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AN EMPOWERMENT DAY FOR PERSONS WITH PARKINSON'S DISEASE

Unit of Social Services and Health Care, Pori
Degree Program in Physiotherapy

2009

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March 2009
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PLC: 59.55
Number of pages: 35 + 6 appendices

Key words: Parkinson's disease, empowerment

The purpose of this bachelor's thesis was to plan and implement an Empowerment Day for persons with Parkinson's disease and their next of kin in cooperation with the Parkinson Association in Pori. The project started in October 2007 and continued until the Empowerment Day 23.4.2008.

The Empowerment Day was primarily directed to the members of the Parkinson Association in Pori and their spouses. Furthermore the marketing of the event enabled other persons to take part as well. The majority of the participants pre-registered one month prior to the event hence the final arrangements for the day was made. The total number of participants was 50. The first activity of the day consisted of physical activity in form of circuit training and relaxation. The following program point was a lecture about peer support that was held by a regional worker from the Parkinson Association. There was also an additional lecture about Parkinson's disease and balance held by a neurologist. The lectures were followed by a panel discussion and the purpose was to address different aspects about Parkinson's disease and discuss those from different view points. The participants could also take part in pause gymnastics and they were able to fill out a questionnaire concerning the program points of the empowerment day.

The questionnaire contained questions about all the program points and the participants were able to grade the questions from 4-10. 4-5 responds to unsatisfactory, 6-7 equals satisfactory, 8-9 means good and 10 is excellent. 38 questionnaires were returned and one was excluded due to that it was not readable. The mean values calculated from all the questions ranged from 7,8 to 8,8 hence the overall outcome of the Empowerment Day can be seen as successful.

VOIMAVARAPÄIVÄ PARKINSONIN TAUTIA SAIRASTAVILLE

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Fysioterapian koulutusohjelma
Maaliskuu 2009
Ohjaaja: Bärlund Esa
YKL: 59.55
Sivumäärä: 35 + 6 liitettä

Asiasanat: Parkinsonin tauti, voimaantuminen

Tämän opinnäytetyön tarkoituksena oli suunnitella ja toteuttaa Voimavarapäivä Parkinsonin tautia sairastaville ja heidän lähiomaisilleen yhteistyössä Porin Parkinson-liiton kanssa. Projekti alkoi lokakuussa 2007 ja jatkui Voimavarapäivän toteuttamiseen asti 23.4.2008.

Voimavarapäivä oli ensisijaisesti suunnattu Porin Parkinson-liiton jäsenille sekä heidän puolisoilleen. Lisäksi markkinointi mahdollisti osallistumisen myös liiton ulkopuolisille henkilöille. Enemmistö osallistujista ilmoittautui ennakkoon, mikä mahdollisti järjestelyjen viimeistelyn. Osallistujen lopullinen määrä oli 50. Päivän ohjelma alkoi kiertoharjoittelulla ja rentoutuksella. Seuraavaksi vuorossa oli Parkinson-liiton aluetyöntekijän pitämä luento vertaistuesta, jota seurasi neurologin luento tasapainoon liityvistä tekijöistä. Luentojen jälkeen oli paneelikeskustelun vuoro, jonka tarkoituksena oli tuoda esiin Parkinsonin tautiin liittyviä asioita eri näkökulmista tarkasteltuna. Osallistujilla oli myös mahdollisuus osallistua taukovoimisteluun sekä täyttää palautelomake ohjelmasta.

Palautelomake sisälsi kysymyksiä ohjelman sisällöstä ja osallistujat arvioivat ohjelman eri osia asteikolla 4-10. Arvosanat 4-5 vastasivat huonoa, 6-7 tyydyttävää, 8-9 hyvää ja 10 kiitettävää. Yhteensä 38 palautelomaketta palautettiin, joista yksi hylättiin. Kaikkien kysymysten keskiarvot vaihtelivat 7,8 ja 8,8 välillä. Näin ollen voimavarapäivän toteutus voidaan todeta menestyksekkääksi. Lisäksi voidaan olettaa että Parkinsonin tautia sairastavat hyötyvät tämän kaltaisesta päivästä ja samantyyppisiä tapahtumia olisi suositeltavaa järjestää myös tulevaisuudessa.

