of the data. It is therefore important to make explicit what I believe in order to understand the choices that I have made throughout the research. First I will review different worldviews and present their characteristics.

There are a range of main worldviews used in research including positivism/postpositivism, constructivism/interpretivism, advocacy, participation and

pragmatism (Creswell and Plano Clark 2007). The main worldviews have common elements including ontology (nature of reality), epistemology (how we gain knowledge of what we know), axiology (the role value plays in research), the process of research (methodology) and rhetoric (the language of research).

3.3 Ontology

The nature of reality and the structure of the world in which we live are interpreted by people differently. The different interpretations which range from single objective and predictable (positivists) to multiple social realities (constructivists) influence the methodology of the research (Guba and Lincoln 2005). A pragmatists' worldview is likely to be between that of a positivist and constructivist, which has been considered to be a realistic way of viewing the world (Morgan 2007). It is this view of being in the 'middle' (Johnson and Onwuegbuzie 2004) that I feel most comfortable with. As a pragmatist I have been able to collect data using the most appropriate methods to investigate the research question but which also reflect my worldview.

3.4 Epistemology

Epistemology is an area in philosophy that is concerned with the theory of knowledge. More specifically it addresses the questions about what knowledge is, how it is acquired and how do we know what we know. It is important for me to discuss my understanding of knowledge, or my epistemological stance, because this has influenced the area of work that has motivated me to study in more detail which has then influenced the research question. Furthermore my epistemological perspective has guided my methodology and methods for this research and influenced how I analyzed and interpreted the data.

The classical understanding of knowledge is that for someone to know something they must believe it is true and that what they believe to be true must be true and they must have valid justification for believing that something is true. This is known as propositional knowledge or 'knowing that'. Ryle (2000) acknowledged that there are other forms of knowledge such as 'know-how' knowledge. For example a clinical pathologist knows the procedures in order to look for certain cellular structures.

The epistemological perspective that someone takes is linked to their ontological view (Johnstone 2004; Guba and Lincoln 2005). A belief in a single reality supports a propositional view of knowledge. This results in a pursuit of objective and bias free research to be able to establish that x is a result of y. Not only is the subject of research and the environment to be free of bias regardless of whether it is an object or a human being but that the researcher is believed to be detached and free of bias from what is being researched. This is a positivist view point and results in quantitative methods of research.

An understanding of knowledge that considers that there is not only one truth, rather that there are multiple realities, and accepts and values 'know-how' and other forms of knowledge, is the basis of a constructivist's view point. In the research situation the researcher is understood to be subjective and can only be subjective due to all the influences, variables and biases that that person brings to a situation. In addition, to obtain knowledge other than propositional knowledge it is indeed necessary and advantageous that the researcher interacts with the participant in the study (Johnstone 2004). This results in a choice of qualitative methods of research.

A pragmatist however, believes that there are proportional and other forms of knowledge which give rise to single and multiple realities. The research question and the methods of research are those that are most suited to the subject to be examined. The pragmatist accepts therefore that it is possible, and sometimes necessary, to remove as much bias as possible while understanding that some bias and subjectivity is inevitable (Johnson and Onwuegbuzie 2004). Mixed methods are then considered to be the most suited to gain in depth knowledge of an area of interest.

I am a pragmatist and firmly believe that there are different forms of knowledge. Knowledge is possessed by everyone and it is not limited to beliefs that have to have valid justification that they are true. For example I do not believe that randomised trials are the only valid way to obtain knowledge in health care. My main aim of the research is to gain knowledge from people with CP in order to gain an insight into the experiences of different pathways of care that they have had. This could be used to expand the knowledge of health professionals who are involved in their care. Qualitative methods are the most appropriate for this, but because surgery is

normally performed to improve functional ability, I felt it important to measure the outcomes and used quantitative methods for this purpose. In addition, the medical profession in Germany continues to believe that propositional knowledge is superior over other forms of knowledge and considers randomised trials as the gold standard in research. Although I do not agree with this, I was interested to see whether it was possible to establish a quantifiable difference in the long term functional outcomes between the two different pathways of care. In addition, as it has already been mentioned, the results of the quantitative phase formed the basis of the qualitative phase.

3.5 Personal worldviews

When I entered physiotherapy in the mid 1980s the teaching, research and treatment was entrenched in post positivism and the medical model (Shepard et al. 1993). Whereas I believed that people were unique, I also believed that if research was to be of value, it had to be performed in a scientific way which removed the element of individuality. I seemed therefore to have conflicting worldviews.

Over the years, views of society have changed which in turn have influenced attitudes in the medical profession moving from the medical model to the social and bio- psychosocial models of disability. This has also influenced the type of research that is carried out to include qualitative research and mixed methods research. In addition and also because of the emergence of different types of research, physiotherapy treatment has become more holistic with the clients becoming equal parties with a recognized and important voice.

This development is very positive and one with which I feel very comfortable. Accepting people as unique individuals would suggest that I follow a constructivist's worldview point. However, I do believe that there are some areas of research that need to, and can, be looked at objectively and should follow a quantitative method. I see myself as having a bias towards constructivism but with an element of post positivism. I also believe that data should be collected by whatever method is best for the research question and this is inevitably influenced by the researchers' own world views. In this study standardized tests for the quantitative phase and semi structured interviews in the qualitative phase were considered to be the most appropriate. In

light of this I regard myself as a pragmatist and this has influenced and directed my research starting with my research question.

3.6 My role and position

My role within the organisation is Head Physiotherapist and I recognised that I would be undertaking the research from inside the organisation. It was therefore very important to explore the issues of 'Insider Researcher'.

3.6.1 Insider researcher

Conducting research as an 'insider' is considered to have both advantages and disadvantages for a study (Arksey and Knight 1999). For the purpose of this study the advantages were considered to be greater than the possible disadvantages.

An insider researcher could be considered by a positivist as a potential source of bias which is to be avoided. Concerns are that participants may respond to questions by giving information that they anticipate the researcher would like to hear. In addition the participants may have concerns about the consequences of their contributions which may result in communication of information that does not accurately represent the participants' experience or views. In addition it is considered that an insider researcher cannot be unbiased so that it is difficult to remain open to comments that are not expected and to formulate questions in order to gain information about all areas of the subject under investigation. This could result in reducing the validity of the research (Arksey and Knight 1999).

These are all valid arguments but it is not the intention of this research to attempt to gain an experimental situation where all possible variables and biases are removed. It is however, important for the researcher to be transparent about all aspects of the research process so that the reader can take this into consideration when forming their own understanding of the research (Hammersley 2000). A possible advantage however of an 'insider researcher' is that participants may talk with fewer inhibitions to someone they know. This may result in them sharing more rather than less of their experiences. In the case of this study, being an insider researcher made it easier to gain contact with the potential participants, set up a meeting to provide necessary information and make further appointments.

However, there are also some important ethical issues of being an ‘Insider Researcher’ which are discussed fully in Chapter 6.2.

3.7 Mixed methods

The name given to the use of both quantitative methods and qualitative methods in a research design has altered over the last 60 years. It has ranged from ‘integrated methods’ (Steckler et al. 1992), ‘mixed methodology’ (Tashakkori and Teddlie 1998) to ‘mixed methods’ which is the term chosen for this research. Johnson et al (2007) listed 19 different definitions of mixed methods. The definition that is most compliant with my understanding is that:

‘Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases of the research process.....Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone’ (Creswell and Plano Clark 2007 p.5).

Not only has the name changed over the years but mixed methods research is becoming increasingly used (Brannen 2005). However, there continue to be issues around the use of mixed methods in particular those related to the philosophical assumptions behind the use of mixed methods which will be discussed.

3.7.1. Paradigm wars

The belief that the choice of research method is dependent on the researcher’s philosophical assumptions or worldviews, has caused a debate or ‘paradigm war’ about the place of mixed methods in research. Quantitative research is associated with a positivist paradigm whereas qualitative research is associated with an interpretist or constructivist worldview. It has been disputed that these different research methods which are underpinned by different philosophical assumptions can be mixed (Howe 1988). On the other hand Bryman (1988) suggested that there was a clear connection between the two paradigms.

The debate continues but it is now widely accepted that pragmatism is the appropriate philosophical foundation for mixed methods research (Tashakkori and Teddlie 2003). Pragmatists understand that the type of research method chosen is influenced more by the research question than the worldview of the researcher which endorses the use of both quantitative and qualitative research methods (Creswell and Plano Clark 2007). Moreover there are other factors that are considered to influence the research methods including the feasibility of particular methods regarding the research population and political issues (Brannen 2005) and financial and time resources (Creswell and Plano Clark 2007).

Others support pragmatism (Feilzer 2009; Schwandt 2000 and 2006) suggesting that pragmatists and people with other worldviews are not in fact different at an epistemological and ontological level and that there are many similarities in their approaches to inquiry. This is endorsed by Feilzer (2009) who wrote that all types of research attempt to produce knowledge that best corresponds to reality. Schwandt (2006) identified other similarities and questioned whether distinction between different research methods is even necessary or meaningful in human inquiry because all research is interpretive. These views support pragmatism which underpins this research of mixed methods.

3.7.2 Design

Although the methodological debate continues more recent lines of inquiry have been on the construction and data collection in mixed methods research (Wheeldon 2010). Many classification systems have been proposed and are used (Green et al. 1989). My bias towards constructivism together with a need to give people a voice that will be listened to, lead me to use a sequential explanatory design (quanQual) (Creswell and Plano Clark 2007) which emphasizes the qualitative phase (Qual) (Morse 1991) carried out after the less dominant quantitative phase (quan). In addition to deciding on the timing (sequential explanatory) and weighting (quanQual) of the research it is important to decide how the data will be mixed. In this research the data were analyzed after the quantitative, and prior to the qualitative, phases. The results served as a basis for participant selection and formed the structure of the interview questions. This strategy for handling the data is known as 'connecting' (Creswell and Plano Clark 2007). The data were then mixed again

once it had all been collected and was merged during discussion. Merging the data makes it possible to ‘develop a more complete picture by presenting two complementary sets of results’ (Plano Clark et al. 2010 p.161).

3.7.3 Guidance of research process

Mixed methods can be used to guide the research process which was evident in this research. The quantitative and less dominant first phase of the research enabled similarities and differences to be identified in functional outcomes, prevalence of pain or satisfaction of life depending on whether the participant had or had not experienced surgery. This had not previously been investigated. The results of the quantitative data provided a basis on which to select the participants for the semi structured interviews which in turn gave rise to themes that were used to frame the interviews. Moreover, the quantitative data enabled purposive sampling to occur to ensure that young people with different levels of ability could be invited into the study. This in turn ensured that a wide range of experiences from a sample of people with cerebral palsy from all levels of ability were captured.

3.7.4 Validity

Using mixed methods endorses the use of all of the tools of data collection rather than being limited to the ones that fit in with the paradigm used. This can produce data in words and numbers where the words can explain and validate the numbers and add breadth to the research. It was important in this research for the participants to be able to explain some of their responses to the questions in the quantitative phase particularly as there are many variables that affect functional outcome and satisfaction of life. In addition it was important to have quantitative data to validate the qualitative data primarily because quantitative research continues to be the gold standard of research in evidenced based medicine in Germany. To be able to influence practice of health professionals it is important to produce knowledge that will be recognized and used as evidence on which to make decisions regarding the care and treatment of people with cerebral palsy.

3.7.5 Depth

Using both qualitative and quantitative methods could be considered to lead to a purely superficial investigation. However, to prevent this it is important to use the

correct method for the research question and the area under research (Creswell and Plano Clark 2007). For this research not being bound to one worldview or the other has meant that the research followed a holistic approach. The different methods and in particular the interviews which have explored the experiences and the views of people with CP have complemented each other to give depth, meaning and relevance to the research.

Mixed methods research does not limit the research to one extreme line of thought and is widely believed to improve the quality of the study (Johnson and Onwuegbuzie 2004). The strengths of one method compensate for the weakness in the other (Fidel 2008). Therefore rather than competing with each other they complement one another. The aim of the interviews was to expand upon the quantitative results and explore in depth, the experiences of people with CP (Morse 1991). The critical view of the methodology indicated that the use of mixed methods was important to be able to answer the research questions.

3.8 Justification of outcome measures

In a recent mapping review of long-term outcomes of adults with a diagnosis of CP, it was reported that although some research measured outcomes of treatment pathways in relation to activity and participation (ICF) as early as 1970, it has become more frequently used in the last two decades (Kembhavi et al. 2011). Outcomes representing the ICF component of personal and environmental contextual factors were first reported in the 1990s and their use has also been reported to have increased between 2000 and 2010. Further review of the literature reporting outcome measures in relation to activity and participation, indicated that only functional activities as measured by the Gross Motor Function Measure which is a standardized outcome measure (Langerak et al. 2009) or walking abilities were used (Bottos et al. 2001b; Jahnsen et al. 2004). No research was found that had included activities of daily living to assess outcomes of pathways of care for people with CP.

The choice of a mixed method approach has permitted the use of a number of outcome measures. The reasoning behind the use of these tools will be discussed in this section.

3.8.1 Functional ability

The Gross Motor Function Classification System (GMFCS) was used to classify the participants according to functional ability so that a comparison could be made between levels of function of those that had surgery compared to those who had not had surgery. Although the GMFCS has been developed for people up to 18 years it has been found to be a useful and relevant tool for classifying adults with CP (Sandström et al. 2004). Clinical experience also supports the use of the GMFCS to classify participants in this study. The individual items that are assessed and the settings in which they are assessed continue to be relevant for young people in ICP and MFZ.

GMFCS levels were not available for the participants as children but it was important for the study to evaluate whether there had been a long term change of function. For participants who had not experienced surgery this time period was between primary school age and the present day and prior to surgery and the present day for participants who had experienced surgery. This information was therefore gained by previous medical and physiotherapy notes if available and a self reporting measure. This distinguished between a subjective evaluation of deterioration in function with a score of 0, no change in function with a score of 1 and a long term improvement in function with a score of 2. Similar to self reporting for pain it was decided that an improvement in function was preferable to deterioration in function and was therefore given a higher score. With two sources of information it was possible to compare the subjective personal estimation of change in function with the information regarding the change in function that was found in the medical and physiotherapy notes.

The GMFCS classifies people with CP by assessing gross motor function. However, the information is insufficient to give a comprehensive picture of the abilities at an activity and participation level. Therefore, the Rivermead Mobility Index (RMI) (Appendix 2) and Rivermead Extended Activities of Daily Living (READL) (Appendix 3) were used.

The Rivermead Mobility Index (RMI) assesses function such as the ability to get out of bed, climb the stairs or run using a 2 level ordinal scale. Like the READL it is

frequently used in neurological rehabilitation centres (Rossier and Wade 2001) but is equally relevant to assess functional abilities of people with CP. Reliability (Wade 1992) and validity (Antonucci et al. 2002) have been established. The Rivermead Extended Activities of Daily Living (READL) has 12 items and is a more comprehensive measure to test activities of daily living. It is reliable and shows evidence of validity (Rossier et al. 2001). Although this measure has not been tested for people with CP it has been tested for people presenting with other neurological impairments including head injuries, multiple sclerosis and muscular dystrophy. The items of the READL are very relevant to people with CP and it is also straightforward to use.

The RMI together with the READL provide a comprehensive assessment of many of the requirements that are needed for independent living. They cover areas of life that are important to young people including using public transport and having a hobby. They are quick and easy to use and were recommended by the advisory group of potential participants for this study.

3.8.2 Satisfaction with life

The movement away from the medical model to the social and bio psychosocial models has resulted in an acknowledgement that it is not just a condition or disease that has an effect on someone but also personal factors (Ravens-Sieberer et al. 2005). Quality of life, health related quality of life and subjective well being assessments have been developed to assess these (Bowling 2005).

Subjective well being has been defined as ‘the evaluation of life in terms of satisfaction and balance between positive and negative affect and psychological well being’ (Keys et al. 2002 p.125). Subjective well being assessments allow people to decide what areas of life are important to them rather than quality of life or health quality of life questionnaires that have predetermined areas of importance (Fuhrer 2000).

The term ‘quality of life’ has different meanings depending on the individual. This can include having a positive psychological outlook and emotional well being, having good physical and mental health and the physical ability to do the things that

one wants to do, having good relationships with friends and family, participating in social activities and recreation, living in a safe environment with good facilities and services, having enough money and being independent (Bowling and Windsor 2001). At the same time health related aspects are considered to play an important role in quality of life (Narayanan et al. 2006).

Quality of life of young people with CP has increasingly become an area of interest in the last decade (Colver and the Sparcle Group 2006) resulting in the development of tools to measure this (Bowling 2005; Young et al. 2010). Some have been developed specifically for young people (Kidscreen) (Ravens-Sieberer et al. 2005) and some more specifically for young people with CP (Cerebral Palsy Quality of Life Questionnaire for Children) (Davis et al. 2010). Quality of life tests have been found to assess participants in predefined areas of functioning (Fuhrer 2000). These factors could influence people's perceptions of what a good quality or satisfaction with life mean.

There have been numerous scales developed to assess subjective well being (Bowling 2005) but the Satisfaction with Life Scale test (SWLS) (Appendix 4) appears to be the only assessment that allows the participant to decide on the important things in life. 'It assesses an individual's conscious evaluative judgment of his or her life by using the person's own criteria' (Pavot and Diener 1993) bearing in mind that every participant interprets and weighs the questions differently (Diener et al. 1985). It is quick and easy to use and it has been shown to have a strong internal reliability and a moderate stability (Magnus et al. 1992).

Allowing people to decide what is important to them and what makes them satisfied was the main reason for choosing the Satisfaction with Life Scale Test (Appendix 4) rather than one of the many quality of life or health related quality of life tests. The Satisfaction with Life Test allows every individual to answer in accordance with how they interpret the question and what is important to them for their satisfaction with life. An additional advantage of the test is that it is quick and easy to understand and use. Using a very simple scoring scheme it is possible to find out the level of satisfaction which ranges from extremely satisfied to very dissatisfied.

3.8.3 Pain

The literature review demonstrated that there is limited agreement regarding the prevalence of pain in people with CP. Finding out the prevalence of pain for the participants of this sample group and the comparison between those who had experienced surgery and those who had not was considered important. A plethora of scales have been designed to measure the prevalence and severity of pain (Bowling 2005). Many of these however, did not provide the information required for this research. The participants were able to understand questions and express themselves so it was decided to use a self reporting measure.

Self reporting measures have been described to be useful in gaining subjective information about experiences and are quick and easy to use (Bowling 2005). A 3 point scale was used giving rise to rank order and ordinal data. Constant pain was scored with 0 points, pain sometimes was scored with 1 point and no pain was scored with 2 points. No pain was considered to be an advantageous outcome and was therefore ranked higher than constant and pain occurring sometimes. This provided information about the prevalence and frequency of pain.

3.8.4 Experiences of life with cerebral palsy

Structured, semi structured and unstructured interviews can be useful in gaining in depth information based on personal experience direct from participants of the study. They can also be used to confirm or dispute the outcomes from quantitative research (Cresswell and Plano Clark 2007). Noronen and Wikström-Grotell (1999) suggested that qualitative research methodology complements quantitative research especially when viewing a person as a whole. This is also emphasized by the World Health Organisation (2001).

Short term outcomes of interventions used in the treatment of people with CP are the focus of much research (Gough et al. 2004; Jahn et al. 2009). Quantitative methods using standardized measures or questionnaires to measure outcomes are used mainly rather than gaining experiences or opinions (Varni et al. 2005; Cuomo et al. 2007).

Questionnaires can also be completed in structured interviews providing a lot of information that can be analyzed but which does not give in depth information

(Bowling and Ebrahim 2007). Data from closed questions must be analyzed with caution because the responses are very likely to be different than those that would be obtained from open ended questions (Arksey and Knight 1999). In a sample of 31 families, Goldsmith (2000) explored parents/carers and children's experiences of sleep systems. Opinions based on responses from a questionnaire and comments were reported. Whilst this study reported opinions, the depth of information was not equitable to that achieved through semi structured or unstructured interviews.

There is limited literature within physiotherapy research that focuses on gaining an understanding of the key issues of people receiving physiotherapeutic interventions or their experiences and opinions of the intervention that they have had (Redmond and Parrish 2008). Other disciplines however, increasingly use qualitative methods to gain an understanding of people's experiences (Walters 1995).

Reduced cognition and communication abilities are considered to be additional problems that people with CP may experience (Bax et al. 2005). This in turn may contribute to why research has not concentrated on finding out the experiences of people with CP using interviews (Redmond and Parrish 2008). Varni et al. (2005) recommended that children's Health Related Quality of Life perceptions should be obtained from the children rather than purely from parents and carers. Whilst many questionnaires have been developed for children with disabilities rarely are children and adults asked for their personal experiences.

Palisano et al. (2009) obtained valuable information about mobility experiences of adolescents with cerebral palsy. They undertook 14 in depth semi structured interviews with 10 participants between 17 and 20 years including participants of all levels of GMFCS. With the exception of one participant, all were able to communicate independently. Themes were identified and coded and the participants had the possibility of checking that the meaning was correctly interpreted.

Interviewing 10 participants with CP does not provide a representative sample of all young people with CP. It does however, describe the experiences of these 10 people with regards to their mobility which readers can interpret for themselves and decide whether this information has relevance for other young people with CP.

Semi structured interviews were considered the most appropriate technique for this research because they give structure to the interview in order that specific areas of enquiry can be addressed but in addition they give participants an opportunity to voice issues that are key to them. They provide large amounts of data that has to be transcribed and evaluated and is extremely time consuming but is less than the data that would be gained by unstructured interviews (Bowling and Ebrahim 2007). Time and funding issues are practical reasons for not using unstructured interviews.

The rationale for using a mixed methods design for this study and the outcome measures has been explained. In order to remain consistent with the design of this study from the timing of the different phases (quanQual), to the handling of the data which used a 'connecting' strategy, the quantitative phase of the study will be reported first. This included the method and analysis of the results, the discussion and the influences of the results on guiding the second, qualitative phase of this study. Subsequently the qualitative phase of the study will be presented and finally the discussion will address the overarching themes that have arisen from both the quantitative and qualitative phases of this study. However, as both the quantitative phase and the qualitative phase form one study there are some aspects that are relevant to both phases including ethical issues, recruitment, development of the research question and quality assurance. To prevent repetition these will be explained together in the following section.

