

AN EXPLORATORY STUDY OF THE REHABILITATION OF PHYSICAL DISABLED ADULTS IN A GROUP SETTING WITH PARTICULAR REFERENCE TO CONDUCTIVE EDUCATION

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ABSTRACT

Conventional rehabilitation for people with physical difficulties is based on mostly a biomedical approach to health focussing on isolated parts of the body without recognizing the patients' other needs. While more holistic and bio-psycho-social rehabilitation models have been developed, these are generally not recognised and as a result multiple needs are unlikely to be addressed.

This qualitative investigation of a rehabilitation in group setting explored the experience and impact of Conductive Education and draws on a complex, person centred, bio-psycho-social rehabilitation method. The research explores physically disabled adult patients', family members' and CE professionals' constructs on group setting in CE with the aim of finding out more about the approach itself and its delivery. Results suggest that CE does not decrease the exceptional result of physical rehabilitation of adult patients but conducts new motivational and developmental factors and broadens elements of rehabilitation in a complex way - holistically providing a life-changing concept. The study concludes with the recommendation for health care providers, rehabilitation institutions, accountable and responsible bodies to introduce and use group setting method in the rehabilitation of adult physical disabled. Furthermore, it is stated that considerably more and

adequate investigation need to be done on CE to better understand its complex offer.

PREFACE

This dissertation is a description of the work carried out in the Faculty of Education, Health and Community, Liverpool John Moores University under the supervision of Professor Jane Springett (Liverpool John Moores University), and Dr. Daz Greenop (Liverpool John Moores University). Except where acknowledged the material presented is the original work of the author, and no part of it has been submitted at this or any other university.

The Megan Baker House

I've been to The Megan Baker House

I hope it did me some good.

We did a lot of exercises

Some sat, some lay, some stood.

We stretched our legs and waggled our toes

We stood or sat or lay.

It was doing us some good

It made for a worthwhile day.

After one and three quarter hours

We stopped and had a rest.

We went for coffee, chocs and cakes.

I think that was the best.

But I'll go again next week

And do the best I can

And hope in time I'm better

I'm glad I joined the gang.'

Brynis Woolley*

***Brynis Wooly, Parkinson Patient of MBH (2011)**

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SECTION ONE

CHAPTER 1 – CONDUCTIVE EDUCATION APPROACH TO REHABILITATION

Introduction

The purpose of this chapter is to clarify definitions and provide an explanation of the Conductive Education (CE) approach to rehabilitation. I will additionally equip readers with contextual information on what type of CE centres for adult clients exist in UK and describe what sorts of training conductive education teachers get and what CE clients could expect to experience in a typical CE program. Over and above this, research supporting effectiveness of components of CE will be described along with gaps in the literature and how this study can contribute to this research knowledge.

Definitions and explanation of CE

Conductive Education is complex and difficult to define. This complexity is the result of a number of factors such as the trans-disciplinary nature of CE, historical contest between proponents of CE in different situations and in different countries, the emergence of different clientele and, the challenge of the evidence based practice. This complexity means that clarification and orientation is particularly important in order to proceed.

At its most basic level Conductive Education is an educational approach to “habilitation and rehabilitation” (Lodge, 2004) for both adults and children with neurological conditions such as Cerebral Palsy, Multiple Sclerosis, Parkinson’s disease, Stroke, Spina-Bifida, Dyspraxia and acquired Head Injuries. Lately, CE’s system is also often being used to help people with global development delay and physical disabilities caused by different diagnoses (Szögeczki, 2013).

CE is a holistic integrated pedagogical/educational system, which enables people with damage to the central nervous system to learn to overcome the challenges they face. CE is a process of experiences which lead the person to work with their motor disabilities, moving towards increased independence (Professional Conductors’ Association, 2009 n.p).

CE originated from Hungary, founded by a Hungarian physician Dr. András Pető (1893-1967) in 1944-45 (Read, 1994). The original name *Conductive Pedagogical System* (CPS) was mistakenly introduced as Conductive Education to the English speaking world. The name was meant to express that the method is an assistive (lifelong) process approach to recovering from, and living with, physical and related complex problems. CE

therefore supports the use of a systematic complex approach to rehabilitation. Pető realised that people with physical difficulties have complex problems; emotional, social, mental, medical issues alongside their physical concerns. He concluded that they therefore require a complex approach. A fundamental belief of CE is that as long as people are alive they are learning and that learning is not passive.

The process of learning, which is widely accepted to be the aim and one of the tools of CE, therefore requires active participation by attendees in CE sessions and is termed orthofunction (UKFCE, 1998). Orthofunction is described in simple terms as:

“...helping people achieve their potential by nurturing and developing an attitude to learning which is based on simultaneous development of movement, function and personality”

(Professional Conductors' Association, 2009 'n p').

One of the early pioneers of CE, Dr. Mária Hári (1923-2001), defines orthofunction as being a process of reorganised “integrated cognitive performance” and an adequate accommodation for life (Hári, 1982). For attendees to achieve “being orthofunctioned” she suggests a complex developmental process is required (cognitive, emotional, social, physical,

functional growth), and not purely the ability to perform some physical activities (Hári, 1997). CE as an educational, habilitation and rehabilitation system therefore incorporates multiple levels of being.

The professional who provides CE is referred to as conductor, or conductive education teacher (CET) highlighting the nature of CE being 'conductive' (Sutton, 2000). CE is delivered by

...Conductors working in teams and they are responsible for planning and implementing the integrated educational programmes aimed at stimulating the learning of the individual.

This is achieved using effective teaching-learning strategies based on an in-depth knowledge of the individual and the impact of their condition on all areas of development - physical, emotional, social, cognitive and educational.

(Professional Conductors' Association, 2009 'n p').

Conductors are trained in UK at the National Institute of Conductive Education's training department called Conductive College, in Birmingham however, students get professional practice as part of their training at several appointed CE centres throughout the UK.

To qualify as a conductor requires a three-year full time undergraduate course. Since September 2012 the BA Hons Conductive Education course has run as a part of the Conductive College training portfolio through Birmingham City University (BCU)....Qualified Conductor Status (QCS) is a worldwide recognized professional qualification...

(National Institute of Conductive Education)

Available at: <http://www.conductive-education.org.uk/training/ba-hons-conductive-education/>

[Accessed: 30th November 2016]

Conductors could reach the Conductive Education Teacher (CET) positions if they additionally accomplished a degree in education to the original conductor training which enables them to teach as CET in schools, especially in CE schools.

CE practice which differs from any known rehabilitation methods and therapies integrates complex responses for physical disabled people's multifaceted, compound needs. It is 'delivered' both in one-to-one and group settings however, the main focus of CE is the latter. The group of patients in CE is created not constructed providing a variety of benefits to participants including social interaction, group dynamics, motivation, healthy competition,

comparators, support and learning from others in similar situations (Brown, 2010).

In the context of physical disability, CE has not been identified or recognized to be part of any rehabilitation model and seemingly has its own trans-disciplinary, thus “trans-modular”, position sharing similarities with the “ideology of independence”, “biopsychosocial”, “International Classification of Functioning (ICF)”, “quality of life”, “social”, and “evidence based practice” despite predating these by several decades. CE did have its own classification system when it was established; conductive observational tools for planning and recording. These tools do not meet with contemporary rehabilitation recording requirements therefore the European Conductive Association (ECA) now uses several evidence based practice measurement tools such as Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Communication Function Classification System (CFCs) Eating and Drinking Ability Classification System (EDACS). In order to identify psychosocial areas tools has been advised by the UK CE’s professional body (CEPEG) to use as KINDL which measures health related quality of life components.

CE’s complexity makes it challenging to evaluate outcomes; therefore it was decided by the International Petró Association at the 6th World Congress on CE in Gothenburg, Sweden in 2007 to map chosen measurement tools against

the ICF CE core set which has been identified by the UK CE professional body in 2010.

Conductive Education for adults - which is one of the main focuses of the current study – is as yet unrecognised by the NHS and is therefore provided exclusively in the private sector through charities and a small number of self-employed practitioners. There are 39 CE centres in the UK each differing in size, activities and funding, 16 of which offered CE services for adults too (Maguire, 2009; Sutton, 2009).

What could clients expect to experience in a typical CE program?

Patient education has become an important feature of health care provision in recent decades. Teaching and learning are lively and essential concepts to be included in the patients' rehabilitation (Dreeben, 2010).

The name Conductive Education - more precisely Conductive Pedagogic System (CPS) - refers to the rehabilitation process which patients experience and it suggests that CE is based on pedagogical fundamentals and uses pedagogical elements to interact with the clients, whereby teaching and learning are everyday basics of their habilitation or rehabilitation. Certainly, one of CE's unique features is that rehabilitation units are formally and systematically organised as educational entities and that the rehabilitation sessions have pedagogical characteristics in group setting. CE considers that

patients are individuals who are in need of *learning* how to overcome physical difficulties and how to live with their altered conditions. In contrast to traditional rehabilitation approaches, CE views patients as active participants rather than passive patients. CE therefore aims to treat people with disability collectively as learners, where the conductive professional is supposed to teach them and facilitate their learning, and patient-students are actively involved in their “education” and have their own responsibilities (Hari, 1982 p.129-131).

Upbringing in pedagogy is understood as a complex mix of treatment and instruction received from parents and carers throughout childhood. The treatment which the conductive education teacher provides for patients is very similar to, and is as complex task as parental care. Patients are looked after, are nurtured responsibly and their complex needs, i.e. emotional, social/environmental, physical, mental-cognitive and spiritual, are well analysed and addressed by the professionals. CE is mostly (not only) delivered in group settings, in the same way that pupils/students participate in education, based on pedagogical foundations. Group setting is unique in the rehabilitation of motor disabled and this could be a new experience for clients (both positive and negative).

Another basic element of CE is that sessions are divided into different activity programs and that these programs follow didactical teaching routines which facilitate participants' complex learning. Therefore, habilitation and rehabilitation of patients turn into a teaching strategy, the main purpose of which is to engage the clients through the use of different available models for each subject, though physical approach is the main but not the only focus. The idea is to introduce patients to specific and complex situations for exploring through their lived experience and through an understanding of their own real capabilities. There are different programs during each CE session delivered in group settings. Most of the programs contain series of physical tasks and the tasks build up gradually and spirally in order to facilitate experience, learning and success. As part of the program, alongside the tasks, there are always pedagogically prepared subjects, topics to be thought about or discussed which are fully built in to the program. Professionals use them simultaneously with the physical tasks in order to deal with emotional, social/environmental and mental-cognitive factors as well.

In order to better understand how an adult CE program is conducted in group settings here is an example (Box 1) of the routine of a session which initiates to give a little idea of the practice. The given example is one of the field notes of the researcher conducting the current study.

BOX 1 ROUTINE OF CE SESSION

5 patients arrived at the Centre which was located in a farm in a rural area and had a main bigger building with reception and two other smaller ones on the land. Before the session patients had a coffee at a community room together without the professionals. After the welcoming process they walked accompanied by two conductors to their activity rooms which was like a gym equipped with plinths, stools, leader-back chairs. Each patient had his or her place sitting on a stool or a leader-back chair in front of a plinth. One of the conductors lead the program like a teacher in school and started to talk about tea subjects and they all discussed how important was to have a tea. With the assistance of the conductor they agreed that it has health and social effects of having tea, then they discussed what make they liked the best and how they drank it. Following that, they went through their fine and gross motor task series using teabags or mugs for some tasks to connect the topic of the day to the physical part of the session. The task series were executed on the plinths in lying position, on the chairs in sitting position and in standing-walking as well. This part of the session contained approximately 140 tasks and lasted 65 minutes whilst they learnt and practiced to carry out movements, change of

postures, positions and places very actively using incidental verbal rhythmical intentions – which facilitation tool is a unique and one of the main characteristics of CE - conducted by the leading conductor and patients received facilitations by the other conductor. As a pause between tasks they were offered to smell blindfolded different teas to find out flavours.

The follow up program part was less directed and did not have precisely built-up task series but focused on using learned abilities, adapting them to everyday life, practising them in different daily life activities, set in everyday situations. The group set up a kitchen with the assistance of conductors to make a tea and used just learned/practiced movements to make their own tea with as less help as it was possible. During this part of the session there was a lot of interaction of the group members and conductors and conductors facilitated a lot of movements/transitions too. At the last part of the session they sit together in the community room to have a tea and talked about different subjects they were interested in. This part was quite social and several interesting themes were discussed raised by the clients. The session ended with saying good bye by the conductors but patients could stay longer if they wanted.

The session was reflectively prepared and delivered, being based on both pedagogical and therapeutic focus, patients spent the whole time together.

Box 1

Why research is needed?

Being trained as a Conductive Education Teacher (CET), a professional who is supposed to address patients' complex needs as a "patient life-style manager", I faced many difficulties adapting to the NHS system. In a desire to convince other professionals of CE's value I searched for evidence but quickly realised there is a distinct lack of research available, particularly on adult CE. Extensive literature review for the efficacy of CE yielded 566 results by ECA group in 2013 - hand searching and internet searching were also employed, studies were published across a range of journals with widely varying reported impact factors. Focusing on adult CE however, just 5 studies remained:

- a) Endres, Nyáry, Bánhidi, Deák (1990) Stroke rehabilitation: method and evaluation, *International journal of rehabilitation research*, 13, 3 p. 225-236

Subjects of this study were 53 patients who presented with cerebrovascular stroke and who took part in a rehabilitation programme that included the basic elements of Bobath's concept and

Peto's Conductive Education. The protocol called for a three point assessment: on admission to the rehabilitation ward and at one month and one year after entry. Baseline and follow-up examinations included clinical and laboratory tests, CT scan, cerebral blood flow studies and angiography. Motor functions were evaluated by the Rivermead Motor Assessment and dependence (ADL) was measured by the Barthel index. Neuropsychological evaluations were also made using Benton's test, Bourdon's letter cancellation test and the Wechsler Adult Intelligence Scale. Significant improvement was found in functional (physical) conditions both one month and one year after entry.

- b) Laver and Brown (1995) *The evaluation of a short term Conductive Education programme for a sample of twelve adults with a primary diagnosis of stroke.*

This short report found positive physical (range of motions) outcomes of CE intervention for 12 Stroke survivors.

- c) Laver (1996) *Research report to Ontario March of Dimes for a one year follow up evaluation of the three week Conductive Education intervention for a sample of twelve subjects with stroke.*

This is a brief unpublished report describing mixed results at 1-year follow up of the former research (b), with improvements reported in only some physical areas (range of motions).

- d) Cott and Wright (2001) An Evaluation of a Conductive Education Program for Adults with Neuro-motor Disability. *Physiotherapy Canada*, 53 Vol 3, p. 182-189.

The purpose of this project was to evaluate a CE program for adults with neurological disability. Forty one persons with Stroke, MS, or other neurological conditions participated in the program. It has been resulted significant improvements in balance, distance walked, motor performance and mastery.

- e) Brittle et al (2008) Short-term effects on mobility, activities of daily living and health-related quality of life of a Conductive Education programme for adults with Multiple Sclerosis, Parkinson's disease and Stroke, *Clinical Rehabilitation*, 22, p. 329-337

This research objective was to evaluate the impact of 10 sessions of Conductive Education on mobility, functional independence and health-related quality of life in adults with Multiple Sclerosis, Parkinson's disease and Stroke. One hundred and twenty-nine self-referred community-living individuals with moderate disability participated in

the research. All participants were assessed using the Barthel Index and the Nottingham Extended Activities of Daily living Index. Stroke, Multiple Sclerosis and Parkinson's disease patients also completed the Short Form 36 (SF-36) Health Survey, the Multiple Sclerosis Quality of Life 54 questionnaire (MSQoL-54) and the Parkinson's disease Questionnaire (PDQ-39) respectively. Results: One hundred and five individuals completed the programme as well as all pre and post-assessments. Of these, 34 had suffered a stroke, 55 had Parkinson's disease and 16 had multiple sclerosis. Stroke patients demonstrated statistically significant improvements in the Nottingham Extended Activities of Daily living Index (mean change 3.4, $P < 0.001$) and the SF-36 mental health subsection (mean change 7.8, $P < 0.001$). Non-significant trends towards improved physical and mental function were demonstrated by other outcome measures across all three diagnoses. The results emphasize potential benefits of Conductive Education for adult individuals.

Reflectively, existing research is clearly limited and, in particular, does not seem to recognise the importance of how CE is delivered, namely, the multidimensional (cognitive, emotional, social and physical) transformative

elements which demand the patients to take personal responsibility and commit themselves to learning, problem solving, participation and perseverance with a positive attitude. Nor does it take into account the contribution made by the rehabilitator who, with the patients, create a group which achieves much more than could be achieved if they all acted alone (Schalkwyk, 2007).

No theories have been developed to explain how CE impacts on emotional, social dimensions, what are the motivational factors for both clients and professionals to take part in CE , what is the professional role of conductors, how clients and their family members experience CE. This present study is intended to address the 'gaps' I have identified and to extend relevant knowledge of the adult CE phenomenon in order to comprehend the psychological and social aspects of the patients' lived experience of CE.

A specific concern is the lack of qualitative research that would address CE as a whole, namely: its complex, trans-disciplinary nature; the psychological and sociological impact of the approach; and most importantly the effect of group participation. Indeed CE's focus on the group setting as a system seems to be unique in the field of rehabilitation of physically disabled adults. This experience persuaded me to undertake this current study with the purpose of exploring the rehabilitation of people with physical disabilities

(PWPD) in group setting through a qualitative approach and provide a much needed contextual understanding of the CE model.

CHAPTER 2 – THE NATURE OF CURRENT REHABILITATION OF ADULTS WITH PHYSICAL DISABILITIES

Introduction

Exploring the nature of the rehabilitation of adults with physical disabilities requires an understanding of the meaning of both physical disability and rehabilitation means. Such background information can provide key understanding of why the group setting used in CE became the focus of my research, and also affords key reasons as to why and how this bio-psycho-social approach is used.

What is physical disability?

The WHO definition of *health* (WHO Constitution, 45th edition 2006, p.1) states:

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”

An individual’s mental, physical and social-cultural standards of existence are, according to the WHO, linked together and not separable. Their definition of *disability* similarly highlights the interwoven status of human existence:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a

problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.' WHO (2013)

Physical disability is usually understood as any condition that permanently prevents normal body movement and/or control. There are many different kinds of physical disabilities but they are usually divided into three anatomically distinct types: visual impairment, hearing impairment and mobility impairment. However, the terminology suggested by the WHO uses the name of "functional disability". This notion could be used to overlap the three named types of disabilities and other disabilities too. Therefore, physical disability and/or functional disability has to be understood as the interaction of different individual components of compromised functions. Physical, emotional, social and cognitive aspects usually interact to produce a complex disability, which is greater than the simple addition of the single impairments,

and affecting the patients' global function and his or her self-dependency (Annicchiarico et al, 2004 p.835).

Consequently, physical disability has no clear limits, and defining different levels in different patients is very challenging, particularly when referring to functional disability.

In addition to this, the temporal status and provisional nature of physical and functional difficulties also need to be acknowledged. Temporary physical disability could range from one or two days, to a much longer periods and it could require considerably more or less attention for short periods of time.

Causes of physical, functional disabilities

According to the WHO's latest World Report On Disability (WRD) in June 2011, there are more than a billion people around the world living with disabilities. A significant proportion of physical disabilities are caused by injuries including those which result from traffic crashes, falls, burns, and acts of violence. Other major causes of physical disabilities are different types of diseases, damages to central nervous system, neurological traumas and congenital condition from birth. Additionally, permanent physical and functional difficulties are also developing as a result of the normal human ageing process. The diversity of causes of physical disabilities is obvious and

accordingly persons with physical, functional, comprehensive disabilities are diverse and heterogeneous.

Prevalence of disability – difficulties in functioning

The current prevalence of difficulties in functioning estimates are based on two large studies reported in the WHO's World Report On Disability (p.24-32); The WHO World Health Survey of 2002-2004, and the WHO Global Burden of Disease study, 2004. The Global Burden of Disease study estimates 15.3% of the world population (about 978 million people of the estimated 6.4 billion) have moderate or severe disability. According to the World Health Survey, across all 59 countries the average prevalence of difficulties in functioning in the adult population (aged 18 years and over) was 15.6 %, about 650 million people of the estimated 4.2 billion adults in 2004 ranging from 11.8% in higher income countries to 18% in lower income countries. The average prevalence rate for adults with significant functioning difficulties was estimated at 2.2%.

The official UK disability statistics from the Office for Disability Issues (2009/10) states that there are over ten million people with a limiting long term illness, impairment or disability in Great Britain, of whom 5.1 million are adults of working age, and 5.0 million are over state pension age (and 0.8 million are children). The most commonly-reported impairments are those

that affect mobility. Subsequently, prevalence of functional disability rises with age in UK.

The effect of environment on disability

The MHADIE project (Measuring Health and Disability in Europe) that supports policy development was founded by the European Commission's Sixth Framework Programme for the period 2004-2008. The purpose of MHADIE was to propose disability according to a bio-psycho-social model, and shed light upon the complex interaction between the person with health condition, and the environment in which he or she lives. A MHADIE document was published (Leonardi et al, 2009) aiming to briefly describe the different impacts of the environment, the different degree of limitations in activities and restrictions to participation. The ICF tool was used to assess capacity, performance and the influence of environment on disability. Capacity and performance are identified as indicators:

...capacity indicates what a person can do in standardised environment, often clinical setting, without the barriers of facilitators of the person's usual environment and performance indicates what a person does in the current or usual environment, with all barriers and facilitators in place.

(WRD, 2011 p.38).

The conditions of migraine (MIG), Parkinson's disease (PD), multiple sclerosis (MS), traumatic brain injury (TBI), stroke, bipolar disorder (BD), depression (DEP), osteoporosis (OP), low back pain (LBP), other musculoskeletal conditions (MUSK-other) were included. High correlation scores were observed in prevalence of problems in both performance and capacity for stroke, DEP, PD, MUSK-other, BD, MS.

The result demonstrates that it is likely to be necessary, in conventional clinical settings, to untangle aspects of disability that are particular to the individual (the capacity score) and from the effects of the person's physical environment – the difference between capacity and performance.

[Available rehabilitation for physically disabled people](#)

At present, drug treatment alone cannot improve physical difficulties in functioning, and comprehensive disability. Therefore different rehabilitation programmes and methods have been developed to help patients to improve skills, abilities or recover the abilities they lost as a result of their disability.

Rehabilitation is defined as an intervention:

“To restore to a former capacity...to restore or bring to a condition of health”
(Merriam-Webster, 2016).

Rehabilitation denotes any process that tries to re-establish the patient/person to an earlier level of health. Different expressions of the rehabilitative process focus on the task of bringing back at least some function to a damaged body, or utilizing the process of education, to equip the individual to compensate for damage that cannot be repaired. Essentially, rehabilitation has the aim of assisting individuals to achieve the highest quality of life and health as possible within their circumstances (Wisegeek, 2012).

According to the White Book on Physical and Rehabilitation Medicine in Europe (2007) conventional rehabilitation for physically and functionally disabled patients incorporates a wide range of services such as: physiotherapy, physical therapy modalities, occupational therapy, equipment and technical aids, manual therapy and speech and language therapy. Other services may include a range of psychological, social and pharmacological interventions. Alongside these conventional therapies, patients with physical, functional disabilities can find (as part of their health services or as independent facilities) other complementary and alternative therapies (CAM). However, they differ greatly from each other. Complementary therapy refers to interventions utilised *alongside* conventional medical treatment while alternative therapy is generally used instead of conventional treatment; however this depends on the nature of the alternative approach.

In the UK, physically disabled patients receive conventional rehabilitation as either in-patients or outpatients. Either way, this is usually provided by multi-disciplinary teams, typically including consultants, doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, social workers and in certain cases dieticians. A multidisciplinary team pattern such as this suggests a complex, “whole-istic” rehabilitation approach towards functional disability however; I was not able to identify research evidence on the provision of holistic rehabilitation within the conventional services of the NHS.

A typical NHS conventional rehabilitation programme for people with physical disability in the UK tends to take an over-emphasis on the physical elements of the rehabilitation. These elements are the most detectable through the use of outcome measures being used by rehabilitation programs by the NHS (Schalkwyk, 2007. p. 35-38) Despite the WHO’s efforts to change the general view of rehabilitation for people with comprehensive disabilities, still not enough attention appears to be spent on emotional, social, psychological and cognitive needs of patients (Burton, 2000; Hochsteinbach, 2000). Some alternative, unconventional therapies and programmes are available currently through the NHS, depending on the patient’s diagnosis but these are very restricted. For example, acupuncture as part of the Traditional

Chinese Medicine treatment is more likely to be accepted and paid for by the NHS in cases where a patient has suffered a stroke. There are also some centres available through the NHS in UK offering different, alternative methods for physically disabled individuals (e.g. Oliver Zangwill Centre in Cambridge). However, I was not able to identify experimental studies on many other alternative approaches. Consequently, the complex needs of the whole person are possibly not being addressed by conventional NHS rehabilitation services.

With the current population of the UK we have no specific database available for how many people suffer from physical disabilities and/or comprehensive motor function difficulties. The figures do not integrate different types of physical disabilities in a single coherent data set. Physical bodies have a range of capacities, so reliable statistical data regarding the prevalence and extent of physical disabilities and/or comprehensive motor function difficulties is impossible to achieve. However, combining medical statistics (see Appendix A) suggests that about 1 in 100 people may have a physical impairment. The treatment, rehabilitation and healthcare of people with physical disabilities is complex, and in many cases requires further applied therapies and a high level of commitment to self-care. The direct expenditure on care is therefore high; costing the UK government

approximately £60, 000, 000 – 80,000,000 a year according to my calculations.

Indirect psychological, social, and economic costs are, of course, higher.

Conductive Education for physically disabled adults in UK

As explained in chapter one, CE is an educational approach, “habilitation and rehabilitation” (Lodge, 2004) for both adults and children with neurological conditions. CE practice differs from other conventional or unconventional therapies available for people with physical difficulties in UK and it approaches patients mainly in group setting. CE for adults - which is one of the main focuses of the current study – is as yet unrecognised by the NHS and is therefore provided exclusively in the private sector (Maguire, 2009; Sutton, 2009). Although CE professionals i.e. conductors and conductive education teachers are trained in UK, the profession is not well known or recognised.

CHAPTER 3 – RESEARCHING LIVED EXPERIENCES OF CONDUCTIVE EDUCATION: PHILOSOPHY, PARADIGM, METHODOLOGY, ETHICAL CONCERNS, REFLEXIVITY, METHODS

Introduction

The aim of this chapter is to present the philosophy, the chosen research paradigm of the research, provide information on phenomenology, hermeneutic phenomenology, and identify useful methodology to support the research context, study participants and data collection methods used.

Philosophy

The philosophy of a research influences the whole process of a study from design to dissemination. The present study concentrated on the lived experience of Conductive Education of patients, their family members and professionals. A philosophy which largely focuses on the nature of human experience, and which also broadly used in qualitative research on lived experience, is phenomenology.