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APPENDICES

1 INTRODUCTION

This Bachelor's Thesis is a project that was carried out in cooperation with the Pori Parkinson Association. The purpose was to arrange an Empowerment Day for persons with Parkinson's disease and their next of kin. The Empowerment Day was implemented 23.4.2008 in the facilities of the Department of Social Services and Health Care at Satakunta University of Applied Sciences in Pori. The Empowerment Day was attended by 50 persons with and without Parkinson's disease and they were able to enjoy a program that consisted of physical activity, relaxation, lectures about peer support and balance and a panel discussion that covered different topics related to Parkinson's disease.

The theoretical framework for the Empowerment Day is initially about the Parkinson Association and Parkinson's disease. Furthermore the theory concerns quality of life of persons with Parkinson's disease and places the Empowerment Day in the concept of ICF. There is also theory concerning Parkinson's disease and physical activity, relaxation and external cueing. Furthermore the theory supports the lectures and the panel discussion. At the end of the day questionnaires were filled out in order to evaluate the day. The main outcome of the questionnaires was that the participants enjoyed the program and that there is a need for this kind of activity.

2 THE AIM OF THE PROJECT

The aim of the project was to plan and implement an Empowerment Day for people with Parkinson's disease and their next of kin in cooperation with the Parkinson Association in Pori. The purpose of the event was to empower persons with Parkinson's disease and their spouses with a programme that contains activities, such as physical activity, relaxation, lectures and discussion.

3 THEORY FOR THE PROJECT

In this Bachelor's Thesis the theoretical background will initially concern the Parkinson Association and Parkinson's disease. The concept of the Empowerment Day and issues related to it will also be brought up. Thereafter the theory will continue around the program of the day. The theory of the morning exercise will include Parkinson's disease and exercise and in addition relaxation and external cueing. The theory that follows is related to the lecture about peer support and the panel discussion. These two program points are located under the same headline as they overlap each other in theory to some extent. The final theory part is related to balance and falling and explains the importance of these topics in Parkinson's disease.

3.1 The Parkinson Association

The Finnish Parkinson Association (Suomen Parkinson-liitto ry) was founded by persons with Parkinson's disease in Kuopio 1984. In 1990 Turku became the home city for the organization. In 2007 the Parkinson Association consisted of 18 associations and about 100 clubs. In addition to persons with Parkinson's disease the Parkinson Association has other subgroups as well. These are: the Finnish Dystonia Association (Suomen Dystonia-yhdistys), the Finnish Huntington Association (Suomen Huntington-yhdistys) and the Finnish Association for Parkinson Nurses (Suomen Parkinsonhoitajat ry). Shortly put, the main purpose of the Parkinson Association is to provide information as well as rehabilitation for its members. In addition peer support and related matters are of great value. One key issue is that the members should be able to life normal lives from which they can extract as much joy as possible despite their illness. (Suomen Parkinson-liitto.)

The Finnish Parkinson Association is a non-profit making organization. The funding is provided by the Social Insurance Institution of Finland (Kela), Finland's Slot Machine Association (Ray) and the Association for Educational Activities (Opintotoiminnan Keskusliitto). Hence the courses and activities are nearly free of charge for the members of the association. Annually over 1000 applications for different courses reach the Parkinson Association. Of these a number of about 600 can be accepted. The courses in question consist of adaptation training and rehabilitation and these are arranged in rehabilitation centres throughout the country as well as in the facilities that belong to the Parkinson Association. The association’s own facilities are Suvituuli in Turku and Kouluranta in Kangasniemi. The Parkinson Association has different project with different co-operational agencies and the empowerment day is a result of a project. (Suomen Parkinson-liitto.)