Chapter 4: Methodical issues relevant for both the quantitative and qualitative phases

4.1 Gatekeepers

The gatekeepers for this research were identified as the managing directors of ICP and MFZ, the Board of Governors, the heads of department and the teachers of the training centre (BBW). Once the research question had been developed they were approached for their approval. A short presentation was held for them explaining the aims and objectives of the research.

4.2 Ethics

Following the guidelines from the University of Brighton Faculty of Health Ethics Committee (FREGC) ethical approval was applied for and obtained. No further applications for ethical approval were necessary. Full support was gained from the gatekeepers of the centres where the research took place. In addition one of the directors, in conjunction with the supervisors from the University who were allocated to the researcher, monitored the progress of the research. The supervisors also visited the centres during data collection.

Ethical issues that needed consideration were that the researcher was head of the physiotherapy department where the research took place. This could have lead to students feeling coerced into taking part in the study. It might have also influenced the responses to both the Satisfaction with Life Scale test and questions in the semi structured interviews by providing information that they thought the researcher would want to hear.

These potential problems were addressed by ensuring that the researcher was not the therapist of the participants. Prior to the assessments and interviews, the role of the researcher was explained, and it was emphasized that the researcher's role was as a researcher and student from the University of Brighton. The potential participants were assured that they were under no pressure to take part in the study and if they decided not to it would not affect their treatment, training or schooling.

There were possible risks that the participants might become upset when describing their experiences or regret decisions that were made. Two psychologists were also available for counselling or support if necessary.

Some of the adults had learning difficulties but they were included in the study only if they understood the information leaflet and consented to taking part.

Medical records that were available to therapists were used to gain additional information regarding the interventions that were carried out. Only information that was necessary to the study was collected and was used for purposes consistent with those in the Student Handbook. All efforts were made to ensure confidentiality, privacy and data protection. The information collected including taped recordings was anonymous and stored in a file in a locked cupboard. Information saved on the computer was accessible only to the researcher.

4.3 Other issues

The population from which the sample was drawn was largely literate and therefore additional sources of assistance with communication were not needed. However, the Speech and Language Therapists agreed to give support if necessary. The researcher has been living in Germany for 15 years and can speak fluent German. The research including questionnaires and interviews was carried out in German. The data for phase one was analysed in German and the interviews were transcribed verbatim. Initially one interview was translated into English by the researcher and sent to the supervisors for comments.

4.4 User Involvement

Prior to gaining ethical approval a representative group of possible participants from the centre was formed. This included 4 people who were doing a job training programme in ICP who could be easily contacted for consultation. They were consulted at the planning stage to ensure that their issues were addressed. They also tested the various outcome measures that were considered for the study and were able to give valuable feedback. The final choice of outcome measures used was influenced by the comments from this user group. The user group provided ongoing advice throughout the study.

4.5 Participants

It has previously been made transparent that it was not the intention of the researcher to aspire to homogeneous groups of people with CP and an environment in which to gain unbiased results. It was accepted, however, that people with similar levels of physical ability could be grouped together using the GMFCS to compare the outcomes of certain treatment procedures. The results should therefore be interpreted cautiously.

The expected sample size to show any statistically significant differences was calculated using a power calculation on the Rivermead Scale data. Using a one sided significance test at 5% level and a probability of 0.05 the sample size was calculated to be 60 for the quantitative phase. Purposive sampling was used for the qualitative phase. The participants were chosen from those who met the inclusion criteria and who had taken part in the quantitative phase.

4.5.1 Inclusion criteria

The participants were able to give informed consent to take part in the research and were male and female between 18-28 years with CP. They either had or had not had surgery to the lower extremities as a child with the first operation being more than 10 years before participating in this study. The participants were past and present students at the ICP and from the MFZ in Munich, Germany. Some trained or were training for a job and others were in sheltered work at the centre.

4.5.2 Exclusion criteria

People with CP were excluded from participating from the study if they were not at or had not attended either of the centres ICP or MFZ. People who were unable to provide informed consent were also excluded from the study.

4.6 Recruitment

An information sheet (Appendix 5) was prepared and initially presented to the gatekeepers of the centre and the heads of departments including the teachers of the potential participants. It was important that everyone was informed and was in agreement that the potential students could be given time (approximately 1 hour) from their training for both the questionnaires and the interviews. Following their

approval an appointment was made for a further presentation with all of the students who were potential participants in the research. They were informed about the nature of the presentation and invited to the presentation. The students had time off for the presentation which explained and gave details about the research. It was emphasized that the attendance was voluntary and no record was kept of those who attended.

Young people contacted the researcher when they had decided that they wanted to participate and signed a consent form (Appendix 6). The information sheet stated that the potential participants would be contacted by the researcher by e-mail 2 weeks following the presentation. However, the heads of department expressed a wish that that the students contacted the researcher and this was respected.

4.7 Quality assurance in mixed methods

For quantitative research to be considered of value for evidence based research it is necessary that procedures are taken to gain validity, reliability and replicability. Although these procedures cannot be applied to qualitative research (Spencer et al. 2003) appropriate measures can be taken to achieve quality in qualitative research. Lincoln and Guba (1985) suggested that credibility or trustworthiness can be compared to internal validity, fittingness to external validity and auditability to reliability. In mixed methods it has been suggested that the dominant phase determines what measures are taken to assure quality. For example if qualitative methods are dominant the measures appropriate to this should be taken (Brannen 2005). However, separate measures can be taken for both phases of the research to produce quality research that will be used as evidence on which to base decisions regarding care and treatment of people with CP. These will be further discussed.

Fitting with a pragmatist's view point the researcher accepted that people with cerebral palsy are heterogeneous and it is not possible to isolate the effects of surgery or conservative treatment on functional outcomes, prevalence of pain and satisfaction with life. It is accepted that other variables will also affect the outcome. However, measures were taken in both the quantitative phase and qualitative phase to reduce researcher and environmental bias.

Within the given limitations of a heterogeneous population of people with cerebral palsy measures were taken to select homogeneous groups related to functional ability using the GMFCS, specifying and limiting the age of the participants and identifying the variables that were under investigation. These were whether participants had experienced surgery to the lower extremities as children or not. Standardized outcome measures were selected to assess functional ability and satisfaction of life.

Functional ability is measured as either having achieved the item or not and can be retested by the tester in the event of uncertainty. However, the level of satisfaction of life, level of pain and changes in functional ability are subjective evaluations made by the participant. Using past physiotherapeutic and medical assessments it was possible to compare these with the participants' evaluation of their changes in functional ability over the years. The measurement of current level of pain and satisfaction of life are subject to the participants' own interpretations. The researcher assured the participants that information given would be kept anonymous and it would not affect their treatment or future training or their physiotherapist. The researcher accepted the subjectivity of these questions and that the participants would share their truth about these areas of research.

As a pragmatist the researcher considered it important to apply these guidelines to produce quality research using the most appropriate concepts for the population sample and research question. Transparency of the measures taken and the reasoning behind the use of the measures taken is key in enabling readers to make their own interpretations of the findings.

In the qualitative phase, quality was established by providing transparency of the research process, selection of participants, questions, framework of analysis used to gain an understanding of the interviews and sharing with the reader the researcher's worldviews and history. The bias that the researcher inevitably brings to the research situation was openly addressed throughout the research. Measures were taken to reduce the researcher's bias to the research question by discussing the results and interpretations with colleagues.

In summary, the methodological issues that were relevant for both the quantitative and qualitative phases have been addressed. Issues specific for the quantitative phase followed by those for the qualitative phase will be highlighted.

Chapter 5: Quantitative phase

5.1 Aim

The aim of this phase of the research was to compare the current functional status, satisfaction with life, the prevalence of pain and long term functional changes between young people who had and those who had not experienced surgery to their lower extremities as children.

5.2 Methods

The outcome measures used were the Rivermead Mobility Index, Rivermead Extended Activities of Daily Living, Satisfaction with Life Scale test and the self reporting measures of function and pain.

The sample size necessary to show any statistically significant differences was calculated using a power calculation on the Rivermead Scale data (Chapter 4.5).

Once the participants had agreed to take part in the study, appointments were made at convenient times for them. A review of their notes indicated whether they had or had not experienced surgery to their lower extremities as children. The type and dates of surgery and any additional information regarding other interventions and particularly functional change over the years were also noted.

Participants were matched according to whether they had or had not experienced surgery to their lower extremities as children. Within this stratification participants were further matched into GMFCS levels I/II, III, IV/V.

All of the young people that agreed to participate and who fitted the inclusion criteria were included in the study. Each participant was assigned a number which was referred to throughout the research and analysis.

5.2.1 Procedure

The data collection commenced at ICP, however there were only small numbers of participants with GMFCS levels of III-V who had not experienced surgery. Therefore, contact was made with potential participants at MFZ. They received the

information sheet and were invited to contact their treating therapist should they require any further information about the research. After 2 weeks they were then asked whether they would like to participate and appointments were made that were convenient to them. In addition to recruiting from MFZ, physiotherapy notes were reviewed from the previous 4 years of approximately 100 past students in BBW (job training) in order to see if there were any other possible participants who were classified with a GMFCS level III and had not experienced surgery. These and potential participants from the list of new students to ICP for 2010/2011 were identified and were later approached.

Written consent was obtained from all of the participants. Translated versions of the outcome measures Rivermead Mobility Index and the Satisfaction with Life Scale test were obtained from the internet. The researcher translated the Rivermead Extended Activity of Daily Living which was subsequently checked and corrected by German speaking physiotherapy colleagues.

The use of a familiar room in which to complete the questionnaires was chosen to prevent or reduce anxiety and give the procedure of assessment a feeling of familiarity. Some of the participants knew the researcher but in all cases she explained her role in the research and explained the use of questionnaires. It was emphasised that during the appointments she was not acting as head of department but as a researcher from the University of Brighton. It was emphasized to all of the participants that all of the information was confidential and that their name would not appear on any published documents. All of the questionnaires were completed by the researcher with all of the participants prior to data entry and data analysis.

5.2.2 Data analysis

The data from this study was analyzed prior to commencement of the qualitative phase. The results served as a basis for participant selection for the qualitative phase and informed the content and structure of the interview questions. This strategy to handling the data is known as 'connecting' (Creswell and Plano Clark 2007). Ultimately the interpretation of the data from the quantitative phase was synthesised with the themes from the interviews to construct new meaning. The results and

findings will be discussed from both parts of the study independently and then as a whole data set.

The initial phase of this sequential explanatory design mixed methods research was to collect quantitative data about the functional and satisfaction with life outcomes and prevalence of pain of people who had and had not experienced surgery as children. All of the participants completed all of the outcome measures which involved ordinal scaling and therefore gave rise to non parametric data. In discussion with a statistician at the University of Brighton, the data were described and further analysed using the Mann Whitney test.

5.3 Results and Findings

The results compare the outcomes between participants of similar functional ability as measured by the GMFCS levels I/II, III and IV/V who had experienced surgery and those who had not had surgery. The demographic characteristics and results of all of the outcome measures are presented in the tables. The results between the surgical group and non surgical group are presented. Additional observations of the data identify characteristics of participants which may help to explain some of the results.

Sixty two participants were recruited into the study from a total population size of 250. Thirty six participants had experienced surgery compared to 28 who had not. Of the participants who had experienced surgery 14 had a GMFCS level of I/II, 10 had a GMFCS level of III and 12 had a GMFCS level of IV/V. Eleven participants who had not had surgery had a GMFCS level of I/II, 6 had a GMFCS level of III and 9 had a GMFCS level of IV/V. Their demographic characteristics are presented in Table 1.

GMFCS	No Surgery / Surgery	Age (years)		Gender (Number)		No. of multilevel surgery in group
		Min-Max	Mean	Female	Male	
I/II	no surgery	18-26	21.2	5	6	-
I/II	surgery	18-27	20.9	5	9	7
III	no surgery	19-22	20.2	3	3	-
III	surgery	19-27	22.9	2	8	6
IV/V	no surgery	21-25	22.3	6	3	-
IV/V	surgery	18-26	22.0	5	7	4

Table 1: Participant Characteristics

[Original in Colour]

The results from the outcome measures are summarized in tables 2-6.

5.3.1 Results from the outcome measures

1. The Rivermead Mobility Index

This was used to measure functional mobility including the ability to transfer from a bed to a chair and to climb a flight of stairs.

Rivermead Mobility Index					
Treatment:	No Surgery		Surgery		
GMFCS	Mean	SD	Mean	SD	U value
I/II	14.55	0.82	13.75	0.59	*34.5
III	9.00	2.58	8.10	2.33	15.5
IV/V	1.33	1.12	2.67	1.72	28.5

Table 2: Mean scores and standard deviation for Rivermead Mobility Index

*Significant score at $p = 0.01$ using Mann-Whitney U test

[Original in Colour]

The results for participants classified in GMFCS levels I/II indicated that the non surgical group had significantly higher scores for RMI ($p = 0.01$) than the surgical group. This suggests that the non surgical group had greater functional mobility than the surgical group with a GMFCS level I/II.

2. The Rivermead Extended Activities of Daily Living

This measures activities of daily living ranging from the ability of making a light meal to being able to buy provisions for one's daily requirements.

Rivermead Extended Activities of Daily Living					
Treatment:	No Surgery		Surgery		
GMFCS	Mean	SD	Mean	SD	U Value
I/II	34.27	2.05	33.47	3.50	76.0
III	21.00	3.37	26.70	10.41	8.0
IV/V	8.78	8.09	17.00	6.94	*21.5

Table 3: Mean scores and standard deviation for Rivermead Extended Activities of Daily Living

*Significant score at $p < 0.05$ using Mann-Whitney U Test

[Original in Colour)

The READL scores were significantly higher ($p = 0.018$) in participants who had experienced surgery who were classified as GMFCS level IV/V. This suggests that people with this classification who had experienced surgery were more independent in performing activities of daily living.

3. The Satisfaction with Life Scale test

This was used to measure how satisfied a person was with their life.

Satisfaction with Life Scale				
Treatment:	No Surgery		Surgery	
GMFCS	Mean	SD	Mean	SD
I/II	23.36	5.26	27.53	4.22
III	25.00	5.60	22.40	3.95
IV/V	22.11	7.47	21.42	4.54

Table 4: Mean scores and standard deviation for Satisfaction with Life Scale test

[Original in Colour]

Using the Mann-Whitney U Test the statistics indicated that there were no significant differences in satisfaction with life scores between those who had and those who had not experienced surgery.

4. Self reported prevalence of pain

Pain was measured using a self reporting 3 point scale. The following table summarises the prevalence of pain between those people who had not and those who had experienced surgery.

GMFCS	Constant: Count (%)	Sometimes: Count (%)	None: Count (%)
I/II N.S.	0 (0%)	0 (0%)	11 (100%)
I/II S.	0 (0%)	5 (33.3%)	10 (66.7%)
III N.S.	0 (0%)	2 (33.3%)	4 (66.7%)
III S.	0 (0%)	6 (60%)	4 (40%)
IV/V N.S.	0 (0%)	3 (33.3%)	6 (66.7%)
IV/V S.	2 (16.7%)	7 (58.3%)	3 (25.0%)

Table 5: Reported prevalence of pain: no surgery (N.S) and surgery (S)

[Original in Colour]

Using the Mann-Whitney U Test the statistics indicated that there were no significant differences in the reported prevalence of pain between people who had and those who had not experienced surgery.

5. Self reported changes in functional ability

The following table summarizes the changes in level of functional ability that were measured using a self reporting scale of people who had and people who had not had surgery. Participants compared their functional ability either prior to surgery or the level at primary school for those young people who had not experienced surgery, to the present day.

GMFCS	Worse: Count (%)	Same: Count (%)	Improved: Count (%)	U Value
I/II N.S	0 (0%)	4 (36.4%)	7 (63.6%)	77.50
I/II S.	1 (6.7%)	5 (33.3%)	9 (60%)	
III N.S	0 (0%)	4 (66.7%)	2 (33.3%)	15.00
III S.	3 (30%)	3 (30%)	4 (40%)	
IV/V N.S	0 (0%)	6 (66.7%)	2 (33.3%)	*22.50
IV/V S.	6 (50%)	5 (41.7%)	1 (8.3%)	

Table 6: Differences in level of function: no surgery (N.S.) and surgery (S)

*Significant score at $p < 0.05$ using Mann-Whitney U Test

[Original in Colour]

Participants of the non surgical group GMFCS IV/V had significantly higher improvement in function scores than those who had experienced surgery ($p=0.023$).

There was no significant difference in any of the results for the participants in GMFCS III. This suggests that people with this level of functional ability can benefit from either a conservative or surgical pathway of care in terms of long term functional ability, satisfaction of life and prevalence of pain.

6. Summary

	Rivermead Mobility	Rivermead Extended Activities of Daily Living	Self reported changes in functional ability
GMFCS	I/II	IV/V	IV/V
	No surgery	Surgery	No surgery

Table 7: Summary of outcome measures with significant scores at $p < 0.05$ using Mann-Whitney U Test

[Original in Colour)

5.3.2 Findings

A more detailed analysis of the data of the two groups with a GMFCS IV/V who had and had not experienced surgery was undertaken where statistically significant results were found. Using both the descriptive statistics and also the findings from the Mann Whitney U Test the following is suggested:-

The participants who had reported deterioration in motor function in the surgical group had experienced their first operation at a mean age of 7 years. However, for those whose motor function had stayed the same in the surgical group, it was noted that they had experienced their first surgical procedure at a mean age of 10 years. The young person who reported that surgery had improved his functional ability long term was 9 years old when he experienced his first operation.

Based on the self reported changes in functional ability, three out of four (75%) of the participants who had multi level surgery had experienced deterioration in function compared to three out of eight (38%) of the participants who had single level surgery.

Single event multi-level surgery may reduce the necessity for future surgery to the lower extremities. Two out of the four (50%) participants who had multi level

surgery had 1 operation compared to only two out of eight (25%) participants who had single level surgery.

The mean Satisfaction with Life scores of people who had surgery and whose function had worsened was higher (mean score 23.5) than people who had experienced an improvement in function (mean score 23) or had stayed the same (mean score 18.6).

Participants who had not had surgery and had not experienced a change in long term function had a lower mean Satisfaction with Life scores (mean score 21) compared to people who identified that they had experienced an improvement in function long term (mean score 24.3).

Characteristics of the participants in the non surgical group with a GMFCS level of IV/V showed that 7/9 (78%) participants were residents at MFZ and 2/9 (22%) were students at ICP. In the surgical group 3/12 (25%) were residents at MFZ and 9/12 (75%) were students or ex students at ICP.

Statistically significant results were also found in the groups with a GMFCS level of I/II. The Rivermead Mobility Index scores were significantly higher ($p = 0.01$) for the non surgical group of people with a GMFCS level I/II compared to people with a GMFCS level I/II who had experienced surgery. The participant characteristics indicated that 2/11 (18%) in the non surgical group were classified as having GMFCS level II and 9/11 (82%) had a GMFCS level I compared to the surgical group which had an even number of people 7/14 (50%) with a GMFCS level of I and II. The possible influence of this on the results will be discussed.

Other participant characteristics, which will be referred to in the discussion, are that 9/16 participants with a GMFCS level of III who had low functional mobility as measured by the RMI, had scores of less than 10. These people however, achieved high READL scores of 20-35. In addition Satisfaction with Life scores showed that 60% of participants were either slightly satisfied or satisfied with life. Three out of 61 (5%) of participants were dissatisfied and 7/61 (11%) of participants were extremely satisfied. None of the participants were extremely dissatisfied. The 3 participants who were least satisfied stated that they had not achieved the things they

wanted to achieve and they would change most things in their lives if they could live their lives again.

5.4 Discussion of results and findings

An aim of this study was to establish whether young people with cerebral palsy who had experienced surgery as children had better outcomes in terms of long term changes in functional ability, current functional ability, satisfaction with life and prevalence of pain compared to young people who had not experienced surgery. An additional aim was to gain an understanding of the participants' experiences of their pathway of care.

To date there is no other research that has compared the long term effects of different pathways of care available to people with CP. In light of this and also the preferred credibility of quantitative research within Germany, the research question was originally approached from a positivist perspective. However, whilst refining the research question it became evident that a positivist approach would not fully answer the question and would only provide evidence on which to base an in depth enquiry. This enlightenment helped to inform the research design.

A mixed methods approach was therefore chosen to explore the outcomes of the surgery in relation to current functional ability, satisfaction with life, prevalence of pain and the young person's experiences of their pathway of care. The intellectual arguments surrounding the choice of a mixed methods approach are discussed in Chapter 3.7.

The participant characteristics that were highlighted in the previous section will be discussed and consideration will be given as to how these might have influenced the results. Subsequently an insight will be given to the reader as to how the results of the quantitative phase were interpreted and how they were used to shape the qualitative phase of the research.

It was intended that the required sample size of 60 participants would be equally split across the 6 identified groups to be investigated. This would have given an equal distribution of 10 in each group which gives strength to the statistics when

comparing outcomes across groups. The population that fitted the inclusion criteria was found to be unevenly distributed across the classification groups or between those who had and those who had not experienced surgery to their lower extremities. In all GMFCS levels the number of potential participants who had experienced surgery far exceeded the number of participants who had not had surgery. The greatest discrepancies between the number of young people in ICP who had and who had not experienced surgery were those with a GMFCS of III and IV/V. It was more likely to find a participant that fitted the inclusion criteria who had a GMFCS level of IV/V and had not had surgery in MFZ than in ICP. It was even more difficult to recruit participants from ICP or MFZ with a GMFCS III who had not had surgery resulting in only 6 participants (5 from ICP and 1 from MFZ) with this level of functional ability who were able to be included in the study.

Once all the possible participants were identified from both centres the search was widened to include ex students of ICP. This however did not increase the number of participants.