“Phenomenology is a philosophic attitude and research approach. Its primary position is that the most basic human truths are accessible only through inner subjectivity and that the person is integral to the environment” (Flood, 2010)

Phenomenology

One can attempt to understand someone else's experience, but never will one be able to exactly know what experience is like for the other. Phenomenology is a philosophy which has been widely used by researchers in healthcare to explore patients' experience. Taken literally, it is the study of "appearance" or "that which shows itself" (Spinelli, 1995, p. 2). It is therefore the study of subjective rather than the objective reality, one's experiences of things. Perhaps most importantly, it investigates experience as a whole and acknowledges that experience does not only happen via sensory input i.e. seeing, hearing, smelling, tasting, feeling through touch, but also via for instances of remembering, imagining things, feeling emotions, etc. (Hammond, et al., 1991). This contrasts with Cartesian dualism which breaks experience down into its constituent parts but rather sees experience as a permanent, common, "single" experience of something. In terms of healthcare research, a phenomenological approach could be said to diverge from positivism in which outsiders (i.e. non-patient researchers) only explore a part of illness experience or condition experience, for instance, pain or range of movement, but neglect the concept of "lived experience", the "felt world" and that which indicates whole-ism, the unity between physical, emotional and social experience (Hughes and Paterson, 1997). Whereas some misunderstanding exists about the nature of the phenomenological project,

the desire to comprehend the lived experience of patients is evident (Finlay, 2009 p. 474). A phenomenological study can take researchers into the lived world of the people they are investigating in a deeper, more comprehensive way, thus producing more complex understanding (Thomas, 2005). According to Kafla (2011), there are 3 types of phenomenology: transcendental phenomenology, hermeneutic phenomenology, and existential phenomenology. Transcendental phenomenology is associated with Edmund Husserl (1859-1938) and the basic principle of his school of thought is the adherence to the idea that experience is to be transcended to discover reality. Husserl's philosophical ideas gave rise to the eidetic phenomenological approach where the elementary attention is to discover and describe the "lived world". Martin Heidegger's (1889-1976) hermeneutic phenomenology is dedicated to subjective experience of individuals and/or groups. It is an effort to explore the world revealed in people's stories. This school of thought emphasizes that interpretations are all we have and description itself is an interpretive process. Existential phenomenology, may also be linked to Heidegger (1889-1976), and also Jean Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961) and their followers who share the opinion that philosophy ought not to be based on objective, unbiased, unfastened standpoint (Warthall 2006). The existential school of phenomenology rejects

Husserl's idea of bracketing and the possibility of simple interaction with the world. Therefore, existential phenomenology stresses description of everyday experience as it is perceived by the consciousness of the individuals.

Husserl's phenomenological method

Husserl was interested in finding an empirical method to study experience with, one that was not informed by dualist knowledge. He subsequently advanced his so-called phenomenological method on which most approaches using phenomenological techniques are based. The key concepts are presented here in a linear way they are however all interrelated (Gearing, 2004; Van Manen, 1990)

Epoché

Epoché, also called phenomenological reduction, refers to the suspension of researchers' own preconceived assumptions of the phenomena. Researchers suppose to practise reflection in order to become aware of their own thoughts and ideas concerning a phenomenon and then push away the thoughts and ideas to prevent them from influencing their description of the phenomenon under study (Lopez and Willis, 2004) this is referred to as the idea of bracketing.

A criticism of Husserl's method is that to be completely value-free when encountering another person's narratives is virtually impossible (Le Vasseur, 2003). An attempt to be free from all values can be compared to positivism's division between the researcher and the researched (Lincoln and Guba, 1985). Spinelli (1995), a frequent supporter of Husserl's method, however argues that even though it might be difficult to put one's own values and thoughts/ideas aside it is possible to bracket a large number of one's assumption. Husserl called it "natural attitude" when people in everyday life think of themselves as being independent from the world around them. A contrasting attitude, one in which one sees a phenomenon for what it really is, without judging it, is termed the "transcendental attitude". Through bracketing of ones' pre-assumptions, one attempts to understand a phenomenon for what it really is. The process of bracketing assumptions often leads scholars to recognize that more assumptions need to be bracketed - a process Husserl referred to "re-bracketing" or moving from a natural attitude to transcendental attitude. Because bracketing and rebracketing is a never-ending process, moreover, a complete reduction is impossible. This movement is a process similar to that involved in the hermeneutic circle, discussed later in this chapter.

Description

An essential piece of Husserl's phenomenology is the subject of *Zu den Sachen* "to the things themselves", (Von Eckartsberg, 1998). The core of phenomenological description is "describe, do not explain" (Spinelli, 1995, p.17) – this indicates the focus on the phenomenon purely as it is, and reminds researchers that one ought to keep one's focus on *Sachen* and refrain from speculation and explanation which could 'contaminate' data.

The German word *Lebenswelt* is used in phenomenology to refer to a person's life-world - the world as experienced by the person which is then described by phenomenology (Spinelli, 1995). The indication of *Zu den Sachen* connects with the concept of *Lebenswelt* in that description of experience while bracketing pre-assumptions, exposes to us the world as experienced by another individual or group of individuals, without contamination by the researcher's pre-assumptions and judgements (Ehrich, 1999).

Horizontalisation and Free Imaginative Variation

These concepts take place during different stages of Description. Horizontalisation is about treating all parts of the data as equal parts of the whole (Spinelli, 1995). Therefore, for the most part of Description, no parts of the phenomenon are put in hierarchical levels. After the analysis has been

completed, the investigator applies Free Imaginative Variation to examine the essence of the described phenomenon in all possible diverse arrangements and conclude which characteristics of the essence are essential to it (Maggs-Rapport, 2001). The significant characteristics help to form the essential structure, which provides better understanding of the essence of the phenomenon.

Intentionality

This phenomenological concept expresses the idea of consciousness being intentional, meaning that consciousness is always directed to something (Le Vasseur, 2003), as experience is also constantly 'of something' (Hammond, et al., 1991). 'Intentionality' derived of this in phenomenology and highlights the inter-relationship between the world around one and his conscious experience (Spinelli, 1995). Husserl's phenomenology is useful for determining what the essence of lived experience is, however, it does not allow for interpretation of the essence (Lopez and Willis, 2004). Interpretation could uncover characteristics of the phenomena that might have stayed hidden if it were presented to the reader through description only.

For this reason it was felt that Husserl's phenomenology was not quite adequate for the present research, however interpretive phenomenology, namely hermeneutic phenomenology seemed to be more suitable.

Hermeneutic phenomenology method

Martin Heidegger was an assistant of Husserl at Freiburg University in Germany and he succeeded Husserl's position as Chair of Philosophy later. Heidegger's phenomenology was based on the philosophy of Husserl's however, he developed an approach to phenomenology referred to it as hermeneutic phenomenology. The following is a discussion of the main concepts of Heidegger's hermeneutic phenomenology.

In contrast to Husserl, who worked the question what we know as person – Heidegger was interested in the nature of being. He agreed with Husserl on *Zu den Sachen* but he considered description to be of no use on its own (Mulhall, 1996). He argued that meaningful understanding of being is to be found in interpretation and his interpretive phenomenology is called hermeneutic phenomenology. According to Annells (1996) the term “hermeneutics” invented from the Greek word *hermenia* which refers to the understanding of language whilst Lopez and Willis, (2004) believed that the word “hermeneutic” is derived from the name Hermes, a Greek god who was responsible for making clear messages between gods. Spiegelberg (1976, cited in Lopez and Willis 2004 p.728) identified hermeneutics as a “process and method for bringing out and making manifest what is normally hidden in human experience and human relations”.

Dasein

Heidegger believed that human beings make sense of the world through being in it, and not through being detached from it (Maggs-Rapport, 2001). One of the main concepts of his approach is “Dasein” which literally translated means “the fact that something is”. This refers to the existentialist view of existence as essentially “being-in-the-world” (Valle, et al., 1998). To be human is to be fixed, embedded and immersed in the physical, literal, tangible day to day world (Steiner, 1978). Heidegger advised that rather than focus on people or phenomena, the examination of the lived experience should be the focus (Flood, 2010 p.9). He believed that the existing world is here, now, and everywhere around us, and that we are totally immersed in it. This sense of the world should also always include an understanding of the experience of time and space as well, due to the fact that temporality and spatiality help to give meaning to Dasein (Mackey, 2005; Mulhall, 1996). Dasein therefore is an entity of the average everydayness of being (Heidegger, 2010).

Co-constitution

Heidegger suggested that there is no separation between the observer and the observed and therefore the bracketing of thoughts is impossible (Le Vasseur, 2003). Dasein proposes the view that all our connections or

associations are also inseparable from what goes on around us (Lopez and Willis, 2004). Consequently, human beings and their life-worlds are co-constituted. Therefore, in Heidegger's hermeneutic phenomenology one's pre-assumptions are seen as a vital part of the explanation and the interpretation of a hermeneutic phenomenological study on lived experience is then an interpretation co-constituted by the researcher and participant (Lopez and Willis, 2004).

Hermeneutic circle

A hermeneutic phenomenological inquiry into lived experience, most often transcribed into narrative texts, takes on a cyclical and open-ended approach to the text (Mackey, 2005). This cyclical approach is referred to 'hermeneutic circle' and includes non-stop dealing (reading, re-reading, analysing) of the text in order to get a close sense of the possible meanings of it. The researchers own history and his 'being-conscious-of', lived experience, his own pre-assumptions are all part of the hermeneutic development, therefore further readings and readers' understanding of research are seldom the same as they are likely to differ according to time and place (Mackey, 2005). The consequences of a hermeneutic reading are not the only imaginable interpretations of data, though conclusions of hermeneutics are

not considered the definitive 'truth' but rather an open ended presentation of informants' realities or "hermeneutic variants" (Finlay, 2009).

Research Paradigm

The main purpose of the current research was to better understand the rehabilitation of physical disabled adults in group setting through CE approach, to widen our knowledge of CE itself, and its psychological and sociological impact on them. Therefore, the lived experience of CE patients, their family members and conductor professionals became the main focus of interest. The research aim fits with the philosophy and intentions of the interpretive research paradigm. According to the interpretive paradigm meanings are constructed by human beings based on their own lived experience and in this type of research findings emerge from experiences communicated and the subjectivity from both research participants and researcher(s) is valued. Though, an interpretive paradigm was chosen as the most suitable for the current study since practical knowledge, psychological and sociological experience were sought.

Methodology

Choosing an appropriate research paradigm and methodology is one of the key factors in conducting a successful research. According to Hammell and

Carpenter (2000; cited in Carpenter and Suto, 2008 p. 46) the term methodology is not used reliably crosswise theoretical disciplines. Therefore, in the present research in order to be unambiguous the definition of methodology used was adapted from Hammell as “a specific philosophical and ethical approach to developing knowledge; theory of how research should, or ought to proceed given the nature of the issue it seeks to address” (2006 p.167). A clearly defined methodological attitude offers coherence and consistency to the research design and plays an important role in the plan of inquiry. Contemporarily, the most dominant methodologies in health care research are grounded theory, phenomenology, ethnography and participatory action research and what hugely influences of the choice what methodology form is the most suitable to a study is the type of the research question(s) being asked (Carpenter and Suto 2008 p. 46).

The current study wished to seek new information on “what’s going on in CE’s group approach” and “how patients, family members and professionals recognise and experience it”. Because patients and professionals are not well represented in research I wanted to focus on the lived experiences of people whose voices have not been heard and whose perspectives have not been acknowledged. To conduct such an exploratory inquiry obvious reasons lead me to hermeneutic phenomenological methodology which was chosen as a

suitable methodology for this research, informed by the work of Max van Manen (1997). Hermeneutic phenomenology is a:

“research methodology aimed at producing rich textual descriptions of the experiencing of selected phenomena in the lifeworld of individuals that are able to connect with the experience of all of us collectively” (Smith, 1997).

The practise of hermeneutic phenomenology enabled the exploration of participants’ lived experiences combined with further notions and interpretation based on my academic and personal knowledge as a researcher. Hermeneutics enhances the revelatory elements to elucidate meanings and assumptions in the participants’ texts that participants themselves may have difficulty in articulating (Crotty, 1998). Communication and language are intertwined and hermeneutics offers a way of understanding such human experiences captured through language and in context (van Manen, 1997).

Table 1 **Overview of research**

Overview of the research	
Paradigm	<ul style="list-style-type: none"> • Interpretive paradigm
Methodology	<ul style="list-style-type: none"> • Hermeneutic phenomenology <p>Ethical issues:</p> <p>Recruitment letter</p> <p>Letter of Invitation - Information sheet</p> <p>Written consent</p>
Data Collection Stage Used Methods	<p>Finding suitable CE centres and possible participants</p> <p>Preparation of technical support</p> <p>Find a professional to transcript audio files</p> <p>into written files, preparation of time, travel, venues</p> <p>Observation of CE centres and research participants -</p> <p>Researcher's notes, memos in written form</p> <p>In-depth interviews</p> <p>Group interviews</p> <p>You Tube narrative</p> <p>Transcribe audio recorded interviews, dialogues, you tube narrative</p> <ul style="list-style-type: none"> • Saving files (Transcript, Personal)

Data Analysis	<ul style="list-style-type: none"> • Grounded Theory analytical stages and constant comparison approach
Product	<ul style="list-style-type: none"> • Discussed themes and sub-themes with conclusion

Heidegger did not provide researchers with a single standardised method with which to perform hermeneutic phenomenological inquiry (Mackey, 2005, Ehrich, 1999, Van Manen, 1997) because he believed it to be difficult to commit oneself to one method only (Mulhall, 1996). Since Heidegger, researchers have developed different sets of guidelines for research which uses hermeneutic phenomenological principles. It is a common and accepted attitude that researchers using phenomenological principles and adapting existing phenomenological techniques to their own study inquiries (Van Manen, 1990). Van Manen (1990) writes in such a straightforward style that it is easy to follow for the reader or other hermeneutic phenomenological researchers (Maggs-Rapport, 2001). Van Manen (1997) recommend six actions that can be adapted for hermeneutic phenomenological inquiries:

- i. Turning to the Nature of Lived Experience
- ii. Investigating Experience as We Live it
- iii. Hermeneutic Phenomenological Reflection

- iv. Hermeneutic Phenomenological Writing
- v. Maintaining a Strong and Oriented Relation
- vi. Balancing the Research Context by Considering Parts and Whole

In the current study I sort to adapt these recommendations for my own purposes as follows:

- i. The study focused on the phenomenon of CE group rehabilitation experience of patients, patients' family members and CE professionals.
- ii. It drew on hermeneutic phenomenological principals while reflecting on subjects
- iii. It drew on hermeneutic phenomenological principles while unfolding and understanding participants' experiences
- iv. It followed the hermeneutic circle's cyclical principle; staying absorbed in data and staying aware of my own pre-assumptions
- v. It reflected all abstracts of subjects on their own as well as in context of a bigger picture of the study

Involving participants – sampling approach and participant recruitment, participant's profile

Whilst conducting qualitative research, the purpose of sampling strategies are invented by the desire to recruit research participants who can

contribute their understanding or experience of the phenomena of interest (Carpenter and Suto 2008, p. 77). According to Carpenter and Suto, the most commonly used sampling strategies are either purposive or convenience sampling. Purposive sampling can be defined as the selection of individuals, groups of individuals or institutions based on specific purposes associated with addressing the research study's question or aim (Teddlie and Yu, 2007 in Carpenter and Suto, 2008, p. 78) whereas convenience sampling involves studying people who are conveniently available and enthusiastic to partake in a research.

As the aim of the current study was to explore the rehabilitation of physical disabled adults in a group setting with particular reference to CE it was necessary to find adequate CE centres delivering physical rehabilitation for adults in group setting and identify participants - patients, family members, health carers, and CE professionals - who felt able to share their experiences of the phenomena of my interest. As mentioned in Chapter 1 that there were 39 CE centres in the UK of which 16 offered CE services for adults (Maguire, 2009; Sutton, 2009). As a founding and active member of the CE professional body (CEPEG) in UK, my personal knowledge on the adequate existing CE centres made my search for suitable CE rehabilitation organisations easier. The leading CE institution for adult CE was the National

Institute of Conductive Education (NICE) in 2009 which dealt with a vast number of physical disabled people. Also, there were 6 other well established services identified that could contribute to my qualitative inquiries and there were 9 smaller services offering CE on a less regular basis. Using my CEPEG position I personally approached directors of CE organisations at one of the CEPEG meetings in the spring of 2009. Three centres voluntarily wished to take part in such a study; these were namely National Institute of Conductive Education (NICE), Legacy Rainbow House (LRH) and Megan Baker House (MBH). I was professionally quite satisfied with the outcome since these centres were representing different kind of services. NICE was a busy superior institute from Birmingham, MBH was twice a week services for three different adult CE groups from a rural area near Ludlow, Shropshire and LRH was a once a week service for one adult rehabilitation group near Ormskirk, Lancashire. In this way the sampling of adult rehabilitation CE institutes became purposive and convenient at the same time. It was convenient because of the volunteer basis of interested organisations and was representative of different circumstances too since these institutions had a great variety of CE rehabilitation groups with different diagnoses, differently experienced CE professionals, special and unique cases, different frequency of CE sessions

offered for a group, and the locations of the centres were also from urban as well as rural areas of UK.

In qualitative research there is no set formula for sample size. The size and choice of participants are proposed to create satisfactory data to explore and identify similarities and differences, contexts, to develop theory and descriptions (Morse, 1998). The key is to achieve participant selection strategically, eloquently and expressively rather than to create a representative sample (Mason, 2002) however, the quality and comprehensiveness of data is likely to vary with different participants or sources of information (Morse, 2000).

Identifying participants for this research I focused on patients (people with conditions of Parkinson Disease, Stroke, Acquired Head Injury, Cerebral Palsy, Multiple Sclerosis), CE professionals - conductors, patient's family members and patients' carers who were actively involved in adult CE rehabilitation through group setting in the above mentioned three CE institutions. Possible candidates were identified by the researcher based on criteria presented in Table 2, Table 3, Table 4, Table 5 below, and recruitment letters were distributed to them (Appendix C). Participants were expected to volunteer to take part in the research. Volunteers were purposefully selected from a demographically broad group of nominees by the researcher in order

to represent a variety of age, time spent in the CE group, professional experience, typical and unique cases. Research participants were nominated from three different CE centres within the UK additionally, one of the conductor participants was an independent self-employed person.

Table 2 Patient participant criteria

<ul style="list-style-type: none"> ● able to communicate verbally or being accompanied by a carer or family member who could help with their communication ● attending CE sessions in group setting at a CE centre in UK ● attending CE sessions for a minimum of 3 months before the interview ● being open to share lived experience, information, opinions, and criticisms

Table 3 Family member criteria

<ul style="list-style-type: none"> ● know CE patient on an everyday basis before and after he/she joined CE group setting ● being open to share lived experience, information, opinions, and criticisms

Table 4 Carer's criteria

<ul style="list-style-type: none"> ● caring for a CE patient on an everyday basis ● being the patient's carer permanently for at least 3 months before the research was conducted ● being open to share lived experience, information, opinions, and criticisms
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Table 5 **Conductor's criteria**

<ul style="list-style-type: none"> • being a qualified conductor at least for a year • working (or have worked) with adults in group setting in UK at least for a year • being open to share lived experiences, information, opinions and criticisms

At the end of the recruitment process there were thirty-one people identified were potential research participants; seven people with Parkinson's Disease, one person with Multiple Sclerosis, one person with Marie Charcot Tooth which was a unique (extreme) case, two persons with Cerebral Palsy, two persons with Acquired Head Injury, one individual who had a Stroke, eight close family members (husbands, wives and one mother), six conductive education professionals and three health care persons. This fact allowed me to explore the experiences between adults having various (heterogeneous) also similar (homogenous) physical disabilities (diagnosis) taking part in CE rehabilitation in group setting. Furthermore, I was able to sample a unique case (individual who had Marie Charcot Tooth disease) which was unusual, special and therefore it was potentially enlightening.

Participants took part in nine individual and four focus group interviews (Table 6). Also, one "you tube narrative" of a CE professional was analysed in the research. The participants were between the ages of 24 and 82 and came from different CE programmes within the UK. The proportion of gender of

research participants were the following; Patients: 29% female, 71% male, Family members: 80% female, 20% male, Conductors: 67% female, 33% male.

Table 6 Table of patient participants

DIAGNOSIS	Cerebral Palsy	Parkinson's Disease	Acquired Head Injury	Stroke	Multiple Sclerosis	Marie Charcot Tooth
NUMBER OF PARTICIPANTS	2	7	2	1	1	1
GENDER MALE (M) FEMALE (F)	M	6M 1F	M	F	F	M
AGE DISTRIBUTION	Between 24 - 30	Between 52-82	Between 20 – 37	50	53	64

Table 7 Table of family member participants

STATUS	Mother	Wife	Husband
NUMBER OF PARTICIPANTS	1	5	2

Table 8 Table of CE professional participants

EXPERIENCE	Entrant	Five years	10 or more than 10 years	Over 20 years
NUMBER OF PARTICIPANTS	1	2	2	1
EMPLOYED BY	Independent CE centre	Independent CE centre	Independent CE centre / Self employed	Independent CE centre
GENDER MALE (M) FEMALE (F)	M	F	F/M	F

Table 9 **Table of health care person participants**

DIAGNOSIS OF CARED PERSON	Cerebral Palsy	Acquired Head Injury
NUMBER OF CARED PRSON	1	2
GENDER MALE (M) FEMALE (F)	F	M/F

Ethical Conduct of the Research

Ethical approval for the research was obtained from Liverpool John Moores University Ethics Committee in 2009, and from appropriate ethics committees at each CE centre from which data were collected. Ethical considerations raised by this research were concerned with informing possible participants about the purpose of the study, obtaining written consent voluntarily and maintaining participants' confidentiality. According to Sim (1986) informed consent is "the voluntary and revocable agreement of a competent individual to participate in a research procedure, based on adequate understanding of its nature, purpose, and implications" (Sim, 1986, p.584) The informed consent may be broken down to four constituent elements: disclosure (providing adequate information), comprehension (understanding information), competence, (ability of participants to make a rational decision), and voluntariness according to Sim (Sim, 1998). The participants were provided with a recruitment letter (Appendix C) and a letter

of invitation (Appendix D, E) detailing the aims of the research and the research process. These documents were provided to the participants directly. All participants were given the opportunity to make inquiries, ask questions about the research and were aware that they could withdraw from it at any time without negative consequences. Written consent was achieved from each volunteer prior to beginning of data collection. There were no existing power relations between the researcher and participants that could be apparent as compulsion. The obtained informed consents were placed and kept in a safe place by the researcher. Confidentiality of participants was maintained through the use of pseudonyms in the research commentary and by changing specific contextual details that could have discovered the identity of the participants.

Reflexivity

Reflexivity is an integral part of qualitative research as it makes important links between the researcher, research participants and the research process from initial design to eventual dissemination. It also provides verification of credibility or authenticity (Carpenter and Suto, 2008 p.155). Throughout the study, opportunities for reflection were built into the research process and are explained in the thesis through thoughtful analysis of the research experience, and the relationship between the researcher and

participants, and the research itself. A reflexive approach enables one to understand how the researcher - who is also a practitioner in my case - has an impact on research participants, and it also means that with such a background he should question his own beliefs and feelings in the same way that he interrogates others. In some phenomenological research this kind of interrogation leads to bracketing or phenomenological reduction (Jootun, et al (2009).

The interaction between researcher and participants is therefore key to the data collection process whilst also being influenced by how the researcher is perceived by the participants (Carpenter and Suto, 2008 p.126). As a researcher, for instance, I had an “insider CE professional status”, so I was able to share a common reality and language with participants which I believe it facilitated interview dialogues, and enabled me to probe for deeper understanding and meaning. An intimate non-hierarchical partnership triggered by the above described insider status and my openness to discuss anything regarding their CE life. As a result, informants often acknowledged me as close partner in creating a real picture of their CE experience. According to Carpenter and Suto (2008 p.125) the reflexivity is a response to the concern of bias. Primeau (2003) argues that it is important to understand how the subject of the study and the collected data could affect us personally. In the

process of undertaking my research, accuracy and credibility were ensured by the research design which involved multiple investigation support such as using outsider transcriptionist, executing constant peer review and open discussions at conferences. Through the implemented reflexive process provided an accurate and credible account of the phenomenon was provided.

Data collection methods

Methods of data collection were observation, researcher's field notes and memos, in-depth interviews, focus groups, audio taping, and You Tube clip. These approaches were chosen because they are well-suited to the philosophical framework of the research paradigm and methodology, and facilitated access to participants' experiences. "In qualitative research, the researcher is a tool or instrument; in other words, the researcher is an integral component of the research" (Carpenter & Suto, 2008 p. 93) and it is clearly reflected in the methods which have been used in the current investigation.

Observation

There were two different types of observation conducted in this research in order to get information;

- a) Simple unobtrusive observation was practiced to gain information on CE centres itself (location, floorplans, and distribution of rooms), their

daily functions, participants' daily routine, understanding of the work setting.

- b) Participant observation was conducted in order to note other people interacting with the participants and identify relationships between participants in context of rehabilitation in group setting.

Using observational methods to get knowledge of functioning CE centres was a bit delicate in the context of the phenomenological methodology (and rarely used) since such an observation ought to reflect the clear objective reality. Unobtrusive methods of data collection in care research have been defined as those that do not actively involve the research participants and data gathered from variety of sources (Kellehear, 1993). Though, sources could be cultural, material, or settings (organizations, rehabilitation units, and wards), physical traces, written records, audio-visual records, simple observation, or electronic database such as computers files or software (Kellehear, 1993). I have chosen and practiced simple unobtrusive observation on CE sites making notes of the plan of the buildings, and the functions of different rooms, and participant's CE daily routine.

Participant observation implicates the researcher in a complex procedure of observing, participating, interrogating, listening,

communicating, negotiating, recording and interacting (Mason, 2002). It needs larger personal investment and time than other methods of data collection and the researcher should position himself as having gained access to settings and contact participants. Angrosino (2005) refers to this as researcher's "situational identity" or Coffey (1999) calls it "ethnographic self". A number of observational methods have been identified to choose from (Wallace, 2005). The "detached observer" does not interact with participants or the member of the groups which was not desire in my research at all, the "marginal participant" is largely passive however, he is familiar and accepted in the group according to Carpenter and Suto (2008, p.91) like a passenger on train observing other passengers. It was thought that being a marginal participant in a group still was not enough to support in-depth understanding of social interactions. I decided to follow Angrosino's recommendations (2005) to seek a "situational identity" and participate in activities. In this role the researcher fully informs the group of the observer role being taken but in addition establishes close relationships with members of the group. This role has built trust and gave me the possibility selectively ask participants to describe several aspects of what was going on which also facilitated the hermeneutical circle.

In practice, a convenient date was arranged with each CE centres to observe carrying out their normal work routines for one day. Participants were asked if they could be observed on the same day. During observation I did not participate in rehabilitation activities (I did not do physical exercises) executed by participants but I participated in every other social actions of the sessions. BOX 1. (page 20) examples the written form of my observation files.

Diary, Field notes and Memos

To turn the lived experience of conducting a research, observations, interviews into data I kept diary, implemented field note and memo writing strategies. From the first action of the research I kept a pen and paper diary - I did not apply diary methods to the study - which was part of my data collection exercise. To use a diary during the study was more like to have a date, time, interval, task, event and prompting protocol for myself which I had found particularly useful as time and research actions progressed.

According to Minichiello, et al (1995) there are three types of field notes have been used (1995); *personal file, the transcript file, and analytical file*.

Alongside keeping a diary I gathered notes of conversations, documents, contacts (of CE centres, participants, and other people), later ethical approvals, informed consents, and anything was to do with my research into personal files. The material contained in the personal files allowed me to

reconstruct several activities I have done before and it facilitated for instance writing up, or to making later decisions regarding the study.

I applied two types of transcribed files during my research; raw data from observations - the majority of them were notes, descriptions about the facts I had experienced often with little explanations and memos attached to it from myself - as well as transcribed files from audio data I recorded during interviews, conversations and from the You Tube clip narrative. I have also generated reflective memos on the research experience and methodological issues and specifically on observable evidence of facts and participants.

The analytical files encompassed the phases and stages of detailed comparative examination of emerging ideas in relation to the research questions as the research has progressed.

In practice, observation and writing field notes and memos were very close related acts as well as keeping them in files and I used similar formats as demonstrated in Box 1. The majority of times notes were taken right away, as I experienced notable things or events, and recorded in an observation book as a rough-cast and later on the same day it was re-written to be useful for the future. Memory note cards, so called memos were written for many purposes and in several forms during the whole research process. Generally, I used 'post it' sticky notes to remind myself on different occasions.