3.2 Parkinson’s Disease

Parkinson’s disease was initially called “the shaking palsy” and in 1817 an English doctor called James Parkinson released the first literature about Parkinson’s disease. The word “palsy” however refers to paralysis hence a French neurologist named Chargot proposed that the disease would be called Parkinson’s disease. In the 1960’s a breakthrough in the medical care of the disease was made as it was noticed that the lack of dopamine in the brain was of great importance. Thereafter the medical development was rapid. A great achievement has been medication with a dopamine type of effect, called dopamine agonists. In this context levodopa can be mentioned as well as medication that affects the dopamine metabolism. Parkinson’s disease is also the first long-term neurological disease to which a symptom based treatment was established due to a brain dysfunction. Although the disease has been widely studied, the underlying cause for the disease has not yet been found. (Marttila 2000, p 4-5.)

The structural reason for Parkinson’s disease is found in a small area of the brain called the substantia nigra. Between substantia nigra and the striatum there is a nerve connection. For some unknown reason the amount of nerve cells in the substantia nigra is reduced. Dopamine acts as an agent that prevents unnecessary exertion of the neural cells. Hence the neural function is disturbed. The substantia nigra is also part of the extrapyramidal system. This system is dependent on the pyramidal system and the two work together as normal movement is impossible otherwise. The systems function together to maintain a position and the muscular functions related to it. In addition it automatically regulates automatic muscle functions. (Teräväinen 2000, p 6.)

Parkinson’s disease is neurodegenerative disorder that can be either primary or secondary. Primary or idiopathic Parkinson’s disease stands for 70% of the cases. Secondary Parkinson’s disease or Parkinsonism can have a variety of causes. Drugs, toxins, infection, vascular diseases and trauma are some of the factors that cause secondary Parkinsonism. (Jones & Pfayfer 2004, p 203.) In order to clarify the terms; Parkinson’s disease is caused by a reducing amount of neurons in the substantia nigra, hence affecting the dopamine metabolism. Parkinsonism is a collection of symptoms (postural discrepancies, rigidity, increased muscle tone, bradykinesia and akinesia) that present in Parkinson’s disease, but the same symptoms can be present in other diseases as well. If there are additional neurological symptoms they are referred to as Parkinson plus. (Teräväinen 2000, p 7-8.)

The prevalence of Parkinson’s disease is slightly higher among Caucasian people compared to Afro-American, Chinese and Japanese. In Finland the prevalence has been studied in Turku and the study revealed that 160 of 100 000 persons have Parkinson’s disease (about 8000 in Finland). The estimated amount is however 10 000 persons. About 700-800 persons get Parkinson’s disease every year in Finland. (Marttila 2000, p 11.) The prevalence is however higher than the incidence as persons with Parkinson’s disease usually live long (Jones & Pfayfer 2004, p 203). Thus the incidence is a better tool for measurement of the occurrence of Parkinson’s disease than prevalence (Kuopio 2000, p 12).

The aetiology of Parkinson’s disease has not yet been explained, but it is believed that factors associated with ageing or with environmental or genetic factors can contribute to the disease. Ageing does not however directly cause Parkinson’s disease. The number of neurons in the brain decrease with age, but the loss is too small to be of importance. In theory it is possible that some event as for example an infection might speed up the process, but nothing has however been proved. In the context of environmental factors, a neurotoxin, MPTP, can be mentioned. This neurotoxin caused many cases of drug-related Parkinsonism in the early 1980’s in California. The onset if Parkinsonism is rapid and the most common symptoms are dyskinesis and problems in the cognitive area. Other environmental factors that can cause Parkinsonism are manganese, copper and pesticides. It is furthermore believed that Parkinson’s disease can be caused by genetic factors. At this stage eight genes associated with Parkinson’s disease have been identified. It is however believed that genetic factors and environmental factors both contribute to the disease. (Jones & Pfayfer 2004, p 204-205.)