It is apparent from the population of people with CP at the centres ICP and MFZ that it is more likely that a young person with CP and with a GMFCS III or IV/V will have surgery at sometime during their childhood than to have conservative treatment only. Research and clinical experience have identified that it is people with a GMFCS level of between IV/V that experience a deterioration in functional ability as they enter adulthood (Rosenbaum 2007; Hanna et al. 2009). These results therefore further reinforce the need to establish whether surgery is in fact preferable to a conservative pathway of care in respect of long term functional abilities, prevalence of pain and satisfaction with life.

Furthermore, the descriptive statistics indicated that although participants who had experienced single level surgical procedures could expect further surgery before reaching adulthood they were less likely to experience long term deterioration in function compared to participants who had experienced single event multi-level surgery. This supports evidence from Gannotti et al. (2010) and Dreher et al. (2012) who identified short term benefits of walking ability following multi-level surgery.

The descriptive statistics also indicated that the age at which surgery is performed may be important in influencing the long term outcomes of functional ability. Although the sample size was small the results indicated that further research is warranted to establish whether single level surgery is preferential to single event multi-level surgery and whether the age at which surgery is performed can influence long term outcomes.

The analysis of the quantitative results shows that there are statistically significant findings for three of the outcome measures. The Rivermead Mobility Index identified differences between the groups with a GMFCS I/II level who had not experienced surgery. The statistically significant results in the Rivermead Extended Activities of Daily Living were found in the group with a GMFCS IV/V level who had experienced surgery and finally in the self assessment of change in functional ability in the group with a GMFCS IV/V level who had not experienced surgery.

Following closer investigation of the participant characteristics and the individual items of the Rivermead tests it was considered that the significant results for both of the Rivermead outcome measures could not be attributed to the success or not of the surgery.

Firstly, significantly higher levels of mobility, as measured by the Rivermead Mobility Index, were found for people with GMFCS levels of I/II who had not had surgery compared to those who had experienced surgery. The participants who had not experienced surgery had a mean of 14.55 from a maximum of 15 points compared to a mean score of 13.75 for participants who had experienced surgery. Even though a statistical difference was found, the differences in the mean scores were negligible and meaningless in terms of difference in mobility. The scores were therefore considered to be clinically insignificant.

Secondly, the READL outcome measure that showed statistically significant values in the group with a GMFCS IV/V who had experienced surgery is used to assess activities of daily living and does not distinguish between those who are capable of performing an activity with the use of assistive devices and those who do not. The participants who had surgery with a GMFCS level IV/V were in ICP and training for

a job compared to those who had not had surgery who were in MFZ and in sheltered workshops. The participants in ICP appear to be able to use assistive devices to improve their independence compared to people who have not had surgery and who are more likely to be in MFZ and in sheltered work. The ability to cross over a road in a powered wheelchair which is, for example an item of the READL outcome measure, has less to do with functional ability but more to do with orientation, planning and awareness of the surroundings. It is known that people who do not complete job training and do not have surgery as children are more likely to be in MFZ than those who are or have completed a job training and who have had surgery.

The date and type of surgical procedures that each participant had experienced was also noted. Throughout all of the surgical groups it became apparent that the participants had experienced such a wide range of surgical procedures and combinations that a comparison of the long term outcomes of the different surgical procedures would not be possible. In the group GMFCS I/II only 3/14 had experienced similar surgical procedures. In GMFCS levels III only 4/10 had experienced similar surgical procedures and participants with a GMFCS levels IV/V all had different surgical experiences. An explanation for this may lie in the type of surgical management they receive for which there is a dearth of evidence on which to make decisions regarding its short or long term efficacy (McGinley et al. 2012; Reinbolt et al. 2009).

The results suggest that people with a GMFCS level IV/V who do not have surgery have better long term function than those who have had surgery. More specifically they are less likely to experience deterioration in function and are more likely to improve their function. The results of this study indicate that surgery may not significantly improve long term mobility for people with a GMFCS level of IV/V when compared to a conservative pathway of care. The experiences from young people confirm these results.

The statistics show that there appears to be little difference in changes to long term functional abilities for people with GMFCS levels I/II or III. Whilst a study with a larger sample size would be necessary to investigate this in more detail the limitations of quantitative research with a heterogeneous population must be

recognized which may in turn also influence the possibility of drawing definite conclusions.

It has previously been mentioned that people with a GMFCS level III who had not had surgery were poorly represented in both ICP and MFZ. This was initially an unexpected finding, but it represents past and present clinical practice. However, the results of the quantitative phase of this study has shown that in all of the outcome measures for people with GMFCS III there are no significant differences in outcomes between those who have and those who have not experienced surgery. This supports clinical experience and will be addressed in the interpretation of the interviews in Chapter 6.5.

The predominance of non significant results in this study would suggest that surgery to the lower extremities in children with cerebral palsy in all levels of GMFCS should not be chosen over a purely conservative pathway of care to improve long term functional ability or satisfaction of life or to reduce the prevalence of pain. However, due to the limitations of quantitative research with people with cerebral palsy the results should be viewed critically and considered together with the understanding gained from the semi structured interviews. These results should however encourage therapists and surgeons together with young people and their parents, to consider what they want to achieve and whether surgery is a realistic option to achieve these goals.

The results of the quantitative data provided a basis on which to select the participants for the semi structured interviews which in turn gave rise to themes that were used to frame the interviews. The quantitative data enabled purposive sampling to occur to ensure that young people with different levels of ability could be invited into the study. This in turn ensured that a wide range of experiences from a sample of people with cerebral palsy from all levels of ability were captured.

Chapter 6: Qualitative phase

6.1 Aim

The aim of this part of the research was to explore and gain an insight and understanding into the experiences of young people with CP using semi structured interviews. The methodological framework that allows me to do that and is in accordance with my world view is known as phenomenology.

6.2 Phenomenology

Phenomenology is normally used with a constructivist's worldview however, I feel justified using it as a pragmatist because I believe my world view is in accordance with a Gadamerian approach to phenomenology. I respect that all of the participants are telling me their experience and that it is unique to them (Fleming et al. 2003; Morgan 2007) and that it is equally as valid as the next persons' view. I do not know what it is like to have CP however, my clinical experience and knowledge has provided me with some insight. In order for me to deepen my understanding and contribute to the literature I needed to explore their world to be to understand what it is like, and be able to construct a world view on behalf of the young people using their dialogue to find similarities in what people have said to me.

Following the quantitative phase, the second part of this research was to explore 'the lived experiences' of young adults with CP. More specifically I wanted to try to understand what it has meant to the participants who have had surgery on their lower extremities as children, in relation to function and satisfaction of life. I have not had the experience myself so I do not presume to think that I know what it is like to have CP and the accompanying experiences.

The participants' experiences of treatment may have been similar but they were all unique to each person and dependent on their background and previous experiences. These experiences need to be interpreted. Interpretation (hermeneutics) is influenced by the interpreter's history, 'his being-in-the world', language, 'prejudices', 'fusion of horizons' and the hermeneutic cycle (Koch 1995).

It is with this understanding that I have chosen Gadamer's philosophy, also known as phenomenological hermeneutics, for my phenomenological approach. There are many different styles of phenomenology. Husserl's descriptive phenomenology sought to understand consciousness as it is lived and experienced in a scientific way (Lawn 2008). There are three main components to Husserl's phenomenology which include intentionality, essences and phenomenological reduction (Koch 1995). As a pragmatist I consider it is possible to try to eliminate some researcher bias and prejudice when conducting quantitative research, although this is not the case when attempting to understand the meaning of human experiences. This therefore resulted in me being unable to choose Husserlian phenomenology.

Gadamer, a student of Heidegger, believed that people are not detached from the world but that they are caught up in and immersed 'being in the world' (Annells 1996). People with CP live in society, are affected by their environment and the people around them. If it were possible to remove all these elements, which undoubtedly have an effect on the outcomes of various treatments, it would be possible to determine whether surgery is beneficial. However, I do not believe that it is possible. Their experiences must be seen in the context of the environment in which they live which also applies to me, the researcher. We can develop an understanding as to what it is like to have CP but we will not know what it is like to experience it (Fleming et al. 2003). Gadamer further developed the idea by concentrating on how it is possible to understand and the ways in which language, understanding and interpretation are inextricably bound (Annells 1996).

I have already stated that my world views have affected the research question but also that my research question has influenced the whole research process. I have chosen to interview and to enter into dialogue with the participants in order to understand their experience. Gadamer (2004) suggests that understanding is possible through language which can be dialogue and text. To gain a deeper understanding in the subject it was important to have as much contact with the participants as possible and immerse myself in the subject (Fleming et al. 2003).

Unlike Husserl who based his philosophy on science, Gadamer identified that we all have pre-understandings or prejudices or 'effective history' that we bring to the

research. It is important to realize that interpretation is the effect of the past upon the present because the interpreter has a history. Unlike Husserl, who saw these as detrimental to the hermeneutic process, Gadamer saw this as an advantage but that it is important to make these pre-understandings or prejudices clear (Annells 1996). The pre-understandings need to be recognised and will change as the research process and analysis of data progress (Lawn 2008). It is therefore important for the researcher to reflect regularly on their individual prejudices which can be assisted by regular conversations with colleagues and with reference to a diary. This has been very important for this research as I have come to this research question with prejudices and pre-understanding about the benefits of surgery for people with CP.

My prejudices have arisen through my experiences of working for more than 10 years with people of all ages with CP where some have and some have not had surgery to their lower extremities. I have witnessed clinically the changes to the functional ability in those people over the years and in my opinion there are very few people where surgery has had a beneficial effect into adulthood. This prejudice has become more apparent when talking to colleagues who, with a few exceptions, have similar pre understandings as I have. As I have progressed with the research this prejudice has grown especially following the interviews. I make this prejudice clear so that the reader can understand my background and the basis on which I make my interpretations.

It is with these pre-understandings that I entered the hermeneutic circle. The idea of the hermeneutic circle, introduced by Schleiermacher, was further developed by Heidegger and Gadamer (Annells 1996). When seeking to understand text the circle represents the movement between how parts relate to the whole and the whole relates to the parts. The researcher brings to the text a background understanding of the world which works in tandem with his prejudices. These cannot be eliminated but can be reflected upon and bring with them new understanding (Koch 1995). The process of interpretation is never complete hence the 'circle'. Readers will interpret the text differently to the researcher and even the researcher may have a different interpretation of the text in the future.

To be able to make recommendations about future treatment possibilities for people with cerebral palsy it is very important that I understand what the participants were telling me. The understanding that I have gained from the research is a blend of interpretations from me, as the researcher, and the participants. The participants and the researcher have a horizon which includes different backgrounds, a history with different ideas, meanings and experiences (Lopez and Willis 2004). These are not static and will change according to new experiences over time (Lawn 2008). It was important to have dialogue with the participants at different stages of the research so that the horizons could overlap and understanding could occur. It is the coming together of the historical horizons and those of the present time that Gadamer described as the ‘fusion of horizons’ which is necessary to hermeneutical inquiry. People constantly gain new experiences which make this process fluid and new understandings will develop. It is these shared meanings that will be reported and possibly influence the management of people with CP.

Gadamer (2004) suggested that experience can be described in different ways. Experience is gained by repetition or it can be seen as something that is non-repeatable and unique (Lawn 2008). Gadamer termed this unique experience as the ‘hermeneutic experience’. Thus each part of the participant’s treatment is unique and therefore not repeatable. This experience is the truth for the participants which I accept to be so when analyzing the texts. The new experience of the truth cannot be seen alone but must be seen together with what has already happened in the past. This refers back to the hermeneutic cycle where the part (i.e. past experience) modifies the whole. When interpreting the texts I valued the participants’ experiences that they had shared with me as their ‘truth’. Although the truth doesn’t change, my interpretation of it may do so.

6.3 Interpretation of qualitative data

Interpretation can be defined as: ‘the sense given by an interpreter’ (Chambers 20th Century Dictionary). However the definition that most closely represents my understanding is that interpretation is ‘a particular view of an artistic work’ (Collins Dictionary of the English Language 1986) and for this research the interviews were the ‘artistic work’ for the participants. Therefore, a view or understanding was gained of the important issues for the participants presented in the

interviews. However, in order to gain an interpretation of the interviews it is necessary to first gain an understanding of the text (Annells 1996). In this research interpretation of the data did not start with the interviews but it commenced after the data from the quantitative phase had been analyzed. This gave valuable information which was used for selecting the participants and modifying interview questions.

The framework that is chosen to gain an understanding of data or information obtained from either semi structured or open interviews is largely influenced by the chosen perspective of phenomenology that underpins the research (Shepard et al. 1993). The main difference between data that is interpreted following Husserl's descriptive phenomenology, and that following Heidegger and Gadamer's interpretative phenomenology is the tolerance of researchers' preconceptions and how they are handled. Data that is collected based on Husserl's phenomenology should be free of researcher bias including the removal of all previous knowledge (Lopez and Willis 2004). In contrast Heidegger and Gadamer's interpretive phenomenology disputes that it is not possible or even advantageous to try to rid oneself of previous knowledge and biases. This is consistent with my philosophy. However, it is important to identify the researchers' preconceptions and to provide transparency throughout the research.

The themes that were identified represent the understanding and the interpretation of the researcher and will be interpreted differently by readers of this research. However, the participants gave confirmation at the feedback meeting that the identified themes represented the issues that were key to them.

This research follows Gadamer's philosophy but as he did not establish a method or methodology for gaining understanding from texts it was decided to use the framework developed by Fleming et al. (2003) which closely follows Gadamer's philosophy.

Fleming et al. (2003) described 4 steps to be followed to gain an understanding of the interviews. Chapter 6.4.2 describes how the researcher incorporated these steps in gaining an understanding of the interviews. To gain understanding it is necessary:-

1. To gain an initial understanding of the whole text. Transcribing the interview starts the process.
2. To gain an understanding of every individual sentence, this may help identify themes. Recognising that during this process it is important that the researchers' pre-understandings are reviewed.
3. That the researcher remains within the hermeneutic circle. This is made possible by a continuous movement from reading and analysing small parts of the interview and then relating it to the whole interview and then relating it back to the individual sentences. Fleming et al. (2003) stressed that understanding can only be gained through this movement from the part to the whole and back.
4. To identify passages that demonstrate shared understandings between researcher and participant. Themes will continue to be identified and modified as often as this entire 4 step process is repeated.

Following recommendations by Twinn (1997), the scripts remained in German for analysis. Twinn (1997) demonstrated in a study 'examining the influence of translation on the validity and reliability of qualitative data in nursing research' that problems can arise if there are words in the interview that cannot be directly translated into the language used for analysis. In addition a change in emphasis or meaning might occur if the two languages have a different grammatical structure which is the case for German and also English.

Qualitative research is not meant to answer a research question rather it should address the questions of what and how (Denzin and Lincoln 2005). It was not the intention of this research to answer the questions that emerged from the quantitative phase or to give a reason for the themes that arose from the semi structured interviews. The process of interpretation following Gadamer's philosophy and based on Fleming's framework of interpretation is based on the understanding that interpretation can continue indefinitely for as long as the researcher remains in the hermeneutic cycle. It was during this process of looking at the parts in relation to the whole that possible reasons emerged for the identified themes. It was important to pursue these in order to establish a possible reason why surgery to the lower limbs of children with cerebral palsy continues to be a widely used pathway of care in

Germany despite the lack of evidence to support its use to improve long term outcomes and satisfaction with life. Providing a possible explanation for this could be the basis on which to elicit change.

6.4 Method

The results of the quantitative phase were central to the selection of the participants for the interviews. The only statistically significant finding identified was that more participants with a GMFCS level of IV/V who had followed a conservative pathway of care had experienced an improvement in long term changes in functional ability. One of the initial assumptions of the researcher was that an improvement of long term functional ability could be considered as a good outcome for people with CP. It was therefore decided that individuals with a GMFCS level of IV/V who had experienced surgery should be strongly represented in the interviews. As the research developed and the focus moved from the expectations of health professionals and became more focused on finding out what was important to the participants, it was decided to include individuals with all levels of functional ability. This meant that young people were included with GMFCS levels I to V and also those who had both positive and negative experiences of their pathway of care.

6.4.1 Interviews

Preparation and interview technique

Interviews are aimed at achieving a deep understanding and to do this Gadamer (1990) emphasised the need to choose the right questions. Therefore the interview and the questions were carefully considered before and noted. This also gave a point of reference during the interview so that both the subject and interviewer could remain oriented to the subject. Gadamer stressed this as important to gain understanding and to be able to enter the 'hermeneutic experience' (Fleming et al. 2003). The researcher carried out the interviews which, through conversation, facilitated an immersion in the subject of both researcher and subject, and enabled the hermeneutic circle to occur.

The participants were approached after the quantitative phase and asked whether they would be prepared to take part in the interview. The participants were told that the interviews would last for approximately 1 hour and that they would need to obtain

permission from their teachers for this appointment. All of the teachers were aware and were in support of this study.

The room that was used for the interviews was neither normally used by the participants nor the researcher to emphasize that the interviews did not have anything to do with their treatment or schooling. It was light and warm to provide a relaxing atmosphere and a sign was placed on the door so that the interview would not be disturbed. It was important that the perceived authoritative role of the researcher as head of the department should be reduced by wearing casual clothes instead of the usual uniform. Participants were also provided with refreshments. The digital recorder that was purchased by the researcher to record the interviews was shown to the participants. It was emphasised that it would be used to listen back to the conversation so that the interviews could then be typed into the computer giving a true representation of what was said and that they could be analysed later. The participants were asked whether they understood that the interview and the recording could be stopped at any time and whether they were in agreement to continue.

The transcripts of the individual interviews are included on a disc at the back of the thesis.

To find out the present level of functional ability and how it may have changed over the years from childhood to adulthood, participants were asked specific questions.

Some examples of these follow:

1. Please describe a typical day for you starting in the morning and finishing at night.
2. Please tell me if you need help with certain activities
3. Are there any activities that are more difficult or easier now compared to when you were a school child?
4. Please explain these changes to me
5. Do you have any hobbies?
6. What are they?

To find out about the interventions they had experienced the participants were asked:

7. Please tell me about the intervention that you have had.
8. How did you feel about it then?

N.B If it was felt the term intervention was not adequately understood or was misleading the researcher asked the question making it more explicit e.g. tell me about the surgery or Botox you have had.

9. What have been the advantages of the intervention that you have had?
10. Would you choose this intervention e.g. surgery again or recommend it to other people if they had similar problems to you?

Questions were also asked in relation to the responses given by the participants about their satisfaction with life.

The term intervention was explained at the short presentation the participants received prior to taking part in the research. It was explained as including physiotherapy, surgery, botulinum injections and splints. These are the main interventions that are available to people with CP in Germany. In most cases the interventions that the participants had were mentioned specifically by the researcher.

The participants were given time to consider the question and answer. At the end of the interview the participants were thanked for their time and any of their questions were answered. Subsequently the researcher transcribed the interview. The typed transcript was then compared to the recording and corrections were made. A summary of the interview was made and the participant was invited to another appointment to go over it. The participant chose a time that was convenient to him and to the job training. This appointment lasted about 15 minutes.

The interview with the first participant (Appendix 7) was transcribed as described above and subsequently translated into English (Appendix 8) and sent to the supervisors at the University of Brighton for comments. Their comments were incorporated into future interviews.

Many of the participants expressed an interest in being informed of the themes once data analysis had taken place and finalised. Some participants had left the centres and moved away from Munich by the time this had taken place but the remainder were invited to an informal presentation. This was used not only to give feedback about the results of the research but to give the participants the opportunity to ask questions and give their feedback. This assisted in drawing a close to the study for the

participants and researcher and gave the researcher an opportunity to thank the participants for their time and cooperation. It also enabled the researcher to inform them of future work that is planned as a result of this research.

The three appointments gave the researcher and the participant opportunities to come into conversation with each other and develop an understanding of each other and the subject matter which changes over time.

The final meeting with the participants and their positive feedback about the themes that had been identified helped to complete the hermeneutic cycle (Fleming et al. 2003) and indicated that the researcher had reached an understanding about the experiences of different pathways of care that they had had and their life as a young person with C P.

6.4.2 Method of analysis

The interviews were interpreted using Flemings Framework of Analysis described in Chapter 6.3. A detailed explanation of how this was used in this research will be given.

The process of gaining understanding of the experiences of young people with CP regarding the pathway of care they took and the possible outcomes on their lives started with the first appointment and with the completion of the first outcome measures. This initial contact gave an insight into the outcomes of various pathways of care that young people with cerebral palsy had pursued. However, the results from the various outcome measures gave limited insight into the long term effects of treatment and did not include personal experiences and opinions. Therefore initially the results had limited meaning. Meaning was given to the results through the semi structured interviews. The process was similar to piecing a jigsaw puzzle together where the border or the results give structure to the puzzle and the middle pieces i.e. the interviews, give the overall picture and detail. Once the overall picture was gained, the structure of the picture could be looked at together with the detail. For this research the quantitative data provided the structure and the interviews gave the overall picture and filled in the detail. Once the detail was gained the structure could then be looked at to see how this influenced the whole picture. This was in keeping

with the hermeneutic cycle that Gadamer described to gain understanding and discussed in Chapter 6.2.

By the time the interviews were completed, an impression had been gained of the experiences of the different pathways of care that had been taken, and the outcomes as experienced by the participants. The process continued and deepened when the interviews were listened to and typed into the computer. Sentences were listened to repeatedly until the researcher was sure that she had typed it correctly. The interviews were therefore initially seen in parts as words or individual sentences. Once the interview was completely transcribed the researcher listened to it again and compared the written word to the typed word. This ensured that the interview had been correctly transcribed. Additionally it helped the researcher to become familiar with what the participant was saying in small sections and then subsequently in context as a whole.

At the next stage of gaining understanding each typed text was taken and read through again initially without making notes. The aim was to gain a general understanding of what the participant wanted to communicate. To gain more detail and following Fleming's framework for analysis the interview was read with attention made to individual words and then individual sentences. At subsequent readings of the interviews sections were read and then the complete interview was re-read.

Fleming (2003) stressed the importance of reviewing the researcher's pre understandings at this point. This was achieved by personal reflection and recognising my bias towards conservative treatment which could influence the themes that were identified. Personal reflection and sharing information with colleagues became more important as more interviews were analysed. This was because many young people explained how surgery had made their lives more difficult in terms of function and pain. This made it increasingly difficult for the researcher to be open to possible positive and important aspects of surgery.