Qualitative interviews

One of the most commonly employed data collection method in qualitative research is the interview (Fontana and Frey, 2000). In some respects, doing an interview is the most natural thing in the world since we live in an “interview society” where interviews surround us (Silverman, 2010 p. 189). Interviewing includes requesting questions and receiving answers from participants in a qualitative research study. Interviewing, i.e. questioning has a variability of methods. These could be individual interviews and group interviews. The interview process can be conducted face to face or mediated by telephone or other electronic devices (e.g. computers), too. Qualitative interviews are often described as structured, semi-structured or unstructured, informal interviews, and group interview process or focus group. The term *structure* in context of qualitative interviewing refers to the process, and the flexibility – limitation correlation of the conversation between the interviewer and interviewees. Table 10 demonstrates the characteristics of the 5 qualitative interviewing forms suggested by the Qualitative Research Project of Robert Wood Johnson Foundation (2016).

Table 10 Characteristics of qualitative interviewing forms according to RWJF

Characteristics of the Structured Interview	<ul style="list-style-type: none"> • The interviewer asks each respondent the same series of questions. • The questions are created prior to the interview, and often have a limited set of response categories. • There is generally little room for variation in responses and there are few open-ended questions included in the interview guide. • Questioning is standardized and the ordering and phrasing of the questions are kept consistent from interview to interview. • The interviewer plays a neutral role and acts casual and friendly, but does not insert his or her opinion in the interview. • Self-administered questionnaires are a type of structured interview.
Characteristics of Semi-structured interviews	<ul style="list-style-type: none"> • The interviewer and respondents engage in a formal interview. • The interviewer develops and uses an 'interview guide.' This is a list of questions and topics that need to be covered during the conversation, usually in a particular order. • The interviewer follows the guide, but is able to follow topical trajectories in the conversation that may stray from the guide when he or she feels this is appropriate.
Characteristics of Unstructured Interviews	<ul style="list-style-type: none"> • The interviewer and respondents engage in a formal interview in that they have a scheduled time to sit and speak with each other and both parties recognize this to be an interview. • The interviewer has a clear plan in mind regarding the focus and goal of the interview. This guides the discussion. • There is not a structured interview guide. Instead, the interviewer builds rapport with respondents, getting respondents to open-up and express themselves in their own way. • Questions tend to be open-ended and express little control over informants' responses.

	<ul style="list-style-type: none"> Ethnographic, in depth interviews are unstructured. Fontana and Frey (1994) identify three types of in depth, ethnographic unstructured interviews – oral history, creative interviews and postmodern interviews.
<i>Characteristics of Informal Interviewing</i>	<ul style="list-style-type: none"> The interviewer talks with people in the field informally, without use of a structured interview guide of any kind. The researcher tries to remember his or her conversations with informants, and uses jottings or brief notes taken in the field to help in the recall and writing of notes from experiences in the field. Informal interviewing goes hand-in-hand with participant observation. While in the field as an observer, informal interviews are casual conversations one might have with the people the researcher is observing.
<i>Characteristics of Group Interviews</i>	<p>The design of focus group research will vary based on the research question being studied. Below, we highlight some general principles to consider:</p> <ul style="list-style-type: none"> Standardization of questions -- Focus groups can vary in the extent to which they follow a structured protocol or permit discussion to emerge Number of focus groups conducted - or sampling will depend on the 'segmentation' or different stratifications (e.g. age, sex, socioeconomic status, health status) that the researcher identifies as important to the research topic Number of participants per group - the rule of thumb has been 6-10 homogeneous strangers, but as Morgan (1996) points out there may be reasons to have smaller or slightly larger groups <p>Level of moderator involvement - can vary from high to low degree of control exercised during focus groups (e.g. extent to which structured questions are asked and group dynamics are actively managed)</p>

In contrast, according to Carpenter and Suto (2008 p.82), statements like “the qualitative interviews are described as being on a continuum with unstructured interviews at one end, structured at the other and semi-structured somewhere in between” are confusing and they express that structured or semi-structured interviews do not constitute qualitative interviewing and for “the sake of clarity” they suggest to use the term “in-depth interview” to describe qualitative interviewing. Referring to Fontana and Frey (2000 p. 646) they argue that in-depth interviews focus on the *hows* of people’s lives as well as the traditional *whats* and the general purpose of qualitative interviewing is to comprehend other people’s constructions of reality. In-depth interviewing is used to generate data in different qualitative methodological approaches such as grounded theory, phenomenology, and ethnography serving their specific purposes. In phenomenology interviews are the main data gathering method with a lesser amount of directive elements in it (Carpenter and Suto, 2008 p.83). In-depth interviewing has a flexible nature regardless of the type since it is characterised as conversation between people however, detailed and rigorous planning and the development of specific set of skills should not be underestimated (Mason, 2002 p.83) From the interviewer point of view there are two main positions in-depth interviewing according to Kvale (1996 p. 139) the “miner metaphor”

and the “traveller metaphor”. Kvale (1996) describes that the miner metaphor perspective is when knowledge is “understood as buried metal and the interviewer is a miner who unearths the valuable metal”, the knowledge is waiting to be uncovered. The interviewer digs data out from interviewee(s). The traveller metaphor position is when the interviewer ask questions and the subject is explored together with the interviewee(s) through conversation. According to Fontana and Frey (2000) the inspiration of postmodernism, constructionism and feminism has brought other perspectives into in-depth interviewing and the choices between in-depth interviews became broader; “postmodern methods” highlight the way in which a reality is constructed in the interview, with particular emphasis upon the relationship that develops between researcher and interviewee. In “creative interviewing” the researcher conducts extensive and/or repeated interviews in everyday situations, and stresses on free expressions (Douglas, 1985). The “dialectical interview” reflects on incongruities between the lived world and on the potential for changes in it focusing on the transformative features of an interview. “Heuristic approaches” value the experience of the interviewer, and interviewing is a process where the relationship and alliance between researcher and participants plays a vital role (Douglass and Moustakas, 1985). “Feminist interviewing” efforts to be reflexive and interactive and trying to

execute non-hierarchical attitude which avoids objectifying the participant. “Biographical”, “narrative”, “life history” and “oral history” approaches (Thompson, 2000) also developed new in-depth interviewing methods which are concerned with understanding cultural milieu and social worlds through personal accounts and participants are given a fairly free rein to shape their own narratives.

Each qualitative interview has its own unique properties however, they show generality in involving a number of stages (Robson, 2002; Rubin and Rubin, 1995; Spradley, 1979) such as arrival to interview, introduction process, beginning the interview, during the interview, ending the interview and round of duties after the interview. There are several similarities in question forms as well according to Legard et al (2003 p. 148 – 151); questions can be “dimension mapping questions” to focus participants on particular topics and concepts, “perspective widening questions” to understand interviewee perspective deeper or fully, “content mining questions” to explore what has been raised by the participants. “Probes” are specific content mining questions used to facilitate the exploration; “amplificatory probes” are encouraging questions to elaborate subjects further, “exploratory probes” used for create more round understanding, “explanatory probes” – one of the

hallmarks of in-depth interviewing – probing for reasons, “clarificatory probes” are asked to elucidate subjects.

Group interview

Focus group method or group interview known as focused group discussion data gathering technique (Fontana & Frey, 2000, p. 651). Focus groups originally developed as a research practice in market research (Bloor et al., 2001). They have also been used in political, and particularly party researches. They are now well established as a qualitative research method mostly in social research, where they are expansively practiced and are particularly appreciated research approach (Ritchie and Lewis, 2003 p. 170) A group interview is different from a face to face in-depth interview however, its main purpose is similar; to explore experiences, opinions, attitudes, and concerns of participants. Data are collected by interaction between group participants. Participants present their own views and experience, but they also hear from other people. They listen, reflect on what is said, ask questions of each other, seek explanation, clarification, comment on what they have heard and prompt others to expose more. As the discussion progresses, individual responses become developed, refined and transfer to a deeper understanding (Ritchie and Lewis, 2003 p. 171). From practical perspective, group interview enables the researcher to generate a large amount of data in

a limited period of time (Holloway, 2005). Typically, focus groups involve around six to eight people who meet once, for a period of around an hour and a half to two hours, the groups can involve strangers, or people who know each other and the composition of a focus group (homogeneity, heterogeneity) depends on research aspects (MacDougall and Fudge, 2001) As with in-depth interviews, there are different choices in between group interview practices. The interviewer can be more structured and having greater influence on discussions or flexible; allowing the group members – participants – to converse subjects freely. A group interview, like in-depth interview has got general stages, these are; the scene setting and ground rules, introductions, opening topic, discussion, ending the discussion and round of duties after the interview. The researcher has specific tasks within each stages to moderate the group, reflecting on group development behaviours introduced by Tuckman and Jenson (1977); forming, storming, norming, performing, adjourning. The role of the researcher involves multitasking in focus group method; partly it involves the role of a moderator, facilitator, as one who “makes easy” or assists the progress of the group, controls the discussion and the scholar who gathers data from interactions (Finch and Lewis, 2003 p. 176-181).

As in individual interviews, the researcher tries to make sure subjects are covered in depth. The goal is to investigate, explore, and delve deeper rather than accepting simple responses. Group members are supposed to take a part actively in the process; questioning each other, discussing and unfolding subjects. The researcher's question forms are not particularly different from it is used in individual interview however, enquiring techniques such as asking generally, repeating question, or fragment it, asking the group directly, looking around or gesturing to the rest of the group to come in, maintaining an expectant silence, to allow the group time to reflect further on the issue, highlighting differences in views and encouraging the group to discuss and explain them should be applied (Finch and Lewis, 2003 p. 181). Finally, practical arrangements are also key to the success; time, the venue, the layout of the room and the quality of recording equipment are all very important in conducting group interviews.

After a careful consideration, I desired to carry out face-to-face individual in-depth interviews - combination of heuristic and feminist styles -, and focus group interviews in order to generate data from different perspectives; personal, common, family and diagnosis specific views. There were nine individual and four focus group interviews conducted all together (Table 11). Having asked participants if they were happy to be interviewed in

groups as well I decided to interview five patients face to face - these patient participants did not want necessarily to be questioned in groups though. Also, I planned to interview CE professionals individually in order to study their personal perspectives and thoughts. Two married couples planned to be interviewed together in order to explore their experiences of CE rehabilitation and group setting as a family. Furthermore, three small groups with family members and health carers were planned. These plans aimed to serve getting data from homogenous – diagnosis specific - and heterogeneous - general – perspectives of the phenomena.

Before interviewing the research participants individually in the current study I prepared myself carefully and mindfully concerning how to approach the subject – what sort of interviews I wanted to use, what were the main areas I wished to enquire about participants, what questions I needed to ask in order to receive possible informative answers to them. I decided on a flexible, in-depth conversation schedule with some prepared questions that allowed enough space for interviewees to engage in subjects but on the other hand also generated data focussing on the main investigation purpose. As I wished to study the lived experience of CE and group setting from different viewpoints – patients, family members, carers and professionals – I prepared

myself with three different interview schedules, so called interview guides (Appendix B).

Table 11 Participants' partaking in interviews

Interviews	Individual Interview	Group Interviews			
		Married Couple	Diagnosis Specific (Parkinson's disease)	Diagnosis Specific (Stroke & Head Injury)	Diagnosis Mixed
<i>Cerebral Palsy</i>	1	X	X	X	1
<i>Multiple Sclerosis</i>	1	X	X	X	X
<i>Head Injury</i>	X	X	X	1	1
<i>Stroke</i>	X	X	X	1	1
<i>Parkinson's Disease</i>	1	2	2	X	2
<i>Marie Charcot Tooth</i>	1	X	X	X	X
<i>Conductor</i>	5	X	X	X	X
<i>Family Member</i>	X	2	4	2	1
<i>Carer</i>	X	X	X		2

Also, before interviewing participants I felt it was important to equip myself with some interviewing skills therefore, I practiced interviewing friends following my schedules until I felt it went well. I had learnt both to be a

“miner” and a “traveller” regarding Kavle’s metaphors, practiced to build up, go through of stages in an interview, and to implement the question types introduced earlier.

Individual interviews took place at the chosen CE centres where participants attended (either professional or client) in between November 2009 and May 2010. The exact time of the interviews was discussed with the participants beforehand, and in every case a convenient date and time was chosen. The involved CE centres were happy to provide calm and light rooms in which to carry out interviews and I was happy to travel in my own car to meet participants. I usually prepared the rooms with beverages and snacks and tried to manage to bring comfortable chairs to sit on. Also, participants were informed in advance that each interview was planned to be audio recorded which they were very flexible indeed.

Very similar preparations and actions were executed before group interviews. The greatest differences were that I had to develop my group moderation skills and group interviewing techniques, too – which was more difficult to organize with 5 to 6 friends - and the interviews took place in different places. One of the first individually interviewed patient participant interviewee offered his business office in Bromyard, Herefordshire for his CE groupmates for the group research action which was a great choice to meet

with two families together doing a diagnosis specific patient – family member interview. Participants in two other focus groups also desired to organise themselves a suitable venue outside the centres and they were very keen on finding the right places. Thus, two groups met in a private homes in Leominster, Herefordshire and in Chorley, Lancashire, and one group at NICE, Birmingham, West Midland region. In each occasions a very friendly, good atmosphere facilitated to execute the interviews.

My role as interviewer and group facilitator

During interviews I followed the prepared interview guides and I listened and responded to interviewees without strict pre-structured assumptions, I also directed interviewees back to key themes if they digressed too far. According to Clandinin and Connelly (1994) methods used to gather data on experience are multi-directional, moving inward, outward, backward, and forward. Inward refers to the internal process involved in experience, for instance internal conditions of feelings and hopes whereas outward means an environmental factors influencing experience. Backward and forward denote temporality i.e. past, present, and future (Clandinin and Connelly, 1994). Undeniably, conversations in this study showed multi-directional aspects in the interviews and talks were encompassed by internal feelings, external

causes and time factors of the participants' life that affected their lived experiences.

A non-hierarchical relationship between the participants as interviewees and myself as interviewer was encouraged by my long term experience in client-centred approach of conductive education. This skill was practiced through habilitation and rehabilitation activities and based on the elements of Person Centred Therapy developed by Carl Rogers (1951). The person-centred approach correlates with the phenomenological principles of accepting someone for who they are and allowing them to be who they are while listening to them or interacting with them (Van Manen, 1990). Such a relationship between interviewees and interviewer is believed to facilitate verbal interaction (Rogers, 1951). It helped to facilitate confidence and trust in the researcher participant relationship that I was accepted as a conductor professional by the participants and this enabled me to create rapport with the members early in the data gathering process, providing access into their thoughts about CE rehabilitation and group setting. My English language skills were limited and this perhaps meant reduced access to their world without the need to frequently ask for clarification. However, this felt also an advantage at the same time since participants wanted eagerly help my understanding and they were generally more open to explaining their

thoughts, feelings, and concerns, which often resulted in modifying their own initial understanding and explanation. Reflexivity was viewed as very important dimension during interviews.

You Tube clip narrative

Unobtrusive methods were earlier described at the observation methods; unobtrusive methods of data collection in care research have been defined as those that do not actively involve the research participants and data gathered from variety of sources. Such sources could be the media, and the internet (Kellehear, 1993). You Tube is an early 21st century developed video-sharing internet website which offers free video viewing for internet accessed people (Oxford Dictionary, 2016). Clips are uploaded by a huge variety of individuals, groups, organisations, etc. to share contents internationally in any subject.

One of the CE professional research participants turned my attention to one of her You Tube clips which was completely related to my research investigation. The video itself was a narrative about CE approach for adult physical disabled people. After judging it as informative data, I decided to use the audio record of this You Tube clip and it was transcribed into written text in a similar way as my own tape records of in-depth and group interviews.

Audio taping

Audiotaping of interviews became primary of qualitative research, both in individual and group interviews (Markle, et al, 2011). Beforehand, handwritten field notes were used by on-site researchers. (Gibbs, et al, 2002). Audiotaping method became more popular from 1970s and it was used to make transcriptions from audio records creating a more viable method of interviewing as researchers could analyse, interpret, and report participants' own words. (Patton, 2002). It was believed that "the creative and judicious use of technology [could] greatly increase the quality of field observations and the utility of the observational record to others" without being obtrusive. This was a significant advancement for interpretive methods (Raplay, 2007 p.308). Recording devices could be uncomfortable for research participants however, advantages of audiotaping are more pronounced; the creation of an accurate record of exactly what was said, emotions of interviewees could be better monitored, and the practicality of collecting data. Audio tapes and other digital records are converted into text through transcription in order to create analysable data (Carpenter and Suto, 2008 p. 99).

In practice, before the interviews I conducted a pilot audio recording test for the purpose of getting good quality records. On the days of encounters, before conducting an interview I informed research participants

that conversations would be audio recorded which was understandingly accepted by the participants in every cases. I used a portable digital Dictaphone device which I put in a small basket and covered with a cloth after start recording, then I placed the basket close enough to us, speakers. After an interview was completed, I checked if everything went well with recording and saved the audio-digital files on my computer into a password protected file.

Transcription

According to the Merriam-Webster Online Dictionary (2016), the official definition of transcribe is "to make a written copy of" or "to make a copy of (dictated or recorded matter) in longhand or on a machine (as a typewriter) which in context of the present study meant to put audiotaped interviews into texts. Transcribing can be done by the researcher or by a paid transcriptionist. There are advantages and disadvantages of both choices. Doing the transcription oneself facilitates the researcher to come thoroughly familiar with data, and has the best chance that content, punctuation and tone of the interview are best reflected in the transcript (Carpenter and Suto, 2008 p.100). It can develop researcher's listening and typing skills, and can easily lead to other tasks, for example, analysing, editing, writing up, proofreading, etc. and the flexibility to transcribe anytime can be seen as benefit. In

contrast, transcribing needs different investments; it must be learned and requires a decent typing skills, some equipment and software may need to be purchased and it is a time-consuming intensive activity (Vargas, 2009). According to Green and Thorogood (2004 p.100) employing a professional, paid transcriptionist is costly, but the quality, speed, and the researcher's time is possibly worth it [as transcriptionists have the required skills, abilities and equipment]. The transcriptionist should be equipped with certain information about the research before doing transcripts (purpose of the research, characteristics of interviews, who are the interviewees, purpose of the transcripts, etc.) also, the required look of the transcript should be discussed in order to best facilitate data analysis. Furthermore, to ensure successful cooperation with transcriptionist it is advisable to supervise the completed transcripts as soon as possible (Vargas, 2009). Working together with a transcriptionist expert suggests that he/she is part of the research team therefore, a confidentiality agreement supposed to be signed with him/her to protect the privacy of interviewees. It is the researcher's responsibility to dealing with ethical issues (Carpenter and Suto, 2008 p. 110).

The present research was not funded and Liverpool John Moores University did not support employing transcription services. However, as I was not a native English speaker this raised concerns. Furthermore not having fast

typing skills, I had no choice to transcribe my planned audiotaped interviews on my own. After two months searching for an appropriate professional transcriptionist it was accidentally brought to my attention that one of my new acquaintances was actually a fully trained professional transcriptionist. After being approached, he was happy to facilitate my research and this incredibly eased my situation. First, he had known about CE and he understood the possible physical conditions of interviewees, furthermore he was familiar with phenomenological approach and fully understood which form of transcript I desired to receive. We settled on a financial and confidential agreement and signed a contract. He was informed with adequate facts before transcribing a recorded interview in each cases and he often got back to me for descriptions to better understand contexts of conversations or CE related issues. Box 2 provides examples of how interview transcripts were formulated according to my request; the top row of the document included the form and number of the interview, the venue where it was conducted and the exact date. Throughout of the transcript the interviewer was labelled with Q, interviewees according to the order in which they started to answer labelled with the word Interviewee with a number and additional information about diagnosis of the participant or the relationship they might had enclosed in parentheses.

BOX 2 SAMPLE INTERVIEW TRANSCRIPT

Group Interview 3

Conducted at NICE

5.11.2009

Q: questioner. Participants are labelled according to the order in which they started answering the questions.

Q – We came together to have some ideas about CE. Let's start off our little dialogue. Would you tell me about your life before Parkinson's?

Interviewee 1 (Parkinson's patient) – It just came on. Before I had Parkinson's I had 10/12 year (she points out her husband).

Interviewee 1's Husband – Basically we went most things no problem didn't give a thought to it, now it's a lot more planning or non-planning. Things may or may not happen depending on how Eileen is.

Interviewee 1 – (unclear) sitting as are sitting, talking and I was looking at my finger it started moving. And that's how show it started moving with my little hand.

Q – For example were you sporty or were you... or just a normal life...?

Interviewee 1's Husband – We used to take ten pin bowls, swimming, dancing, go out for meals.

Q – So quite an active life?

Interviewee 1 – We both still are.

Interviewee 1's Husband – It's difficult to do it to a timetable now. We have to do it to Eileen's on and off periods.

Q – How about yours?

Interviewee 2 (Parkinson's patient) – I was a teacher and then one day I went to the dentist and I apologised to the dentist because my hand was shaking. And I said I don't know why it's doing this. He said have you got Parkinson's? He knew me well, he wasn't betraying any confidence {he would keep it private}. I said I don't know I don't know much about it. So I went to doctors and he informed me that it was indeed Parkinson's.

Interviewee 2's wife – I think we can look back a very long way can't we? You were diagnosed in 2003, but we can go back twenty years before that. We didn't realise it, but the symptoms were actually coming on.

Box 2

CHAPTER 4 - RESEARCHING LIVED EXPERIENCES OF CONDUCTIVE EDUCATION: APPLIED ANALYTICAL DATA PROCESSING

Introduction

The research design of the study was introduced in Chapter 1. The aim of Chapter 4 is to explain and depict the deliberate phases and characteristics of the applied analytical data process which was used in the current study. It aims to explain how phenomenological and hermeneutic principles and grounded theoretical approach was used to analyse the data applying initial coding, colour coding, focused coding, in-vivo methods, how constant comparison facilitated finding and synthesizing subjects, how hermeneutical circle became reality through member checking and finally what themes and sub-themes emerged.

Data analysis

In keeping with the methodology adopted in this research, data analysis methods were considered to preserve phenomenological and hermeneutic principles and to apply certain Grounded Theory (GT) structured analytic phases to better engage with the transcribed texts. Table 12 illustrates the six main stages and the ten major tasks of data analysis applied to the current research.

Table 12 Stages of data analysis applied to this research

Analytic Stages	Tasks
Immersion	<ul style="list-style-type: none"> Organizing the data-set into texts First reading and first selection of texts
Understanding participants' constructs using GT approach	<ul style="list-style-type: none"> Initial coding: Incident to incident & colour coding parallel with memo writing Focused coding parallel with In Vivo coding & member checking & peer review
Identify interconnections between participant's constructs and researcher's constructs & observation	<ul style="list-style-type: none"> Comparison, selection
Synthesis and theme development	<ul style="list-style-type: none"> Grouping subjects towards main themes Further elaboration towards sub-themes
Illumination and Illustration of phenomena	<ul style="list-style-type: none"> Linking the literature to identified themes & subthemes Examples from data
Integration	<ul style="list-style-type: none"> Interpretation of findings with reflections

Phenomenological strategies

According to van Manen (1997, p.36) the purpose of phenomenological data analysis is to convert lived experience into a “textual expression of its essence” and phenomenological themes could be understood as structures of experience. Consequently, researchers using phenomenology to create

suggestive descriptions (texts) of lived experiences and attempt to construct rich and evocative explanation of the phenomena. In this research, a systematic method of thematic data analysis was adopted from Ajjavi & Higgs (2007) with the alteration of using grounded theory analysis methods at certain phases of the analysis. Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data (Braun and Clark, 2006). This method allowed the identification of participants' interpretations, constructs, which were then compound with the researchers' own observation, understandings, and linked to professional literature to arrive to integration and interpretation of phenomena.

Hermeneutic strategies

There were two major strategies applied from hermeneutic literature in this research; hermeneutic circle and conversation, dialogue of subjects. The aim of a hermeneutic approach is to pursue understanding, rather than to provide a cherished reading or conceptual analysis of a text (Kinsella, 2006). Central to hermeneutic understanding is the belief in the hermeneutic circle which is coming to the meaning of the whole of a text and coming to understand its parts. In this regard, "construing the meaning of the whole meant making sense of the parts and grasping the meaning of the parts depended on having some sense of the whole" (Schwandt, 2001 p.112). In

conversations and dialogue the researcher remains open to questions and then allows transcribed text to speak to him. It is believed that understanding the phenomena emerges of these conversations and dialogue. The act of interpretation itself represents a gradual convergence of insight on the part of the researcher and the text (Bontekoe, 1996).

Immersion

According to Carpenter and Suto (2008 p.115) immersion is a phase of analysis in which the researcher immerses himself in the data to get familiar with organize the collected information. This first phase of analysis enabled me to better engage with the data, namely the transcripts. These together with other written texts (field notes which were written by observations) were read and re-read in order to become familiar with the data set. I also listened to the audio recording of the interviews in some cases when I was not really sure about the first meaning of the text. This phase also facilitated initial selection of data to save them into different files in addressing my investigation interest. These groups were:

- a) patients' individual interviews with relevant field notes,
- b) conductors' individual interviews with relevant field notes,
- c) Parkinson's patients with family members' interviews with relevant field notes

- d) mixed group interviews with different diagnosed patients with family members and carers with relevant field notes
- e) other field notes from observations

Understanding participants' constructs using GT approach

This phase of the thematic analysis of the research aimed to understand participants' ideas, what they had expressed in their own words or phrases, what they were saying and what meaning could be behind their words. Grounded theory coding methods were chosen to analyse data at this stage as it seemed to be a very useful and structured way of dealing with large amounts of data. Grounded theory coding means categorising data segments in order to summarise and account for each part of data. The codes show how data were selected, divided, organised to begin analysis. The prudence of grounded theory coding contrasts with quantitative logic that applies fixed categories or codes to the data, the grounded theory researcher rather creates his own codes by defining what he sees in data (Charmaz, 2006 p.46).

In this study two main steps were used for coding i.e. initial and focused coding. Parallel with initial coding I began to select, organise data in order to facilitate latter constant comparison, too. The whole process involved going back and forth among analytical steps, and additional coding tools like memo

writing and in vivo codes facilitated my analysis procedure. Logically, the analytical process starts with initial coding which, as its appellation suggests, keeps the researcher close to data as they attempt to code with words which reflect on statements, facts, actions, and phenomena. I decided to apply *incident to incident coding* type to explore what the data suggests about participants' experience on the phenomena. The example of incident to incident coding (Box 3) demonstrates how exactly I went through the transcribed data and noted incidents on the left side of the document. These codes facilitated the reduction of data in order to focus on areas of interest and I kept the rest of the codes open and active since they ranged across a variety of topics. From the beginning of the research process and during initial coding of transcribed texts I started to write memos, notes in order to expedite my analytic work and accelerate my productivity. At the initial coding stage memo writing helped me to be more focused on the task and supported well the later colour coding.

The next analytical step was colour coding which is a type of coding to identify and differentiate areas or subjects that participants shared on the topic of interest.