Bradykinesia, rigidity and tremor at rest are the three cardinal signs of Parkinson’s disease and two signs are needed in order to make a diagnosis. In addition to these three, postural instability is considered to be the fourth cardinal sign. Postural instability however normally occurs in the latter stages of Parkinson’s disease thus it can not contribute to the diagnosis. In relation to the diagnosis bradykinesia is a mandatory sign and the term refers to slowness of movement. Bradykinesia is initially generally observed and reciprocal movements often lack and there are little spontaneous movements. Repetitive movements also cause difficulties. (Jones & Pfayfer 2004, p 205.) When it comes to bradykinesia there are other terms related as well. Micrography means that the handwriting becomes smaller and hypomimia refers to the lack of facial expressions. Bradykinesia is a general term and in fact it means that the performance of movement slows down. Hypokinesia is slowness of movement and akinesia means that the movements become smaller. In relation to these symptoms it can be noticed that the whole gait cycle slows down. (Teräväinen 2000, p 13.)

The second cardinal sign is rigidity. Persons with Parkinson’s disease often describe rigidity as stiffness that occasionally involves muscle pain. The rigidity appears as resistance when a movement is tested. Cog-wheel type of resistance means that the resistance stays the same during the whole range of motion and led pipe resistance involves ratchets. Shortly put, rigidity is caused by an increased muscle tone. Rigidity varies significantly between persons and throughout the day it alters as well. (Jones & Pfayfer 2004, p 205-206.) The third cardinal sign, tremor at rest is present in 70% of people with Parkinson’s disease. The tremor normally presents itself at rest and disappears during activity. Furthermore the tremor is usually asymmetrical and in the beginning of the disease one hand is usually affected. The tremor is stated to be “pill rolling” and occurs in thumb and forefinger. (Jones & Pfayfer 2004, p 206.) As the disease progresses the tremor typically moves down from the hand to the lower extremity to later on affect the other side of the body as well. Tremor might be present in the upper and lower extremities, but it can also affect the chin and tongue. (Teräväinen 2000, p 12.)

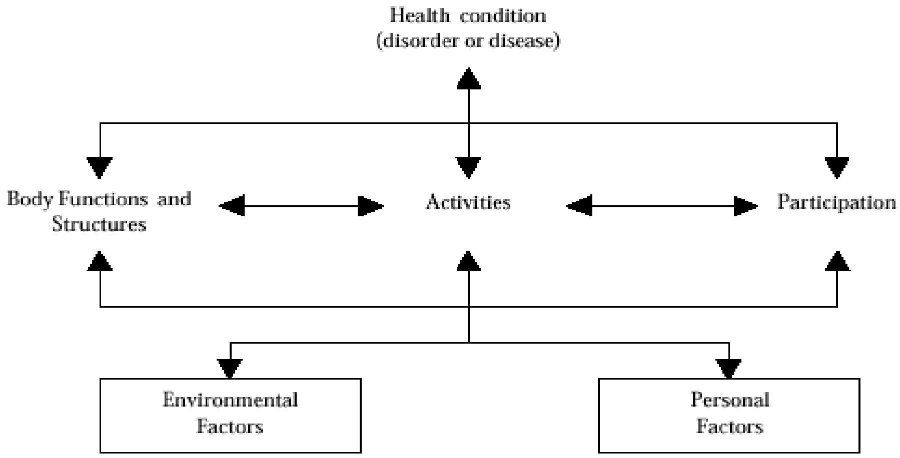
The fourth cardinal sign of Parkinson’s disease, postural instability, usually develops when the disease has progressed (Jones & Pfayfer 2004, p 206). The posture is often flexed forward and there is an increased risk of falling. This is due to that the automatic regulations of the body are disrupted (Teräväinen 2000, p 13). In relation to the muscle tone, there is a significant flexor dominance that is easily seen by the forward flexed posture. Retropulsion and/ or propulsion (falling backwards/ forwards) can occur during the examination. Due to the postural changes the gait changes and especially the stride length shortens. Hence the steps become smaller and the typical shuffling gait in Parkinson’s disease appears. Another typical event that might occur is freezing of the movement that is caused by a lack of voluntary movements. Freezing is often a consequence of medical failure. In addition festination can occur and this refers to the movement becoming faster and faster in gait. (Jones & Pfayfer 2004, p 206.)