The researcher's pre understandings can be read in more detail in Chapter 6.2.

The process of gaining understanding continued and themes emerged as words and phrases that the researcher considered important to the participant were highlighted. The initial understanding that the researcher gained from the phrases and individual words were summarised and written next to the text. An example of this raw data can be seen in Figure 1.

- 5 wie möglich. Wenn der ~~Aufzug immer~~
- 6 ich frage meistens jemand, weil es mir mehr Sicherheit gibt. *Stolz auf Selbstständigkeit*
- 7 Wie ist es für dich jemanden zu fragen zu müssen?
- 8 Das ist überhaupt kein Problem für mich, ich gehe auf Leute zu. Wenn Leute vorbei gehen, suche ich auch andere aus. Damit habe ich kein Problem. Ich schaue schon dass es kein Kind oder älter Menschen sind aber junge Erwachsene frage ich.
- 9 *Bereitschaft* Hast du es im Internet gelernt? *Kann Selbstständigkeit lernen*
- 10 Ja ich habe es im Internet gelernt. Am Anfang bin ich mit dem Bus vom Internat gefahren aber dann wollte ich selber machen. Dann bin ich erst mit anderen mitgegangen mit denen die es schon konnten und habe es gelernt an und aus zu steigen und umzusteigen. Bei meine Eltern gibt es keine U-Bahn. Ich hatte keine Erfahrung vorher mit MVV. *- zu Hause keine MVV*
- 11 Ich kann jetzt auch mit dem Bus fahren. Ich gehe vorne um, dass der Busfahrer mich sieht und dann tut er die Rampe raus und ich kann alleine rein fahren. Es ist mir sehr wichtig, dass ich so viel wie möglich mache. Wenn ich nicht weiter komme dann frage ich jemanden und lass ich mich helfen. *Selbstständigkeit wichtig*
- 12 Gibt es was du nicht machen kannst, dass du machen möchtest? *um Hilfe*
- 13 Also, ich vermisste nichts in meinem Leben muss ich sagen.- Manchmal schon wenn es ein Bürgersteig gibt wo ich nicht hoch komme, denke ich es wäre schön wenn ich laufen konnte oder so aber in Alltag bin ich ganz zufrieden. *muss Barrierefrei sein*
- 14 Ich kann Brot alleine schmieren, ich kann Kaffee oder Tee kochen, das ist alles kein Problem. *Barrierefrei*
- 15 In meiner neue Wohnung ist es Behindert gerecht. Es ist eine komplette unterfahrbare Küche. Die Mikrowelle kann ich bedienen. Ich habe es über MFZ und Kontakte dort gefunden. Es ist ganz schön. *Selbstständig sein*
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- 42 **Wie wichtig ist das Laufen?**
- 43 Es ist schon auch wichtig. Ich mache es auch schon aber es strengt es mich sehr an. Ich muss gestehen, dass ich immer wieder ein bisschen Faul bin. *paar Schritte gut aber anstrengend*
- 44 Es ist wichtiger für mich, dass ich mich umsetzen kann, dass ich mit meinem Alltag zurechtkomme als, dass ich weiter Strecken gehen kann. Es ist wichtiger, dass ich mit dem Alltag zurechtkomme es steht schon im Vordergrund. Ich kann Treppen steigen wenn ich mich auf beiden Seiten festhalten kann. Sonst geht nicht. Eine Stufe geht, es ist schon gut. Unterwegs bin ich schon im Rollstuhl unterwegs. Wenn es eine kleine Stufe ist, frage ich jemand, ob sie mir mit dem Rollstuhl helfen kann. Das mache ich schon. *Basics Wichtig*
- 45 *Transfers/ Stufe wichtig*

Figure 1: Two excerpts from an interview with participant No. 11 and the researcher's initial comments.

This process continued and the words and phrases that had been identified were reviewed. Excerpts of the translated interview of Participant No. 1 which had been reviewed and shows the key words or phrases from which some of the themes emerged can be seen in Figure 2. The original interview in German can be read in Appendix 7 and the complete translated interview can be read in Appendix 8.

1. Please describe a typical day for you starting in the morning and finishing at night?

2. In Internat (residential care) I get out of bed. I can get into my wheelchair
3. myself.
4. When I'm sitting in my wheelchair I dress my top half and then the early shift
5. helper comes and helps me with my lower half. It works also while sitting. I
6. can't put the shoes on myself. Then I go to eat because of the tablets.
7. I can choose what I want to eat and it is put on the table. I just have to get the
8. food. I can do that myself, bread with sausage.
9. I get a drink from the fridge.
10. **I can't use the microwave because it is too high. For that I need to get help.**
11. (not barrier free- results in less independence/participation- frustration
12. experienced by participant- it would be straight forward to adapt- YP has no
13. voice that is listened to).

66 Is it important to you that you can still crawl?

- 67 Yes it is because if I can't get somewhere with my wheelchair then I can
- 68 manage it on the floor. **I can walk alone with the rollator. At first someone**
- 69 **was with me and then I was able to do it alone.** (further example of
- 70 improvement in functional ability following conservative pathway of care). I
- 71 can stand up from sitting and walk off with my rollator.
- 72 **I had learnt to climb the stairs better. I was in the Ukraine for 2 weeks. I**
- 73 **learnt to climb stairs there.** (Intensive therapy can help improve function). It
- 74 lasted for 2 weeks and then I couldn't do it anymore. I had intensive therapy.
- 75 I don't have intensive therapy anymore because of the time and costs.
- 76 I was there 7 times. If I had the time I wouldn't do it again (hard work).

91 Do you go out in the evenings?

92 Not really. The day is so tiring and then in the evening I can't be bothered. **If**
93 **I want to go anywhere I have to go with someone because I haven't got the**
94 **other wheels and I can't push myself** (inadequate assistive devices reducing
95 level of participation and satisfaction with life. YP need to be listened to to
96 find out what is important to them).

110 Did anyone suggest that you should have an operation?

111 Yes. We didn't do it because it meant that if we had it done then I would need
112 another operation in 5 years time. We didn't want that. The surgeon also said
113 it could go wrong. **The doctor didn't know me and didn't really carry out a**
114 **full assessment. He saw that I couldn't straighten my legs and suggested that I**
115 **should be operated on** (medical model of care). I am so happy that I can do so
116 much alone and if it had gone wrong I would be able to do less. I was able to
117 decide with my parents (good to make the decision oneself).

Figure 2: Four excerpts of the interview with Participant No. 1 translated into English. Key words and phrases have been highlighted in red. The thoughts and the researchers' understanding of the text have been written in brackets.

[Original in Colour]

Themes started to emerge but while reflecting on them in relation to the interviews as a whole, it became apparent that these did not adequately represent the experiences that were most important to the participants. Therefore the process of analysis was then reviewed. Plano Clark et al. (2010) recommended the use of visual displays. The researcher revisited each interview and using large pieces of paper wrote the words and phrases that the researcher had highlighted and identified as key issues for each of the participants and formed a flow chart.

In the next step of analysis the words and phrases from all of the interviews that had been identified as key issues and were believed to have similar meanings were identified and listed together. These subsequently formed sub themes. An example of this is given in Chapter 6.5.1.

The flow charts and the lists of the statements relating to each sub theme were revisited. Following Fleming's framework of analysis the main themes developed from considering the sub themes in a wider context and identifying the main issues that were key for the participants. Two examples of this are given in Chapter 6.5.2 and a summary is given in Figure 3.

Finally the overarching theme was identified. This connected the individual experiences and experiences from all of the participants. Examples of statements from participant No. 1 that identify the overarching theme have been highlighted in Figure 3. In addition, specific examples from different participants highlighting the reasoning for choosing the overarching theme are given in Chapter 7.

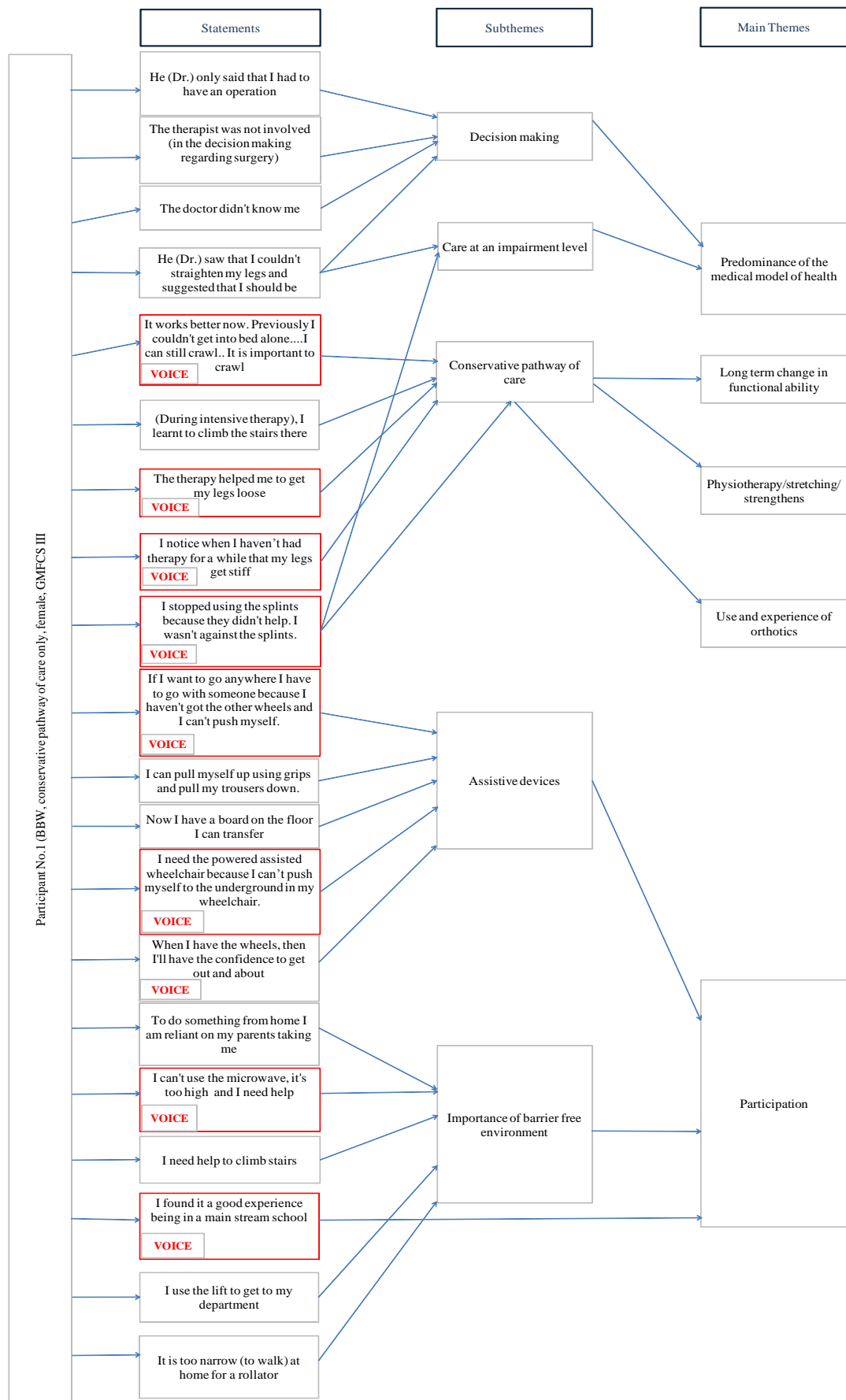


Figure 3: An overview of the development of themes

The in depth description of the young peoples' experiences in the qualitative phase added insightful meaning to the quantitative results. Thus the findings from both phases are complementary to each other and provide clarity and depth. They also serve as a form of triangulation where the experiences of the young people confirm the data obtained from the quantitative phase and vice versa. This is important especially as many health professionals continue to question the use of qualitative research in evidenced based medicine (Meulen et al. 2005).

All the information that has been collected using both quantitative and qualitative methods has provided evidence on which to base treatment of people with cerebral palsy using a bio psychosocial model of health.

The findings and interpretations from the interviews will be discussed in detail.

6.5 Findings and Interpretation

Young people with a GMFCS level IV/V who had surgery specifically emphasized their wish to be interviewed. In total 8 young people with a GMFCS level of IV/V were interviewed. From the eight people 5 had experienced and 3 had not experienced surgery. Four participants were interviewed who had a GMFCS level of III (2 who had and 2 who had not had surgery). Participants who had a GMFCS level of I/II were evenly represented with 3 people who had experienced surgery and 3 who had not.

The interpretation of the individual interviews has given rise to themes. In sharing their experiences of life with CP it has become very clear that young people have a voice that should be listened to. The other themes include changes in long term functional ability following surgery and a conservative pathway of care, physiotherapy, muscle strengthening and the stiffness of muscles, the use and experiences of orthotics, predominance of a medical model of care, and the importance of participation in achieving satisfaction with life. These are not ranked or prioritized and will be discussed in depth in turn.

An important element of gaining understanding of people's experiences is the movement from the part to the whole and back again (Annells 1996). In the context

of interviews this is the continuing review of individual words and statements compared to the overall interview. This process enabled identification of themes within the individual texts and then subsequently the identification of themes that were common to the participants. To provide the reader with greater understanding of this process, participant statements that were interpreted to have similar meaning and from which the sub theme of ‘decision making’ developed are listed below. Subsequently examples of the development from sub themes to main themes will be given using the main themes ‘the predominance of the medical model of care’ and ‘participation’.

6.5.1 Decision Making

Most statements that were made about decision making identified the person or people who made decisions regarding future care. Some young people however, recalled what factors were taken into consideration when a specific pathway of care was suggested. These statements were therefore also understood to be related to ‘decision making’.

In the following first six statements young people did not appear to be involved in the decision making process.

Participant (No. 1), female with a GMFCS III in BBW and who had not had surgery said:

‘He (Dr.) said I had to have an OP. The therapist was not involved in the decision. The doctor didn’t know me. He saw that I couldn’t straighten my legs and suggested that I should be operated on’.

Participant (No. 2), male with a GMFCS III in BBW who had experienced surgery said:

‘The doctor suggested it and my parents made the decision on the doctor’s advice’.

Participant (No. 3), female with a GMFCS II in BBW who had experienced surgery said:

‘...my parents and the doctor made the decision’.

Participant (No. 14), male with a GMFCS II in BBW who had not had surgery said:

‘The doctors examined me quickly. They didn’t do a gait analysis. They said that the tendons were too short’.

Participant (No. 15), male with a GMFCS IV/V in BBW who had experienced surgery said:

‘The orthopaedic surgeon suggested surgery...he decided’.

and participant (No. 8), female with a GMFCS IV/V in BBW who had experienced surgery said:

‘My doctors thought it wouldn’t be nice if it (shortening of the Achilles tendon) stayed that way....the therapists suggested it’.

Other participants were involved in the decision making process.

Participant (No. 5), male with a GMFCS III in MFZ who had not experienced surgery said:

‘...we decided together....the final decision came naturally from my parents’.

Participant (No.6), female with a GMFCS IV/V in BBW who had not had surgery said:

‘...my parents and I decided... Thank God that I didn’t have it done’.

and participant (No.12), female with a GMFCS IV/V in BBW who had experienced surgery was given information on which to base her decision:

‘...they gave me information how it would be after surgery...I also made the decision’.

Participant (No.11), male with a GMFCS III in BBW and had experienced surgery also received information on which to base his decision:

‘...I had several talks with the doctor...he explained what should be done and what my chances were that I would become more independent...he explained the risks’.

The statements relate mainly to who was involved in decision making. Occasionally young people were actively involved but frequently it was the medical consultants who decided.

6.5.2 Sub themes and their development into main themes

Examples of the meanings that were gained from statements and sub themes that lead to the development of main themes will be given.

A statement from participant No. 1 was:

‘He (Dr.) saw that I couldn’t straighten my legs and suggested that I should be operated on’.

The meaning gained from this was that firstly the doctor decided on the pathway of care which was understood to be a sub theme of ‘decision making’. Secondly the decision to perform surgery was made at an impairment level which was understood to be a sub theme of ‘care at an impairment level’. Together however, they indicate the predominance of a medical model of care which formed a main theme and was discussed in Chapter 2.6.

A further example of the development of sub themes to a main theme is also taken from statements from participant No.1. The sub themes are ‘assistive devices’ and ‘importance of a barrier free environment’ developing into the main theme of ‘participation’.

The first statement identifies that the participant did not have the wheelchair or assistive device she required to be able to go out independently:

‘If I want to go anywhere I have to go with someone because I haven’t got the other wheels and I can’t push myself’

However, secondly the wider meaning for her is that because she is dependent on others it prevents her participating in areas of life that would otherwise be possible with the necessary assistive device. Equally the statement:

‘It is too narrow to (walk) at home for a rollator’

identified that a barrier free environment is also key for a person to be able to participate in society.

Further examples of statements from other participants that were identified to form a sub theme and subsequently a main theme are presented in Chapter 6.5.3 to 6.5.9.

The themes that emerged made the researcher consider the bigger picture. This was not just in terms of the main themes and the overarching theme that emerged but other factors that influence the type of pathway of care which a person with cerebral palsy might have experienced and particularly in Germany today. These include child politics, the autonomy of physiotherapists, the evidence on which decisions are based and the health insurance system which exists in Germany.

The main themes provide an evidence base for all physiotherapists and other health professionals when advising on different pathways of care and for constructing a treatment plan regardless of the country they work in. Together with the quantitative phase this information answers the research question.

These main themes from the results and interviews will be presented followed by the overarching theme and finally the political issues that have been identified. The findings will also be discussed in the context of the quantitative results.

6.5.3 Changes in long term functional ability

Sub theme: Changes in long term functional ability following a surgical pathway of care.

One of the main aims of surgery to the lower extremities is to improve functional ability (Abel et al. 2003). Research has demonstrated that short term functional improvements can be expected for children that are ambulant and have had surgery (GMFCS I/II) (Saraph et al. 2005). Little evidence however has been found that supports the use of surgery to improve long term functional ability (Gannotti et al. 2010).

The results from the quantitative phase of this study suggest that statistically there are no significant differences in changes in long term functional ability for people with GMFCS levels I/II and III between those who have and those who have and have not experienced surgery to the lower extremities as children. A statistical difference was found for the less physically able young people with a GMFCS level of IV/V between the two groups. The clinical implications for this are that non ambulant children who have surgery to their lower extremities as children are less likely to experience a long term improvement in function compared to other non ambulant children who did not have surgery. The interviews were used to explore these results and also to illuminate young people's opinions in order to give them a voice.

A number of reasons including pain (Jahnsen et al. 2004) and change in body mass index (van Eck et al. 2008) have been proposed as possible causes for deterioration in long term function of people with cerebral palsy. The findings of this research indicate that surgery to the lower extremities of children may be a contributing factor for deterioration in long term function. This has been articulated by some of the participants through their descriptions of function before and after surgery.

The first three quotations describe how walking and specific activities were altered after surgery:

P4. 'I could previously walk a few steps alone (with an assistive device). This has got worse (after surgery) and also my scoliosis.....I couldn't sit cross legged or crawl (after surgery). I used to like sitting on the floor'.

Another young person said:

P9. 'To begin with I could walk better (than before surgery) but then it got worse quickly'

In addition to a loss of independence, young people articulated frustration at having to relearn activities:

P8. 'before my surgery I could get dressed alone. After my surgery I had to learn everything again. It was difficult because the hips were strange.....Now it's just about alright again. I didn't have a scoliosis before the first surgery. After the surgery the hip jumped out and then my body became slanty and I developed a scoliosis'.

Another participant also expressed his frustration

P4 '.....it took weeks or months after the surgery before I could walk again'.

In addition to these emotions young people also expressed feelings of anger about the surgery they had experienced:

P13. 'but I wouldn't have it done again because the tendons will get short again. Why should I suffer if it is like that? It wasn't a nice time (after the surgery)'.

P12. 'for me I made 2 steps forward before surgery and 3 back after surgery'.

The experiences were wide ranging but overall suggest that prior to surgery the young people had higher levels of ability than after surgery. In some cases the impact of surgery resulted in losing the ability to walk. Comments from others also highlighted that the impact of surgery resulted in a struggle to regain their function.

Whilst previous research has found a relationship between function and muscle strength (Kim and Park 2011) the experiences of the participants has highlighted that surgery may be a contributing factor for deterioration in muscle strength. The

following quotes from two participants are very explicit in identifying the loss of muscle strength following surgery:

P13. 'I couldn't get any strength' (in legs)

and

P8. 'I couldn't move my legs, the muscles were gone and I couldn't do anything'.

Seniorou et al. (2007) concluded that it can take up to 1 year to gain pre operative muscle strength in the lower extremities. However, the results of this study and the comments of some of the participants indicate that pre operative strength is never regained in some young people resulting in a deterioration of functional ability. Some individuals had positive or equivocal experiences regarding long term functional outcomes following surgery. Participants with ability scored at GMFCS level I/II and III who had experienced surgery did not appear to be either more advantaged or disadvantaged by the surgery long term. The interviews endorsed this result and clearly showed that for some, surgery was perceived as being helpful, but for others outcomes were equivocal.

One participant stated that

P16 'after the OP I could walk better and can do more because I don't walk on my toes anymore'....

Another participant commented that

P3 'my walking, I think; hasn't changed much'.

Although the results and many of the comments from less physically able young people with a GMFCS level IV/V give evidence that surgery is not advantageous there were however, some young people who expressed the benefits they had experienced from surgery.

P2. '...the second and third operations made the most sense....the first was a mistake. I could walk again. It was hard work. I was able to walk 50 metres with a rollator after 2 years. The straightening of the leg was better. It wasn't just the walking, it was easier for me to pull up my trousers because I could get my legs apart. I haven't ever been able to do as much as after the

second op....I have been able to maintain the straightening of my legs I can push myself up better, do transfers or stand up better without my legs coming so close together’.