BOX 3 INITIAL CODING: INCIDENT TO INCIDENT CODING

<p>Patients tend to compare themselves to the others in CE group situations.</p> <p>CE sessions are ability sessions; he was in a more capable group but after 6 months he was transferred to a less able one and that was a shock for him.</p> <p>He understands it is better to be in the appropriate group but still that did not feel good.</p> <p>Similar abilities in CE groups.</p>	<p>Q: Because you're coming to this point I should ask how do you like group setting, do you like being together with other people who are also having Parkinson's? better, rather than a one to one session, or...?</p> <p>A: You always compare, that's the only thing, you tend to compare yourself, you tend to look at other people and think god they're worse than me, I'm worse than them, you can't help but do that. But I think the situation over at Megan Baker is that we're sorted out into... whether we like it or not into ability sessions.</p> <p>And I was demoted I would say because I was in Len's session, and I would consider Len and Helen and some of the other people in the other group not to be quite so badly affected as I am myself. Which was a bit of a shock, because we had a session together probably for about six months, then suddenly I wasn't in that group, and you're thinking oh what's changed. But I think there's no doubt about it the reason for that change was to try and keep people with similar abilities together in a group you know.</p>
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<p>CE professionals try to be sensitive, careful enough not to cause shock to patients.</p> <p>CE is a social event too; CE is the only possibility to have contact people with same disease for him.</p> <p>He is realising that he might be able to get other contacts if he changes attitude or take on drugs more.</p> <p>CE in group setting supports to create a realistic picture about themselves, their conditions as well as gives opportunity to chat with each other.</p>	<p>Q: Yes??</p> <p>A: Although... although the conductive education people were very careful to disguise that so you didn't feel bad about it, but the facts are the facts at the end of the day.</p> <p>Q: Right. So, when you were together with the other people you said that you actually compare?? but you mentioned also how important for you the CE coffee time when you can interact with them, why is it important?</p> <p>A: It's the only contact you have with people with the same disease really, I mean unless you... I'm sure like I'm probably missing out and I need to change my attitude, nothing to do with conductive education, I'm going to have to take on the drugs more. Which we're all reluctant to take drugs on because what else do they do to your body and your system and all the rest of it, you become more and more dependent. But that session would show you that you think well he or she's better than me, then you'll find out they're taking all sorts of things, different medications, cos you chat over what you're taking basically</p>
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<p>The group atmosphere is positive. “Workmanlike”; with a bit of humour and laugh beside the strict ‘exercising’.</p> <p>The group gets enjoyable: after get used to people and exercises, participants become less stressed about their execution of tasks and they feel more confident, balanced.</p>	<p>Q: Oh right, so you like to chat about the...?</p> <p>A: Not just that, I mean there is a bit of light-hearted you know talk as well. But yeah you’re fishing to find out what other people are doing and how other people are dealing with it, and what other people are capable of as well.</p> <p>Q: And how about the atmosphere in the classroom or the session room, do you like the atmosphere or what is it about actually, positive, negative?</p> <p>A: The atmosphere in the classroom is I would say workmanlike, with a bit of humour, whatever... whoever’s taking the class, there’s been three or four different people since I’ve been there. They’re all slightly different, it’s got to be a little bit strict otherwise you wouldn’t do the exercises properly, which we understand. There’s always a laugh at the end of it, a joke at the end of it, and if you get your left arm or your right arm mixed up initially you’ll be quite concerned about it and think you’re a fool. But as the time goes on you get less self-conscious, not caring less about what you’re doing, otherwise you wouldn’t enjoy the session, you’d be too uptight in case you made a</p>
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	<p>mistake or something. So I'd say the balance is... the balance is about as good as you can get it really taking into account five or six people who've all got different ways of thinking as well, five or six patients or participants. I think they've got it as good as you can get it to be</p>
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Box 3

Colour codes were not definitive categories but sorted data which prompted my initial thoughts and analysis yet colour codes contained oblique contours of later themes. I found it very helpful to have colour codes since they gave me a very simple but noticeable data to work with. I endeavoured to use as many new colours as the areas or subjects were mentioned by the participants. The Box 4 samples how colour codes were introduced.

BOX 4 INITIAL CODING: COLOUR CODING	
<p>What Conductive Education is from the point of view of participants? YELLOW</p>	<p>Q: OK. And then if this person would ask you what conductive education is, how would you describe it to that person?</p> <p>A: Well I'd describe it as a lot of exercises that are geared towards the processes of everyday life to assist us in different movements, and that's the way I'd describe it really. Either walking and things like that which when you're</p>

<p>What is the atmosphere during conductive sessions in group setting? PURPLE</p>	<p>normal you take for granted, but that's how I would describe it, that it's a good exercise session anyway, but at the end of it all everything relates to living your life and making things a bit easier and a bit better. So I think that's what I would say, if you look into it deeply you'll find that each exercise has got a reason, and that reason is transferred into day to day life.</p> <p>...</p> <p>Q: So you would say that the atmosphere is then...</p>
<p>What CE teaches participants? RED</p>	<p>A: ... Nice and friendly, professional I would say. With a friendly touch, yeah professional with a friendly touch. If you... if you don't... if you stray off the line, if you get straightened up which is... which I have done myself, which we take on the chin you know because we should have been more careful. So it can be very professional as well, as you know this is a straightforward interview, if you sort of strayed from... when you're not doing the session if you were to get up in an unprofessional manner you'd find yourself being told off, which is really saying what's the point of me teaching you then as soon as you're out of the room you're not doing what you're told, so you deserve that. But it's good as well because it's also pointing that there's a reason for this, it's not just an exercise you do now, you go out of the room and forget it, this is the way you get</p>

<p>What CE professional is doing? TURKUOISE</p>	<p>up because this is going to stop you falling over, this is going to stop you getting your feet tied together and stumbling, and you know there's a reason for it.</p> <p>...</p> <p>Q: What about the relationship with the Conductor? How she helps to move you?</p> <p>First of all I think she's extremely observant. I get the feeling she's looking for every single thing I do. She has a good balance between her professional relationship and a sort of social relationship which is chatty and pleasant. She doesn't switch it on and off, but you do know when she's thinking professionally. She could be talking to you very pleasantly and then (she will say) your feet are in the wrong place. And I feel it's just a professional session, but it's very low key, it's not pressurised. I think she realises when I get tired and enough is enough and we do as much as we can without too much pressure. I enjoy it immensely. THIS REFLECTS ON ATMOSPHERE AS WELL</p> <p>...</p>
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<p>What CE brings to participants? LIGHT GREEN</p>	<p>Q: Why do think that CE is successful for you?</p> <p>I think it's – it has a holistic factor to it, it has woken me up a little bit to thinking about my sort of being in the environment and not just can I move my foot, but how I conduct my daily life, but how I conduct my life physically.</p> <p>Q: Amazing.</p> <p>I'm starting to think about what I'm doing all the time. I'm even thinking about getting enough rest so that when I am active I have enough energy. Thinking about my diet, so that I can digest my food properly. It's a bit like a wakeup call really. It's been flashing lights –wake up and think about life, about thing being, this life.</p> <hr/>
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Box 4

In vivo means “within the living” when literally translated from Latin. Grounded theorists refer to in vivo codes as participants’ special terms or symbolic expressions about the meanings of their views. I coded in vivo from the beginning of the analysis as they appeared in texts. When using in vivo coding, a deeper understanding of situations, actions and views emerged and helped me to make comparisons later between data. Furthermore, at a

concluding phase of analysis these codes “flavoured” consecutive drafts of the thesis itself. Box 5 illustrates how in vivo codes reflect on assumptions, actions, and meanings and how these condensed meanings were covered and coded.

BOX 5 IN VIVO CODING	
Conductive Education:	<p>s give and take. You are receiving help and encouragement. At the same time you are helping and encouraging others.”</p> <p>s an engrossed learning.”</p> <p>s an intense activity with pleasant socialising.”</p> <p>s a wakeup call.” It is been “flashing lights”: wake up and think about life, about think being, this life”</p>

Box 5

The second main phase in coding is focused coding. These codes are more directed, selective, and conceptual than incident to incident coding (Glaser, 1978). The strength of grounded theory coding comes from this focused, selective, conceptual approach of data through focused coding. As a result of this active involvement of the records I was able to identify the range of perspectives and major and minor themes. Box 6 demonstrates how former initial codes alongside with notes and memos were used to arrive to more focused codes i.e. major topics, themes. Analogous ideas, alike descriptions of the phenomenon, similar meanings from initial codes were selected and put

into one group. For instance, in Box 6 the theme “What happens to me?” - from point of view of differently diagnosed physical disabled patients – emerged from a paragraph from incident to incident codes, from three different colour codes and from one of my memos.

BOX 3.4 FOCUSED CODING	
INDUCTION	SELECTED CODES
<p>Emerging Theme:</p> <p>What happens to me (from point of view of patients)?</p>	<p>From Incident to incident codes:</p> <p>CE sessions are ability sessions. CE is physical and mental exercise. CE raises self-esteem, self-confidence. Great relationship, “friendship” with the professional. Patients tend to compare themselves to the others in CE group situations. CE in group setting supports to create a realistic picture about themselves (patients), their conditions as well as gives opportunity to chat with each other. Patients tend to gain different motivations (self & external). Family members closely involved to rehabilitation process. Patients tend to remember what happened in sessions and try to adapt techniques into their life at home.</p> <p>From colour codes:</p>

	<p>I'm starting to think about what I'm doing all the time.</p> <p>I'm even thinking about getting enough rest so that when I am active I have enough energy. Thinking about my diet, so that I can digest my food properly. It's a bit like a wakeup call really. It's been flashing lights –wake up and think about life, about thing being, this life.</p> <p>I feel it's just a professional session, but it's very low key, it's not pressurised.</p> <p>... Nice and friendly, professional I would say. With a friendly touch,</p> <p>From my memos:</p> <p>The participants and accompanying family members (wives and husbands) were sitting in the centre's coffee area chatting friendly about what happened to them during the last week (the time period since they last met). These people obviously knew each other very well; the atmosphere was very friendly.</p> <p>Everything seemed to be well prepared and organised. Patients and professionals seemingly were fully aware of the routine of different phases of the session (2.5 hours' session in the afternoon). Patients took an active part in executing, running the session with their help of preparing, moving, putting away equipment, move</p>
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	<p>from place to place, help each other. They seemed to be co-workers of the conductors.</p> <p>Patients were saying (vocalising) initiated exercise from time to time and followed the session leading conductor's given rhythm with counting 1-5.</p>
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Box 6

Member checking

Another important analytical strategy was applied to this phase of the analysis by seeking further clarification and explanation from participants involved in the study to enhance validity and credibility. This strategy is referred to as “member checking”. Member checking is, according to Cohen and Crabtree (2006) testing the meaning of the interpretations, conclusions with members of those groups from whom the data were originally obtained and they also express that it is viewed as a technique for establishing to the validity of an account. They refer to Lincoln and Guba (1985) that member checking is the most crucial technique for establishing credibility. As contrast, Morse (1994) and Sandelowski (2004) are quite critical of the use of member checking for establishing the validity of qualitative research. I primarily applied member checking techniques to better understand, and test participants’ meanings, to review my understanding of participants’ interpretation, and to comprehend with their constructs of phenomena.

Member checking also provided me the opportunity to receive additional information in certain cases. I conducted member checking in different ways; in some cases, I personally meet up and asked participants, in other cases I gave them a phone call and often we kept in touch through text or audio messages through Facebook or on WhatsApp and in one particular case I kept in touch through Skype as well.

Peer review

In order to question the linkages being established between data, categories, codes, emerging themes I asked one of the supervisors of my study who had a general understanding of the research topic to analytically review my work and discuss participants' constructions. This analytical strategy is often referred to as "expert checking" or "peer review" (Lincoln & Guba, 1985, Carpenter & Dyck, 2000). According to Carpenter & Hammel (2000) peer review is designed to help clarify the researcher's perspectives and it should not to obtain a second opinion nor represent a standard against the findings. Critics of this strategy state that peer review, although widely used, is largely untested and its effects are uncertain (Jefferson et al, 2002) and there are real dangers 'that one person may defer to the other on the basis on unequal power/relations', particularly if the researcher is a student or novice researcher and the peer reviewer is a supervisor or more experienced

researcher (Carpenter and Suto, 2008 p.155). In contrast, regarding to Shuttelworth (2016) peer reviewing allows a diversity of opinions which could support removing personal biases and pre-set ideas from the phenomena. In the present case, as it mentioned above, I asked one of my supervisors to support my analysis at this phase to better understand participants' constructions. This was definitely supportive helped develop my investigative skills and my understanding since he was an experienced researcher. Despite the fact that the primary goal of peer review was the support of understanding of participants, it also assigned a basic trustworthiness to the study since the supervisor reviewed collected data and witnessed my analysis step by step, thus (intentionally or unintentionally) enhancing validity and authenticity.

Identify interconnections between participant's constructs and researcher's constructs & observation

The next step of the analysis was to implement selection exercises and an initial comparison strategy to identify interconnections between participant's constructs and researcher's constructs together with observations to establish major analytic divergences or convergences based on similarities and differences. Thus, at the end of this stage all relevant text material was in order and ready for use comparative methods to seek answers to the main research questions and identify possible sub- or any new themes.

Synthesis and theme development

During synthesis and theme development stage I compared interview statements and incidents within the same interview and in different interviews, I made sequential comparisons, and I also paralleled what different participants stated on similar topics. Strauss and Corbin (1998) label a third type of coding in grounded theory, axial coding, to relate categories to sub-categories. Charmaz (2006 p.60) explains that during axial coding the researcher “specifies the properties and dimensions” of a category. Although I did not do such coding according to Strauss and Corbin’s formal GT procedures, my aim was to sort and organise the large amount of data and gather them in new coherent; linking relations between first emerged dimensions and converting coded texts towards concepts, themes and sub-themes. I compared experiences of events at different times and places. I believed that my own observations and ideas during the comparative process did matter as well therefore, I made notes in order to make analytic sense of the data which challenged taken-for-granted understandings. This is how I gained more awareness of understanding and increased more mindfulness of emerging themes. Themes and sub-themes emerged quite clearly at the end of this stage.

Illumination and illustration of phenomena

In illuminating and illustrating stage I examined the literature for links to the themes and sub-themes identified from the entire data set. I searched for relations in between themes and subthemes to support further theoretical development. Themes and sub-themes in relationship with professional literature were presented at Liverpool John Moores University Faculty Research Conference on 28th June 2013 in order to gain feedback on the fit and credibility of themes and subthemes. The importance of presenting findings at the conference was being able to discuss the study and gain feedback on research topic that helped to perfect and further develop research themes. Most importantly, it was an opportunity to reflect on emerged subjects before the process of writing up. Finlay (2003, p. 108) argued that reflexivity in a research sense is the “process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings.” In addition, consideration of the applicability of findings to other educators’ contexts was important in highlighting the perceived value of research findings for future implementation by other practitioners, CE educators, and researchers. I returned to the coded data and specifically looked for and collected participants’ own words to illustrate each theme and sub-theme and linked them up with the literature.

Integration

The last step of analysis was the integration which involved a shorter interpretation of findings - technically, the following chapter of this work, chapter 5, an overview of the research which systematically brings forward the research findings - and a detailed interpretation of the findings with reflection. The detailed interpretation with reflection alongside with conclusion is the second section of this study.

CHAPTER 5 - AN OVERVIEW OF THE RESEARCH FINDINGS

Introduction

In the previous chapters the philosophy, paradigm, methodology, used methods and the stages of analysis of the research were discussed. In this chapter, a short overview of the phenomenon of rehabilitation of physically disabled adults in a group setting with particular reference to Conductive Education is outlined. The themes and sub-themes that emerged from the interviews with participants who have experienced Conductive Education are also introduced.

Introducing findings

Table 13 below demonstrates the findings of the study and reveals the relationship between the four themes and the thirty-two sub-themes which were identified to reflect on the rehabilitation of physically disabled adults in a group setting through Conductive Education.

Table 13 Emerged themes and Sub-themes

Emerging themes	Sub-themes
The CE phenomenon	<p>Philosophy of life</p> <p>Holistic elements</p> <p>Person centred approach</p> <p>Positive regard for learners</p>
Group setting (through CE)	<p>Community of people with similar problems (age and symptom specific requirements) – Social elements</p> <p>Learning environment</p> <p>Collective approach</p> <p>Relationship with others</p> <p>Communication with others</p> <p>Motivation</p> <p>Positive atmosphere</p> <p>Regularity, routine</p> <p>Consistency</p> <p>Perseverance from both clients and rehabilitator –</p> <p>Pygmalion effect</p> <p>Group ethos facilitates the individual</p>

The CE professional	<p>Specific relationship with clients</p> <p>Empathy</p> <p>Meticulously observant</p> <p>Reactive attitude</p> <p>Positive approach</p> <p>Positive language, body language</p> <p>Values, appreciates patients</p> <p>Ability focus model</p>
<p>What happens to me?</p> <p>What's going on?</p>	<p>Feeling looked after, nurtured, valued</p> <p>Perceive commitment from conductors</p> <p>Learning –Transforming</p> <p>Positive change of patients</p> <p>Social confidence</p> <p>Life – Confidence</p> <p>CE activities are often experienced to be challenging</p>

Table 13 illustrates that four core themes were identified as a result of the analysis: 'The Conductive Education Phenomenon', 'CE Rehabilitation Through Group Setting', 'The CE Professional' and 'What happens to me? What's going

on?'. Through the sub-themes, each core theme also then revealed some new additional information and aspects about CE itself and gave me the possibility to better understand holistically what is going on in CE. The results of the analysis facilitated deeper investigation into additional subjects in the context of CE's adult rehabilitation and looked into the scientific background of the approach – which is very much missing from the available literature up to date. Some of these themes have been identified and investigated in psychology, sociology, in education, in health science, etc., but not in the context of CE.

Core theme one: The CE phenomenon

The core theme 'CE phenomenon' suggests that CE is regarded by the research participants as a philosophy of life. This contrasts with existing professional literature which only rarely mentions the philosophical and psychological effects of this form of habilitation/rehabilitation. The pedagogical fundamentals; an integrated effect of holistic components of the process of CE strongly emerged from the data and reinforced the information that had been gathered from professional literature. Although CE is a group approach, the study also discovered how much detailed professional attention is paid to individuals and their complex needs, for example, using

psychological techniques such as 'positive regard' to enhance the development of participants.

Core theme two: The group setting (through CE)

It was not surprising that the second core theme of 'group setting through CE' resulted in the most sub-themes, since the exploration of the group setting was one of the main aims of the research. Several of the parameters of the group setting through CE that arose correlated with formerly acknowledged factors of group science. However, there were some special characteristics identified in context of CE. Participants of the research highlighted that being in the community of people with similar problems/difficulties is key factor and that the group of people with similar conditions created a useful learning and progressing environment. It became apparent that CE is a collective approach within which individuals receive person-centred attention. The relationships, communication with others and the positive atmosphere increase the possibility of successful rehabilitation which is fundamentally given whilst in a group setting. Furthermore, different motivational factors were identified in the CE system and it clearly emerged that regularity, the routine and consistency supported the progression of the clients. The perseverance of clients and rehabilitators, the Pygmalion effect as

part of the CE system (which will be discussed later in the thesis) and the group ethos was also shown to facilitate an increase in self-confidence.

Core theme three: The CE professional

The research results also provided to useful information about CE professionals and this information widens our knowledge of what and how conductors/ conductive education teachers do during their work.

In the 'group setting through CE' theme it was discovered how important the role of the relationship between clients, and between the clients and their professionals in the group setting is within CE. A similar topic emerged as a sub-theme in the 'CE professional' section that reinforced the facts that arose from the perspective of the CE professional. Alongside those, it was exposed that most of the CE professionals show a great amount of empathy towards their clients which did not focus on regret/sadness but focussed on how to overcome difficulties. Also, it became clear that conductors are meticulously observant – which is part of their training – in many ways, and are very reactive when delivering their approach. Additionally, they use a positive approach and positive communication during their work; they value and appreciate clients as well as focusing on their ability rather than their disability.

Core theme four: What happens to me? What's going on?

The final area which emerged provided information on what happens to clients whilst participating in CE from their own perspectives; i.e. how they feel about it, what is their lived experience of rehabilitation through a group setting. The resulting 'What happens to me? What's going on?' core theme fell into six sub-themes and they were delineated with specific knowledge about CE which was not clear before this study regarding to the literature review of CE. Patients and clients feel looked after, nurtured and valued – a theme which emerged visibly and simultaneously in parallel and within the CE professional core theme, too. Likewise, clients recognise true commitment from conductors. Many patients experienced their CE rehabilitation as learning how to better live with their medical issues, how to better use their existing skills alongside developing new ones, and how to overcome of different problems instead of seeking a medical cure. They informed me about increasing social and/or life confidence and more independence. People involved with CE often go through a transformation which in many cases leads clients to change positively. In contrast to these positive changes through CE, patients and family members also shed light upon the CE physical activities often being experienced as challenging, and that the group setting is not everybody's favourite approach.

SECTION TWO: THE REHABILITATION OF PHYSICALLY DISABLED ADULTS IN GROUP SETTING WITH PARTICULAR REFERENCE TO CONDUCTIVE EDUCATION

CHAPTER 1 – ADDITIONAL DIMENSIONS OF THE CONDUCTIVE EDUCATION PHENOMENON

Introduction

Conductive Education for adults has been delivered since 1945. First in Hungary it then slowly started to spread internationally from the late 1980's. One of the first centres in Western Europe was established in Birmingham in 1990 and since then more than 16 settings offering adult CE in UK and several articles and academic papers have described the CE system and introduced the characteristics of its delivery worldwide. Despite the interest of the community, introduction of the system and academic papers about CE's success in habilitation and rehabilitation, there was no formal evaluation of the potential benefit and impact of this system until 2008. That quantitative research, conducted by Brittle, Brown et al (2008), demonstrated that CE has a positive impact on patients' physical conditions. Prior to this, academic papers tended to focus on the fundamental ideas and the characteristics of CE. This chapter will outline and extend these ideas.

Conductive Education as philosophy of life

The professional literature of CE does not mention anywhere that CE would directly focus on clients' lifestyle or would systematically target psychological issues of the patients. However, discussing characteristics of CE each example in the literature mentions motivational factors in different dimensions (Hari and Akos, 1971, Bourke-Taylor et al, p.59, 2007, Hari, 1990) although emotional and social psychological effects are mentioned as well (Schwarzenbacher, 2009).

The result of the present research suggests a new insight to CE. Generally, people who are involved with CE; patients, family members, personal carers and professionals, all participants uniformly reported that there is an evolving "conductive lifestyle" which affects them after they have joined conductive education. Ruth, for example, stated:

It [CE] helps, builds that person's confidence, it's specifically tailored within the constraints of a conductive education style. They [conductors] will do things to the person that they don't do to other people. It's literally specific to that person...CE is how you cope with your life, it's a posh word, but it's a kind of philosophy of life.

(Ruth – Parkinson's patient)

This “philosophy” is re-iterated by Diana, a conductor, who similarly sees CE as “a way of life”:

You can talk about that CE is a philosophy: a way of life, it views the person as a whole, does not call them patient. It treats people very friendly from the first meeting and always tries to create a positive, warm, happy atmosphere. The relationship between professional and the treated person much closer than in any other therapy: very personal. Trust is crucial. You can mention the complexity of CE: It deals parallel with the body, mind and soul – physical, functional, emotional, social: which occurs complex confidence – complete change/transformation of life.

(Diana – conductor)

As a philosophy CE can be understood as a set of beliefs, standards, ideologies and motives of one’s existence: a way of life. This is essential for human survival and has been described variously by sociologists, psychologists and philosophers. This phenomenon was called by Frankl “meaning of life” (Frankl, 2000), Ventegodt referred to it simply “being” (Ventegodt, 2003). Antonovsky named it “coherence” (Antonovsky, 1987), Maslow called it “transcendence” (Maslow, 1962). Dilthey termed it “Weltanschauung” (Dilthey, 1962). According to what participants in the study informed me about CE’s impact on

them, philosophy of life in CE is about realizing opportunities and potential, finding drive(s) in order to change life towards using all abilities and skills, striving to maximise or develop them and to live an active individual and social life, whereby it is acknowledged that we are part of a larger whole. Nathan, a CP patient, tells a short story (below) about how he believes CE has impacted on in his skills and abilities:

I went on holiday to Scotland with my parents they own a motor home. My dad parked it downhill and I slept on the bed downwards. I accidentally fell out of bed. The side rail that was on the bed broke. My mum and dad got out of bed and said “what are we going to do here?” and I said “It’s OK. I just need time to think about it”. And I got up with minimal support and my mum just went “Oh my god. He’s done that himself”. I went “See I can do it. Told you.” I always think about it. If I fall down at home, I think how I would get up if this was a normal conductive education setting. If I fell on the floor in conductive education how would I get up?’

(Nathan, CP patient)

Obviously, people with genuine self-confidence have more positive experience of their existence. The continuous efforts, which help them to learn all the time and improve themselves, will lead them to success ultimately (Ventegodt et al, 2003). A balanced stream of achievements gives the self-confidence that is required for overcoming adversity. CE seems to provide this energetic motivation for clients, instilling the belief that they can rise to the challenge to achieve a better quality of life. In the lives of people with physical disabilities, it is crucial to have clear awareness of the reality of their situation and condition in order to undergo a successful rehabilitation. One of the great issues in traditional rehabilitation is that patients are not adequately directed towards creating clear awareness of their situation and condition. As Steve, for example, experienced:

I've always been told by consultants that there is no treatment. I think probably after the first session [at CE] I saw that this was an opportunity.... I was told [by CE professionals] couple of things I can still do despite of my condition and that was helpful. I feel positive about doing something about this particular problem instead of let it get worse and worse and worse.

(Steve - Marie Charcot Tooth patient)

With disabilities, many people are caught in a snare created by social stigma and their own self-suggestion so that generally have a more negative picture of themselves than should be the case (Schakwyk, 2007). To realise their dreams and wishes effectively, they need professional psychological support, which, as Steve (above) illustrated, gives them an opportunity to navigate 'reality', delivered by those who fully understand both their physical and applied conditions (Jokūbpreikšas, 2013).

According to Merleau-Ponty (2002) life is to realistically know the world we are living in. That is, to be aware of what we want; to know our personal dreams; to realise and be aware of opportunities around us and to have ideals that make it possible to unite our dreams with the opportunities that reality presents for us. Merleau-Ponty's definition of life perfectly describes what CE professionals are trying to work towards during the rehabilitation process. That is to change patients' view of their lives. Clients are therefore, 'transformed' as they adopt CE as the philosophy of their life. As Sonia states:

The whole idea of CE is that the person will come in – and there's nothing you can do about this – the person will come in and they have to leave thinking of the things they can do. You have to change them over that time. It's a positive environment. It's an environment where the consequence of trying is only positive...

we are focusing more on the psychological than the physical,
rather than the physical leading the psychological.

(Sonia – conductor)

Sonia's understanding, and that of the other participants in this study, contrasts starkly with the reductionist assumptions underpinning traditional biomedicine which, Ventegodt (2003 p.1169) surmises:

...regards a human being as an ingenious machine that physicians are able to repair with little interference from the patient. Generally, the medical profession does not believe much in the causality of consciousness, in spiritual dimensions of existence, or in that people can help themselves get well to any appreciable degree. There is very little faith in the power of the individual over his or her own existence.

In contrast, CE offers an alternative philosophy where every modification begins with the individual person, meaning that the disabled person is able to do much more for him- or herself. CE professionals who spent a substantial time with patients in CE groups and learn in depth about their personal needs and conditions, and who develop a unique friendly relationship with them have a good chance to understand better what these patients are missing

from a clear self-awareness. CE basically works with the idea of human potential which, if it meets with a supportive drive force of life, could result in huge change in various conditions of the person (Hari, 1988). To achieve general well-being of the patients therefore, is not a main aim in CE but rather to provide support to encourage a fighting attitude which is always ready for new challenges. As David indeed experienced:

It's just... it opens up the future, it suddenly makes everything seem so possible. I am a fighter now.

(David – Head injured patient)

As already noted, understanding CE as a philosophy of life, is not common in the professional literature. Rather, the main aim of CE's habilitation and rehabilitation is stipulated as the achievement of orthofunction. Orthofunction is a CE term and concept which has been defined variously and its meaning is not clear to date. Some prefer a narrow meaning, referring to one's physical capabilities, suggesting that orthofunction is the ability to function independently without physical aids (Aubrey, 1986). However, this narrow definition is contested by other CE professionals and by Brown & Mikula (1988) who prefer to see orthofunction as a process whereby the disabled person is performing an activity with maximum independence and minimum assistance. This wider interpretation

of orthofunction relates to the whole personality and therefore once again links with the concept of human potential, positive thinking and the “personal best” (Gonczy, 2011) and what I have been describing as a philosophy of life.