Apart from the four cardinal symptoms there is a variety of other symptoms that can present themselves in Parkinson’s disease. When speech is affected, problems with swallowing and drooling commonly occur. The voice becomes lower and more monotonous and there is a lack of rhythm. Dystonia can also happen and it refers to clawing of the toes in a cramp-like manner that can be very painful. Frozen shoulder syndrome might also occur due to muscular inactivity and rigidity. Problems with the digestive system are also quite common as the autonomic nervous system does not function normally. Orthostatic hypotonia might also occur as well as sleep disorders. Cognitive changes are moreover common in Parkinson’s disease and a result of that is depression. 25% also develop dementia that often involves visual hallucination due to medication. (Jones & Pfayfer 2004, p 206.)

3.3 Empowerment and Quality of Life

The International Classification of Functioning, Disability and Health (Picture 1) or shortly put ICF is one of WHO’s (World Health Organization) tools for the measurement of health. One central issue that considers ICF is that it does not focus on the disability alone; instead it has a more holistic view. ICF classifies the individual or population from body, individual and social perspectives. In addition to this it uses three lists. One concerns body functions and structure and one activity and participation. As all issues have to be put in a context a list of environmental factors is used as well. The main point is that the focus is on the impact of the disability in all these areas and not on the disability. (WHO 2001, p 5-9.)

Picture 1. The International Classification of Functioning, Disability and Health



The Empowerment Day for persons with Parkinson’s disease can be placed in the context of ICF. The participants are either persons with Parkinson’s disease or a next of kin to a person with Parkinson’s disease. The aim is to empower people with varying activities that are connected to ICF. The program contains physical activity in varying forms and lectures with topics that concern Parkinson’s disease from different aspects. The program also offers the opportunity to peer support, discussion and perhaps also new information. The Empowerment Day also attempts to approach the life with Parkinson's disease from diverse viewpoints with the help of persons with and without Parkinson's disease. Furthermore people with Parkinson-related knowledge contribute to the Empowerment Day as well. In addition one program point especially focuses on discussion about the disease and covers social life, physical activity, medication, limitations, difficulties etc.

When it comes to Parkinson's disease the quality of life is affected and a survey concerning this matter was conducted in 2007. 31 persons with Parkinson's disease took part and 18 were male and 13 were female. The age of the participants ranged from 57 to 87 and the average age was 70. At the time of the study 90% of the respondents lived with no external help, but 70% felt that they needed it. The participants were asked about their current health situation (table 1) and 63% of the respondents thought it was satisfactory. 13% experienced that they had poor health, 20% that they had good health, 3% that it was good enough and none of the respondents felt that they had excellent health. 15 persons thought that the statement "I believe that my health will deteriorate" was true. When it comes to the functional ability (table 2) 70% of the respondents said that the health condition was restricted especially in tasks that demand considerable exertion such as running, heavy lifting and strenuous sports. Only 7% of the respondents experienced no restriction at all and 23% experienced some restriction. (Reiman 2007, p 33-35.)