The results and experiences of the participants give evidence to support conservative treatment for people with a GMFCS IV/V. However, as some participants reported the benefits of surgery more research needs to be undertaken to be able to identify the people who might benefit from surgical procedures. However, participants have clearly expressed side effects that may not be considered by health professionals such as pain and the psychological stress that an operation may cause.

P8. ‘I wouldn’t ever again, ever again have another operation. I would recommend to others that if you only have a Spitzfuß (shortened Achilles tendon) or have a slanty hip not to be operated on. Only if they have pain. It is a burden on your psyche and you can’t do anything for ages’.

Another participant expressed his experience concisely.

P15. ‘it is stress making and I had pain. I wouldn’t recommend it to others’.

Sub theme: Changes in long term functional ability following a conservative pathway of care.

The results from the quantitative phase of the study identified that conservative treatment may be more beneficial in improving long term functional ability for people with a GMFCS level IV/V. The understanding gained from the participants would endorse this result. These participants were more positive about the change in functional ability over the years compared to participants of the same GMFCS level who had surgery.

P1. (GMFCS III) ‘It (ADL) is better now. I couldn’t previously get into bed by myself. Now I can.....I have a board on the floor (so that the bed is the same height as the wheelchair), I put my feet on it and then I transfer. I was never able to walk alone but I could crawl. I am still able to do that’

Another suggested:

P6. (GMFCS IV/V) ‘I haven’t got worse over the years. In fact I can now sit better on a bench’.

One participant who had followed a conservative pathway of care had improved from a GMFCS level III to GMFCS level II.

P14. 'I have had a wheelchair since I was 7 years old. I can walk independently since I was 10/11. It wasn't possible before. I have also learnt to climb the stairs with one hand.....before; I crawled up and down the stairs.I had a lot of therapy at kindergarten age. They placed emphasis on strengthening the muscles'.

The results of this study, together with the many experiences from participants, suggest that surgery may not be the best pathway of care for all people with cerebral palsy to improve long term functional ability. This is evidence based information that should be taken into consideration when recommending surgery to participants in order that they can make informed decisions about their future.

6.5.4 Physiotherapy

Despite the dearth of evidence that is available to support the efficacy of the main physiotherapy concepts that are used in the pathway of care for people with cerebral palsy, participants shared positive experiences about physiotherapy they had received.

P14. 'because of therapy I can stand longer and better and I can do the vacuum cleaning'. Note: This participant lives alone and it is important to be able to household jobs to remain independent.

P.6 'without therapy, for example on holiday, I lose the ability to sit alone'.

The importance of physiotherapy was also identified by the deterioration that was experienced when participants do not have therapy or when the frequency is reduced.

The young people who participated in the research were either in a 3 year job training scheme or in sheltered workshops. Normally their physiotherapy appointments were arranged outside of the working day in order not to disrupt their job training or work. Many of the participants were in their final year of job training and would have an evening appointment. However, the evening may not be the most suitable time for physiotherapy because the young people could be tired. This also applies to those who wished to follow a hobby after work.

One participant said:

P16. 'Since I started my studies (and have less time for physio) I have got worse (less mobile)'.

The effect that this can have on activities of daily living has possibly been underestimated by health professionals but has been expressed as being a problem for some participants.

Similar comments were made by other participants indicating the importance of physiotherapy:

P14. 'One doesn't have any time for therapy (because of work training). I notice my endurance isn't as good. I notice that when I go home and stand that I have pain in my thigh'.

and

P2. 'I have a problem with my back. Since I started the job training I sit more and move less and my back pain is dependent on the daily activities. In order to fit in with the work day (training), I must sit for longer at one time. I can't lie down anymore at 16:00'.

The comments strongly indicate the need for physiotherapy for young people and with all levels of GMFCS. An evaluation of the current service should be undertaken to establish whether a more accessible physiotherapy service would better meet the requirements of the participants. Some of the comments indicate that currently their needs are not being met. Evaluating whether people with CP are satisfied with the physiotherapy service is an area of research that has received little attention although it has been identified that service provision and intervention is an area which consumers have identified as being a research priority (McIntyre et al. 2010).

Whilst the experiences shared by the participants support the use of physiotherapy and provided a general overview and evaluation about the importance of physiotherapy other participants identified muscle strengthening and reducing stiffness as important elements of their treatment. This is valuable information as there is a dearth of evidence to support the various physiotherapy concepts.

6.5.5 Muscle strengthening

Muscle weakness has been identified as being a common problem for people with CP (Stackhouse et al. 2005). However, the efficacy of strength training is disputed. A systematic review of 5 studies could not confirm the efficacy of strength training for ambulant children (Scianni et al. 2009). Subsequent research however, has demonstrated that strength training can significantly improve gross motor function for ambulant (Nystrom Eek et al. 2008) and non ambulant children (Bryant et al. 2012).

The findings based on the participants' experiences endorse those of Nystrom Eek et al. (2008) and Bryant et al. (2012) who strongly advocate the use of strength training as part of a treatment program

Participants with a GMFCS level of I/II have stated the following:

P14. 'muscle training is important for me, the muscles are my stability'

P17. 'It has been very useful (therapy). Most important is muscle training. I notice that if I do muscle training then I can walk much better'.

Other young people also emphasized the need of muscle strengthening during their therapy:

P9... 'I changed here from a physio. practice that didn't know much about CP. I started strength training which has been useful. I become less mobile (joints) if I don't have physio'.

Another participant said:

P14 'My legs have got better (due to therapy). I had to strengthen my muscles'

The experiences from participants with a GMFCS level of III are also in agreement:

P15 ' ... my legs are stiffer without therapy. Important is to strengthen muscles'.

Participants identified that an increase in strength improved their functional ability. This supports evidence by Kim and Park (2011) and Ross and Engsberg (2007) who

reported that there is a relationship between muscle strength and gross motor function and functional ability.

P11 'I notice that with strength training I have more strength in my legs and then transfers are easier and I can handle my wheelchair better'.

Participants with a GMFCS level of IV/V also identified the importance of strength training to improve functional ability:

P4. 'If I walk more (with equipment) then it gets easier. My muscles get stronger and then I can walk better'.

6.5.6 Muscle stiffness

Muscle strengthening was reported to be important for people of all functional abilities but predominantly for people that were ambulant. Non ambulant participants emphasized the importance of reducing 'stiffness'.

In Chapter 2.7.4 it was discussed that despite the common use of stretching with the aim of reducing muscle stiffness caused by contractures or spasticity there is little significant evidence that supports its use (Pin et al. 2006). The participant's experiences indicate that therapy has a positive effect in reducing stiffness:

P12. 'I am less stiff after therapy'.

P15. 'my legs are stiffer without therapy'.

Additional in depth questioning might identify what elements of therapy are responsible for reducing stiffness. This knowledge would be valuable in providing evidence on which to base treatment.

6.5.7 Use and experiences of orthotics

The use of orthotics is common following either a conservative or a surgical pathway of care and has been explored in Chapter 2.7.4. The use of night splints is a common orthotic used as a prophylaxis to help prevent contractures and hip displacement, or help prevent further development of contractures and a deterioration of hip displacement (Mol et al. 2012). They are likely to be prescribed until a child has stopped growing.

They continue to play a large role in ICP in the management of young people with CP. Photographs showing examples of both long leg night splints and below knee splints can be seen in Appendix 9.

During the interviews the participants chose to share their experiences about night splints. These highlighted the importance of evaluating their use. The comments demonstrated that night splints can be uncomfortable and frequently disturb sleep:

P8. 'I had night splints. I couldn't turn, they were painful'

P5. 'The night splints weren't great, they hurt and were unpleasant. I couldn't sleep'.

Participants also highlighted that splints can cause a disturbance to sleep which can affect performance at school.

P2. 'I had night splints for 2 years. I couldn't really sleep nights. I slept sometimes for just 3 hours. They were hot, I couldn't move, turn, lie on my side, nothing. You lie stiff on your stomach or on your back. They didn't rub but they were very unpleasant. I was in boarding school but I was very tired during school. If you go to school every day with thick eyes then you have to do something.....it would be good if an alternative could be found....I could have managed with 3 hours less sleep but not the whole night'.

and

P12` They were worse than the operation', 'I couldn't sleep', 'I was tired at school', 'they were torture'.

Disturbed sleep for children with cerebral palsy has been reported to be more prevalent than for normally developing children (Newman et al. 2006). This can result in excessive daytime sleepiness and lead to a decrease in physical activity which has been shown to have a detrimental effect on quality of life (Sandella et al. 2011). Improving sleep patterns may therefore be more important than improving sleep positions in the management of young people with CP.

Some comments also emphasized that children are tolerant and will put up with discomfort if they are told to do so.

P16. 'I have had night splints since my operation (10 years ago). They annoy a bit in the night but they are meant to help so I wear them. If I don't wear my splints I can sleep longer. They itch and I can sleep longer without them'.

Although recent research with 82 young people with CP showed no statistical difference between sleep disturbance in children who used night splints and those who did not, the experiences of the participants of this research are so powerful that their use should be critically evaluated (Mol et al. 2012). Moreover additional research is indicated with an emphasis on gaining further opinions and experiences of the users.

Anecdotal evidence: Some older students who did not take part in the research had however, positive experiences of night splints. They reported that they can help in relaxing their muscles and maintaining range of movement. There is therefore a need to establish evidence on which to base their continued use.

In light of these findings it was necessary to take immediate action to ensure that children who were currently using night splints were not suffering from sleep deprivation and discomfort. Parents and young people were asked about their experiences using the night splints. The consequence of this was that although they continue to be prescribed, children have become much more active in the decision making process about their use. A questionnaire about young people's and parents experiences with night splints is being developed to further evaluate their use.

6.5.8 Predominance of the medical model of health

There was extensive evidence from the reported experiences from participants that they were rarely included in decision making. Moreover there was a dearth of information on which to base decisions. From my current clinical experience it is evident that the decision making process regarding surgery in many centres has not changed and the medical model of health predominates for the care and treatment for people with cerebral palsy. This is despite the introduction of the ICF model of health and legal rights for children. Whilst there is a plethora of information now

available via the internet concerning surgical procedures, not much of it is research or evidence based. Moreover, too much information can result in confusion within the families who may in turn seek advice and become reliant on the opinion of the doctor. It is not uncommon that parents obtain 3-4 different medical opinions.

Good practice regarding decision making for the most appropriate pathway of care (Kembhavi et al. (2011) includes pre operative gait analysis, a detailed physical assessment and a considered team decision with a child, his parents and other health professionals. This is however not current standard practice in ICP or in many other clinics or centres for people with CP in Germany.

The limited pre-operative assessment was highlighted by several participants:

P14. 'The doctors examined me quickly. They didn't do a gait analysis. They said that the tendons were too short'.

Another said:

P1. 'the doctor didn't know me and didn't really examine me. He saw that I couldn't straighten my legs and thought I should be operated on'.

Surgery was recommended to improve the impairments that were seen to be the problem. This again highlights the predominance of the medical model ideology:

P8. 'I had my surgery because of my Spitzfuß (shortening of the Achilles) and my doctor said it wouldn't be nice if it stayed that way. The aim was that I should put my weight through my whole foot'.

Participants also gave similar examples illuminating the lack of team approach used in the decision making process:

P15. 'the orthopaedic surgeon suggested surgery.....he decided....'.

In addition to a lack of involvement of all health professionals in the decision making process it was evident that a child's opinion was not sought after. This shows evidence of disempowerment of the child.

P2 'the doctor suggested it and my parents made the decision on the doctor's advice'.

However, there were some occasions where the children were involved and actively participated in the decision making. In these cases the young people were positive about their decisions.

P6. 'The doctor suggested that I have an Achilles lengthening.....so that I could stand better.....my physiotherapist thought it wouldn't be helpful and that the tendon would become shortened again and I would most likely need another operation. My parents and I decided.....I haven't got a problem that they are a bit shortened.

Thank God that I didn't have it done'.

P5. '....the doctors said that I wouldn't be able to go on my knees.....I was often on my knees.....we were frightened.....all my friends have had surgery.....one friend has a problem with his hip, the other lost a lot of blood and after problems with his knees.....we decided together..... the final decision came naturally from my parents'.

The experience of being involved in the decision making process was empowering:

P1. 'The doctor didn't know me. He saw that I couldn't straighten my legs and thought that I should be operated on. I was able to decide with my parents. I would make the decision again'.

The experiences shared by the participants highlight the need to provide relevant information and include children, their parents and health professionals in the decision making process and therefore progress from a medical model of health towards a bio psychosocial model of health.

6.5.9 Participation

The quantitative results indicate that level of satisfaction with life was not related to either a conservative or surgical pathway of care. This was evident for participants in all levels of GMFCS. The interviews however provided depth and enabled a greater insight and understanding of the issues that the young people found important and also ways to improve their satisfaction with life.

The ability to participate was a strong factor in improving satisfaction with life amongst the participants.

The International Classification of Functioning, Disability and Health (WHO 2001) defines participation as: 'Involvement in life situations'. It is classified as 'learning and applying knowledge, general tasks and demands, communication, mobility, self care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life' (Colver 2003 p 642).

It is well documented that the ability to participate is related to quality of life (WHO 2001). Although participation is considered the ultimate goal for people, this study highlights that in practice it has not yet achieved priority. The participants from all levels of motor ability reported resistance when pursuing their ultimate goal of being able to participate in society.

Accessibility and assistive technology were areas that were key factors for many of the young people in order to participate in society and the implications of this for their families' and friends. In practice assistive devices are not always available to those that need it to enable them to be independent. Examples of this are given by the participants:

P1. 'I have tried out a powered wheelchair and then I (can) manage the way to the underground.....if I want to go out somewhere I have to ask somebody because I haven't got the other wheels yet and I have to be pushed....When I see others in our residential care and they can do it (go out spontaneously e.g. in the evening) it is depressing. When I have the wheels I would go out alone.....I feel a bit alone at home.... To go somewhere my parents have to take me or I have to go with other people'.

Another participant highlights the impact of having access to the appropriate assistive devices on the level of independence that can be enjoyed and quality of life:

P13. 'I wanted a manual wheelchair (as well as my E-Rolli) but I can't. You can only have one wheelchair. I need another wheelchair if my wheelchair is broken or if I want to go to parties which are on the 3rd floor. I've had an E-

Rolli for 6 years. Before that I didn't have any friends. I came and found friends. I can go shopping alone; I can go where I want to. I can go to the cinema. I can go over carpet'.

Munich is responding to the equality act of making public places and transport accessible and in the regional paper it was reported that considerable investments were going to be made to achieve this. However, not only does the infrastructure need to be accessible but the assistive devices need to be available. This is however, dependent on the Stakeholders of healthcare, the Krankenkassen (public health insurance companies), understanding the need for assistive devices and the effect this has on satisfaction with life.

Since 1st May 2002 there has been a German law for 'Equality' for people with disabilities. Buildings, products, transport and the environment should be barrier free or accessible so that they can be accessed by everyone. This has been followed by the Convention on the Rights of Persons with Disabilities which came into force in May 2008. Measures have to be taken to enable people to enjoy full inclusion and participation in all aspects of life. This includes the 'availability, knowledge and use of devices and technology'.

Universal Design is a development of the concept of 'barrier free' which is also known as accessibility. Joines (2009) describes the difference between accessibility and universal design as 'accessibility is what is legal - what is required to meet building codes and requirements' (Joines 2009). For example an entrance to a building might be raised and therefore have a ramp and a step to make it accessible. Using the concept of Universal Design however, the building would have only one entrance that can be used for all.

This is an important development for people with disabilities. The impact that assistive devices have on young people and caregivers has been investigated widely using predominately quantitative research methods (Henderson et al 2008). One piece of research was reviewed that used interviews to gain a 'Mother's perception of their child's use of powered mobility' (Wiaart et al. 2004). In the review by Henderson et al. (2008) no research was mentioned that investigated the child's

views. It is therefore surprising that no available research was found that explored the experiences of young people who have assistive devices. In addition although it can be assumed that accessibility is important to young people with CP there is currently no research that supports this notion.

While the participants are in Internat (residential care) they enjoy the accessibility of the bathroom, bedroom, living room and kitchen and to outdoors. However, when they leave Internat or visit family and friends at weekends the independence that they have enjoyed is often no longer available. Thus they become dependent on their relatives or friends.

P1. 'I have a rollator in residential care. At home it is too narrow for a rollator. I use either a wheelchair or I sit on the sofa'.

P2. 'I am more independent in boarding school than at home because we moved 6 months ago and the bathroom is not barrier free'.

While accessibility and assistive devices are considered important predominately for people with GMFCS III/IV/V participants emphasized that it also plays an important role in affecting satisfaction with life for people with less physical limitations but who have other needs.

P16. 'I actually wanted to do the training to become a cook.....The agency didn't allow itthe agency didn't want it because of my disability. Because I can't stand long enough and after the training I wouldn't be able to get a job because of it and because of that I'm in the office.....I tried it and I think I would have managed it (training to be a cook) but the agency didn't want it'.

The reason given by the agency for not allowing the person to do the training was that to be able to work in commercial kitchens it is necessary to stand for long periods. The use of a high stool to assist is not considered acceptable practice by employers.

Another participant highlighted his disability as a reason for not following his training of choice.

P17. '...if I didn't have this handicap then I would do something else... woodwork or painter. With my handicap I must work in the office....it is nice but I would prefer to be outside...'

Not only is it necessary for young people to have the opportunity to participate but the interviews highlight the need for this in their childhood. Some participants report that they were challenged by their parents to try out the same everyday activities as their siblings. The participants who had been given this opportunity were grateful for it. Others reported that their parents were 'over protective' and regretted the lack of opportunity. There is evidence that parents of young people should encourage their child's independence (Reid et al. 2011).

It is evident that this is an issue for young people and their parents. It is therefore important that this valuable experience is articulated to both parents and physiotherapists in order to be able to support the children and parents and achieve this aim.

The interviews highlighted the need for the young people to be spontaneous and independent. The use of a powered wheelchair provides this and affords the young people the opportunity to go out in the evenings and not be reliant on people pushing the wheelchairs. The insurance companies classify surgical procedures and certain orthotics as standard medical practice and therefore approve them whereas assistive devices in many cases are considered to be non essential and are therefore frequently rejected by the insurance system. The insurance companies are guided by the recommendations of doctors and surgeons which continue to be based on the medical model. There is available research regarding short term benefits of surgery but not of the advantages of assistive devices in relation to participation and satisfaction with life. A change in priorities will only occur when there is a general shift away from the medical model of health to a bio psychosocial model of health.

One participant summarized the points that were important to him which is representative of the wishes of many young people with cerebral palsy.

P12. 'It is important that I can take the same life path as others. That my disability doesn't play a roll, job training, driving license and flat. I have

everything I need. It is important that I can stand and that my scoliosis stays the same as it is and that my mobility stays the same'. `

This could be a quote from someone who has or has not experienced surgery. Satisfaction with life is dependent on many factors and not solely on functional ability. Therefore the decision to operate should be considered very carefully taking into consideration that conservative management and the provision of assistive devices and accessibility may have a favorable influence on the satisfaction of life.

In Gough's rather critical appraisal of postural management he suggested that resources should be used to enhance 'communication, participation, and transition into adulthood' rather than funding postural management programs (Gough 2009). The results of this research indicate that surgery is no more effective in improving long term functional ability, reducing prevalence of pain or increasing satisfaction with life than conservative care which includes postural management. It may be therefore preferable to invest resources into conservative treatment approaches such as postural management rather than surgery.

6.5.10 Summary

The evidence from these findings suggests that surgical treatment does not meet the needs of many people with cerebral palsy. Evaluation of current practice is necessary to identify the key interventions that do fulfill the needs and expectations of people with cerebral palsy. This knowledge will increase the evidence available for health professionals, children and their parents on which to base decisions to achieve the best possible outcome.

The understanding and the themes gained from the interviews were the researcher's interpretation and will be interpreted differently by every reader of this study. However it was important that measures were taken to test for trustworthiness to demonstrate that the interpretation of the interviews represented the views of the participants. A feedback meeting was used for this purpose.

6.6 Comments from participants at the feedback meeting

Following the presentation of the findings the participants were invited to give their feedback. Six of the 18 participants were able to attend the feedback meeting. Six had finished their job training and were no longer in Munich, two were sick and four were unable to attend or did not attend for other reasons.

All levels of people with a GMFCS I-V were represented. One participant had a GMFCS I, two had a GMFCS III and three had a GMFCS IV/V. Four out of six participants had had surgery and two had not.

One participant said:

P 5. 'You have hit the nail on the head'

This was then met with agreement from the other participants. Gestures and vocal comments indicating agreement were most obvious for four of the themes namely muscle weakness, strengthening exercises, participation ranging from a choice of training to being able to go to the cinema without assistance for all participants regardless of their GMFCS level. There is a lack of information for all people of all ages who have cerebral palsy and their parents to assist in the decision making process regarding the most appropriate pathway of care. Finally it was agreed that young people of all ages lack autonomy which can result in frustration at the lack of their involvement in deciding the best pathway of care for them. A very interesting comment was added at the end of the meeting that expressed the need to be listened to and treated equally to people in the normal workplace.

The informal presentation and the feedback from the participants endorsed that the researcher had identified their issues and that the research was invaluable to the young people with cerebral palsy as it gave them a 'voice'. They believe that this voice will result in them being listened to.

A participant concluded the meeting by saying:

P12. 'you are the first person who has asked me (what I think). I think that your research is really important, thank you'.

Chapter 7: Discussion

As previously discussed, the aims of this research were to develop an understanding of the experience of young people with cerebral palsy, to describe and evaluate the type of treatment and management they had experienced and to make suggestions to optimize both the pathway of care and also the decision making process leading to the chosen treatment.

The main themes identified from the interviews together with the results from the quantitative phase of this research have suggested that surgery to the lower extremities of young people with CP may not be the most beneficial pathway of care to improve long term functional ability, reduce the prevalence of pain and to improve satisfaction with life. It is therefore suggested that other pathways of care may be more appropriate to achieve this aim. This is currently contrary to the thinking and practice of many medical practitioners in and around Munich.