Holistic elements in CE

People in many ancient cultures believed in the complete harmony of the world. In that complete harmony, individuals were thought to have a personal unity, where emotional, social-cultural, spiritual, intellectual and physical entities in combination created the human existence. A complete harmony means, in other words, a united structure, which refers to a holistic world view. The term ‘holism’ was first used by Jan Smuts in his book; *Holism and Evolution: The Original Source of the Holistic Approach to Life* (1926). Smuts defined holism as the tendency in nature to form wholes that are greater than the sum of their parts. He argued that this propensity was result of creative evaluation. Accordingly, holism and the search “to be whole” are naturally part of every living being and to deny this kind of seeking would imply a huge disrespect for all life. The principles of a holistic approach to health were investigated by several scholars (Bell, 2003; Galantino, at al., 2003; Kim,1999; Vickers and Zollman, 1999; Bakx, 1991; O’Donnell, 1989) and following Dossey and Guzetta’s (2005) compiled form, may be seen in many aspects of CE as one conductor in this study commented:

We see the whole person, always the whole person, the personality and not just the medical problem like they [patients] cannot walk or cannot talk.

(Viktoria – conductor)

CE understands that a person comprises multiple levels of being and consequently has multiple health needs, relating to his different levels of being i.e. emotional, social/environmental, physical, mental/cognitive, and spiritual. It is expressed that the whole person is larger than the sum of those individual levels and this does not indicate a quantifiable size, rather a metaphysical dimension of magnitude. Although the main aim is to develop physical conditions, CE sees that there is no hierarchy between the different levels of a person's being and makes the greatest effort comprehensively to facilitate the other levels. CE employs interactive connections between all the different levels as well as between the person and his society/environment. Also, CE believes that a change in one level of a person's being causes a change in all levels, but interaction or relationship between levels are non-linear. The person is expected to have a more responsible role in his own healing trajectory, in partnership with his professionals and with other participants. As Viktoria again notes:

...patients have the possibility to discuss and, are involved in setting personal aims. They tend to create more like physical, functional goals such as getting in and out of their car or bath, roll over in bed, peel carrots, etc. but it occurs that they wish to set more complex goals like how to find a suitable table at a restaurant, how to tell/communicate people/ business partners what they have [disability]. They often give tips each other what goals they could work on. They have the opportunity to have one to one consultation with the conductor as well as goals are often discussed in group situation as well. This exercise I believe unique to CE. On top of this, they [patients] are expected to work on their aims at home in daily living situations, and they love to discuss on the next sessions how it went.

(Viktoria – conductor)

Andy has shared that he was quite surprised to be asked to take part in setting his rehabilitative aims and he expressed how amazed he was to do so:

To be perfectly honest I went into it with my eyes wide open. And there was a meeting at one thirty, was it Tuesday or something? I was asked if I wanted to improve on something. I am logical. I

am very logical, so I wanted to break things down...I found that my foot freezes I was actually able to give it a different direction like turn left. I wanted to improve on this. Well, they listened and I am still working on it. Mmm. It's nice isn't it?

(Andy – Parkinson's patient)

Although CE is not recognized by the NHS and is not specifically acknowledged as a holistic approach, but according to conductors and patients in this study the system undeniably applies “whole-istic” ideas and includes holistic elements.

CE is a person centered approach

Research indicates that augmented patient education in health services (Johansson, et al., 2003; Dreeben, 2010) and the involvement of patients regarding their own rehabilitation leads to increased feelings of empowerment, which in turn lead to an improved outcome of better health and cure (Ford, et al., 2003). An approach to health whereby one of the main aims is to involve patients to their own health care, is called person- or client-centered approach (Ford, et al., 2003; Fossum and Arborelius, 2003). There is no single definition of person-centered practice (Kirschenbaum, 1989; Ford, et al. 2003) but there are several useful circumscriptions by scholars.

Kirschenbaum (1989) outlines person-centered approach as a set of humanistic beliefs about human growth and development, whereby the relationship between patient and rehabilitator is very friendly and the action of the therapy is essentially less prescriptive, or non-directive. Stewart (2001) defined that person-centered approach “takes into account the clients’ desire for information and for sharing decision making and responding appropriately”. He also mentions the characteristics of person-centered approach and expresses them as:

- (i) understanding of the whole person,
- (ii) the improvement of patient-doctor relationship, and
- (iii) that exploration of both the patients’ disease and their own experiences are all core characteristics of the approach. (Stewart, et al. 1995).

Bensing (2000) believes that

...it has a basically humanistic, bio-psycho-social perspective, combining ethical values on the “ideal physician”, psychotherapeutic theories on facilitating patients’ disclosure or real worries, and negotiation theories on decision making.

The above definitions indicate significant overlap with some of holistic principles and the characteristics of practice of the CE habilitation and rehabilitation system. Again, a review of the CE literature does not indicate that CE was developed as a person-centered approach, however according to the results of the present research; it is obvious that several principles, characteristics, and elements of CE entirely correlate with the person-centered approach depicted above, as Susan illustrates:

The conductor discusses the aims for the participants [patients] from the first contact (usually via an initial consultation). She asks the participants and their family what their hopes and/or goals are and then offers up his/her own opinions of what is realistic and achievable. Due to the nature of the dynamic CE sessions, close contact and relationships are fostered between the conductor and the participant and this allows aims to be consistently discussed, problem solved and moved towards. The conductor has the ultimate aim of orthofunction in mind and as such desires to lead the participant towards a time in which they can formulate and problem-solve their own goals. Until this time is reached the conductor uses a gradual process of short term aim setting, observation, considered facilitation and feedback – at all

stages in collaboration with the participant. As the CE environment fosters a trusting, friendly, non-hierarchical and non-clinical relationship between all members of the CE group (participants and conductors) it allows for regular and open discussion of personal aims. The importance of the strong conductor-participant relationship is that it provides opportunities for frank and honest discussions without putting limitations on the potential for progress to be made.

(Susan – conductor)

One of CE's basic principles is to believe in human growth and development of what Rogers (1951, 1980) called "actualizing tendency" and CE refers to "human dimension" (Hari, 1988); the innate drive and capacity in humans to grow, develop and mature. A result of the current study, CE is that professionals trust in their client's capacity to improve and seek to understand what to work on and what choices to make. Hence the perseverance of both patients and conductors is well characterized in CE and the Pygmalion effect (patient benefits resulting from high expectations), which will be discussed later in this thesis, noticeably increases their successful rehabilitation. CE practitioners understand and approach the person as a whole, and the system

is acknowledged to hold a bio-psycho-social perspective since its complex approach addresses the comprehensive needs of the clients such as emotional, social/environmental, physical, mental/cognitive and spiritual needs. CE professionals have an empathic connection with the clients and the clients really experience that empathy. The conductors' empathic listening and acceptance do have the result of helping patients to focus on their inner experience, too. Conductors make the utmost effort to learn and understand patients, their complex needs, their close environment, their feelings, thoughts and meaning. The professionals facilitate clients stay with them, and delve deeper into their experience. Drawing on Susan's' comments (above) and the wider literature I would suggest that CE involves patients and their family members in the rehabilitation process by;

- (i) amicably informing them about the probable plan of their rehabilitation,
- (ii) discussing it with them and listening to their preferences,
- (iii) continuously giving them opportunities to discuss issues,
- (iv) continuously giving them positive feedback and
- (v) focusing on developing non-hierarchical, friendly relationship.

Furthermore, CE provides a kind of combination of directive and non-directive rehabilitation which gives gradually more space for clients with regard to their developing confidence. This technique is termed “fading” in special education, meaning that directive factors are gradually withdrawn until they fade away (Park, et al., 2007).

Positive regard for learners

According to Schalkwyk (2007 p. 158) Conductive Education shows a sharing relationship, rather than separation, between professionals and their clients. A conductor’s focus of attention is on what his or her clients are able to do, rather than what they cannot do, and how their abilities and skills can be developed further. Sonia, one of the interviewed conductors, explained that:

...at the end of the day one of the things with Conductive Education is to say what is the level of ability with the person and how can I build on that, not what they are missing. I always think that the medical model works on a deficit model; these are the things you can’t do and what we are going to work on. Whereas with our model we say I know there are things you can’t do...what I want to know is what can you do and how can I build on that. It doesn’t take away from my understanding of there are things you

can't do. But if removes the pressure from asking you to do something that you find hard. So it balances the chances with a group of people they are all going to have specific problems. And the balance in our class has to be that you are doing things that you can do as well as things you find difficult. If I work on a one to one with somebody, then my relationship is immediately 'I can, you can't'. I can't change that. Because that is fact. Yes, I can lift my leg up you find it difficult. So what would motivate you to lift your leg up? Because there's no-one else around who finds it hard. And it's very important that numbers of conductors to numbers of participants is the right balance, so I want' to make sure they feel safe, but if you have one to one within the group you are still creating that same situation. So if I have five conductors and five people I'm still creating a situation were five of us can, five of us can't. So I'm never going to influence you within that group. If you are part of the majority in that group and you find things hard you feel ok... If you are part of a minority that finds things hard you'll stop feeling good. So again looking at the staffing, looking at the way that's...yes we focus on what they can do, but we have to have enough staffing to try the things they

find hard and not too many to do remove from things they can do. If I find emotionally I'm (?) moved in a group as I'm actually leading it I can see that they've just done a really hard task the whole atmosphere has gone down because I've focused on something they can't do, I must immediately put in a number of tasks that they can do more easily.

(Sonia – conductor)

According to Sonia, CE is premised on the ongoing encouragement of the skills participants (i.e. learners) already have, and of celebrating their success rather than only focusing on their disabilities. It is intended that participants depart CE premises celebrating what they have achieved on that day, rather than feeling pessimistic about the activities they could not do (Brown, 2003). Positive regard for learners is also noted in CE literature (for instance Brown, 2003, Beardshaw, 1989) as well as literature on parents' experience of CE's services (James & Taylor, 1997). It is also clearly evidenced in the following response from an older participant:

This is a fantastic place to come to [a CE institute]. They'll [conductors] never say a cross word to you they'll always be positive. If you do it wrong that's alright. Do it again and again. Repeat all the movements with your hands, how to move and how to stand

up. How to sit down, I never thought of that before I came here. I had Parkinson's disease since 1964. I'm now 83 and I'm still here still alive!

(Michael – Parkinson patient)

Although a specific technique for developing positive regard for patients accessing CE, is not mentioned in CE literature. Professionals are trained to display their own personal pedagogical attitude of positive psychology in order to encourage patients towards a “positive self-awareness” (Hári et al, 1991).

CHAPTER 2 – GROUP SETTING THROUGH CE

CE: Community of people with similar difficulties

In CE, a group setting is the preferred format of approach for rehabilitation - except for in special cases when one to one sessions are also obtainable. Patients work together in relatively homogeneous ability groups, where group members are thoughtfully selected by CE experts after professional assessments. Group creating criteria include: diagnosis, level of physical performance, level of mental performance and age. People with disabilities who have similar interests i.e. who have experience similar difficulties in life, tend to seek to discuss problems between themselves and exchange ideas (Brown, 2008). This is based on the fact that people who have endured and/or overcome a difficulty could offer useful support, encouragement, and hope to their peers (Walker, 2013). CE centres therefore provide a relatively rare institution where patients can have opportunities to make continuous personal contact; even make new friendships, with companions in distress. The fact that CE actively involves family members, close acquaintance, and/or personal carers in the rehabilitation process leads the service to have broader impact of patients' life (Hári, 1991). CE professionals consciously facilitate interactions, and/or evolving associations, and encourage social events to happen. According to the outcome of the

present study, the majority of participants mentioned the CE community as one of the main reasons why they like or have chosen to stick with CE. A dialogue between Allison and me about Simon's (one of the clients) motivation highlights this:

I think Simon would have stayed there [CE] all day, every day given the chance. I think it's because it was the first time he really felt someone could show him how to work on improving himself, and so when he came away from there, I mean he would have loved the sessions to go on for hours because he feels it was something so positive happening. Also, I think because doing it on his own wouldn't achieve the same and being with David [Head injured patient] the group and commands are helping. He loves to meet here with him [who's got similar difficulties] and they try stuff together.

(Allison – Carer of Simon, Stroke, Aphasia patient)

Other conversations with patients and conductors also expressed that CE's learning environment, i.e. community of people with similar difficulties a huge motivation factor to do CE rehabilitation for clients. Ben for example explained in our dialogue the following:

Q: What causes you to stay with CE?

A: I think the fun that I have in the...

Q: Fun?

A: The fun yes, because of the people, being with other people with Parkinson's you can talk about it whereas you don't necessarily with other people. You can make jokes about it where it wouldn't perhaps be appropriate elsewhere. And also in the group that I'm in there are people with different problems with Parkinson's and you... I can see from my point of view that I have very mild symptoms, certainly on medication. But now I think coming here [CE] is.... I look forward to it every Tuesday.

(Ben – Parkinson's patient)

Also, a freshly graduated conductor stated that the social element of being together with "friends" – people with similar difficulties – "works wonders" i.e. to keep clients' motivation to stay active and take part in CE rehabilitation.

It's obvious to say clients [patients] are motivated being with each other [similar difficulties]. The social element of sitting down and having a laugh and a joke and a cup of tea and of course

doing CE together. I think it just works wonders. In a lot of cases they wouldn't have a lot of contact with people who weren't they carer. It feels it is good for them to be in a room of their friends [companions of distress].

(Lou – conductor)

Mrs. Smith, a wife of a Parkinson's patient who is involved with CE for many years assured me that in CE it is very important for clients that they meet with people with similar difficulties and she highlights that not only patients but families are also happy to meet and have a contact with each other:

You find people come in here who haven't got anybody it's just a whole new beginning to them, you're meeting people in more or less the same position – maybe worse, maybe not so bad – and it uplifts them and give them the purpose to go on. And that's important.' No comparison between the hospital and here. Similarity in a way, but nothing as intense as here. Families tend to get involved; we are always going around to each other's. You talk to these people and you put their mind at ease. They come in here and they see what's going on.'

(Mrs. Smith – wife of Parkinson's patient)

Sonia talked about how family members were affected and involved with the condition of their spouse have and logically deduce why CE does a lot of work with them. This brings together evidence that CE clients find it beneficial to be connected with each other and that this is an attractive, motivating feature of CE. Also, she stated that in her institute there was a program for carers as well:

We have a distinction; people living with a condition and people living alongside a condition. If your partner's had a stroke, then you have. We see the family members as having the condition without having the physical disability. So a lot of work is done with them, they are going to be just as stressed and frightened. Their lives are going to be turned upside down as well. And you can't work with one without the other. But for the carer's there is a role, they have got a choice. They can come in the sessions and many of them like to see... They can come into the session whenever they want. And they come in and out during the session. They can stay in the coffee area if they want and they can meet with other carers. And a lot of times they are doing that and they are talking to each other...Some of them [family members] will use the time to leave their partner safe knowing

they are doing something and they'll go off and do some shopping and have a bit of time to themselves. Some of them will come with a friend and go down the park to have a coffee. Generally speaking, they are in the session or in the coffee area. Also, we've run specific groups just for the carers.

(Sonia – conductor)

The context of CE as a forum for developing a community of people with similar difficulties warrants further research.

Learning environment

The fundamental tenet of CE is that rehabilitation is considered as part of a pedagogical process whereby comprehensive disorders could be brought under control by an educational approach aiming at generating mental development – it is a cognitive approach - which leads expansion in a holistic way, transforming patients and their close environment towards a more confident life (Cottam, 1986). Consequently, the setting for the rehabilitation, the created learning situations and the whole environment are engineered to facilitate teaching and learning.

CE institutes are not like hospitals or rehabilitation centres. All those CE places I have visited during data collection were

independent buildings or CE rooms were created in school buildings. Most of them had reception, offices, one or more community rooms and spacious activity rooms. In the community rooms were sofas or big dining tables and a kitchen unit in order to have coffee events. The CE sessions were held in the activity rooms using unique furniture like, wall-racks, stools, leatherback chairs, plinths - which were used as tables, beds, or walking supports - different leathers for walking exercises, stairs, and slopes. Definitely they remembered me on sport rooms. It was interesting that the same room and same furniture were used for very different activities; lying, sitting, writing, standing, speech, singing, playing sports, etc. and between these activities patients with conductors together changed the room. I have found people extremely friendly when visited them, and I had low tone conversations with them which also felt very positive as a researcher. (The researcher's note)

CE considers the full range of human capacities that are involved in teaching and learning – perception, thought, language, other symbol systems, creativity, intuition, personality and motivation. Emotional well-being is seen as being at the root of involvement. Through active participation in CE,

patients have a lived experience of emotional, social, physical, cognitive life-situations where environmental components of experience are emphasised. Therefore, the rehabilitation provided in CE is a unique combination of the segregated and inclusive influence of educational methods and creates a 'new kind of experience'. This has been recognized by the clientele of CE, as Ben illustrates:

Now me doing it [CE] on my own wouldn't be the same thing, and the group setting suits me very well, it feels like you were in school again...I don't know whether that in parts of my experience in terms of physical response but it certainly does... emotionally it's great to be with other people with the same condition and also, I can see them doing what they're being asked to do, whereas I cannot actually see myself. It is really like at school...

(Ben – Parkinson's patient)

Also, Nathan claims that:

I do not think I am treated like in a hospital. CE is a bit similar to a school. Yeah, spot on... In my view it's a school where anyone is accepted. I learn stuffs here [at CE] like a student surrounded

by other students...It is a different experience of hospital's rehabilitation unit.

(Nathan – CP patient)

Segregated education tends to create protective environment for disabled people in which to lead a separate life however, inclusive education seeks to carry out complete participation for special need learners in “mainstream” environment (both premises and human resources) and committed to removing barriers wherever education is provided (Bowe, 2005), “Inclusive practice can be defined as attitudes, approaches and strategies that we take to ensure that no learners are excluded or isolated from the education on offer”.

The CE patient has “new experience” through a “social funnel” which is composed of the learning environment layers in CE, modelled in Figure 1.

The narrow learning environment of the CE group; the group of patients together with the conductors (Cottam, 1986 p.70) – could be described as segregation. At this layer of segregation, the group dynamic, cohesion, personal relationship, stimulation, interactions, motivation, etc., are facilitated.

A wider learning environment is the close community of CE initiatives in which each patient has a given space of existence, and where other co-workers of

the CE setting are involved in the collective approach – this layer has inclusive elements since numerous healthy people take part in it and the establishments are changed to the people's needs. At this layer, the aim is that patients feel not only part of their CE group, but they realistically experience that they are appreciated as part of a small community where their input is important. They desire to feel valued in this environment and are not considered as only a patient. CE communities organise a lot of social events throughout the year where patients and their families have useful opportunities to socialize.

The Legacy Rainbow House [a CE institution] have an average of 1 social event a month they organise for their community including "Rainbow Rambles", "Chorely Carnival", "Winter and Summer Balls" etc., but 1 or 2 more a month that are hosted by other people to raise money for them. (The researcher's note)

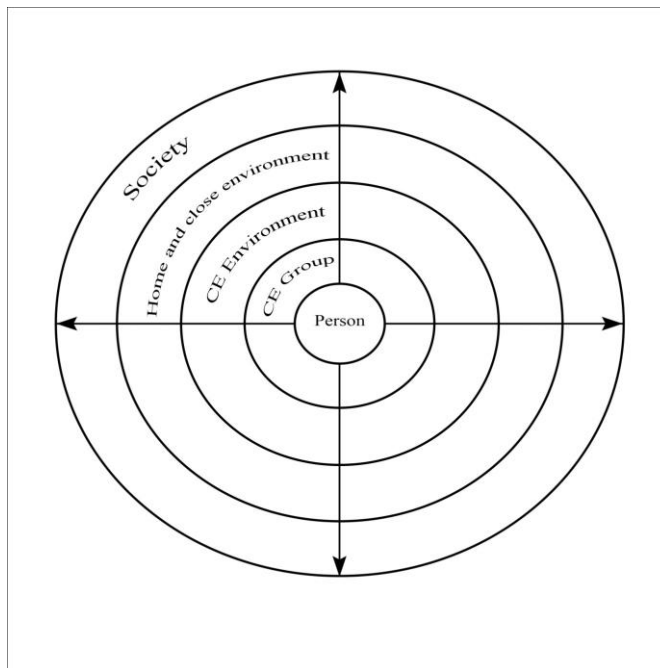
We have Christmas things, they have so many things [organised by themselves]. The summer barbeque and if you're coming here for sessions after each session there's our coffee time.

(Sonia – conductor)

The even broader learning environment is the patients' real surroundings at home and communities where they live. As CE involves family

members and friends in the rehabilitation practice i.e. the learning and teaching process does not stay inside CE buildings and is constant. This brings a new aspect to rehabilitation for adult disabled people. Obviously, the widest learning environment is the society. The whole learning and rehabilitation process of CE aims to facilitate people to find their places in the society, which is the space of everyone's life, and where we all adapt and conform ourselves to everyday requirements. The learning environments provided in CE also warrants further research.

Figure 1 Social funnel – Learning environment layers in CE



Collective approach

CE is a collective approach at different levels. Firstly, according to CE, an individual's rehabilitation should not be his or her (or a professional's) sole aim. Rehabilitation should not be isolated. That is to say that the transformative impact of rehabilitation must be more collective than that in order to have a chance for successful healing (Gyenei, 1973).

CE's collective impact comes through of the dedication of professional and non-professional groups of people from different backgrounds i.e. a broad habilitation or rehabilitation of the comprehensively disabled individual (Hári, 1971). Professionals' dedication to their clientele was obvious according

to my personal experiences at CE centres where I often felt a huge collective wish towards successive rehabilitation and interviewees were equally determined and motivated to express this. For example, Susan stated:

We are all very enthusiastic you know, and everybody [the whole team] wants them [patients] to improve.

(Susan – conductor)

Also, the nonprofessional co-workers at CE centres seemed to share a positive interest towards patients and they often had positive impact on them. Nathan, a CP patient, told a story about how he stood up from his wheelchair in front of the receptionist, evidently because she showed interest:

...I suddenly thought to stand up [from his wheelchair] to talk to Claire [receptionist] cos I learnt it after all.

(Nathan – CP patient)

The second element of CE's collectivity is the group setting. It is a collective approach where participants work on their personal aims but they share vision for change including a common understanding of their active role. They share measurement and across all participants CE ensures efforts remain aligned and participants hold each other accountable (Pető, 1998). CE groups mutually reinforce complex activities and patients are guided with differentiation whilst still being coordinated through a jointly reinforcing plan

of accomplishment. Group members are facilitated to have interactions, continuous open communication to build trust, assure mutual objectives, and enjoy common motivation (Medveczki, 2006).

Relationship with others

One of the most fundamental ways in which people simplify and understand their world is that they categorise themselves into different social groups. People automatically categorize others based on outlook, gender, age, etc. (Dovidio & Gartner, 2010). Patients at CE, according to the present research, tend to categorise themselves into a CE social group where they emphasise the relationship with other members and regard it as a very important element of CE. Nathan expressed it as follows:

You know I belong to this community, I mean Legacy's [Legacy Rainbow House, CE institution] I am part of the "family".

(Nathan – CP patient)

According to Oyserman, Coon, and Kemmelmeier (2002), the primary feature of collectivism is that groups bind individuals. Collectivist individuals are more approachable and motivated by social bonding, and this is regarded as particularly significant with a centre of attention on personal factors such as trust or common needs (Williams et al, 1998). In CE's habilitation and rehabilitation process - in which relationship building, enjoyment of social

interactions is fundamental - aims and activities associated with relationships and relationship quality are of great importance.

According to the current research, in some of the CE institutes conductors facilitate CE groups, participants and task-effectiveness using applied sociometry.

To better understand the group, support the group dynamic and individuals we do sociometric assessments every half year.

(Viktoria – conductor)

Sociometry was developed to measure the degree of acceptance and rejection in different social groups and to measure an individual's impact on the group's structure and cohesion, and vice versa (Moreno, 1953, 1978). Today's sociometry applies a variety of exercises and activities in order to develop the social skills of the group members (i.e. belonging, cooperation, openness and access to roles). Group, emotional and relationship building are embedded sociometric events within CE which are also meant to facilitate the personal progress of the clients. Sonia informed me about how she pays attention to place people to close to each other in the group:

All those groups – as in any groups – are going to have a complete range of people and where I place somebody in the group is going to be important. If I've got someone who has some in who is

emotionally really low and I've got somebody who is having a great day then I will place those people close to each other, so that one person can push off the other. Also the personality will play a role as well. We've got some people here who take more pleasure in seeing someone else being able to do something than themselves. And that's almost being able to recognise human difference. So where I place someone is going to be important if they are frightened they're going to be in the middle of others, they are not going to be one the edge, they are not going to be isolated. If someone is concerned that they are holding the group back, then I might put them at the back of the group to make them follow the others and make them see. If someone lacks confidence, I may put them at the front so they don't notice that the others are doing something different. So all the time we are constantly playing with where you put people in the room, we'll be moving people around...

(Sonia – conductor)

The application sociometry in the process of habilitation, rehabilitation of adult physically disabled people is a new concept in the field.

Communication with others

Within the group setting in CE, there is a complex interaction. This remains at the very core of the CE process and has a pronounced impact on participants' progress/recovery. The patient–professional and patient–patient communication has long been seen as a critical source of influence on comprehensive habilitation and rehabilitation. The level and value of communication fully affects the inter-relationship participants have and has short and long-term implications on the progress of the whole rehabilitation (Westbrook, 2011). A special relationship between patients and professionals within CE will be discussed later. However, the possibility of communication itself is one of the main features according to the result of the present research. This subject links very closely with the earlier discussion regarding a “community of people with similar distress”, and leads us to the “special experience” within CE. Evidently, patients put particular emphasis upon the fact that they can meet up and communicate with others within CE. For instance, Elisabeth explained why she liked CE and mentioned that alongside of other aspects she enjoyed the environment and communicate to the others:

The other aspect is...there's the work environment and people to talk to. Getting together at the cafe over a cup of tea.

(Elisabeth – MS patient)

Michael told it this way:

You see a lot of people.... they are wonderful. We understand each other... we are all happy together. Mentally we are all in the same position, not in the same position, but you are all looking to achieve something. Talk, ask them questions, love that...

(Michael – Parkinson's patient)

Mrs. Smith found the social elements of CE approach very important:

...and I think the whole social element of when we meet in there. The wives, the partners. Or we go down to the park for a coffee. Discusses the local coffee shop in park and meeting other people there – Gene & Les. We all meet – great discussions about life in general. And a lot of men find that great because they wouldn't have seen anybody, they wouldn't get out, and they meet up with people in the same position and it's uplifting. Whereas if they are in the house they get into that little thing inside them and they don't want to go out; they don't want to do this and they don't want to do that. And that's a fairly big problem.

(Mrs. Smith – wife of a Parkinson's patient)

In an environment where they do not have the pressure and rhythm of “normal” life, where they can re-learn and practice situations, functions, activities and being to find confidence despite of their present conditions. CE’s “social funnel” in turn further facilitates the gradual progress of comprehensive disabilities. Participants were/are particularly happy with the second layer when they have the opportunity to communicate.

Motivation

The significance of motivation in CE is one of the most prominent subjects in literature, and motivation as an activity-generator and pedagogical tool, in the rehabilitation group setting, has prime importance (Hári, 1991 p.43). However, an expansively studied, complete panorama of dimensions of motivation factors of CE has not been published. According to the present study, patients experienced the following areas of motivation; intrinsic motivation, extrinsic motivation and achievement motivation. Intrinsic motivation occurs when individuals occupy freely in activities for their own sake, while, extrinsic motivation occurs when individuals are motivated by external factors, such as social recognition, collective attraction, rewards, individuals’ encouragements (Gill, 2000). The following quotes demonstrate participants’ different areas of motivations they experienced whilst

participating in CE. Andy talked about his intrinsic motivation whereas Luke experienced a mixture of intrinsic and extrinsic motivation to go CE sessions every week. Chris acknowledged that he is pushed/motivated by watching others trying hard:

...it's because you've got Parkinson's, you can't get away from the fact, so I'll try anything, and that is the reason I tried it [CE]. I'm the world's biggest cynic but I'll give anything a try, and it [CE] did me the world of good.