Table 1. The current health experienced by persons with Parkinson's disease

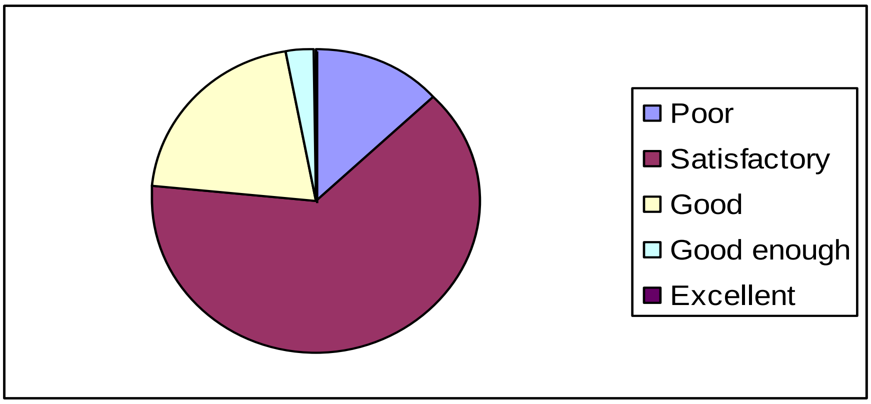
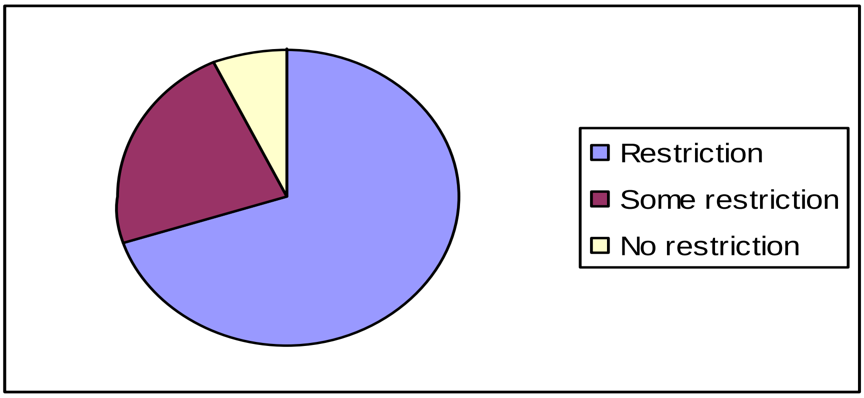


Table 2. Functional ability and the amount of restriction experienced by persons with Parkinson’s disease.



55% of the respondents experienced limitations in bending the trunk, kneeling and forward flexion and 52% experience problems when carrying shopping bags. When it comes to bathing and dressing 40% experienced a lot of limitations. In addition 80% of the respondents experienced difficulties in work or duties. 68% of the respondents also felt that they achieved less than they wanted. When it comes to the social ability a question concerning the last four weeks was posed. The participants were asked if they had felt some health- or emotional related difficulties in their social life during the previous four weeks. In table 3 the figures for this question are represented. 20% of the respondents experienced no difficulties at all, while 30% experienced some difficulties. Moderate difficulties were experienced by 20% and quite a lot of difficulties were also experienced by 20%. 7% of the respondents experienced a lot of difficulties. Table 4 represents how energetic the respondents had felt during the previous 4 weeks. 28% of the respondents had not felt energetic at all and 24% had felt energetic little time. 31% had felt energetic some time and 3% a considerable amount of time. 10% of the respondents had felt energetic a majority of the time and 3% all the time. (Reiman 2007 p. 27-29.)

Table 3. Experienced difficulties in the social life during the past four weeks.

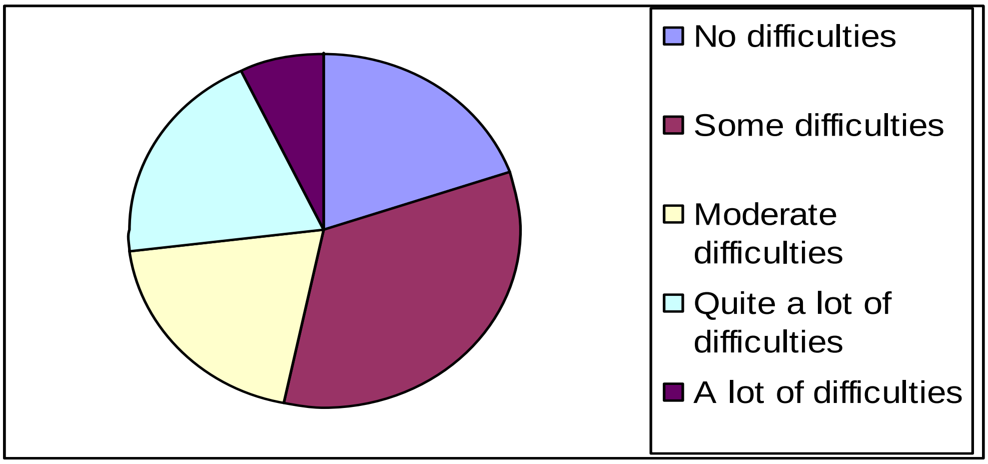
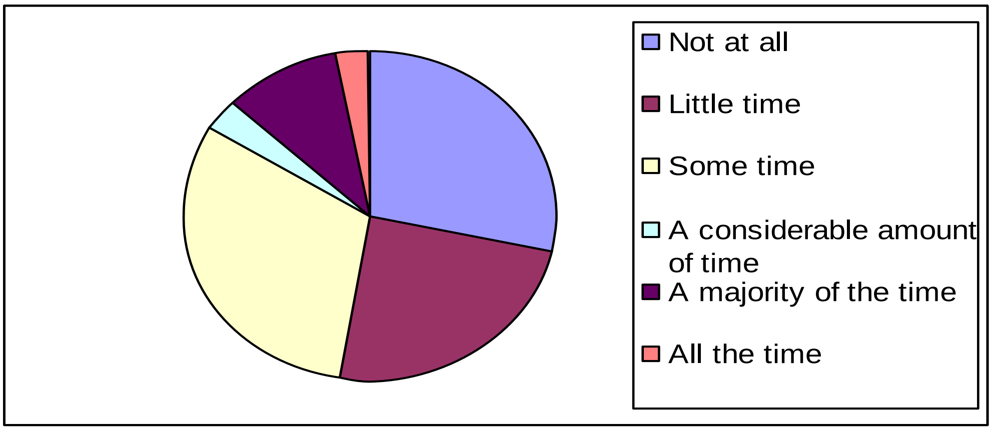