The interviews identified that different pathways of care were offered to people with CP by health providers without always taking into consideration the needs and wishes of young people and that decision making was not always evidence based. Health professionals generally believe that people strive to improve their functional ability and many consider surgery to be the favoured pathway of care if conservative treatment fails. However, there is little evidence that explores the needs and wishes of people with cerebral palsy (Redmond and Parrish 2008) and little evidence to support the use of surgery for long term improvement of function. The findings of this research would endorse this notion, with participants clearly identifying that being able to participate in society is more important to them than how they physically achieve this. It is important that health professionals are aware of such evidence in order that they can consider the most appropriate form of care and treatment they offer to people with CP. In addition the literature review also revealed that many physiotherapeutic interventions have little evidence to support their use. This research has however demonstrated that experiences and opinions from young people can provide valuable information on which to base treatment and should be used to complement quantitative research methods.

It has been highlighted that young people with CP in Germany were and continue to be largely offered care based on a medical model of health rather than a bio psychosocial model of health which is practised in the UK (Chartered Society of Physiotherapy 2009). The adoption of such a hierarchical model does not encourage users to make their voice heard.

7.1 Overarching theme: The voice of young people

The interviews highlighted very clearly that young people as children did not have a voice that was listened to and in fact this perpetuates today. The lack of voice and importance of having a voice was a major issue which permeated several aspects of young people's lives and examples of this can be seen across many of the themes that have been identified (Chapter 6.5). It is my understanding from the interviews that this is a key issue for young people with CP and has therefore been chosen as the overarching theme resulting from the interviews.

Examples of how this overarching theme links the general themes together can be found in Chapter 6.5. A summary of them however, will be highlighted.

Many of the young people reported that as a child they did not have the opportunity to be involved in the decision making process regarding their pathway of care and therefore were not given a voice:

P15 'the orthopaedic surgeon suggested the op.....he decided'

However, this was also true in many other areas of their lives including the type of career they were following:

P16 'I actually wanted to do the training to become a cook....The agency didn't allow it....the agency didn't want it because of my disability.....I tried it and I think I would have managed it but the agency didn't want it'.

Alternatively young people were not asked or listened to regarding areas of treatment they experienced:

P12 'They (night splints) were worse than the operation. I couldn't sleep, I was tired at school, and they were torture'.

Additionally their needs regarding assistive devices that would increase independence were not listened to:

P13 'I wanted a manual wheelchair (as well as my E-Rolli) but I can't. You can only have one wheelchair. I need another wheelchair if my wheelchair is broken or if I want to go to parties which are on the 3rd floor....'

One of the most important outcomes from the research was that participants had the opportunity to express their desires which in turn has resulted in the need for attitudes to change towards young people with CP. They were adamant that they should be given the opportunity to express what is important to them and from that basis to develop an appropriate pathway of care.

Possible reasons for the lack of voice that young people have will be considered in 4 sections namely child politics, the status of physiotherapists, evidence based medicine and finally the health insurance system.

7.2 Child politics

It has been highlighted by the participants that as children they did not have a voice that was listened. This lack of voice permeated many aspects of their lives and continues to be an issue for the participants who are now young adults. This research has made the participants aware that they do have a voice that should be listened to and choices. Exposure of this has led to some participants articulating that they want to be involved in decision making and that current practice is unsatisfactory.

However, confusion can occur when the child's opinion is considered not to be in the child's best interest. In many clinics in Germany, doctors suggest the pathway of care which they consider to be in the child's best interests and the parents ultimately make the decision. In such cases the child's opinion is by passed and they are rarely involved in the decision at all. Agreeing on a pathway of care for a child can be difficult and where there is disagreement between parties the decision may be made in a court of law (Baines 2008).

Beauchamp and Childress (2001) developed an ethical approach (Principlism) to decision making which consists of four principles that are widely used in medical

ethics. These will be discussed in relation to their appropriateness to young people that are considered not competent to make their own decision (Baines 2008). Health professionals should be aware of and respect the principles when considering the management of a person with CP.

The four principles are autonomy, beneficence, non-maleficence and justice.

Autonomy is defined as the 'freedom to determine one's own actions, behaviour etc. From a philosophical perspective it is 'the doctrine that the individual human will is or ought to be governed only by its own principles and laws' (The Collins English Dictionary 1986).

This is also advocated by the United Nations Convention of the Rights of the Child. However, health professionals and parents inevitably ask whether children should always have autonomy in health decisions. A very young child is considered not to be able to make his or her own decisions about healthcare (Baines 2008). Older children may or may not be able to make the best decision but they should be involved in the decision making process and given the opportunity to express their views (Taub 2003). Children's autonomy is sometimes denied because parents, doctors and other health professionals consider that they know what is best for a child. There is an ethical and moral question of what constitutes knowing best and who has the right to impose such a decision particularly where evidence is lacking. Everyone will have their own interpretation of their idea of an ideal life and should be allowed to make their own decisions depending on what is important for each individual (Pavot and Diener 1993).

My philosophy concurs with this way of thinking and was a reason for choosing the Satisfaction with Life Scale Test which allows each individual to decide what the best is for them. In addition it underpins my fundamental philosophy and reason for doing this research that as a health profession I cannot decide what is the best pathway of care based on my values and wishes. It is more important that I have an understanding of the general findings of research and can listen to the young people in order to help them implement their desires and wishes.

It is therefore ethically imperative that a health care provider finds out the personal goals and desires of each individual (Brody 1992). It is not always possible to know what the best decision for a child is, however it is possible to enable them to make an informed decision. This is particularly important for children who are not capable of being autonomous in decision making. This informed decision making process should involve all parties including the child, health professionals and carers that know and work with the child (Streuli et al. 2011). Clinical experience has shown that team work and consultation is lacking in many clinics in and around Munich and was highlighted in the interviews.

Baines (2008) considered that the reason why a child does not have the final say is because he may not have considered the long term consequences of his decisions. This is an argument commonly presented by physiotherapists particularly in regard to surgery or the use of splints. However, the evidence base which physiotherapists and other health professionals are using is not established and no more justified than the desires and opinions of the child. Therefore healthcare professionals should not recommend surgery when the research is equivocal.

Parents of young people with CP reported the necessity of children advocating for themselves (Reid et al. 2011) and the participants from this study endorsed this. There is therefore evidence that young people should be involved in decision making together with support from a team of specialists. This study also endorses the need to listen to these young people, give them a voice and enable them to lobby to gain more power to have a chance of asserting their wishes rather than accepting the decisions of other people.

The second principle is beneficence which is 'the act of doing well; kindness (The Collins English Dictionary 1986). It is assumed that healthcare professionals act to benefit the patient. This could be considered to be the same as acting in the child's best interests.

There are no set of rules or agreement about what constitutes a good life. Baines (2008) suggests that decisions made for example by doctors deciding on a pathway of care will be influenced by their own values, philosophical stand points and

consequently on the model of health care they adopt. The experiences of participants have shown examples of this and emphasize that health professionals need to concentrate on finding out what is important to young people with CP.

The third principle is non-maleficence or ‘not causing or producing evil or mischief’ (The Collins English Dictionary 1986) or in the case of a healthcare professional they should not harm the patient.

The evidence presented in this research suggests that healthcare professionals could theoretically harm the young person if decisions made about surgery are poorly considered and not based on evidence. In all cases information must be given to young people and their parents to enable them to make an informed decision on the best pathway of care (Brody 1992).

Not only is it possible for health professionals to harm a child but parents also are in a position to harm their child if they do not make the best decision (Baines 2008). However, it is difficult for parents to make appropriate decisions about care when the availability of information explaining the possible benefits and possible disadvantages of surgery or other forms of treatment are not available to them. It should be considered that parents may not take a decision that is recommended because of their love and dedication to the child and their fear of causing them pain or harm. This may result in parents not making an impartial assessment of their child’s interests (Black 2006). It should therefore be considered that parents may not be the best people to make important medical decisions for their children.

The final principle is justice which in context of providing healthcare can be considered as the fair distribution of benefits for people with similar needs. There is clinical evidence that the distribution of assistive devices and more specifically manual and powered wheelchairs is unequal. Moreover, people with similar needs may receive different amounts of financial support from the insurance companies. This is unjust and can have an effect on quality and satisfaction with life.

The ethical guidelines by Beauchamp and Childress (2001) follow the guidelines of the UNCRC (1989) and can be related to issues that should be considered by health professionals when considering the pathway of care for a person with cerebral palsy.

There are other factors that may influence the opportunity of young people to be heard and therefore the treatment pathway that they follow. These were identified in the themes and can be divided into 3 areas:

7.3 Autonomy and status of physiotherapists

In Germany, where the health system is largely based on a medical model, young people require support to make informed decisions about the best pathway of care. Physiotherapists are suitable to assist in decision making as in Germany they are likely to have contact with a young person over many years into adulthood and can gain an understanding of people's physical abilities and the key issues that are important to them. However, to be able to influence decision making physiotherapists need to improve their status and increase their autonomy.

Possible reasons for the difference in autonomy and status between physiotherapy in Germany and UK were identified in Chapter 1.2.2. These differences should be acknowledged and addressed in order to effect change in physiotherapy practice in Germany.

Changes should commence by establishing an influential professional body that will make changes to education and continuing education of physiotherapists. The transition from a diploma to a graduate training should be completed. The introduction of the baccalaureate and advanced education in nursing and physiotherapy has contributed to increasing professional status and autonomy in the UK (Wade 1999). The introduction of physiotherapy as a degree in UK resulted in changes in the curriculum. Research methods, designing, critically evaluating and using research on which to base practice are key areas that have been added. These are not taught in physiotherapy schools in Germany and journals providing research and evidence for treatment are not made available. The result is that physiotherapy practice in Germany is not always based on current evidence (this will be discussed in Chapter 7.4) and little research is carried out by physiotherapists. Doctors are assumed to have expert knowledge in areas where physiotherapists may indeed have more practical knowledge. Most physiotherapists and other health professionals also expect doctors to make decisions. This perpetuates the medical model of decision making and the hierarchical model of health care that exists.

Not only is it important to strive for an all graduate entry but in addition it is necessary that postgraduate courses to Master level are available, with the possibility of progressing to undertaking PhD's and professional doctorate courses. An improvement in the education system for physiotherapists will result in an increase in physiotherapists' knowledge. Knowledge is a key source of power (Foucault, 1972 and Toffler, 1990) which can be used to influence other health professionals and the people in their care. In addition it may assist in physiotherapists gaining recognition as experts in certain fields. At present doctors rather than physiotherapists are seen as specialists in many areas of the care of people with CP, as for example in assessing and supplying assistive devices. The failure of physiotherapists to be recognised as experts in specialist fields prevents professional autonomy (Mandy 2008).

From experience it is difficult for a physiotherapist to influence parents and children in their decision making once a doctor has made a recommendation. Not only does physiotherapy have low status and no professional autonomy, it is a common opinion amongst physiotherapists at ICP that they also have a low public status. This is a subjective evaluation (Lipset 1968) and is dependent on peoples' perceptions (Turner 1988). Abbott (1981) considered that there are common indicators that determine public status namely income, power, client status and the complexity of the work. These indicators appear to be true for physiotherapists. In Munich, an average income is €4128 a month (Salary Explorer 2012). Physiotherapists however, can expect to earn about €2465 a month (Gehaltsvergleich 2012). They have little power to influence decisions made by doctors regarding treatment and there continues to be little public understanding of their work. Without public status it will remain difficult for physiotherapists to influence parents about the treatment and care of their child and the medical model of care will continue to dominate.

To improve public status it is imperative that the public awareness about the work of physiotherapists increases. This can be done at a local level by involving parents in and informing them of the care of their child. At a national level a strong professional organization would increase public awareness about the role and specialties of the physiotherapist.

A barrier to the improvement and change of status of physiotherapists in Germany is that the state run insurance companies only recognize the opinion of medical doctors for the allocation of medical resources. So, only physiotherapy treatment prescribed by a doctor will be paid for by the insurance companies. Improving the autonomy of physiotherapists would require a major change to the way resources are allocated by the health insurance system. Such a change would be politically extremely difficult to implement due to the strong vested interests in the current system.

However, despite the challenges that physiotherapists in ICP are confronted with, they are committed to bringing about change which has already been initiated. There has been a move away from paternalism towards a bio psycho-social model of health, which is practiced in the UK. Young people are empowered to make decisions that meet their needs and are given available evidence and support on which they can base their decisions. In addition physiotherapists engage in discussions with consultants and parents supporting their reasoning for decisions made regarding the best possible pathway of care for young people in their care.

7.4 Evidence on which decisions are made

This research has demonstrated that particularly non ambulant people express a wish and benefit from an approach to their pathway of care that focuses on enabling participation. However current practice in Germany continues to focus treatment based on an impairment and activity level. Treatment does not appear to be meeting the needs of people with CP. Child politics in Germany and physiotherapists autonomy have been discussed as possible reasons for this. An additional reason is that the evidence on which decisions are made is largely based on a positivist perspective. This was evident from the literature that was reviewed and presented in Chapter 2. The possible reasons for this are twofold. Health professionals who carry out research continue to believe that treatment based on a medical model of health is preferable for people with CP to that based on a bio psychosocial model of health. The latter requires a different methodological approach which includes gaining an understanding of the requirements of people with cerebral palsy from people who themselves have CP. An additional reason for the continued bias towards quantitative research could be because it continues to be considered the gold standard of research amongst the majority of health professionals in Germany.

Health professionals at the ICP have been encouraged to reconsider their approach to people with disabilities with an emphasis on identifying the goals that are key to young people and their parents, sharing of information and empowering people to make decisions on their pathway of care that are best suited to their needs. Relevant research is now needed which can assist health professionals and people with CP in deciding on the best pathway of care.

The amount of research based on qualitative or mixed methods has increased in the last 15 years (Creswell and Plano Clark 2007) however quantitative research predominates and continues to be considered the gold standard of evidence based medicine. Evidenced based medicine was introduced by Cochrane in 1972. He was critical of the medical profession suggesting that treatment recommendations were frequently based on unknown outcomes possibly resulting in harm to patients and wasting resources. He recommended that treatment should be based on results of unbiased research such as randomised trials also known as 'external evidence' (Porzsolt and Leonhardt-Huober 2005) and that the medical profession should continue to review and update their knowledge (Meulen et al. 2005). This has perpetuated the notion amongst health professionals that quantitative research is a superior method of research.

There are however, critics of evidence based medicine who acknowledge different types of evidence including 'internal evidence' which is evidence acquired through professional training and clinical experience (Porzsolt and Leonhardt-Huober 2005). They also emphasize the importance of critically reviewing the external evidence before comparing with the internal evidence to make a decision on treatment. Decision makers, who are generally doctors, should not only consider their own experience of treating people with CP, but also the experience of other health professionals and the clients. This may result in an evaluation of the outcome of care which increasingly involves the experiences of people with CP together with a greater awareness for the bio psychosocial approach to health.

7.5 Health insurance system

The structure of the health system has been discussed in Chapter 1.2. In summary, the health insurance system gives doctors power to control pathways of care offered

to clients. (An example of this use of power can be read in vignette no.1). Insurance companies impose tight controls on assistive equipment that is recommended by physiotherapists and occupational therapists, whereas surgery, specific orthotics and consultations regarding treatment recommendations are considered standard practice and no justification appears necessary (For an example of the extensive orthotics commonly prescribed please see Appendix 9) .

Moreover, the continuation of prescriptive therapy prevents physiotherapists gaining autonomy and reinforces the power of doctors (Toffler 1990). This in turn reinforces the attitude of the public that physiotherapists are not experts but technicians who carry out the recommendations made by doctors. If physiotherapists and other allied health professionals had a higher professional status and became recognised autonomous experts in specialist fields of practice they could increase their influence over the allocation of resources by the insurance system. This will be explained through the following example.

The ICP receives a budget from the insurance company to cover therapy, care and medical costs. In addition to prescribing therapy (including occupational therapy) the consultant is required to assess all of the children and young people still attending school twice a year. For many children this is in addition to external consultancy. Many young people who start at ICP for example already have a paediatrician who they continue to see annually for developmental checks or a prescription if assistive devices are required. Other children will go to an external consultant if the parents wish for a second, third or fourth opinion regarding treatment.

It is not uncommon that differing opinions are given regarding the best pathway of care and assistive equipment such as shoes, orthotics, walking appliances, wheelchairs and other assistive devices. Although it can be considered a privilege to have access to further consultations paid by the insurance, it may not always be advantageous to the parents or their child. From experience, and understandably parents continue to search for a consultant who provides the most optimistic estimate of the potential of their child's functional ability. This can result in unrealistic expectations and, as has already been mentioned, in frustration and confusion for the parents and their child.

In cases where physiotherapists and other health professionals are not consulted by doctors ethical issues can occur where the physiotherapists feel that they are not acting in the child's best interests. In the case of ICP, parents are now advised, when they agree to the terms and conditions of the centre, that in the case of conflicting opinions they will need to look for a different centre of care for their child.

The health insurance system therefore reinforces and perpetuates a medical model of health. It financially favours surgery rather than supplying the necessary equipment to assist people being able to participate in society. There is little evidence on which the insurance companies can support their principles and decisions. It is therefore evident that these processes and procedures need to be addressed.

7.6 Limitations of the study

Throughout this study it has been highlighted that the suggestions that have been made about long term outcomes of surgery on functional ability, pain and satisfaction of life based on the results from the quantitative phase, should be viewed critically. The results do however, demonstrate that further research is necessary in this area and that a surgical pathway of care may not be preferential to a conservative pathway of care for young people with cerebral palsy. Reflecting on the research process however, modifications to the research design have been identified, that could be used in future research to verify the findings.

A larger sample size, for example, with an equal distribution across all levels of Gross Motor Function Classification System (I-V) and between the two groups of participants who had and had not experienced surgery would have been advantageous to compare outcomes following different interventions. To achieve a larger sample size it would be necessary to extend the search to other similar centres outside Munich or to extend the period of research and to recruit from one centre.

In addition, the findings of this research have indicated that the level of cognitive ability may influence the long term outcomes following different treatment interventions. Limiting the inclusion criteria to present or past students of the BBW or to people who were in sheltered work may exclude a variable that may influence the results.

Participants were classified for this research using the GMFCS. The comparison of long term functional changes was made however, using self assessment scores, personal accounts and available physiotherapy and medical notes. The comparison of long term change in function was therefore not based on the same outcome measure. Using different tools to compare functional ability raises questions about the reliability of the results.

Finally, the steps and process that were used to gain an understanding of the interviews and examples of how themes developed have been described for the readers who in turn will make their own interpretation of the interviews. However, the inclusion of a description of body language and paralanguage used by the participants may have added to the transparency in the interpretation process. This could be included for future research.

Chapter 8: Summary

This research has aimed to compare long outcomes between young people with CP who had and those who had not experienced surgery to their lower extremities as children and to explore and describe their experiences. The research is unique in its design and use of mixed methods. The findings challenge the rationale of current practice in Germany, raised concerns about the autonomy and independence of physiotherapists in a medically dominated health system and most importantly it has given young people with CP a voice that was listened to. The mixed methods research has resulted in an understanding being gained about the personal experiences of the participants and their evaluation of the pathway of care they have followed.

The experience gained from completing this research has highlighted aspects of the design which could be modified to verify the results gained from the quantitative phase. These will be addressed in Chapter 10. However, it is possible to suggest from the findings that surgical intervention may not be the best possible pathway of care for young people with CP to improve their long term functional ability, satisfaction of life and reduce the prevalence of pain. Conservative treatment including the provision of assistive devices should be given more priority especially to young people with a GMFCS level of IV/V. Surgery continues to be recommended frequently in Germany as the best pathway of care with little reflection of all aspects of a young person's life and that commonly they were not included in decision making.

There is a dearth of information for young people and their parents on which they can base their decisions for choosing the best pathway of care. Research is biased towards quantitative methods and measuring short term functional outcomes (Kembhavi et al. 2011). Providing information on possible long term outcomes of surgery and that of conservative treatment and sharing the experiences of young people who have experienced different forms of treatment may empower children together with their parents to make the best decision.

The move towards involving and informing clients should theoretically be well established with the introduction of ICF. There are many changes that are needed to achieve this but it is important to remain realistic on what is possible. Therefore, as a physiotherapist, the researcher suggests that the focus of change should start with physiotherapists. Moore (2006) summarized the prerequisites to achieve this change and recommended that therapists should continue to increase their knowledge and that there should be 'a balanced therapeutic partnership/relationship which consists of trust, respect and understanding for patient ideas, beliefs, knowledge and values'.

Chapter 9: Recommendations for change

Many changes are needed to improve and optimize the service to people with cerebral palsy to ensure that the best pathway of care is offered.

Young people need to have an informed voice and be given a choice about the pathway of care they wish to follow. This requires physiotherapists, doctors and other professionals to work together. Together they need to find out what people want and how this can be most effectively achieved. All health professionals should respect the wishes of young people with cerebral palsy and the knowledge and expertise of other professional groups.

Throughout the discussion recommendations were made with the aim to improve the service provided by health care professionals to people with cerebral palsy with the ultimate aim of giving young people a voice to express their choices regarding their future. A summary of those recommendations will be made firstly considering changes that can be made at a local level.

1. Young people with CP must be given a voice that is listened to. A forum must be found for this to be made possible throughout the ICP. Change is being implemented at a local level in the physiotherapy department at ICP. Physiotherapists have become aware of the Children's Rights Act giving children a right to be involved in decision making and to be listened to. In addition physiotherapists have moved their focus of care from one based at an impairment and activity level to one that is child centered with an ultimate aim of enabling people with CP to participate in society.

2. Not only is it important for physiotherapists to be aware of the need for change but they need to increase their profile with the gatekeepers and parents of the children and young people in ICP and consultants working in local clinics. Physiotherapists are beginning to change the dynamics between these groups of people.

Communication channels are being opened up. Examples of this are that physiotherapists are scheduled to give presentations at the biannual open days of the centre and make contributions to the ICP newsletter. These enable them to explain

the treatment concept and the evidence on which it is based. These are also used to inform parents of some of the other concepts of treatment that are offered including surgical intervention with the possible advantages and disadvantages. The use of extensive orthotics that is frequently recommended by consultants in other centres and clinics should be discussed. In addition parents could be made aware of the potential problems and conflict of opinions that can occur when they take their children to external consultants.