(Andy – Parkinson's patient)

I can go there [CE] every week, and every week I make everybody laugh and smile, and as long as I do that that's more than enough for me.

(Luke – Parkinson's patient)

...and also do you think is there an element of sort of, oh what's the word, not competition but if you see someone else having a go and really pushing themselves does that make you want to push harder.

(David – Head Injured patient)

Achievement motivation involves both intrinsic and extrinsic components; achievement goals and motivational climate (Carpenter and Morgan 1999; Roberts 2001). Ben expressed that he was quite motivated by his achievements and he was really happy with that:

It [CE] works you know; it improves my life. I... when I get up out of the chair I remember the correct way of doing that, and sometimes as I say I hear the words [of the conductor] in my brain to do it. You know it suits me.

(Ben – Parkinson's patient)

In literature, achievement goals are created through task-goal orientation - the correct conductive task is a great motivating factor (Cotton and Kinsman, 1983 p.15). Ego-goal orientation allows one to demonstrate ability (Nicholls, 1989). These are also known as "learning and performance" goals (Dweck and Leggett 1988) or "mastery and ability" goals (Ames 1992). A persons' motivation can be piqued and maintained by the motivational climate (Weinberg and Gould 2003). An encompassing setting, such as group setting, which is supposed to involve positive reinforcement of effort, improvement, and cooperation, is termed as a "mastery climate". CE is concerned with providing a "mastery climate" and factors that energize behaviour and give it direction. The motivation components of CE are embedded into the layers of

the social funnel and have different strengths and directions in different level. They also aim to support and maintain consistency and continuity (Cotton and Kinsman, 1983).

Positive atmosphere

A consistent result of the present research is that CE professionals consciously working on to create positive atmosphere – the mastery climate - in CE sessions and participants do believe it comes to fruition most of the times which energize them both to continue with CE and participate in challenging activities. Lou informed me about that creating positive atmosphere, an engaging frame i.e. “fun” in CE is a conscious effort:

No matter how wide range you are working with it should always be fun. Obviously different types of fun. Singing songs with 60-year-old people isn't going to always work. But that doesn't mean you can't have fun, you can chat with them in between tasks and keeping the group together. Bringing each person in talking to one and chatting with each other. Making them hold together, but it should always be fun. It should always be engaging. Working with adults is something they are going to find useful, informative as well as fun. And I think as I graduated, in the short time, the important thing I've learned is that it has to be a great

atmosphere... It's all about fun, having everybody in a good mood...

(Lou – conductor)

Scholars and psychologists agree that positive atmosphere is the hallmark of high-quality educational environments and it provides an essential basic for motivation, learning, and development. Outcomes of responsive practices include increased social skills, greater emotional regulation, and ongoing motivation for participants. In addition, positive mood support resiliency, compensate for stress experienced and help patients achieve their full potential (Kersey & Masterson, 2011). According to Anderson (2009), creating positive environment gives an excellent setting for exploration, mastery. Focusing on what we want, instead of dealing with or thinking of difficulties, stress, results in higher corporation and more time spent on learning. Both researched patients and professionals talked about the value of participating in activities whilst enjoying a positive atmosphere which allows them to push beyond their limits and develop new abilities.

I do not even realise how long a session last you know we just keep doing it. I go with the flow cos it's energising.

(Nathan – CP patient)

These moments usually happen when a person's body and/or mind is stretched to capacity. Mihaly Csikszentmihalyi calls this state “flow” experience (Marsch, 2005). During flow, the experience becomes “autotelic”, meaning that the activity actually becomes its own reward.

“To improve life, one must improve the quality of experience” (Csikszentmihalyi, 1997). The “flow experience” in CE, facilitates people to become more self-confident, capable, and goal sensitive, it enables them to escape the state of “psychic entropy”, the distraction, depression that constantly threatens them (Brown, 2012).

Regularity and routine

Burns (1958) described routine as a monotonous action that resembles the cyclical performance of a machine. “Routine is usually thought of as blind. Its control purpose is either taken for granted or lost sight of” (p.148). However, regularity and routine in education aim to facilitate the teaching - learning process. Regularity is a great facilitation strategy when managing people with different temperaments whereas routine should support education to be smooth and aid people to better imbibe topics, manners, and activities. Regularity is one of the qualities which define temper and personality. People and children who are regular are predictable in their daily activities like eating, sleeping, and have bowel movements at about the same

time almost every day. Maintaining a consistent routine helps people to self-regulate (Jensen, 2003). The result of the current research suggests that CE builds its educational-rehabilitation acts on this knowledge in order to facilitate confidence and development to happen. Ruth summarized what routine means for her in CE with the following words:

The routine? It helps, it is useful, it helps you through the up and odd surprise, you can expect what comes and that is relaxing.

Isn't it?

(Ruth – Parkinson's patient)

According to Hári, routine and regularity are determined by both rehabilitative and educational aims and it is reasonable, flexible, consequent and energising process. There is no a single event in sessions which does not serve its education-rehabilitation purposes (Hári et al, 1991. p. 131-134). The programme i.e. session routine is a schedule of activities which reflect an integrated system of learning. It is vigilantly planned and exceedingly structured with a congregation point on meeting goals in an interconnected manner. Sessions are complex in the way they were designed, but simple for patients to understand.

It provides the individual with a learning environment rich with relevance, fun, and opportunities to practice and clear pathways to achievement.

(Professional Conductor's Association, 2009 'np')

The session routine will depend on the age and the specific requirements of the individual and the group. Nevertheless, recommended routine for home is discussed with patients, family members or/and with personal carers which gives a lot of support for life away from the institution, as analysis shed light upon.

The conductors often share helpful ideas for the clients in order to create a useful home routine to live with their comprehensive disabilities.

(The researchers' note)

Consistency

According to Hári (1990, p.41-42) regularity, routine and consistency are fundamental characteristics of CE and they are inseparable in order to achieve successful education or rehabilitation. Consistency commonly seen in education as to refer to disciplined attitude of the teacher and to a learning

environment which is predictable and follows a sense of structure in order to do “well” (Jones, 2007 p.183-193). Setting and then sticking to teaching - learning rules, creating clear expectations alongside with constant monitoring and feedback giving to learners assures a disciplined framework of education (Szántó, 1986).

The outcome of this research suggests that CE professionals are quite education disciplined, and they are very consistent in planning complex programs, time keeping, program leading and demand of performance or in document writing.

One of the interesting things was to experience in the Cerebral Palsy adult class how the conductor held the session. When participants took their places - like pupils in classrooms at school - and they were ready to start the conductor gave them personal aims (such as try to concentrate on to put your feet fully flat on the plinth, or try to measure and find enough place on your own before you roll over) to concentrate on during the session. During the whole program a lot of nonverbal and verbal praising and correction were used to assist patients alongside the manual facilitation. The personal aims were recalled at the end of the session and participants were asked if they could achieve them.

Then the conductor gave them feedback which somehow always turned to be a positive encouragement and reassured them working on those aims at home too. I was told that it is a consistent pattern of each session because they think it supports patients to be involved in their own development.

(The researcher's note)

Patients are therefore considerably monitored and they give feedback as many times as if they were pupils in school if not more. This reportedly does not result in stress because of the way professionals deliver it, hence, it facilitates patients to better focus on individual goals. One unique result was to recognize that CE professionals are consistent in expecting patients to use newly learned or re-learned skills, movements, abilities, functions from the time patients achieved it, also from that point they were instantly focusing teaching the next level of (the) performance. Steve noted that the conductor was so consistent that she did not help him to execute a task again after he performed it alone:

She [conductor] always had to help me to roll over on the plinth.

Once she saw I did it by myself she never helped me again.

(Steve – Marie Tooth patient)

This kind of consistency therefore is described as one of the most important tools of CE and seems to be a strange instrument in rehabilitation of adult physically disabled. This characteristic of CE correlates with the general high expectations of conductors and the perseverance from both clients and rehabilitator.

Perseverance from both clients and rehabilitator – Pygmalion effect

Some physical exercises practised in CE attest to be challenging for some patients. The exercises are sometimes described as tough work, requiring perseverance and dedication from patients as well as from professionals, what seemingly they all have (Schalkwyk, 2007 p.138). Furthermore, as the present research in addition propose, family members and/or carers also facilitate the patients' learning as they are encouraged many times to be present at CE sessions to observe and learn how to help challenging tasks at home. Mrs. Robinson shared that one of the reasons they returned to CE was this kind of perseverance of professionals:

They are [conductors] very nice and concerned. They seem to worry about you. Having sat in on the procedure I can see the re-training, repetition and doing things differently. And that's one of the main reasons we come back. They believe in your progress.

(Mrs. Robinson – wife of Parkinson's patient)

Brown (2003, p. 21-32) assumes that it is because of professionals' "belief in learners" highest potential regardless of the disabilities they presented which meet the philosophy of CE. Analysed data for the current research correlate and affirm Brown's statement and finds that conductors expect patients to perform at a high level. Susan, one of the interviewed conductors, explained that how and why conductors' expectation could remain high:

I often find, when asking a child to do something challenging 'don't worry, I won't let you fall'.... but in order to be in a position to ask the challenge of them they must already know this – I'm just reminding them... and they know that I may let them fall but I will make sure they are safe and it doesn't matter because I believe they won't fall! Self-belief is something that many people lack, but that children and adults with disabilities crucially need. However, you can only develop self-belief if someone else believes in you. The conductor ALWAYS believes in the child or adult. They must be shown this through words, eye-contact, and physical contact, praise, facilitation etc... Otherwise there is no way that the individual will ever try something that is hard. This

must also be sustained for long periods as it may take months or years to acquire a skill. If the person has to constantly try at something they need to know that someone believes they can achieve it or they will stop trying. So this belief puts us in a position to ask the challenge of them all the time. The conductor's expectation is therefore always high.

(Susan – conductor)

Earlier in the 1940s and 50s it was found in education that teachers with high expectations of their students directed specific behaviors at them, and the productivity of students were likely excellent (Rosenthal, 1974). Some years later this effect was defined as Pygmalion or Rosenthal effect (Rosenthal, Jacobson 1968).

Regarding to the present study's outcome, Pygmalion effect is a detectable related profit of CE and the CE professionals do not deny that expectations are different or higher at CE than at other rehabilitation methods in terms of goal setting however, reliable data is currently not available.

Oliver (1989) - without having consulted with patients who had experience in CE - criticised CE in the past as a "military kind" of rehabilitation because of the "force" that patients go through and claimed CE to be imperious. Regularity, routine, consistency, challenging physical exercises and tough

work obviously could suggest coercive approach however, as Read (1998) warns, without rigorous research incorrect conclusions might be made. Indeed, this present research which aimed to discover facts through phenomenological methodology and analysed information coming directly from people who have lived participatory experience in CE, suggests that the challenging nature of CE in fact increases most of the patients' inner drive and will. A good example is what Andy stated for instance about his own motivation:

And I don't care what they say, Anna [the conductor] is top dog for me. Yeah that's what, she keeps really on top...You want to work for her... and it is very important to me that I keep going.

(Andy – Parkinson's patient)

Perseverance from each side of CE environment rising from the philosophy of the approach and facilitates working patients towards orthofunction. Victor Frankl (2000) suggested that there are three ways in which human find meaning in life; doing something creative, loving someone and

"Facing a fate we cannot change, we are called upon to make the best of it by rising above ourselves and growing beyond ourselves, in a word, by changing

ourselves... (to) see in life's transitoriness an incentive to take responsible action." (Frankl, 2000, p. 142).

The present study suggests that patients, family members, carers and professionals challenging to grow beyond themselves which serves a collective perseverance, and indicates to take full effort for responsible action.

Group ethos facilitates the individual

Group ethos works like a micro society so that members adopt and meet common beliefs and rules. Earlier in this thesis CE was described as philosophy of life which guides people's life style. Group setting offers the possibility that smaller group of people within CE society could develop their own group ethos. Evidence of the benefits of doing group work in CE, such as sharing each other's success and progressing from watching, hearing others in the group was found by Schalkwick (2007, p.133-134) and she stated that the opportunity of being with other group members was helpful for learner patients who could not succeed immediately.

According to findings of this study CE seems to facilitate patient learners so that they are able to lift themselves from an "existential vacuum" (Frankl, 2000 p. 141) i.e. from hopelessness, dreamlessness. Sonia spoke of the common ethos in one of her groups that talked about how emotional state links with the physical condition:

The emotional state links with the physical condition. When they are coming here [patients] we can tell from their movements, communication, from carers what their emotional state is. From the moment they come in we've got a pretty good idea of what state they are in. If they are feeling low, we can facilitate that in the actual session. If someone's having a really good day we will (for example) bend their legs in the maximum possible way. If they are feeling low and worried we will facilitate the bending of the legs in a way that makes them feel like they can achieve something. So you are not, it's almost back to when "you correct them/when don't you correct", but if I tell them it was good, because of the situation they are in, then they will do it again and again. Confidence will grow and then I can correct them. It's really the whole thing is based on how the person is solving not the mechanical structure and that is our common ethos in the group.

(Sonia – conductor)

Brown (2003 p. 21-32.) concludes that CE's belief in patients increases their confidence in themselves and lends a new motivation to continue their

renewed relationship with their own bodies furthermore, aid them to get in touch with a sense of self identity, albeit often a new identity. A collective helpfulness also found to be part of the ethos that CE groups develop which includes physical help as well as emotional and social support from each other. Werner et al. (2003) writes that these groups make patients feel stronger in themselves and more able to overcome their own everyday life. Camaraderie indorses to positive experiences says Schalkwyk (2007 p.147) and ensures that CE group members through positive experiences generally increase self-confidence.

CHAPTER 3 – THE CE PROFESSIONAL

Specific relationship with clients

One of the fundamental assumptions of CE is that rehabilitation, considered as part of a pedagogical process, assumes a new framework to the patient–rehabilitator relationship. Indeed, the complete organizational pathway of CE is different from the traditional view of rehabilitation at a medical centre and, therefore, we can recognize that CE centres are educational places rather than medical institutions. Also, most CE centres function with outside agencies and provide outreach services in schools or other settings. In addition, home visits and additional support for families or carers are often provided (Professional Conductor’s Association, 2009 ‘np’). Over and above this, CE professionals work in teams, planning and implementing complex rehabilitation programs, as teachers do in schools, by the use of effective teaching-learning strategies based on a comprehensive knowledge of the individual patient. These facts establish the possibility of building a lesser, or non-medical relationship between patients and professionals.

The relationship between patients and professionals has been described by Shalkwyk (2007 p. 167) as a “sharing relationship”. In her research she found that there was no separation between patients and

professionals as in a traditional rehabilitation unit. Cottam and Sutton (1986 p.173) argue that humanistic qualities of warmth, empathy and genuineness are particularly effective in CE. Lou's words about the relationship between conductors and clients demonstrate a deliberate concept of creating a specific patient-professional relationship in CE. Also, he talked about his very personal experience of how, as a freshly graduated conductor, picked up his respectful attitude towards clientele:

... [relationship between professional and clients] is definitely a positive thing. It gives them a number of things it makes them more comfortable to ask for help if they need it. Or again if they've experience something or they can see someone in their group and they can use that information and it may help them. They pass that information along and it would give them a good feeling. So yes, it's a very deliberate thing that's done and in that setting it works really well. They get the introductions out of the way so they are focused when it's time to work and I always felt if I could get in there early and develop that trust with them and myself I could just...it made my job a lot easier. The trust is there. Trust is the key word, someone who is not going to let them down. If I was working with someone who was a similar age,

when we chat we'd have conversations that were appropriate to two men people of that age. So providing where do you find the balance between remaining professional and you want to help and to care for the person. Make a clear boundary. Then when you are working with people who are considerably older in some cases - had a stroke –there's obviously a clearer age gap between those people and myself. At that point in my life I was newly qualified so I was very careful I didn't want to sound bossy, I didn't want people to think I knew better than them. So I always tried to be very respectful. With how I was treating them. I wanted them to remain dignified and to have dignity, sometimes when I was asking them natural things that they did comfortably. So that's another balancing act as well. It something that all conductors, well not all conductors, think about more. And I know during my training we moved to different areas we were asked to consider, how we would approach our users so it's something to think about. I don't know how that is in other professions, I know it's very key thing to us. I think it was like we were told to work with each person on an individual basis. You've

had different relationships and you just try and maximise the relationship between each person.

(Lou – conductor)

Isabella, a family member, and Nathan, a CP patient differently described the (specific) relationship with professionals but both expressed the friendliness:

The staffs are really friendly; they will do anything for you. You can approach them any time with any kind of problems. Very supportive.

(Isabella – Parkinson's patient's wife)

Their [physiotherapists] attitude was come in, do the work and just go home again. It was different at NICE [a CE institution]. It was a friendship. Even now at Legacy [another CE institution] the relationship is friendly, professional mixed with wacky sense of humour...

(Nathan – CP patient)

Indeed, a “friendly leader attitude” of a teacher is a basic requirement and conductors should acquire it during training (Hári et al, 1991. p. 106 -113). The present study reveals that, from the professional side of CE, there is a great effort to learn about patients' personalities and medical needs in order to

create a true understanding of people's situation and of their needs and to deliver a complex, fruitful rehabilitation which benefits their clients. The following quotes of two conductors exhibit how important they think the personal factors in CE rehabilitation:

And for example here, we've had people who have been discharged from therapies purely because they've been told they lack motivation or that they are not trying hard enough. Whereas we [CE] would never get to that stage because you need to lock into that person first. Once you have locked into that person, what did they do before? What were their interests? What was their lifestyle like? What type of person were they? Once you can do that you can bring them to (?) their disability (?)

(Sonia – conductor)

As a conductor it is always my first job to find out who is my client. What will motivate my client to learn, by what way clients they motivated to move forwards, what inspires their lust for life? When conductors know this then we can start the teaching process. (Diana – conductor)

A frank, direct, friendly and consistent relationship is what conductors try to create with their patients and a close environment. One of the research professional participants put it this way:

The difference in CE is that we are involved in the development of a personality! The first lecture on the first day of training as a conductor was about the conductor - client relationship – not about facilitation or equipment or even CP - but about the huge importance of the interpersonal relationships within CE and essentially that without these relationships there is no CE.

(Susan – conductor)

On the other hand, patients and their families apparently experience friendly, positive, helpful, motivating interpersonal relationships with conductors as has been found in data. Participants often describe their relationship with CE professionals mixing with conductors' actions towards them. For instance, [the conductor] "is a bit bossy but very friendly", "patient and reliable person", "beyond the belief", "beyond the call of duty", "very informal", "positive interactions indeed", and again, [the conductor is] "altruist, with low tone", "interested in us", "chatty but very concerned about what to do". It was evident from the data that several facts support the development of

positive relationships between parties. Patients, family members, and carers remarked that conductors “know” them and that they perceive a high level of commitment in the care they provide. Patients are involved in problem solving and feel that CE professionals are also concerned about issues outside of CE. Moreover, the attitude that “words like ‘cannot’ seemingly do not exist in CE’s dictionary” and the fact that patients, families are continuously motivated, and frequently experience some improvements despite the medical prognosis of conventional rehabilitation professionals. Feeling increasingly confident, nurtured and valued opens them to very friendly and sharing interactions.

It was also found that interaction and communication during a CE session seemingly has a frame; by arriving and preparing to a session is very informal; friendly, direct type of interactions. However, when focused education/rehabilitation program starts, in a more explicit professional manner with consistent work interactions, a clear teaching/learning partnership could be detected. Then, after a task series, during a coffee-session, interactions returned to a flexible and warm tone of communication. One thing, however, that is consistent is the relationship based on a learning partnership (Gonczy, 2011) and interactions which are based on positive mutual regard.

Empathy

As previously noted, for Hári et al (1991. p. 106 -113) empathy is one of the human capacities which conductors are supposed to understand and develop in themselves during their training. This cannot be taught but it can be learned so professionals who work with people with comprehensive disabilities need to develop their empathy through practice in order to better understand the needs of others (Beck, 1995). Sonia assured me about empathy at CE and blazoned how conductors supposed to be able to see situations:

There is empathy of course and you can only develop empathy if you can put yourself in that person's situation. So when we are looking at why something has happened the conductor has to be able to look from the participant's eyes out not from their eyes in.

(Sonia – conductor)

Empathy itself is a diverse phenomenon that has received considerable attention during the last few years (Decety & Svetlova, 2012). In the CE literature empathy usually relates to “cognitive empathy”, the capacity to recognize, comprehend and mentalize other people's affects (Carré et al, 2013). With regard to the findings of the present study however, CE

professionals explain their empathy as being more like “critical consciousness”. Viktoria express it this way:

I do not feel sorry; it is a kind of empathy. It is better to say I try to understand everybody's [patients, clients] medical and personal issues and from that point of view I create my own conductive education way which is I believe super conscious of the cognitive and physical possibilities [of rehabilitation]. I am critical with my patients but full with love and they seem to accept me this way.

(Viktoria – conductor)

The empathy of the CE professional is not simply regret about a patient's situation but rather a professional understanding of the initial stance to adopt and the perseverance required to facilitate patients. Personality plays a very important role in our interactions and empathy facilitates this process (Yashwant, and Kaplana, 2012).

One of the patient participants reporting a conversation with a conductor, and he states:

....and I got this funny little foreign voice on the end of the phone.

[...] and she seemed to be empathetic and pushing me, oh you must do it, you must do it, really no, no no it's not a problem, however, whatever, you must do it. And I more or less felt obliged to do the sort of ... the way she was just asking me.

(Andy – Parkinson's patient)

Meticulously observant

Observation, as one of the most important tools of CE, is very well documented (Hári, 1982, p.88; Pető, 1998, p.65-66; Hári, et al 1991; Cotton and Kinsman, 1983; Akos & Akos, 1991, p.21-23; Akos and Hári, 1989; Horvath, et al, 2000; Brown, and Mikula-Toth, 1988, p.10-13, CE Glossary, 2012, p.51). In the literature it is described as an integral, continuous part of the global practice and is thought to have a multifactorial role. CE's special way of observation, the so-called conductive observation, includes (i) operative (ii) comparative and (iii) and progressive forms.

(i) Operative observation is a dynamic process, by which interconnections can be found and situations are created which assist with the solution of particular problems.

(ii) Progressive observation is required so that the educator can carry out, and check every step of development. It can be broken down into logical steps – the point of departure being Conductive Education.

(iii) Comparative observation: Depending upon the effort needed to perform a task the same performance can be judged quite differently and the requirements for future activities are set accordingly.

(CE Glossary, 2012, p.52)

Patient participants in the present research attested to the fact that observation was important in CE through the way in which conductors treated and interacted with them. For example, being reminded to correct their position, use their body or body parts in a certain way, and use a particular technique to execute tasks. Steve and Ben experienced and shared that:

First of all, I think she's [conductor] extremely observant. I get the feeling she's looking for every single thing I do. She has a good balance between her professional relationship and a sort of social relationship which is chatty and pleasant... She could be talking to you very pleasantly and then (she will say) your feet are in the wrong place.

(Steve - Marie Charcot Tooth patient)

...she [conductor] is excellent and she's positive and she doesn't miss a trick, she's watching... there's six of us in our group, she's watching us all at once and correcting posture and feet position and backs, back posture position.

(Ben – Parkinson's patient)

Also, if something had already been achieved and was not being used in the learned way, they received immediate feedback. Furthermore, patients reported conductors' attentive, observant attitude in the context of the whole person, the life of the person. Many patients mentioned that CE professionals are 'always at work' meaning that CE people are reminding them about movement, function, social behaviour, etc. not only in CE centres but anywhere they accidentally meet.

After the interview a CP patient told a story that he accidentally bumped into his conductor at Liverpool World Museum where the conductor wanted to shake hands and he [conductor] expected to use the patient's right hand and facilitated him like they were in CE session. Then chatted with him and before saying good bye he reminded him bending right knee higher whilst

walking. The patient meant that was outstanding and very nice from the professional and thought it was unbelievable that he is always at “work”.

(The researcher’s note)

This could also have a disturbing and stressing impact on patients. However, based on analysed data, patients appear to experience this attitude as a caring, nurturing, mentoring approach and they consider this fact as an important difference between CE and other traditional rehabilitation services. The following quotes demonstrate clients’ lived experience of CE in this case:

...if your exercises are a bit slack you’ll find they’re being repeated until they’re right, which is what we’re there for, to gain benefit from these exercises. And if we’ve got a weak spot it’s sussed out immediately I would say, and the vision that these people have got doing the conductive education, I mean don’t forget there’s six of us sat there, and perhaps when we do the exercises when we’re sitting at tables doing the arm stretches and things like that. If one of your heels is pointing outwards or inwards it’s spotted straight away, so somebody’s taking a great attention to detail definitely to make it... Which is what we want you know

because we want to benefit from it if we can. There's no downside to that part of it and I also find this is caring...

(Elisabeth – MS patient)

One thing I remember, I was sitting in the coffee room waiting for David and she [CE professional] came through and said, how else can we help you, what else can we do? Who else is going to say that to you? It was just so lovely. And I thought it was wonderful.

(Mrs. Robinson – wife of Parkinson's patient)

You know like I said the call beyond the call of duty that is given to you by the conductive education it was incredible. And I can only assume that happens in all the different centres as well and its part and parcel of it. It's a caring, nurturing side that I've never seen in life before. I mean I tend to think that in somewhere like Britain we're spoiled to death, a lot of the countries, probably even your own country, perhaps people with Parkinson's don't get... even though this is where the Peto Institute originated, don't get the chance that we do. I wouldn't be surprised at all, that would be my way of thinking, that just because this is a richer

place we benefit more, which seems totally unfair. I mean this is... started in Hungary, that's the way I look at it and I think we're spoiled to death basically, absolutely, lucky, lucky to be part of it. There's nothing else for us, nothing else, which helps to a degree but in a different way, apart from that I can't think of anything, there's nothing they do, there's drugs and that's it.

(Thomas – Parkinson's patient)

Family members and personal carers suggested that CE professionals seemingly 'know everything' about the patients - often more than they do - and they are continuously informed of progression and encouraged taught how to deal with certain difficulties at home step by step. These participants in the research find it very important and unique that so much time and interest can be invested in their own flesh and blood. Rebecca was for example very thankful for the professionals and she mentioned knowledge and experience regarding the staff:

...words cannot express the gratitude I feel for the staff here.

They are extremely helpful. The conductors are knowledgeable and very experienced. We are very thankful and pleased with the

service here....and she [conductor] spent a great deal of time helping us.

(Rebecca – mother of Head injured patient)

Sonia underlined the personal factors, too:

They see that specialism and appreciate it. They know, we know their partner inside out – all of us. So they are not just ringing up and asking to talk to/about Mr Jones. Someone doesn't say, I can't remember Mr Jones, I'll get his notes. We don't need the notes. They respect the fact that we know about their partners. We have participants who have been coming ten years, they've been coming every week. We know all of the wider family. We'll know spouse, children, and grandchildren. Some people have quite an extended family (carers, conductors and participants) – so there's an option, they can have it or they don't want it.

(Sonia – conductor)

Jack, a husband of a patient, thought to be very important to note that CE is specific to the disease, too:

I think something valued that we haven't mentioned about CE is that it's specific to the disease, not only that it's specific to the person. I think that's absolutely crucial.

(Jack – husband of a Parkinson's patient)

This implies ongoing observation from the professionals and correlates with the literature review. From a professional aspect, it has been discovered that conductors' practical training takes place in placements where senior conductors facilitate students in how to approach clients in a professional way. However, it is not clear if they receive specifically focused psychological training in approaching people with post-traumatic stress disorder.

Reactive attitude

The literature on reactive attitude(s) indicates that, as a scientific phenomenon, it first came into focus in the education philosophy of Peter F. Strawson, an English philosopher. Strawson (1974) has suggested that, "Reactive attitudes are essentially natural human reactions to the good or ill will or indifference of others towards us, as displayed in their attitudes and actions."

According to Hurley and McNamara (2009 p.17) reactive attitude:

...are forms of positive or negative affective regards for others (or ourselves) that are ways of fully taking up their (or one's own) normatively significant conduct and that thereby constitute impairments or enhancements in our relationships with those others (or oneself)

and also stated that reactive attitudes accomplish three things:

- (i) generate changes in relationships
- (ii) positively or negatively and affectively reorient people; normatively and significant effect
- (iii) Conduct the normatively significant conduct of one party in a relationship must be properly recognized by the other party to constitute impairment or an enhancement in the relationship

The patient and family member participants of the present research clearly identified the general working attitudes of CE professionals, as former themes of this thesis suggest i.e. friendly, positive, observant, consistent, etc., and the participants suggested that reactivity, as an approachable manner of conductors, tightly relates to the observant attitude discussed above. The quotes of Steve (below) were already used to underline the observant and consistent attitudes of CE professional, but at the same time they are good examples how observant and reactive attitudes work together:

First of all, I think she's [conductor] extremely observant. I get the feeling she's looking for every single thing I do. She has a good balance between her professional relationship and a sort of social relationship which is chatty and pleasant... She could be talking to you very pleasantly and then (she will say) your feet are in the wrong place.

She [conductor] always had to help me to roll over on the plinth.
Once she saw I did it by myself she never helped me again.

(Steve - Marie Charcot Tooth patient)

Patient participants recognized emotional, social, task and function oriented reactivity from them. Regarding the prior one, they emphasize a constant positive emotional approach which they believe is very conducive. The therapists' emotional reactions to the clients, has been broadly discussed in the context of other therapies (Kernberg, 1965, Winnicott, 1949, Reich, 1960) and contemporary relational theory (Benjamin, 2003). A therapist's reactions to patients are believed significant to monitor and work with them and counter-transference reflects the therapist's emotional engagement (Heimann, 1950, Singer and Luborsky, 1977, Weiner, 1975).

Outcomes of the present study suggest that a greater early positive reaction to clients, especially liking, keenness and friendliness, enjoyment and optimism about their future is consistently associated with significant changes (reductions) in patient resistance. Andy made it very clear that his conductor's stance at the beginning of his CE experience helped him a lot to change his resistance of his rehabilitation:

I'd applied on the Monday....then her friendliness and optimism...it's just like somebody gave me a good shaking and said now look here, look what you've got, you've got a house, you've got a car, you've got your kids, you've got... sort of got your health, get off your arse and... And after that day, once I'd come to terms with it, I was fine ...She's captured...I don't know.... oozes stability, friendship. She sort of offered me a new opportunity...

(Andy – Parkinson's patient)

However, there is still little known about conductors' contributions to client resistance therefore, future research should investigate particular patterns about possible conductor's negative reactions in order to more elucidate the

relationship between professional's negative emotional reactions and patient's resistance.

Regarding the task and function oriented reactive attitudes of conductors both patients and professionals commonly declared that during the teaching or learning process, reactivity serve as accurate, meticulous feedback and at the same time there is the expression of a high level of expectations and appreciation from clients. For example, Thomas, a Parkinson's patient, told that during carrying out a task series; when completing a movement if it is not executed in the expected way "exercises are a bit slack", the conductor will be reactive and stops the activity, and explains a better way of tackling the task and then makes the participants repeat the exercise. Just like a musician conductor would do it in an orchestra rehearsal. In addition, from the moment the client is able to progress their movement or function they will always be expected to perform the task in that way as Steve's foregoing quote demonstrated. From the above written information – emerged from data grounded in interviews - one could conclude that Hurley and McNamara's (2009 p.17) three points about what reactive attitude cause is seemingly happening and the reality in CE i.e. the relation between parties are changing which reorient patients.

Positive language and body language

Positive regard for learners in CE settings was discussed earlier in this section and it was introduced that conductor professionals are trained to act, using their own personal pedagogical attitude of positive psychology in order to encourage patients towards a “positive self-awareness”. According to Hadfield (2012 p.19) the language reflects what we believe is possible and what we will do about it. A very consistent outcome of the present study is that patient and family member participants of the research suggest that CE professionals and generally CE involved community, focus on positive thinking, and this is reflected in the language they use, which is overall encouraging, motivating and in fact, positive language. Nathan a CP patient reported for instance in his interview that his conductor and people from his CE institute were ‘always encouraging, motivating’ whilst addressing him and that was both in language and attitude of people caught in the act. Patient participants of the research point out, that positive communication of conductors are not confined to sessions only, but it is commonly experienced in any contact situation. It is affirmed that conductor and assistant participants of the study expressed that they consciously reflected on positive feelings regarding clients and positive language knowingly used. Susan, conductor, summarized this characteristic of her profession:

Conductors always use positive language that is emotionally and psychologically supportive and motivating. This becomes very habitual to conductors and they use it with clients, carers, other practitioners. They will instinctively use it in any situation when conversing both within the formal CE sessions and outside of it.'

(Susan – conductor)

Sonia, another conductor, explained about the meta-communication between patients and conductors during sessions:

They [patients] are concerned that they are doing their best thing. That interaction between the conductor and the person, most of which is normal, will enable someone to feel competent; Yes, I'm doing it right! And the fact that you smile at them; Yes, I'm doing it right! So a lot of non-verbal feedback for adults. You don't want everyone to know where you are it's just between you and the person.

(Sonia – conductor)

Based on my own observation in different CE settings and sessions, I also experienced the use of positive language as well as an intensive use of

positive body language, gesticulations and mimicry. I felt they were more actively used, in these sessions, than people generally do so in everyday life, and however, this obviously needs to be further investigated.

Ability focus model

Many client participants in the study humorously remarked, several times, in their narratives and interviews, that the word 'cannot' is not known in CE, as the fact that conductors always appear to find solutions to a problem or arising problems. Most of the time, patients, and family members are involved in this process. Clients do report that they feel to have been taught to realize their useful existing abilities, which they 'often forget' and based on those abilities they build a plan and strive to work towards this plan with professionals. Elisabeth, an MS patient, explained how they learned taking steps forward and mentioned that she did not realized before CE that she was still able to execute some of those movements:

Taking a step forward was broken down into the number of smaller, individual movements that achieve forward motion, and first of all we practised those. I did not know I was able to do them. Then we put all of those smaller movements together...

(Elisabeth – MS patient)

Conductors also informed me during interviews that they consciously focused on the patients' abilities and celebrated every little success rather than spotlight their disabilities. Sonia explained it very clearly:

One of the main tools that we use is we are not looking at what a person is or isn't doing... at the end of the day one of the things with Conductive Education is to say what is the level of ability with the person and how can I build on that, not what they are missing. I always think that the medical model works on a deficit model; these are the things you can't do and what we are going to work on. Whereas with our model we say I know there are things you can't do...what I want to know is what can you do and how can I build on that.

(Sonia – conductor)

The focal point is therefore shifted from inability to ability. This approach seems to be helpful to increase the clients' self-esteem and on their abilities opposed to their disabilities. Interestingly, CE literature hardly expresses this, despite the fact that Schalkwyk (2007 p.124-130) pointed it out several years ago. This facet of CE would need further investigation as well, in order to better understand such an important element of its rehabilitation approach.

Values, appreciation of clients

The holistic elements, person centred focus, positive regards for learners with the use of positive language alongside with CE professionals' perseverance, empathy, specific relationship to clients, and focus on ability rather than disability discussed in this section are characteristic of CE. These characteristics could suggest a possible high level of reciprocal appreciation between professionals and clients. According to Epstein and Street (2011), to be appreciated in person centred practice means:

...deep respect for patients as unique living beings, and the obligation to care for them on their terms. Thus, patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care and their wishes are honoured (but not mindlessly enacted) during their health care journey.

Patient and family member participant's interviews reflected on their being well respected, valued and appreciated individually, not as like a number, and they reported of feeling known, respected, involved, engaged, and acknowledged.

...we are very much appreciated here as we are...

(Mrs. Gridley – wife of a Parkinson's patient)

Little literature can be found appraising the framework of CE's professional approach towards clients. Hári (1991, p.48-51) writes about conductor's aims and outlook in her course book and there she portrays a friendly, communicative but professional approach of CE professionals. Also, Brown and Mikula (1997, p.125 – 126) describe CE consultation in their practical guide and suggest deep respect and appreciation from conductors towards their patients. The analysis of conductors' interviews, member checking and my further investigation in this area made it clear that there is a conscious appreciation of the client and it is a basic requirement of a professional in CE situations. Susan made it obvious that she appreciates clients and she tries to create a trusting relationship with them:

From the first interaction with a new client and his family members I try to make sure I have already learnt their names and try and remember something about them to make them feel expected, welcome and comfortable in the CE environment. This sets a precedent for how we treat people individually in CE and helps to work towards a trusting relationship between the clients and the conductor. It is crucial. ... and ultimately beneficial.

(Susan – conductor)

The conductor experience and acquire this attitude during their practical trainings. Conductive clients often describe that they are invited by professionals to participate in different actions and they believe that conductors have the initiative drive to approach them, and that conductors are self-starters in interactions. Here is a short collection of how CE client participants referred this process:

“She’s captured [me]...”, “the conductor welcomed us and invited to watch the session”, “She never miss a trick”, “...her laughs and jokes are...”, “I sat there, she came and we had a chat, and there was just something about the warmth...”

I identify this characteristic of CE as *proactive patient appreciation* since it elicits a feeling of reciprocity, making patients, family members more likely to feel on the same platform with the professionals.

Positive approach

The Positive Approach as a characteristic way of dealing with individuals, that emphasizes affirmative, and motivating elements of life has historical roots in ancient Greek philosophy and twentieth century Humanism also articulates theories of the good life, pleasure, wholeness, purpose,

health, and actualization (Duckworth, et al., 2005; Ryff, 2003). In addition, empirical work exists on adaptation, resilience, thriving, spirituality, and growth (Aspinwall and Tedeschi, 2010). Positive psychology's contribution pulled these different areas together under one umbrella (Peterson and Park, 2010) and provided a conceptual map that has been used in many areas. Thus, the positive approach in general and in health services is emerging from positive psychology.

In the earlier discussion CE was described as a person centred approach, characterised by a positive regard for learners. Later, focusing on group setting of CE it was found to create a positive atmosphere in working groups and develops friendly relationships between clients and professionals. Conductors' empathy, the use of positive language, and the focus on ability rather than disability were also addressed. These characteristics of CE are per se, enough to indicate a positive approach to learners. However, positive effects on clients' levels of confidence can also be found in the interview data in which participants describe the conductors' positive approach as early as during their first assessment in the CE settings. Here is how Mrs. Gridley explained the first meeting, an assessment of her husband with the professionals:

Well, Anna [conductor] was very thorough when she assessed you wasn't she, and Katie [conductor], both fair. And they did various sort of tests with you, and they talked you through what they were doing and why they were doing it. That was very positive. And I think that impressed you. I don't know, it was so different to anything you've... and there is hope that comes with it doesn't it that if you can do something yourself and make the effort to go there.

(Mrs. Gridley – wife of a Parkinson's patient)

The data revealed that the CE professionals' positive approach includes the provision of a sense of hope, regardless of a person's disability. This overt provision of hope seems to encourage learners in working towards reaching their goals as far as is possible. According to Hadfield (2012 p. 3) positive thinking is not just the feeling we have when good things are happening to us, but more like being able to maintain that feeling of hopefulness and motivation regardless to what is happening in our life. Sonia expressed it as follows:

They [patients] are concerned that they are doing their best thing. That interaction between the conductor and the person,

most of which is normal, will enable someone to feel competent.

Yes, I'm doing it right! And the fact that you smile at them Yes,

I'm doing it right!

(Sonia – conductor)

CHAPTER 4 – WHAT HAPPENS TO ME? WHAT’S GOING ON?

Feeling looked after, nurtured, valued; respected

According to Clucas and St Claire (2011) very little research in the UK has focused on studying patients’ experiences of feeling respected. The meaning of dignity for patients in health services includes feeling comfortable, in control, valued and respect (Leung 2009). Earlier discussion indicated clients feel comfortable and looked after in CE places because of good and continuous interpersonal relationships between them and the professionals and they assumed that everything related to their rehabilitation is under control. They receive up to date verbal information, even written reports if requested, about anything linked to their rehabilitation almost at any time which was considered to be an extraordinary service. The value of being treated with unconditional positive regard was also evident in participants’ interviews. Participants described how they felt cared for and nurtured at CE, creating a feeling of belonging there despite the group setting. Data also has shown that people with more positive self-respect sought positive information allowing them both to self-enhance and self-verify whilst clients with less self-respect, sought positive information to self-enhance, but negative information to self-verify. This means that participants with less self-respect seemed to be happy getting positive feedback from professionals but

at the same time they wanted to be known and understood by fellow patients according to their less positive feelings and beliefs. For example, David, a head injured patient, explained that he was pleased about a lot of things that he already learnt at CE – he obviously noticed them - but he wanted others to recognise that he is not as good than before:

I am seventy-five per cent better and I am happy about it...whereas I think of myself of being, still being well not as able as I was ...

(David – Head Injured patients)

CE professionals reportedly look for altering this attitude in less self-respected clients however; the study did not suggest possible approaches. This area should also be further investigated by future researchers.

Perceived commitment from conductors

Health care providers are expected to offer quality care at all times (Pitney, 2010). Conductive professionals' roles require them to deal with multiple responsibilities therefore one can assume that these responsibilities may challenge conductors' motivation and commitment and could lead to negative consequences. The remarks of clients' however express the opposite

and they reported a high level of involvement from conductors in the care provided towards them. Mrs. Smith underlined the 'wonderful' service:

Wonderful. They [CE professionals} make you do what you really need to do. They are very nice. No-one ever did anything like that. You talk to these people and you put their mind at ease. They come in here and they see what's going on...and there's no pushing at all. You sit and you look, and if you think it's for you then you take it on board...No comparison between the hospital and here. Similarity in a way, but nothing as intense as here. Intense physically and mentally. And it gives people a whole new meaning, because hospital is so different from here...Here it's overall mentally physically, concentration the whole lot is dealt with here. It's just wonderful.

(Mrs. Smith – wife of a Parkinson's patient)

Participants particularly commented on how CE professionals were committed to everyone's individual progress. They experienced high levels of dedication and they commonly described that they did not feel they received more or less attention than the other clients. The analysis of conductors' interviews affirmed the clients' perceptions and due to a smaller community of people involved with CE rehabilitation, conductors felt they had a better

chance to develop humanistic relationship and commitment towards clients' progress. These regular and frequent encounters between clients and professionals also provided a stronger foundation to develop a service highly dedicated to individual cases.

Learning – Transforming

To study the possible answer of what happens to clients, especially to adult patient clients - from different diagnosed background - experiencing CE, is an exciting research activity since no previous study has been conducted. From a CE professional's perspective, it is expected that patients develop an orthofunction personality (CE Glossary, 2012. P. 52-53) by living as actively as possible (Hári, 1991 p.10).

The focus therefore became what patients had experienced through participation in CE and their narratives. The resulting interviews were very informative. From the data a general idea emerged that patients talk - at first hand - about their hard physical exercises which lead them to function better at the physical level.

Well I'd describe it [what is going on in CE] as a lot of exercises that are geared towards the processes of everyday life...

(Thomas - Parkinson patient)

However, reasoning why they stick to CE for longer if it is (only) a hard physical challenge, patients articulated a much deeper understanding of what is going on. It was commonly stated by participants that they gain skills and knowledge through an experience of exercises and different life situations in the group. Also via the numerous things being taught by conductors and self-learned through watching others.

Ben for example states:

It [CE] improves my life, social life but I mean like as we're doing this now we're just having the first session after Christmas. I feel invigorated now and I was looking forward to getting back to it, you know it is something I miss when we're not doing it...emotionally it's great to be with other people with the same condition. And also I can see them doing what they're being asked to do, whereas I can't actually see myself. I learn techniques... I have some techniques in my brain so that in my normal life I can employ those techniques if I feel... CE is off-putting people builds confidence too.

(Ben – Parkinson's patient)

According to Sarason (2004 p. vii) learning “occurs in an interpersonal and group context, and it is always composed of an interaction of factors to which we append labels such as motivation, cognition, emotion or affect, and attitude”. Szántó (1986 p. 91-93) adds that learning is acquiring consciously or unconsciously new, or modifying and reinforcing existing knowledge, behaviours, skills, values, or preferences and may involve synthesizing different types of information. However, it is understood, learning is clearly complex and contextual. It happens in continuum as a process and thus builds upon and is shaped by what we have already personalized i.e. embodied. Learning also produces changes in the organism and the changes produced are relatively permanent.

Patient participants of this research stated that they learn new things, and that they “learn” in different ways with CE, as the following illustrate:

I have learnt now techniques of squaring my feet, straightening my knees and keeping the balance correct to do it. And every day of the week I remember conductive education techniques.

(Isabella - Parkinson patient)

She [the conductor] was teaching me think about what I was doing instead of doing things automatically. When I move my arm

I think about it, but the way I do it is totally automatic – I don't think about moving this muscle and this muscle – it's totally automatic. But once that automatic system breaks down then nothing moves and it seems to me that there could possibly be a system of learning to move muscles by thinking about and thinking about which ones should move and how you move. And it just worked to me moving leg or foot. It's about thinking doing it correctly. Thinking where it is how it is.

(Steve –Marie Charcot Tooth patient)

... when I get up out of the chair I remember the correct [taught] way of doing that [standing up], and sometimes as I say I hear the words in my brain how to do it

(Andy - Parkinson patient)

...the senior conductor would stand in the middle of the room and say achieve putting a ball between your legs by the count of five – I'm only using this as an example I hope you don't mind – and there would be a chair by the side of your plinth, because more

often than not we'd work on the plinths. The conductors would sit on these chairs by the side of you and just study, explain and if you needed help.... then tell how you were progressing.

(Nathan - CP patient)

Through reflection on past experiences, individuals not only reflect on the changes that are significant to them, but also learn from their own experiences and grow a sense of connection with their future and present life (Dewey, 1916). It is suggested that learning, constructive, disciplined education, pedagogy is able to transform both learners and teachers (Owen, 1991 p.16) Transformation is a complex effect that could and should happen to learners during the teaching – learning process.

"I believe that the teacher is engaged, not simply in the training of the individuals, but in the formation of a proper social life." (Dewey in Pound, 2006, p.21). Freire (1972) describes that education is presented as a world-mediated mutual process and it is to make the individual as a whole actively engaged in society.

Participants shared their lived experiences in CE and openly talked about how they were re-forming their learning skills, re-shaping their social attitudes, re-building a sense of self and planning their futures. As a matter of fact, research

participant clients who have been involved with CE firmly expressed that they have been through some transformation process.

I started to think about what I'm doing all the time. I'm even thinking about getting enough rest so that when I am active I have enough energy. Thinking about my diet... thinking about my sort of being in the environment and not just can I move my foot, but how I conduct my daily life, but how I conduct my life physically...and thinking about life, this life.

(Steve – Marie Charcot Tooth patient)

Being touched by a new environment and practicing CE on weekly basis changed some social attitudes, physical activities and improved the ability to control emotions. Despite of participants' motor disability, one important change was in attitude towards the self-value of their existence and life. Mrs. Robinson drew upon it this way:

What keeps us here? Having set in on the procedure I can see the re-training, repetition and doing things differently. I become confident and that's one of the main reasons we come back.

(Mrs. Robinson – wife of Parkinson's patient)

The analysis of narratives and interviews show that patients felt, think that their skills and personalities were transformed. It would appear that transformation occurred by both formal and informal CE. Formal CE seemed to help patients to consciously learn, re-learn in a complex way and develop all emotional, social, physical, cognitive skills. Whereas informal CE more likely advocates an embodiment of the re-learnt skills and assist people through of emotional, social difficulties. The following quote was already used in another context to demonstrate that the patient felt motivated to stand up in front of the receptionist at a CE centre and here illustrates the new point:

...and going to the reception desk [at CE institute] I suddenly thought to stand up [from his wheelchair] to talk to Claire [receptionist] 'cos I learnt it after all.

(Nathan - CP participant)

This participant for instance decided to use his recently learnt skill in a simple social situation in the premises of the CE institute, feeling more confident to try it there than somewhere else where he would not know people. This example illustrates very well how informal CE works in between the walls of CE centres and give patients a good opportunity to practice new things while simultaneously decreasing the possible stress of an outside situation.

This study shed light upon the process of participants' adjustment in terms of their personal life since involved with CE. It seems that as a result of a series of adjustments, social attitudes, future plans and their sense of self were also changed which will be discussed in the next part (Positive change of patients). These on-going experiences influenced participants' thinking and lifestyles towards the CE desired orthofunction attitude. The participants who had disabilities learnt several physical techniques to overcome their difficulties but most importantly they experienced a complex personal transformation towards living a more confident and active life. Learners in CE not only revise knowledge, behaviours, skills, values but learn to live with their altered physical abilities in the society and through their active presence they are shape society as a whole.

Positive change of patients – renewed goals of life – reappraising relationships

Research has, since Holmes and Rahe's (1967) seminal work, highlighted the fact that major life changes impact negatively on well-being, at least in the short-term (Haslam et al, 2008 p. 671). When people endure negative life transitions in particular e.g. loss of important personal belongings, loss of job, serious health issues, the probable threat to well-being is more pronounced (Dyson & Renk, 2006). This is especially true if alterations entail some social, physical, or intellectual disorders — as is the case when

individuals suffer from trauma or late onset disabilities (Clarke & Black, 2005).

Bergman and his colleagues (Bergmann et al, 1991) discuss that individuals who have complex disabilities - like acquired brain injury or stroke – experience changes in their social and personal identity.

Patient participants in this current study not only spoke about loss of self but also the extent to which they felt the disability experience had become a part of their ongoing daily life. The disability even became part of their identity coupled with their original sense of self and other has been debased and renewed. Thomas described the initial ‘shock’ and subsequent ‘tremors’ which he now accepts as part of his life:

I suppose our lifestyle before, every weekend we used to go for a long walk didn't we, sometimes between eight and ten miles. And we used to go on walking holidays with family for a week, two weeks; we went all over the world didn't we, South Africa, Morocco, all sorts of places. I used to bike to work... It's a shock that happened you know...I live with tremor; it is with me all the time and everywhere.

(Thomas – Parkinson's patient)

Patients' changed identity is mirrored in the spouse's reactions so that their identity as a couple also fundamentally changed, not just as individuals (Roger and Medved, 2010). Brown (2003) writes that CE's belief in patients increases their confidence in themselves and lends a new motivation to continue their renewed relationship with their own bodies furthermore, aid them to get in touch with a sense of self identity, albeit often a new identity. This seems to be supported by patient and family member participants of this study too. One of the patients who had a "lot of frustrations" because of his condition, described that he now feels he can be an example to others after regaining confidence through CE:

You may have noticed one of the people sitting next to me was a banker others are scientists, doctors even, nurses, and they're all calling me every time to say something.

(Michael - Parkinson patient)

Another participant draws on a positive change that his wife confirms:

- Now I am coping and become more confident, I believe in me again (husband).
- It [CE] gives you a light at the end of the tunnel really. There is something there that you are aiming for and it's up to you. - If

you think back to when you first came. They gave you a new lease of life, complete new (wife).

(Mr. and Mrs. Gridley – Parkinson's patient and his wife)

This study sheds light upon that CE's rehabilitation approach has the potential to facilitate positive change of patients that have felt discredited and debased by illness.

Social confidence

Patients with physical disabilities such as Stroke, CP, MS, Parkinson's disease, acquired head injury, etc. are potentially less active than before. For instance, research conducted on stroke inpatients suggests that patients spend as little as 20% of their day engaged in physical activity related to rehabilitation (Janssen et al, 2014). Little emphasis has been placed on non-physical behaviours in those studies. However, participants in this current research highlighted a decreased motivation for physical activities which in turn led them to be less active cognitively (reading, watching TV programs or listening to music) as well as socially. The altered physical abilities were frequently a result of their decreased social confidence. This often made them apprehensive of engaging in simple social activities and/or going to public places.

.... I can't... I can't go round pubs any more, I can't even... I can't negotiate the people; I can't do the high street and the pubs.

(Luke – Parkinson's patient)

Many patients and family members are usually expected to accept their fate by conventional rehabilitation professionals (Ellis-Hill & Horn, in Schalkwyk, 2007, p.144) on the other hand in this study they were given an overt provision of hope, and experienced huge and complex support and 'real-will' from professionals to work towards their goals. The CE system facilitates personal development and physical rehabilitation which is embedded in social rehabilitation. The possibility to re-learn and use lost abilities in the CE environment creates the opportunity to re-gain social confidence that often happens according to participants of the study. The following text describes how one of the patients started to use techniques learnt at CE making him confident enough to go into public places.

I'm out in public it's hard work for me because I can't... if somebody steps out of the doorway I've always got my hand on their shoulder, I'm walking into them, I fall over and I can't negotiate, footpath I step off, the curbs go up and down.... I'm having a hell of a lot of trouble, I'm having to stop and I've got my hand on somebody's shoulder and... and I thought whoa, OK,

Anne-Marie's voice [the CE professional] come into my head, OK that's where I want to go and I'm going. And I'm going to be as selfish... all them people came bumping into me cos they don't know what I got, if I was in a wheelchair, if I'd got a big stick, they'd step round me. And by the same token I've thought like them people, I'm not thinking, I'm going from A to B and that's what I'm going to do. And I'm going to be selfish, I'm not going to worry about knocking that man, I'm not going to be worrying about knocking that woman, I'm going to go to B, and whoever's in my way will move. So I did it. Here we go. And it was all in little taps, little knocks, but I walked from A to B through the middle of a crowd, and that was a big thing for me to do. And that's the way I conduct my life now, and I have to think about it all the time.

(Andy - Parkinson patient)

Despite an apparent improvement in social confidence resulting from CE, it is not clear what CE could achieve with people who are less self-motivated. Also it is not defined as to what CE could achieve in conventional circumstances when choosing other forms of rehabilitation. Further investigation of this topic would be very substantial.

Life – Confidence

As already noted, patients and their family members feel looked after, nurtured, valued, and that they often go through of a positive change. Furthermore, the results of former studies on CE's physical impact on patients (Endres, et al 1990; Laver & Brown, 1995; Cott & Wright, 2001; Bandyopadhyay, S., et al 2002; Brittle, et al 2008) suggest that CE clients' life confidence could positively change as a result of CE's approach.

The analysis of this study's data clearly demonstrates that several patients and families underwent an enormous change in their lives because of CE. These changes seemingly drive people to think more positively about their existence and future with a physical disability. It gives them a certain inspiration to embrace their life fully with a feeling of courage, trust, fulfilment and joy. Furthermore, it is more likely to expand their physical limits and help them achieve a new balance into their life.

Many participants of this research study were delighted to share their experience of increased independence when succeeding in performing physical activities:

It is [CE] made my life easier at home as well because I can get out of my bed on my own. Oh, it is wonderful. It has made such a difference...Oh I could not believe it, the confidence it's given me...I just feel a new person, coming here [to CE].