Other changes that have been implemented are that physiotherapists are now proactive in establishing contact with the surrounding clinics. Physiotherapists accompany children whenever possible to clinics when decisions are being made about their pathway of care.

3. In collaboration with other health professionals information sheets need to be developed and become readily available to explain the concept used at the centre and the indications and aims of surgery. In addition the pre operative preparation and post operative treatment and the effects of these on the child, family and schooling need to be clearly explained.

4. Health insurance companies will be contacted in order to explain the use of assistive devices and how they can help people to participate in society.

5. Contact with the European Physiotherapy Working Group will be made to facilitate the dissemination of current developments in physiotherapy to physiotherapy schools and to qualified physiotherapists. This would help physiotherapists in Germany become informed about changes and developments in Europe.

6. Further training in research methods would be advantageous for physiotherapists to be able to be actively involved in research projects. This can be achieved within the centres of research, in addition to physiotherapists undertaking graduate and post graduate courses. These are currently being supported by the gatekeepers.

7. A larger project would be to become involved with the equivalent of the CSP (ZVK) to try to promote change to the physiotherapy training system to a graduate entry.

Chapter 10: Reflection and evaluation of the research process

There are many different pathways of care available to a person with CP but few are based on evidence. My experience over time had enabled me to follow children through adolescence and into adulthood. During this time I have questioned the efficacy of many of the different concepts. My observations were that children who had surgery required subsequent surgery to improve function. Moreover, as they entered adulthood they lost functional ability and many preferred powered or manual wheelchairs as their means of mobility rather than struggling with assistive devices.

I questioned surgeons and experienced physiotherapists but most were convinced that surgery was beneficial in reducing contractures and pain and improving mobility. This did not convince me and then 5 years ago I decided to enroll at the University of Brighton to study for a PhD.

Initially my intention was to carry out a quantitative study with the aim of evaluating whether young people who had surgery as children had contractures and pain compared to those who had not experienced surgery to their lower extremities. I considered that a good long term outcome following surgery could be measured by an improvement to the pre operative level of mobility and whether contractures were present. However, this assumed that an acceptable outcome could be measured by a change in function. That people with CP might have a different perception of a good long term outcome only became apparent as I started the literature review and following discussions with colleagues. This is when I realized that my worldview point had changed from a pragmatist with a bias towards positivism to that of a pragmatist with a bias towards constructivism.

This insight has directed the design of the study. It became clear that purely quantitative research would look only at the issue from impairment and activity levels and that this was only a small part of a bigger question. In order to answer that question, I needed to have some understanding of what it might be like to have CP. If I was able to understand that, I would be able to review the provision of care and whether it was meeting the needs of the users. This made me realize that using a quantitative research approach would give me only part of the answer, and that in

order to gain an understanding of life with cerebral palsy I would have to ask a different question.

The research question has developed from:

‘What are the long term functional outcomes and satisfaction with life of young people with cerebral palsy who have had surgery compared to those who have not?’
to:

‘Functional status and satisfaction of life of young people with cerebral palsy who have and who have not experienced surgery to their lower extremities: A Mixed Methods Study’.

and finally to:

‘Long term outcomes of surgery as experienced by young people with cerebral palsy’.

The importance of trying to understand the key issues for people with CP that contribute to improving satisfaction of life has become an increasingly significant element of this research. This was reflected in the choice of the interview questions.

My change in thinking exposed to me the quantitative way in which my colleagues and I were working and how the medical model was being endorsed. This realization has had consequences on my treatment approach to people with cerebral palsy. My emphasis now is on giving young people information on which to base decisions and to give them a voice that is listened to. My aim is to gain an understanding of the needs of each individual person and to plan the pathway of care as a team approach.

Change had already occurred in the area of BBW (job training department) towards patient focused care before I embarked on this research. However, in the area caring for children most decisions regarding physiotherapy treatment were made by the therapists, although some children were involved in goal setting. Having contact with the parents has always been important but physiotherapists were hesitant in responding to questions regarding possible future surgery and realistic future outcomes. My colleagues were generally cautious in giving any information or opinions and generally referred the parents to the in house consultant. This lack of confidence was also apparent in the weekly clinic when the therapist and consultant

discussed specific issues regarding the child. This could range from requesting a new walking device to splints to surgery. Therapists were reluctant to give their opinions and the main reason for this was that the therapists were constantly reminded that doctors make decisions and that the physiotherapists are not qualified to give their opinions.

Although I had other experience of working with, rather than under, other health professionals, through my training and work in the UK I also found that I was at times reluctant to voice my opinion about the relevance of different pathways of care that had been recommended to the child and his parents. As a result of an extensive literature search for this research I have gained knowledge which has given me confidence to question some recommendations that parents, children and young adults are given about the best pathway of care which frequently involves surgery. Perhaps more importantly I have passed my knowledge onto my colleagues so that they can also critically consider whether the best decision has been recommended for the young person and that they can encourage parents and their children to express what their expectations and wishes are.

This increase in knowledge and consequent confidence has resulted in more discussions with parents and participants about the advantages and possible disadvantages of different pathways of care. This is slowly having the effect that parents ask the physiotherapists for advice and share with us the recommendations that they have from other health professionals.

This is a positive development and because of closer contact with the parents, physiotherapists have become more informed about the decision making process regarding treatment. This has resulted in frustration and disappointment about the hierarchy and power in the health profession and how decisions are made about the future of young people with CP. All too frequently decisions are made by consultants without parents or their children fully understanding or being fully informed about the possible consequences of their decisions. An example of the lack of involvement of all health professionals in the decision making process can be read in vignette No.2.

The affiliation to the University has made me aware of the current standards of practice in England which has increased my awareness of the differences between UK and Germany training and status for physiotherapists and the effects of this on communication with other health professionals.

It has been necessary throughout this study to be aware and revisit the prejudices that I have that do not support the use of surgery in the form and frequency that it is performed in Germany for people with CP, or the excessive use of some forms of orthotics for which there is little evidence based research. Colleagues have provided valuable support in sharing their opinions.

A consequence of being involved in research is that people, and in this case parents and other health care workers started to share their experience of decisions made regarding surgery or orthotics. This has increased my frustration and disappointment of the health profession in that decisions that are made are not thoroughly considered or thought through, bearing in mind that all children and their parents have different expectations and needs. Too little consideration is made about the demands surgery and orthotics have on children and their families and too little information is available to assist those concerned in making decisions.

Speaking to young people has provided valuable information and it is indeed frustrating that research is normally directed to quantitative outcomes which may not be the most appropriate methods. It should not be forgotten that some people with CP may require information that will give them objective answers on which to base decisions. Throughout the research my conviction for the use of mixed methods research has grown as I have experienced that it provides a wider perspective on a research question than using a single method of research.

The feedback session gave me an incentive to complete this research because the participants felt so strongly that they wanted their voice to be heard and that they should be given the chance to make decisions and be treated and have the same opportunities as other young people. It also provided confirmation that I had identified, with my overarching theme, the key issue for children and young people with cerebral palsy.

Finally my confidence has increased since starting the PhD which has positively affected my working relationship and status with other members of the team.

Summary

This research has highlighted the problems of performing quantitative research and obtaining statistics in the area of CP. The intention was to gain an indication of whether there was a difference in long term functional outcomes and satisfaction of life and prevalence of pain between those who had surgery as children and those who did not. This is possibly not recognized as gold standard research due to the inevitable variables which cannot be negated. Although I can accept the limitations that this research has, it demonstrates reality, and that each person with CP is an individual and has different experiences. It also contributes new findings in terms of giving young people a voice. The experience of carrying out mixed methods has demonstrated its strengths and how both the quantitative and qualitative phases are important to giving depth to a research question.

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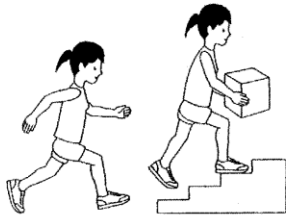
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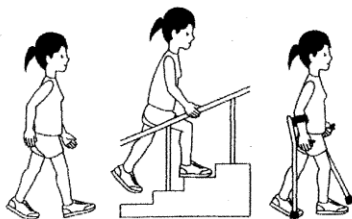
Appendix 1: Gross Motor Function Classification System

GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations



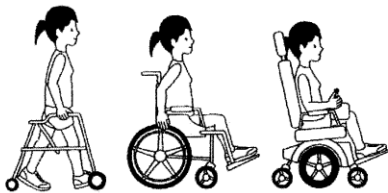
GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.



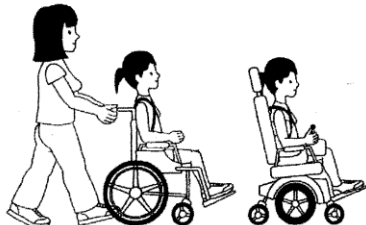
GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.



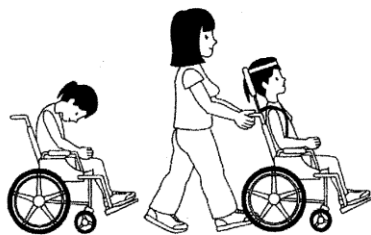
GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.



GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.



GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

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The Royal Children's Hospital, Melbourne

Appendix 2: Rivermead Mobility Index

1 Do you turn over from your back to your side without help?
2 From lying in bed, do you get up to sit on the edge of the bed on your own?
3 Do you sit on the edge of the bed without holding on for 10 seconds?
4 Do you stand up (from any chair) in less than 15 seconds, and stand there for 15 seconds (using hands and with an aid if necessary)?
5 Observe standing for 10 seconds without any aid or support.
6 Do you manage to move, eg, from bed to chair and back without any help?
7 Do you walk 10m, with an aid or furniture if necessary, but with no standby help?
8 Do you manage a flight of stairs without help?
9 Do you walk around outside, on pavements without help?
10 Do you walk 10m inside with no caliper, splint, aid or use of furniture, and no standby help?
11 If you drop something on the floor, do you manage to walk 5m, pick it up and then walk back?
12 Do you walk over uneven ground (grass, gravel, dirt, snow, ice, etc) without help?
13 Do you get in/out of bath or shower unsupervised and wash self?
14 Do you manage to go up and down four steps with no rail and without help, but using an aid if necessary?
15 Do you run 10m without limping in 4 seconds (fast walk is acceptable)?

Appendix 3: Rivermead Extended Activities of Daily Living

In the last four weeks how has the patient undertaken the following activities. Score as below:

0 = Not at all

1 = Participated, but only with major physical and/or supervisory assistance

2 = Undertaken spontaneously, but needed some minor physical and/or supervisory support

3 = Undertaken independently, without any support (and as often as needed/requested)

Day							
Month							
Year							
Domestic activities							
Prepare a hot drink Make a cup of tea/coffee/chocolate with all equipment and consumables on work surface. Needs to fill kettle or saucepan, heat up water and/or milk.							
Prepare cold or hot snack Make a snack of a sandwich, or cheese on toast or beans on toast using cooker or microwave if needed. Materials to be available in cupboards or in shelves as appropriate.							
Prepare a hot main meal Prepare and cook a main meal. Materials to be available in kitchen cupboards or on shelves as appropriate.							
Use the vacuum cleaner Take from storage place, switch on, vacuum clean room/area, switch off and return to storage place.							
Do some washing up (dishes) Take dirty utensils previously assembled (at least 12 items—plates, cups, cutlery, etc.). Fill bowl or sink. Use detergent and dry or leave to dry.							
Wash dirty clothes Take dirty clothes and wash them (any method) and prepare them ready for wearing.							
Community activities							
Use the phone Find and write down a number from the phone book. Use the telephone to convey a message.							
Go to local shop Leave home (or hospital ward), visit shop and return with two or more minor items such as newspaper and sweets.							
Go to large shop and buy 10+ items Leave home (or hospital ward), buy and return with correct items (decided upon in advance). Travel by any means.							
Cross a road Cross any road with significant traffic (more than one car per minute) at a pedestrian crossing.							
Use bus/train/taxi or car Leave home or hospital ward, catch a public bus or train, or use a taxi or own car. Travel to correct destination and return.							
Undertake a leisure activity Go to church, cinema, theatre, pub or participate in any leisure activity (includes going to day centre where actively participates).							
TOTAL							

Appendix 4: Satisfaction with Life Scale test

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

1 = strongly disagree

2 = disagree

3 = slightly disagree

4 = neither agree nor disagree

5 = slightly agree

6 = agree

7 = strongly agree

___ 1. In most ways my life is close to my ideal.

___ 2. The conditions of my life are excellent.

___ 3. I am satisfied with my life.

___ 4. So far I have gotten the important things I want in life.

___ 5. If I could live my life over, I would change almost nothing.

Appendix 5: Information Sheet



University of Brighton

Clinical Research Centre
For Health Professions

INFORMATION SHEET

Title of the research:

What are the long term functional and quality of life outcomes of young people with cerebral palsy who have had surgery to their lower extremities compared to those who have not?

My name is Heather Jackson. I am a researcher and physiotherapist at the Integrationszentrum für Cerebralpareesen (ICP). I am inviting you to take part in a research project that is being supported by the University of Brighton, in England.

What is research? Research is a way of looking at what we do so that we can improve our practices and treatments.

Why is this research being done? To find out how young people with cerebral palsy manage with activities that are necessary for daily life, to find out their quality of life and to find out their experiences of the intervention they have had.

Why have I been asked to take part? Because I would like to know from you what it is like to have had the intervention you have had compared to those who did not have that intervention and what impact it has had on you.

Do I have to take part? No, it's up to you. If you do not want to take part you just need to say no.

If you are interested in taking part in the research please read further.

What will happen to me if I take part in the research? You will initially be given 1 appointment that suits you which will last about 1 hour. The first appointment will be to find out how you manage with daily activities e.g. whether you can manage to move from the bed to a chair without help or whether you can make a hot drink and how you view your quality of life. With the help of your physiotherapist you will be asked to complete 3 questionnaires. These are called the Rivermead Mobility Index, Rivermead Activities of Daily Living and Satisfaction with Life Scale test.

When I have analysed the results I might ask you to make another appointment also lasting 1 hour. The second appointment will be to ask you

about your experiences of the intervention you had and how this has helped you.

During the interview I will make notes and use a tape recorder. I will tell you when I am going to start recording. If you want me to stop recording at any time I will turn the tape recorder off immediately.

The appointments will take place either in a room in ICP or in Münchener Förderzentrum (MFZ) in Freimann or MFZ in Giesing. If you are at any of these centres I will travel to you. Your travel expenses will be paid if you have to travel to me.

What will happen to the information?

The information will be used by me to write a report. I will publish the findings of the study. I will also give presentations about the research. I will probably use some of your comments as examples of how people feel about the treatment they have had but all the information will be kept anonymous. That means your name will not appear in any papers.

All information collected will be kept locked up in a cupboard in my office where I have sole access. My computer that might hold any of your details is password protected.

You will have access and be able to read my finished report.

Did anyone else check the study is OK to do?

Yes. All research has to be checked by a group of people called a Research Ethics Committee at the University of Brighton. They make sure that the research is fair. Professor Lampe has also approved the research.

Are there any disadvantages to me if I take part?

There should be no disadvantages to you and the information you give will not affect your future treatment or training. If talking about your experiences has made you upset you can arrange to see Hr. Heizer (ext. 239) or Dr. Stadler (ext. 315)

Are there any advantages to me if I take part?

It is unlikely that there will be advantages for you but it will give you the opportunity to tell me your experiences about the treatment you have had. This might help to advise other people with CP on the most appropriate treatment for them.

What if I don't want to do the research any more? Participation is voluntary and you can withdraw from the study at any time. Just tell someone in the physiotherapy department (089 71007338), your teacher or me (089 71007337).

If you have any concerns regarding the conduct of the research you can contact me on 089 71007337 or by Email. My address is heather.jackson@icpmuenchen.de.

You can also contact Dr. Anne Mandy at the University of Brighton Tel: 0044 1273 643946 or Herr Heizer 089 71007239

Thank you very much for reading this leaflet and for thinking about taking part in this study. Please ask any questions that you need to.

I will send you an e-mail in 14 days asking you if you would like to take part.

Appendix 6: Consent Form



University of Brighton

Clinical Research Centre
For Health Professions

Consent Form

What are the long term functional and quality of life outcomes of young people with cerebral palsy who have had surgery to their lower extremities compared to those who have not?

- ◆ I agree to take part in this research which is to find out how young adults with cerebral palsy manage with activities that are necessary for daily life, to find out their quality of life and to find out their experiences of the intervention they have had.
- ◆ The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.
- ◆ I have had the procedure explained to me and I have also read the information sheet. I understand the procedure fully.
- ◆ I am aware that I will be required to answer questions and take part in an interview.
- ◆ I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else.
- ◆ I understand that I am free to withdraw from the investigation at any time.

Name (please print).....

Signed.....

Date.....

Appendix 7: Transcribed version of interview with Participant No. 1 in German

Kannst du bitte beschreiben, wie einen typischen Tag, vom in der Früh bis Abend, für dich ist?

Im Internat, stehe ich auf. Ich kann mich selber im Rollstuhl umsetzen. Im Rollstuhl ziehe ich mich oben drum an und dann kommt der Frühdienst um mit Unten zu helfen. Es geht auch im Sitzen. Die Schuhe kann ich nicht anziehen. Dann gehe ich zum Essen wegen den Tabletten. Ich darf selber entscheiden was ich esse und es liegt alles auf dem Tisch. Wir müssen nur das Essen holen. Das kann ich selber. Brot mit Wurst. Zum Trinken hole ich selber es vom Kühlschrank. Ich kann nicht die Mikrowelle benutzen, weil es zu hoch ist. Da muss ich geholfen werden. Waschen mache ich bevor ich mich anziehe. Ich wasche mich im Schlafzimmer. Da ist ein Becken und ich wasch allein meine Hände, Zähne und Gesicht. Wenn ich Dusche brauche ich helfe. Wir machen es abends weil ich doch Hilfe brauche. Oben kann ich mich alleine waschen, unten brauche ich Hilfe. Ich sitze auf dem Duschstuhl. Beim ausziehen ist das Gleiche. Ich ziehe mich im Rollstuhl oben aus, ziehe mich an der Stange hoch, meine Hose wird runter gezogen. Dann setze ich mich auf dem Duschstuhl. Ich brauche auch Hilfe um mich zu ab zu trockenen. Ich kann auch alleine auf die Toilette gehen. Ich kann mich an einem Griff halten und meine Hose runter ziehen. Es klappt alleine außer wenn ich meine Tage habe. Dann brauche ich Hilfe.

Wie ist es für dich auf Hilfe angewiesen zu sein?

Vor allem wenn ich auf der Toilette Hilfe brauche, dass finde ich Total doof. Weil normalerweise kann ich es alleine machen nur dann nicht. Es ist blöd weil ich Hilfe brauche. Normalerweise dann nicht. Es ist nervig weil ich jemanden brauche.

Hast du immer die gleichen Pflegeleute?

Nein. Ich habe oft andere Leute aber die kennen mich alle. Ich finde es nicht schlimm, weil sie mich kennen. Wenn ich immer erklären muss wie es geht, dann wäre es blöd.

Nach dem Frühstück muss ich nochmal ins Zimmer zum Zähneputzen, meine Tabletten holen und die Sachen für den Tag zusammen zu packen.

Danach um 6:45 gehen wir runter zum Bus. Wir müssen dann auf die anderen warten.

Zu Hause kannst du genau so viel selbständig machen wie hier im Internat?

Ich brauche zu Hause Hilfe mit den Treppen. Ich muss mich hinsetzen und dann komme ich die Treppen runter. Ich brauche aber dann Hilfe um hoch zu kommen. Von so weit runter komme ich nicht hoch. Für das Hochlaufen gibt es ein Geländer. Ich halte mich mit einer Hand fest und meine Mutter geht hinter mich her. Es ist zu eng für einen Treppenlift. Ich habe einen Rollator im Internat bei mir zu Hause ist es zu eng für ein Rollator. Ich nütze entweder einen Rollstuhl oder ich setze mich auf dem Sofa. Im Internat laufe ich mit dem Rollator am meistens am Wochenende weil ich erst am 5:30 komme. Dann bin ich müde. Hier im Haus laufe ich nur wenn ich Therapie habe.

Wie ist es für dich den ganzen Tag im Rollstuhl zu sitzen?

Ich habe mich mittlerweile dran gewöhnt, weil ich weiß, dass es nicht anderes geht. Wenn meine Mutter nicht mehr mir helfen kann, müssen wir einen Pflegedienst beantragen.

Wir haben oben einen Rollstuhl und unten auch einen Rollstuhl.

Wir haben einen Badelift. Ich schaffe alleine auf die Toilette zu gehen weil wir einen Aufsatz mit 2 Griffen haben.

Gibt es bestimmte Alltagstätigkeiten die jetzt einfacher oder schwierig sind im Vergleich zu Früher (als du ein Schulkind warst).

Es klappt jetzt schon besser. Ich konnte damals nicht alleine ins Bett gehen. Jetzt kann ich. Raus vom Bett hat es immer geklappt aber rein ins Bett hat nicht geklappt. Zu Hause habe ich es geschafft weil, das Bett höher ist. Im Heim hat es nicht geklappt. Im Internat hat es sofort geklappt. Das Bett hat die gleiche Höhe. Jetzt habe ich ein Brett auf dem Boden, ich tue meine Füße da drauf und dann kann ich mich umsetzen. Die haben es hier im Internat vorgeschlagen. Es ging sofort. Zu Hause habe ich kein Brett ich sitze erst vor dem Brett, komme raus, liege ich mich auf dem Bauch und drehe ich mich um. Im Internat mit dem Brett kann ich seitlich einen Transfer machen.

Wie schaut dein Tag hier im BW aus?

Ich gehe mit dem Aufzug hoch in die Abteilung und ziehe die Jacke aus und fange ich an zu arbeiten. Beim Essen muss jemanden mir mein Essen bringen weil sonst alles raus läuft. Ich habe es schon geübt aber es hat nicht funktioniert. Ich suche aus was ich essen will, dann wird es mir gebracht.