(Nathan - CP patient)

It is little things you know, the standing up and the sitting down. And I mean do you know when I used to be on the floor before if I knelt down or whatever on the floor or the lawnmower. And then to get up off the floor was such an effort, I climbed up things, and if I had no things to climb up I'd climb up my own legs, you know you... And it took so much energy that by the time you were standing up it was the equivalent of walking a hundred yards, you used everything up to do it. But applying the methods of Megan Baker [CE] now and shifting your body weight now to do things it's made so much difference... When you're lying in bed half asleep and you're sort of... you're trying to move and you can't... you know and you're struggling to move and to change your position, it's hard work, it takes a long time then to sort of get a lot of energy to make your move. But now I can think well

if I move that out of the way, roll over the top if it, if I throw this arm over the momentum will take the shoulders over you know and it'll... And it's things like that that you learn isn't it you know to... I learned the technique and I apply that technique a lot. It's like I've been sitting in this chair, now to get up out of this chair is hard work, but by throwing your body forward you do it now without really thinking about it don't you. This is confidence isn't it?

(William - Parkinson patient)

The examples show that increased physical independence results in feeling more confidence in life generally. When the physical approach is supported by psychosocial factors as described in earlier sections – individuals feel more positive about their lives, as Sarah said.

It was the first time he really felt someone [the conductor] could show him how to work on improving himself, and so when he came away from there, I mean he would have loved the sessions to go on for hours because he feels it was something so positive happening. CE opens up the future, it suddenly makes everything seem so possible. His life has been given back.

(Rebecca - Mother of a head injured patient)

CE activities are often experienced to be challenging

It has been mentioned previously in this section (Learning – Transforming), that when patients tried to explain what CE was, they focused on the physical dimension and depicted it as doing a lot of exercises in order to improve their physical skills and abilities. Also, it has emerged from interviews of family members that initially CE seemed to be primarily a physical approach where clients ‘work’ very hard:

...it seems as though you’re just doing an exercise session ...
bending arms and stretching fingers...

(Diana - Family member of Stroke patient)

...sort of coming back having been in Lemster all afternoon and then I come back, they all actually seem more physically able doing things...walking around, and Jeanette, she...I have an awful struggle getting her to there in the first place [in the car] but when I take her home at night she’s oooh, she’s off. It’s a physical boost.

(Jack - Parkinson participant’s husband)

Furthermore, scholars who did not research participants' opinion on CE concluded that CE was very hard physical intervention - based on simply of an observation of the approach (Oliver, 1989 p. 273 - 280).

Clinical observation alone sufficiently demonstrates that CE is hard work (Oliver, 1989). Unsurprisingly, narratives and interviews of participants in this study also suggested that the physical exercises practiced in CE can be very challenging, especially in the beginning:

Well, the first couple of weeks were difficult; I mean I felt exhausted after sessions.

(Elisabeth – MS patient)

...the first couple of weeks I'm like "phew" this isn't for me, but I was talking to Nicola Graham who was...Susan...Susan was a trainer at the time and I was talking to her and she said, "No, you are making good progress. Keep going". In fact, it took 2-3 months to get on with it.

(Nathan - CP participant)

Oh I was terrible, I'd give up on myself, I wanted to go home cause I always expect 110 % of myself. I felt I was the only one that wouldn't get through it.

(William – Parkinson's patient)

Very hard work indeed...after ½ hour I felt tired, after ¾ hour I was pooped – would have given up if given the chance but my mum pushed me through.

(David – Head injured patient)

Obviously, hard work could lead to frustration. CE activities sometimes create dissatisfaction, disappointment, and disturbance due to their degree of difficulty as clients' narratives reveal.

I was cross... my hand did not want to do it.

(Simon - Stroke patient)

...and the criticism I'd make is a combination of things. It's her [conductor] voice, in that particular acoustic sometimes it's hard to understand what she says and then we get the action wrong...sometimes I get frustrated because of very hard exercises. (Thomas - Parkinson participant)

I returned to the data to find out how CE handles such frustrations when they occur and found different professional responses. For instance, one of the conductors described the 'beautiffulness' of her job was to convince and encourage people to keep going when they reached their emotional, physical, social or mental limitations. However, another interviewee expressed that after confronting the deep frustration of some clients he felt unable to manage individually, but instead asked the professional team for advice. There are no specific CE policies about managing such situations but all CE centres set up problem solving meetings involving the patient, their family members or/and carers and the conductors working with the patient's group. Other research participants sometimes consulted more experienced colleagues in order to solve problems, convince people to carry on and broaden the patient's emotional, social and physical limits. This suggests mindful care of the clients at CE. However, it is not clear what method(s) conductors are using to overcome such difficulties since there is no evidence that they receive any training on conflict management. During clinical placements and practice, conductor students face difficult and challenging situations with patients and gain first-hand experience of how skilled conductors solve such issues. Yet this seems to remain using the 'natural wisdom' of the professional which obviously is not an optimal approach.

In summary, it seems that CE activities are frequently challenging and professionals are there to tackle difficulties. However, in order to assist managing patients who have continued frustration with this method of rehabilitation, even though CE has the aforementioned safeguards in place, conductors clearly need more training.

CHAPTER 5 – CONCLUSION

For assessing research quality in the interpretive paradigm there were several standards, principles and approaches introduced. Koch (1996) contended that the criteria used should be reliable and steady with the philosophical and methodological assumptions on which the research is constructed (Koch 1996; Koch and Harrington, 1998; Leininger, 1994). Regarding to this view, I have chosen the criteria of ethical conduct, rigour and credibility as appropriate for this research. Ethical conduct is an essential criterion for all research and has been discussed earlier.

Rigor

According to Lincoln and Guba (2000) ensuring quality in any research involves the rigorous use of systematic methods of data collection and analysis, transparency in documenting these methods and consistency in working within the philosophical assumptions and traditions of the research paradigm and approach. Several approaches have been acknowledged in the literature as enhancing rigour in interpretive research such as congruence between the implemented paradigm and chosen methods, continued engagement with the research participants and the phenomena, various methods of data collection, and auditable records. The application of each of these strategies in this research is considered.

Congruence refers to the consistency between the aim of the research, the methodology and the methods used to collect and analyse data, and the philosophical assumptions of the research paradigm (Crotty, 1998; Higgs and Adams, 1997). In this study, I have attempted to establish congruence by specifying the philosophical foundations of the chosen paradigm and relevance to this research, and conduct adequate methods of data collection and analysis.

Prolonged engagement with the research participants and repeat interactions ensure that data collection is rigorous (Guba and Lincoln, 1994). Data were collected from CE institutions I used to work in and I established friendly working relationship with the participants before conducting the research. This gave participants the comfort and freedom to discuss their views and learning experiences with me, increasing the rigour and trustworthiness of the research findings.

Various methods and sources of data collection provide multiple constructions of phenomena, thereby enhancing the depth and richness of the data (Denzin and Lincoln, 2000). The use of various data sources and strategies reduces systematic bias in the data, adding rigour to interpretive research (Denzin and Lincoln, 2000; Koch, 1996). In this research, data were collected using several attentive methods discussed in chapter 3.

According to Ajjawi (2006 p.170)

An audit trail is a record of decision-making or turning points in the research, and the development of the research questions and design. It serves two purposes, first as a mode of transparency that enables readers to judge the quality and trustworthiness of the research and second as a methodological tool that aids the critique and development of the research process by researchers themselves.

The audit path for this research included the transcript files, personal files and analytical files documenting all ethical, contextual, methodological, analytical and personal thoughts and decisions.

Credibility

Credibility refers to the richness and correctness of the description to the phenomena (Koch and Harrington, 1998), or trustworthiness of the findings of the research (Denzin and Lincoln, 2000). Certain strategies have been suggested that ensure and enhance credibility of interpretive research, such as rigorous and systematic data collection and analysis methods, authenticity and transferability of findings.

Authenticity is established when researchers show a range of different genuineness in a fair and balanced manner (Denzin and Lincoln, 1994).

Crystallisation is suggested by Denzin and Lincoln (2000) and it refers to the practise of various data-gathering methods and methodological practices to make sure an in-depth understanding of the phenomenon. Using multiple methods and sources of data collection, exploring different perspectives of lived human experiences of the research participants in this research therefore supports my credibility, fair dealing in enlightening phenomena.

A vital indicator of quality in qualitative research the transferability of the research findings (Hammersley, 1992). As a researcher I attempted to describe the study context sufficiently such that readers can judge for themselves the applicability of the research findings to their own contexts (Koch, 1996; Seale, 1999).

The researcher's reflections on the study

My thesis has aimed to explore of the rehabilitation of physically disabled adults in a group setting with particular reference to Conductive Education. The study discovered what CE participants (i.e. physical disabled people) their family members, personal carers and CE professionals articulated about their lived experience of the group setting in CE. As a secondary occurrence this gathering of information additionally informed me about other elements of knowledge regarding CE which was very beneficial to ascertain from those who have self-experience of this art of rehabilitation.

The research aimed to develop my knowledge and understanding of how people experience rehabilitation in group settings, specifically through CE. In order to better understand the outcomes, emergent topics were explored inductively and without describing prior evidence on CE. However, several subjects overlapped with previously investigated matters. Despite my experience, I have learned several new things about the phenomenon of CE and widened my knowledge about CE professionals considerably. But most importantly, the study shed light upon what people i.e. patients, family members, personal carers think about adult physically-disabled rehabilitation through a group setting, what their own experience and opinion of this was and not least what happened to them whilst within the group setting in CE.

Explicitly, the most important discovery of this research on adult physically disabled people's rehabilitation in a group setting is that the group setting is a very feasible structure of collective physical rehabilitation that could be an effective innovation of rehabilitation within health care services – such a statement must not be made without also adding that CE has developed one possible way to deliver it. Group science has been investigated at length and has revealed a lot of facts about people's behavior and the progression of their relationships. It has also clearly identified common group developments, group performance patterns, goal settings in groups, task

complexity, and the benefits and disadvantages of participation in homogenous and heterogeneous groups. That huge knowledge seems to be apposite to use in the examination of adult physically disabled rehabilitation and it seemingly could support the effectiveness of previously developed motor-developmental methods.

Important information emerged through the study, for example, that patients and families are very happy to meet up and participate together in rehabilitation with people who have similar difficulties and thus the delivery of services may be more efficient when provided in this way. The group setting provides an optimal complex learning environment for adult physically disabled people to develop and practice their overall abilities, skills, and existence. Also, considerable emotional and social facilitation provided through group settings where relationships between professionals and clients, as well as between clients and clients, vigorously facilitating the process of recovery. Verbal and meta-communication becomes an incredibly effective part of the rehabilitation. There are several educational practices that also turned out to be extraordinarily useful in adult rehabilitation delivered in a group setting. The person-centered motivation, self-and group-motivation and patients' positive group atmosphere experiences in rehabilitation, all appeared to increase the health care benefits in different

dimensions. Routine, regularity, consistency, setting goals and giving positive feedback are old 'tricks' of education which are practiced best in group settings. These elements, referred to as the Pygmalion effect, and simply developed with a group ethos are also shown to be beneficial in physically-disabled adult rehabilitation whilst in a group setting. Subsequently, a group approach seemingly does not decrease the exceptional result of physical rehabilitation but it promotes new motivational and developmental factors what are not always available in one to one sessions. As there is very few quantitative, and no qualitative, research evidence on group settings in physical rehabilitation before the professional recognition of this rehabilitation approach is still developing.

The first prominent idea that emerged regarding CE through the whole study is that CE approach not only targets physical issues of the patients, but provides a life-changing concept. In this context of this it is recognizable that the elements of rehabilitation broaden in a complex way - holistically - and managing physical difficulties is embedded in a complex facilitation of the person. This linked with another finding that CE is both a patient/person centered and collective approach. This model is still new in the health delivery system worldwide. The model seemingly comes from psychotherapeutic interventional care and again, from education. It integrates different

components; (a) understanding the person in need as a whole, (b) developing rehabilitation aims with patients and with family together regarding life management, (c) enhancing client – professional relationship, (d) teaching patients and family to better understand the disorder, and the possible ways to decrease difficulties and stress, (e) deliver rehabilitation sessions in groups of similar disordered clients, (f) offer a secure, firm social background for customers where they feel they could always come ‘home’. The conscious ambition of positive regard for learners seems to grow also from psychotherapeutic interventional care, based on that realization that any person who has difficulties generally needs spiritual and psychological support and positive feedback to find it easier to move out of a situation of ‘trouble’. Evidently, CE is able to integrate positive regards for the clients, which fundamentally is a very human element, and that means a lot to patients and families. Also, the study helped me to identify specific professional attitudes of CE professionals that suggest a simple but rarely experienced human dimension of care. The single components of this type of professional behavior and professional acts are not unique or new but in CE’s specific configuration seems to be very fruitful for the clientele.

Regarding strengths and limitations of the study, I would express that my interest in learning came from working with people with physical

disabilities in group setting for several years in CE and the lack of professional recognition of the method. This in turn could have affected the way I interviewed participants and/or analysed the studies and could be seen as limitation of the study. On the other hand, the nature of phenomenological methodology, analysis of the researcher's self-interpretation and self-lived experience throughout the study is part of the research process therefore, I believe the described limitation could be a strength.

In fact, this research has generated many questions in need of further investigation in group setting and CE areas, and suggests that considerably more work would need to be done to settle on the following directions:

- (a) CE as a forum for developing a community of people with similar difficulties
- (b) The whole learning (and rehabilitation) environments provided in CE
- (c) The application of sociometry in the process of habilitation and rehabilitation of adult physically disabled people
- (d) A complete panorama of dimensions of motivation factors of CE
- (e) Particular patterns on possible conductors' negative emotional reactions and patient resistance

- (f) The impact of intensive use of positive language and body language, gesticulations and mimics in the rehabilitation process whilst group setting
- (g) The ability focus model in rehabilitation approach
- (h) The process of altering physically disabled patients' self-respect
- (i) What could group setting or CE achieve in conventional circumstances

Taken together, the findings of this research support strong recommendations for health care providers, rehabilitation institutions, accountable and responsible bodies to introduce and use group setting method in the rehabilitation of adult physical disabled. Principally in UK, I would recommend for Health Education England (HEE) to consider such an act, as HEE is the main body responsible for the education and training of NHS and public health staff, and has a major role to indicate such implications. Regarding particularly CE, the findings of this research together with former quantitative research results in the field definitely support the recommendation that the NHS recognize CE as a possible rehabilitation method for people with physical comprehensive disabilities. Furthermore, I would advocate rehabilitation providers, rehabilitation

institutions, accountable and responsible bodies employ CE professionals to broaden their services.

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APPENDICES

APPENDIX A: Statistics information on how many people could be physically effected by different disabilities

Dyspraxia

The Dyspraxia Foundation supplies specialist publications about dyspraxia; statistically, it is likely that there is one child in every class of 30 children. We need to make sure that everyone understands and knows how best to help this significant minority.

Available at:

http://www.dyspraxiafoundation.org.uk/professionals/pr_intro.php

[Accessed: 27th November 2014]

Parkinson Disease

Every hour, someone in the UK is told they have Parkinson's. One person in every 500 has Parkinson's. That's about 127,000 people in the UK. Most people who get Parkinson's are aged 50 or over but younger people can get it too.

Available at:

<http://www.parkinsons.org.uk/content/facts-journalists>

[Accessed: 27th November 2014]

About 5 in 1,000 people in their 60s and about 40 in 1,000 people in their 80s have PD.

Available at:

<http://www.patient.co.uk/health/parkinsons-disease>

[Accessed: 27th November 2014]

Multiple Sclerosis

Multiple Sclerosis is common disabling neurological condition, affecting more than 100,000 people in the UK.

Available at :

<http://www.mssociety.org.uk>

[Accessed: 27th November 2014]

Stroke

At least 450,000 people are severely disabled as a result of stroke in England.

Available at :

<http://www.stroke.org.uk/about-stroke>

[Accessed: 27th November 2014]

Cerebral Palsy

Cerebral palsy affects about one in every 400 people in UK.

Available at:

<https://www.scope.org.uk/support/families/diagnosis/cerebral-palsy>

[Accessed: 7th August 2014]

Motor Neuron Disease

ALS-MND is uncommon in the UK. Around 2 people in 100,000 develop ALS-MND each year. There are about 5,000 people in the UK with ALS-MND.

Available at:

<http://www.patient.co.uk/health/motor-neurone-disease-leaflet>

[Accessed: 13th October 2014]

APPENDIX B: Flexible Interview schedules

Directive questions for CE patients their family members

Can you tell me about your life before Conductive Education? Why did you decide to enrol CE? Why did you stay? What happens to you there in detail, what is going on? What is different from other therapies? Does it help for you? How? Why? What motivates you to do it? What do you think about group setting? Why? Please tell about the group! What is the atmosphere in the group? What do you do in the group? What do you think about the conductors as professionals? What kind of relationship you have with them? What do they do different from other therapists? Would you recommend group setting? Why? Why not? What is CE at all in your words?

For CE professionals

Could you tell how CE is different from other therapies from your point of view? Can you tell me about group setting? How CE organise groups of people? Why do you think group setting is beneficial or unhelpful for you as a professional, and for the clientele? Do you think CE has an emotional, psycho-social impact on patients, too? What is your personal role in the delivery of CE? Do you need to deal with stressful situations?

Directive questions for CE patients their family members & carers

How was life before CE? Why your family member came to CE? What has been changed since? What does he/she like or not like in CE? Why CE is different from other therapies? Are you involved in your family member's/care person's rehabilitation? How? Do you get enough support? What kind of? What do you think about the group setting? Would you recommend it for others? Why? Do you think that CE has emotional, social impact? What do you think about the conductors as professionals? How is the communication with them?

APPENDIX C: Recruitment letter



Recruitment Letter

Liverpool John Moores University

www.ljmu.ac.uk

Contact: Professor Jane Springett

Tel: 0151 231 8006

Email: r.j.springett@ljmu.ac.uk

Dear CE Participant,

I am writing to inform you that you are happily nominated to participate in the research study being conducted by Liverpool John Moores University.

The Principal Investigator is Laszlo Szogeczki, Senior Conductive Education Teacher. Supervisors: Professor Jane Springett, Faculty of Health and Applied Social Science Liverpool John Moores University, Darren Greenop, Research Fellow, Faculty of Health and Applied Social Science Liverpool John Moors University, Professor B. Lancaster, Professor of Transpersonal Psychology School of Natural Sciences and Psychology, LJMU.

The research will be conducted at: National Institute of Conductive Education (NICE), Birmingham, Megan Baker House, and Legacy Rainbow Hoause.

Title of the Research: An exploratory study of the rehabilitation of physically disabled adults in a group setting with particular reference to Conductive Education

The research aim is to explore the characteristics of the delivery of adult Conductive Education in a group setting and to investigate the relationship between the cognitive, emotional, social and functional dimensions of the delivery.

You have been invited to take part in the research because you are one of the participants (or family member/personal carer) of ongoing adult CE sessions at NICE, Megan Baker House or Legacy Rainbow House.

Your role will be simply to carry on CE and you will be asked to talk about your lived experience of the CE delivery in a dialogue situation conducted by the principal researcher which dialogue will be recorded by a video camera. Although the interviews will not be dealing with particularly sensitive issues, it is possible that you may become distressed. This is not expected but as a skilled practitioner, the principal researcher will deal with such a scenario, if it were to occur. Once data has been collected, notes and tapes will be kept in a safe condition. After having interviews transcribed to a laptop computer, they will be anonymised, coded and protected by a secure password. Codes will be known and assessed by the principal investigator alone and will be kept in a locked cabinet. Any quotations or information that could possibly lead to participant identification will be removed from materials intended for distribution, circulation or publication.

Although you decided to voluntary this research study you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Participation is on a voluntary basis and as such, the participants are not going to be provided with any payments or compensation for the time, travel and any out-of-pocket expenses. The total duration of the study is 2 years, however, the duration of your participatory in the study through being involved with CE will be the time of a dialogue/ interview and each dialogue/interview is going to be not longer than one hour and thirty minutes. The research will be conducted at NICE, Birmingham, Megan Baker House or Legacy Rainbow House. In addition, to the writing of an unpublished thesis the research are intended to be disseminated at different levels and different ways. Short summaries will be sent to all research participants and co-workers.

Similar short summaries will be published through the internet, peer reviewed scientific journals and presentations will be held at international and UK professional conferences. Longer and more detailed research findings will be published in scientific journal(s) and presentations will be held at National Institute of Conductive Education, UK, at the Parkinson Society, UK, at the Dyspraxia Foundation Conference and in the International Peto Institute, Hungary.

I declare that the principal researcher who will have access to you has undergone a satisfactory criminal records check.

Contact for further information:

By the Principal Researcher, Laszlo Szogeczki at 07725071301 mobile number

Furthermore at NICE, Dr. Melanie Brown,

Tel: Liverpool John Moors University,

Professor Jane Springett, Director of the Study

Tel: 0151 231 8006 Email: r.j.springett@ljmu.ac.uk

Thank you for volunteering the research study.

Sincerely,

Laszlo Szogeczki, principal researcher

APPENDIX D: Letter of invitation for CE patients



Participant Information Sheet

You are being invited to take part in a research study as part of a project at Megan Baker House corporate with Liverpool John Moores University.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Take your time to decide whether or not you wish to take part.

Thank you for reading this.

Who will conduct the research?

Principal Investigator is Laszlo Szogeczki, Senior Conductive Education Teacher and Head of CE Services, Megan Baker House, Supervisors: Professor Jane Springett, Faculty of Health and Applied Social Science Liverpool John Moores University, Darren Greenop, Research Fellow, Faculty of Health and Applied Social Science Liverpool John Moores University, Professor B

Lancaster, Professor of Transpersonal Psychology School of Natural Sciences and Psychology, LJMU.

The research will be conducted at: Megan Baker House, Moreton Eye, Leominster, Hereford, NICE, Birmingham, Legacy Rainbow House, Ormskirk, UK

Title of the Research

An exploratory study of the rehabilitation of physically disabled adults in a group setting with particular reference to Conductive Education

What is the aim of the research?

The research aim is to explore the characteristics of the delivery of adult Conductive Education in a group setting and to investigate the relationship between the cognitive, emotional, social and functional dimensions of the delivery.

Why have I been chosen?

You have been invited to take part in the research because you are one of the participants of ongoing adult CE sessions of Megan Baker House.

What would I be asked to do if I took part?

In case you chose to volunteer in this research, your role will be simply to carry on CE at Megan Baker House. Documents which have been created earlier by CE professional(s) will be used as research data. Later, you and one of your family members will be asked to talk about your and his/her lived experience of the CE delivery in the way which best suits you; either in writing or verbal. At the end of the study, all of you who took part in the research will be asked to collectively create a dialogue about your experience of CE.

Although the interviews will not be dealing with particularly sensitive issues, it is possible that you may become distressed. This is not expected but as a skilled practitioner, the principal researcher will deal with such a scenario, if it were to occur.

What happens to the data collected? How is confidentiality maintained?

Once data has been collected, notes and tapes will be kept in a safe condition. After having interviews transcribed to a laptop computer, they will be anonymised, coded and protected by a secure password. Codes will be known and assessed by the principal investigator alone and will be kept in a locked cabinet. Any quotations or information

that could possibly lead to participant identification will be removed from materials intended for distribution, circulation or publication.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

Participation is on a voluntary basis and as such, the participants are not going to be provided with any payments or compensation for the time, travel and any out-of-pocket expenses.

What is the duration of the research?

The total duration of the study is 2 years, however, the duration of your participatory in the study through being involved with CE will be one year and each interview is going to be not longer than one hour and thirty minutes.

Where will the research be conducted?

Megan Baker House, Moreton Eye, Leominster, Herefordshire, HR6 0DP, UK
Tel: 01568 616179

A choice of locations (MBH or home) will be offered for family members.

Will the outcomes of the research be published?

In addition to the writing of an unpublished thesis the research are intended to be disseminated at different levels and different ways. Short summaries will be sent to all research participants and co-workers of NICE, Megan Baker House and Legacy Rainbow House. Similar short summaries will be published through the internet, peer reviewed scientific journals and presentations will be held at international and UK professional conferences. Longer and more detailed research findings will be published in scientific journal(s) and presentations will be held at National Institute of Conductive Education, UK,

at the Parkinson Society, UK, at the Dyspraxia Foundation Conference and in the International Peto Institute, Hungary.

Criminal Records Check

I declare that the Principal researcher who will have access to you has undergone a satisfactory criminal records check.

Contact for further information

By the Principal Researcher, Laszlo Szogeczki at 07725071301 mobile number or at Megan Baker House, Moreton Eye, Leominster, Herefordshire, HR6 0DP, UK

Tel: 01568 616179,

Liverpool John Moors University,

Contact: Professor Jane Springett, Director of the Study

Tel: 0151 231 8006

Email: r.j.springett@ljmu.ac.uk

APPENDIX E: Letter of invitation for Rehabilitator/Carer



Rehabilitator/Carer Information Sheet

Liverpool John Moores University

www.ljmu.ac.uk

Contact: Professor Jane Springett

Tel: 0151 231 8006

Email: r.j.springett@ljmu.ac.uk

You are being invited to take part in a research study as part of a project at Liverpool John Moores University. Before you decide it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

Thank you for reading this.

Who will conduct the research?

Principal Investigator is Laszlo Szogeczki, Senior Conductive Education Teacher. Supervisors: Professor Jane Springett, Faculty of Health and Applied Social Science Liverpool John Moores University, Darren Greenop, Research Fellow, Faculty of Health and Applied Social Science Liverpool John Moores University, Professor B Lancaster, Professor of Transpersonal Psychology School of Natural Sciences and Psychology, LJMU.

The research will be conducted at: National Institute of Conductive Education, Cannon Hill House, Russel Road, Moseley, Birmingham B13 8RD
Tel: 0121 449 1569.

Title of the Research

An exploratory study of the rehabilitation of physically disabled adults in a group setting with particular reference to Conductive Education

What is the aim of the research?

The research aim is to explore the characteristics of the delivery of adult Conductive Education in a group setting and to investigate the relationship between the cognitive, emotional, social and functional dimensions of the delivery.

Why have I been chosen?

You have been invited to take part in the research because you are one of the CE (conductor) professionals of ongoing adult CE sessions at NICE.

What would I be asked to do if I took part?

In case you chose to volunteer in this research, your role will be simply to carry on providing CE sessions for adult PD groups at NICE. Later, you will be asked to take part in a dialogue to talk about your experience of CE which dialogue will be video recorded.

Although the interviews will not be dealing with particularly sensitive issues, it is possible that you may become distressed. This is not expected but as a skilled practitioner, the principal researcher will deal with such a scenario, if it were to occur.

What happens to the data collected? How is confidentiality maintained?

Once data has been collected, notes and tapes will be kept in safe condition. After having interviews transcribed to a laptop computer, they will be anonymised, coded and protected by a secure password. Codes will be known and assessed by the principal investigator alone and will be kept in

locked cabinet. Any quotations or information that could possibly lead to participant identification.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

The research is going to be voluntary based research and as such, the participants are not going to be provided any payments or compensation for the time, travel and any out-of-pocket expenses.

What is the duration of the research?

The total duration of the study is 2 years, however, the duration of your participatory in the study through being involved with CE will be one year and each interview is going to be not longer than one hour and thirty minutes.

Where will the research be conducted?

National Institute of Conductive Education, Cannon Hill House, Russel Road, Moseley, Birmingham B13 8RD Tel: 0121 449 1569

Will the outcomes of the research be published?

The findings of the research are intended to be disseminated at different levels and different ways. Short summaries will be sent to all research participants and co-workers

of NICE. Similar short summaries will be published through the internet, peer reviewed scientific journals and presentations will be hold at international and UK professional conferences. Longer and more detailed research findings will be published in scientific journal(s) and presentations will be hold at National Institute of Conductive Education, UK, at Parkinson Society,

UK, at Dyspraxia Foundation Conference and in the International Peto Institute, Hungary.

Criminal Records Check

I declare that the Principal Researcher who will have access to you has undergone a satisfactory criminal records check.

Contact for further information

By the Principal Researcher: Laszlo Szogeczki at 07725071301 mobile numbers.

Furthermore at NICE, Dr. Melanie Brown, Tel: 0121 449 1569

Liverpool John Moors University,

Professor Jane Springett, Director of the Study

Tel: 0151 231 8006

Email: r.j.springett@ljmu.ac.uk