Bist du immer mit einem Rollator gegangen?

Freilaufen konnte ich nie, ich konnte krabbeln, das kann ich auch immer noch.

Ist es für dich wichtig, dass du noch krabbeln kannst?

Ja, weil wenn ich mit dem Rollstuhl irgendwo nicht hin komme, kann ich auf dem Boden es schaffen.

Ich kann frei mit dem Rollator laufen. Um Anfang war jemand dabei und dann konnte ich es allein machen. Ich kann vom Sitzen zum Stehen alleine und dann mit dem Rollator los laufen.

Die Treppen konnte ich mal besser laufen. Ich war in der Ukraine für 2 Wochen. Treppensteigen habe ich gelernt, es hat 2 Wochen gehalten und dann konnte ich es dann nicht mehr. Ich habe intensiv Therapie gehabt. Ich habe jetzt keine Intensivtherapie weil mir die Zeit und Geld fehlt und ich war schon 7 Mal dabei. Auch wenn ich die Zeit hätte würde ich es nicht nochmal machen. Es reicht irgendwann auch. Es war sehr anstrengend fast zu anstrengend. Das Essen war auch nicht gut. Es war auch für meine Mutter schwierig, weil ich weniger selbstständig war. Z.B im Badezimmer gab es keine Griffe. Es war nicht wirklich behindert gerecht war.

Kannst du mit öffentlichem Verkehrsmittel fahren?

Noch nicht. Ich bin dabei mit der Ergotherapeutin es zu üben.

Was musst du noch üben?

Die E-Motion Räder weil ich nicht zur U-Bahn im Rollstuhl mich schieben kann. Die Kraft in den Armen fehlt. Ich habe E- Rollstuhl ausprobiert und dann schaffe ich den Weg zur U-Bahn.

Wie ist für dich Leute anzusprechen wenn du in der U-Bahn Hilfe brauchst?

Ich habe keine Probleme. Solange die Leute mitmachen. Bis jetzt hat es immer ganz gut geklappt. Ich gib anweisen von kippen und einschieben.

Bis du abends dann unterwegs?

Eigentlich eher nicht. Vielleicht weil der Tag so anstrengend ist und dann habe ich abends keine Lust. Wenn ich wohin fahren möchte muss ich noch mit jemanden gehen, weil ich noch nicht die anderen Räder habe und muss geschoben werden.

Gehen Leute mit dir?

Ja

Wie ist es dass du immer mit Leute gehen muss und nicht spontan alleine was machen kannst?

Ich finde es doch Blöd. Wenn ich die andere im Internat sehe und die können es und ich sitze da. Es ist doch schon deprimiert. Wenn ich die Räder habe dann würde ich mich trauen allein weg zu gehen.

Hast du Freunde?

Von zu Hause weniger. Entweder sind sie vom Internat oder vom Heim wo ich die letzten 2 Jahre war.

Vom meiner alter Schule habe ich noch ein Paar. Es war eine normale Hauptschule. Die Leute hatten keine Probleme, dass ich im Rollstuhl saß, es war selbstverständlich, dass sie mir helfen würden.

Ich fand es eine gute Erfahrung in einer Regelschule zu sein.

Hat jemand vorgeschlagen, dass du operiert werden solltest?

Ja. Wir haben es nicht gemacht. Weil es heißt wenn wir es machen lassen, muss ich nach ca. 5 Jahre es nochmal machen lassen. Das wollten wir nicht. Der Arzt hat gesagt es könnte schief laufen. Der Arzt hat mich nicht gekannt und mich nicht so wirklich untersucht. Er hat gesehen, dass ich meine Beine nicht strecken konnte und gemeint ich muss mich operieren lassen. Ich bin so froh, dass ich so viel kann alleine und wenn es schief gelaufen wäre, könnte ich weniger machen. Ich dürfte mitentscheiden mit meinen Eltern.

Hat er dich über die OP aufgeklärt?

Nein. Er hat nur gesagt, dass ich mich operieren lassen muss. Die Achilles. Ich weiß nicht wie er auf die Idee kam. Die Therapeutin war nicht involviert.

Bis du mit der Entscheidung von damals zufrieden?

Ja. Ich würde die Entscheidung nochmal so treffen. Ich habe von anderen gehört wie es schief gelaufen ist. Ich habe genau gesehen wie Freunde vorher waren und wie es nachher ist und es war nicht so Toll. Ich kenne Leute die vor der OP laufen konnten und jetzt sitzen sie im Rollstuhl. Ich will es gar nicht wissen wie es mir gegangen wäre. Wenn ich ehe im Rollstuhl sitzen dann wäre es sehr schlimm gewesen. Ich kann jetzt viel machen und wenn es schief gegangen wäre dann könnte ich gar nicht. Seit dann hat sonst niemand vorgeschlagen.

Ich sehe, dass du dich mit der linken Hand festhältst. Ist das anstrengend?

Ja aber ich bekomme für die Seite eine Pelotte. Es war immer so, es hat sich nicht verschlechtert.

Hast du Schienen gehabt?

Ich habe Schienen gehabt aber wir haben gemerkt dass sie nichts bringen. Die waren Tageschienen. Ich habe sie abgesetzt aber sie haben nichts gebracht. Ich habe nicht gegen die Schienen gehabt.

Kannst du mir bitte über andere Behandlungen die du hattest, erzählen?

Ich habe länger Vojta gehabt und auch als ich hier warst. Es hat geholfen die Beine locker zu kriegen um dass ich besser stehen konnte. Die Therapie hilft um die Beine lockerer zu kriegen.

Hast du genug Therapie?

Ja

Was sind die Vorteile der Therapie gewesen?

Das die Beine locker bleiben um damit ich besser klar komme, mit dem Stehen. Ich merke wenn ich eine Zeit lang keine Therapie habe werden meine Beine steife. Ich kein Botox gehabt.

Du hast die Frage ob du was mit deinen Leben ändern würdest wenn du nochmal dein Leben hättest mit 4 bewertet. Was würdest du ändern?

Ich würde nicht mehr in einem Rollstuhl sitzen um dass ich mit Freunden weg gehen könnte. Zu Hause jetzt dass die alten Freunde älter geworden sind wenden sie von mir ab. Es hat sich über die Jahre geändert. In der Schule war es kein Problem da kam jemand fast jeden Tag oder jeden 2ten Tag. Jetzt kommt fast niemand mehr.

Könnte es an deine Behinderung liegen?

Ja. Die haben es mir auch gesagt. Es ist nicht dass ich es denke, die haben es mir gesagt.

Die sagen, dass ich nicht laufen kann und dass ich nicht alles machen kann. Die sind nicht bereit mich mit zu nehmen. Jetzt wollen sie es nicht, früher war es kein Problem. Ich versuche noch Kontakt zu halten aber es bringt nicht.

Ich fühle mich ein Bisschen einsam zu Hause. Meine Cousine kommt ca. jedes 2te Wochenende, es ist sehr schön.

Um weg zu gehen von zu Hause müssen meine Eltern mich wo hin fahren oder ich muss mit anderen Leuten gehen.

Im Internat gibt es viele die mit mir gehen würden.

Ich will nach Hause alle 2 Wochen. Ich kann nicht häufiger weil es zu viel kostet.

Hast du Schmerzen?

Ich habe keine Schmerzen.

Hast du ein Hobby?

Ich spiele Boccia ohne Rampe. Ich war neulich auf einem Lehrgang. Es war sehr schön.

Was gefällt dir an Boccia?

Ich weiß es nicht.

Gibt es noch etwas, das ich wissen sollte?

Andere Leute sollen froh sein, dass sie nicht im Rollstuhl sitzen. Manche denken es ist so witzig im Rollstuhl zu sitzen. Die wissen nicht warum ich es manchmal doof finde dass ich im Rollstuhl sitze.

Ich wurde Leute abraten um eine OP machen zu lassen weil es schief gehen kann.

Danke

Resume

Hat sich über die Jahre nicht verschlechtert. Kann Transfers alleine, braucht Hilfe beim An und Ausziehen Unterextremitäten- kein Problem

Arzt hat gemeint sie muss operiert werden aber hat auch ihr die Risiken erzählt.- nicht mehr Kniestand, vielleicht geht es schief. Sie hat mit den Eltern dagegen entschieden.

Sie ist froh drüber. Kennt Leute wo die jetzt weniger machen können als vor der OP
Hat Strategien um noch selbständige zu sein.

Therapie wichtig um die Beine locker zu halten. Merkt wenn keine Therapie.

Lernt mit der U-Bahn zu fahren. Kein Problem Leute anzusprechen, bekommt immer Hilfe. Braucht E- Motion dann kann zu U Bahn alleine fahren.

Frühere Freunde wollen nicht mehr mit ihr weg, weil sie behindert ist und nicht gehen kann.

Wichtig noch für den Alltag, dass sie auf die Knie kann.

Kein Schmerzen

Hilfe o.k. wenn sie nicht im neue Leute anlernen soll.

Appendix 8: Translated interview with Participant No. 1

Key words and phrases have been highlighted in red. The thoughts and the researchers' understanding of the text have been written in brackets.

1. Please describe a typical day for you starting in the morning and finishing at night?

3. In Internat (residential care) I get out of bed. I can get into my wheelchair
4. myself.

5. When I'm sitting in my wheelchair I dress my top half and then the early shift
6. helper comes and helps me with my lower half. It works also while sitting. I
7. can't put the shoes on myself. Then I go to eat because of the tablets.

8. I can choose what I want to eat and it is put on the table. I just have to get the
9. food. I can do that myself, bread with sausage.

10. I get a drink from the fridge.

11. **I can't use the microwave because it is too high. For that I need to get help.**

12. (not barrier free- results in less independence/participation- frustration
13. experienced by participant- it would be straight forward to adapt- YP has no
14. voice that is listened to).

15. I get washed before I get dressed. I get washed in the bedroom. There is a
16. basin and I wash my hands, teeth and face. I need help if I have a shower.

17. We do it in the evenings because I need help. I can wash the upper half alone,
18. I need help for the lower half. I sit on the shower chair. Undressing is the
19. same. I get undressed in my wheelchair, I pull myself up on the grip and my
20. trousers are pulled down. Then I sit myself on the wheelchair. I need to dry
21. myself. I can also get on the toilet myself. **I can pull myself up using the**

22 grip and pull my trousers down. (assistive devices increase independence).

23 It works unless I have my period then I need help.

24. How is it for you to be reliant on help?

25. Especially when I need help on the toilet, I find that horrible/bad because I
26. can normally do it alone just not then. It is horrible because I need help.

27. Normally not. It is annoying because I need someone.

28. Do you always have the same carers?

29. No. I often have other people but they all know me. I don't think it is bad

30. because they know me. If I always need to explain what they need to do, then
31. it would be horrible/ bad.

32. After breakfast I have to go into the room (bedroom) again to clean my teeth,
33. collect my tablets and pack the things for the day.

34. At 6:45 we go down to get the bus. We have to then wait for the others.
35. (very early and then have to wait- always reliant on others)

36. Are you as independent when you go home as you are in Internat?

37. **I need help to climb the stairs at home** (more independence possible in
38. Internat) . I
39. have to sit down and then I come
40. down the stairs. I need help then to get up. I can't get up from so far down.
To 41. go up the stairs there is a rail. I hold on with one hand and my mother goes
42. behind me. It is too narrow for a step lift. **I have a rollator in Internet, it is too**
43. **narrow at home for a rollator. I use either a wheelchair or I sit on the sofa.**
44. (lack of barrier free environment can result in dependency).

45. In Internat I walk with the rollator mainly at the weekend because I only get
46. back at 5:30 during the week. Then I'm tired. Here in ICP I only walk when I
47. have therapy (long day).

48. Please tell me how it is for you to be a wheelchair user?

49. I have got used to it now because I know it is the only way. When my mother
50. can't help me anymore then we'll have to apply for help. We have wheelchair
51. upstairs and downstairs. We have a bath lift. **I manage to go to the toilet**
52. **myself because we have 2 grips** (assistive equipment plays a large role in
53. acquiring independence).

54. Are there any activities that are more difficult or easier now compared to
55. when you were a school child?

56. **It works better now. Previously I couldn't get into bed alone** (voice of YP
57. sharing experience of improvement in function without surgery). Now I can.
58. Getting out of bed always worked but getting in didn't work. I managed it at
59. home because the bed is higher. In the (previous) boarding school it didn't
60. work. In Internat it worked straight away. The bed was at the same height.
61. **Now I have a board on the floor, I put my feet on it and then I can transfer.**
62. (again the importance of assistive devices).

63. They suggested it in Internat. It worked straight away. At home I don't have
64. a board. First I sit in front of the board, get out, and lie on my stomach and
65. turn over. In Internat I can do a side transfer which is better.

66. What is your day like here in BBW (College)?

67. **I use the lift to go to the department** (independence with lift) and take off my
68. jacket and then I start to work .Someone has to bring me my food at
69. mealtimes because otherwise it spills. I have tried to practice it (carrying the
70. food) but it didn't work. I choose what I want to eat and then someone brings
71. it to me (always reliant on people to help).

72. Have you always used a rollator?

73. I was never able to walk alone, **I could crawl. I can still do that** (has
74. maintained important functional ability. Health professionals need to listen
75. what is important to people with CP- some report of not being able to crawl
76. after surgery).

77. Is it important to you that you can still crawl?

78. Yes it is because if I can't get somewhere with my wheelchair then I can
79. manage it on the floor. **I can walk alone with the rollator. At first someone**
80. **was with me and then I was able to do it alone.** (further example of
81. improvement in functional ability following conservative pathway of care). I
82. can stand up from sitting and walk off with my rollator.

83. **I had learnt to climb the stairs better. I was in the Ukraine for 2 weeks. I**
84. **learnt to climb stairs there.** (intensive therapy can help improve function) It
85. lasted for 2 weeks and then I couldn't do it
86. anymore. I had intensive therapy. I don't have intensive therapy anymore
87. because of the time and costs. I was there 7 times. If I had the time I wouldn't
88. do it again. The food wasn't good. **It was also difficult for my mother because**
89. **I was less independent e.g. in the bathroom there weren't any grips.**
90. (lack of assistive devices reduce independence for YP and increase manual
91. work for carer) It wasn't really barrier free. (again the importance of being
92. barrier free).

93. Can you use public transport?

94. Not yet. I am practicing it with the Occupational Therapist.

95. What part do you still need to practice?

96. I need the 'Restkraft' wheels because **I can't push myself to the underground**
97. **in my wheelchair.**(Krankenkasse will not approve the necessary wheelchair to
98. enable independence and participation) I haven't got the strength in my arms.
99. **I have tried the other wheelchair and then I can manage the way to the**
100. **underground.** (importance of assistive devices).

101. How is it for you when you have to ask for help at the underground?

102. I don't have a problem with it so long the people agree to help. Up until now
103. it has always worked very well. I tell them how to tip the wheelchair and push
104. it in. (being in charge)

105. Do you go out in the evenings?

106. Not really. The day is so tiring and then in the evening I can't be bothered. **If**
107. **I want to go anywhere I have to go with someone because I haven't got the**
108. **other wheels and I can't push myself** (inadequate assistive devices reducing
109. level of participation and satisfaction with life. YP need to be listened to find
110. out what is important to them).

111. Do people go with you?

112. Yes.

113. How is it for you that you need someone to go with?

114. **I think it is bad/horrible. It is depressing when I see what the others can do in**
115. **Internat and I just sit there. When I have the wheels then I will have the**
116. **confidence to get out and about** (assistive devices clearly can improve
117. participation and satisfaction with life).

118. Do you have friends?

119. Not many friends. They are either from Internat or boarding school
120. where I was the last 2 years. I've got a few from my last school. It was a
121. normal 'Hauptschule'. They didn't have any problems that I was in a
122. wheelchair. It was a matter of course that they would help me.
123. **I found it a good experience being in a main stream school.**(inclusion
124. important)

125. Did anyone suggest that you should have an operation?

126. Yes. We didn't do it because it meant that if we had it done then I would need
127. another operation in 5 years time. We didn't want that. The surgeon also said
128. it could go wrong. **The doctor didn't know me and didn't really carry out a**

129. full assessment. He saw that I couldn't straighten my legs and suggested that I
130. should be operated on.(medical model of care) I am so happy that I can do so
131. much alone and if it had gone wrong I would be able to do less. I was able to
132. decide with my parents.(good to make the decision oneself)

133. Did he tell you about the surgery?

134. No. He only said that I had to have an operation.(Dr. made decision and with
135. authority) The Achilles. I don't know how he came to that idea. The therapist
136. was not involved. (doctor making decision alone, no other health
137. professionals to consider person as a whole and suitability of an OP).

138. How do you feel about the decision?

139. I would make the same decision again. I have heard from others how it
140. goes wrong. I have seen exactly how friends were before and how it is after
141. and it wasn't very good. I know people who could walk before surgery and
142. are now sitting in a wheelchair. I don't want to know how it might have been
143. for me. If it made me so that I could only sit in a wheelchair it would have
144. been very bad. I can do a lot and if it had gone wrong then I couldn't do
145. anything. (interesting that she describes that she can do a lot)
146. Since then no one has suggested it.

147. I can see that you are holding on with your left hand. Is that strenuous?

148. Yes, but I am getting a side support. It was always like that. It hasn't got
149. worse.

150. Have you ever had splints?

151. I have had splints but we noticed that they didn't help. They were day splints.
152. I stopped using them but they didn't help. I wasn't against the splints
153. (Children and YP feel guilty if they do not follow advice from health
154. professionals- medical model and power. Health professionals need to
155. evaluate the care they are giving, by giving young people a voice- using
156. splints has an emphasis of treatment at an impairment level).

157. Please tell me about other interventions you have had

158. I had Vojta for a long time and during the time that I was here. It helped to
159. get the legs loose and helped me to stand better. (despite little evidence for
160. physiotherapy and the different concepts participants, if they are asked, share
161. their experiences and the importance of therapy). The therapy helped to get
162. my legs loose.

163. Do you have enough therapy now?

164. Yes.

165. What have been the advantages of the therapy?

166. That my legs stay loose so I manage better, standing. **I notice when I haven't**

167. **had therapy for a while that my legs get stiff** (therapy can help reduce

168. stiffness. Listening to people with CP can give the answers to health

169. professionals about the best pathway of care for people with CP)

170. I haven't had Botox.

171. You answered the question which asked whether you would change your

172. life if you could live your life again with a score of 4. What would you

173. change?

174. I wouldn't sit in a wheelchair anymore so that I could go out with friends.

175. Now that my friends at home are older they have turned away from me. It has

176. changed over the years. While I was at school it wasn't a problem somebody

177. came every day or every second day. Now hardly anyone comes

178. (very lonely and abandoned)

179. Could it be to do with your disability?

180. Yes. They have also told me so. It is not that I just think it, they have told me.

181. They say that I can't walk and that I can't do everything. They are not

182. prepared to take me with them, earlier it wasn't a problem. I try to stay in

183. contact but it doesn't help.

184. I feel a bit alone at home. My cousin comes every second weekend. That is

185. very nice. **To do something from home I am reliant on my parents taking me**

186. **or I have to go with other people** (dependence on others, affecting satisfaction

187. with life, a lot of patience is required).

188. In Internat there are many more people who would go with me.

189. I would like to go home every second week. I can't go more often because it

190. costs too much.

191. Have you got pain?

192. I haven't got any pain.

193. Do you have any hobbies?

194. **I play Boccia** without a ramp. I was recently at a training camp. **It was very**

195. **good** (participating in a hobby can increase satisfaction with life).

196. What do you like about Boccia?

197. I don't know

198. What else would you like to tell me?

199. Other people should be happy that they don't sit in wheelchair. Some people

200. think it is fun to sit in a wheelchair. They don't know why I think it is

201. sometimes bad/horrible to sit in a wheelchair.

202. I would advise people not to have an operation because it can go wrong.

203. Thank you

[Original in colour]

Appendix 9: Photographs of typical night splints

Night splints with an abduction bar.



Night splints without abduction bar.



[Original in Colour]

Appendix 10: Photographs of orthotics

Photographs No. 1-3 demonstrate standard orthotics prescribed by an external consultant for a child

Photo No. 1.



[Original in Colour]

Photo No. 2



[Original in Colour]

Photo No. 3



[Original in Colour]

Vignettes

Vignette No.1

An example is given that demonstrates how health professionals use their power on parents, children and the health insurance system in influencing the pathway of care. The mother of a 3 year old child with a GMFCS level III who has received therapy for the last 2 years in ICP was recommended to try the Lokomat- a supportive walking machine. This idea was supported by the therapists. The child and mother were resident at a clinic where the treatment was carried out. During their stay an employee of an orthotic firm which had a workshop on site of the clinic told the mother that her child would need orthotics (similar to those in Appendix 9). The mother described her surprise at the suggestion and confusion about not knowing what to do. She assumed that there must be a good reason and agreed for the orthotics to be made at a cost of about €5000 that the health insurance would pay for. The physiotherapist back at ICP agreed to evaluate their use and came to the conclusion that they stopped the child moving freely on the floor and it worsened his gait pattern. More importantly the child cried for much of the time and wanted to remove the orthotics. They were meant to be worn for 23 hours a day with the aim of improving standing and lengthening shortened muscles. The mother decided against the use of the splints but was left feeling confused and angry.

Vignette No. 2

Parents of a child who decided against surgery for their child 2 years ago recently had an appointment with a surgeon. The parents informed the therapist of their appointment and that the surgeon recommended extensive orthotics which can be seen in the photographs 1-3. The parents then explained that the surgeon had said that the child would learn to walk if he had the orthoses. This was a reason why they were very impressed with the surgeon. They explained that he was the first person who had told them that their child will be able to walk. At that time their child was walking independently with a posterior walker and had started to use crutches. However, based on his GMFCS level there was evidence to suggest that their child would not learn to walk without assistive devices. This child become less mobile with the orthotics and has subsequently had surgery to his lower extremities.

This example demonstrates firstly how important parents rate the ability to walk and secondly how parents are easily influenced by surgeons who may have very little knowledge about their child. In addition it emphasizes that the decision making process frequently does not involve other health professionals and how doctors can use their status and power to influence parents.