Table 4. The amount of time the respondents have felt energetic during the past four weeks.



This study revealed that persons with Parkinson's disease experience difficulties in many aspects of their lives. There is obviously deterioration in the physical health and as a consequence the social life is affected. Hence it can be assumed that the disease affects almost every part of a person's life. The quality of life is important to address and the Empowerment Day can provide some support in this context. Furthermore other activities that expand knowledge or bring people with a similar condition together can work in an empowering way.

Another study about quality of life and Parkinson's disease was done in 2003. The study concerned questionnaires from 238 persons with Parkinson's disease in Oulu University Hospital. The study wanted to describe quality of life in relation to health and compare it to the general population over 65 years. The experienced quality of life-related health was highest in psychic well-being and social capacity. The lowest scores were in the area that focused on physical well-being. There were also significant differences between genders and women experienced more difficulties than men. Women scored lower in all areas despite of the social function. The overall experienced quality of live was also lower among women and in addition women had more pain than men. The majority of the study population experienced symptoms connected with Parkinson’s disease, but only a few felt that it hindered the every day life. The most common symptoms were rigidity, bradykinesia, tremor, difficulties in moving and writing. In the comparison between the Parkinson population and the general population (all 65+), the quality of life scores were lower among persons with Parkinson’s disease in all areas. The largest differences are in functional ability, physical functions and in the overall experienced health. The smallest deviations concerned emotions, energy and pain. (Toljamo, Hentinen, Jämsä, Heikkinen, Hiltunen & Järvimäki 2003, p. 251, 256-258.) This study also supports the theory that the quality of life is poorer among persons with Parkinson’s disease compared to the general public. As a consequence of this it can be assumed that persons with Parkinson’s disease need support and guidance in certain fields. In relation to the Empowerment Day it can be pointed out that it is crucial to be familiar with the problems and difficulties in quality of life to be able to arrange a suitable program.

In direct relation to empowerment an education program for persons with Parkinson’s disease has been made. The education program involved seven European countries and it consisted of eight lectures, each with a duration of ninety minutes. Shortly, the program addresses psychosocial factors that often appear in Parkinson’s disease and involves both sufferer and carer. The program has been evaluated and short term positive affects on mood have been detected. Statistically the program can not yet show any quality of life-related effects, but it however initially shows a positive trend in empowerment related to psychosocial factors. (Simons, Thompson & Pasqualini 2006, p 478.)

3.4 Theory for Physical Activity

Physical activity is essential for persons with Parkinson's disease. The physical activity should be done on regular basis and both relaxation and stretching should be included in the daily routines. In the beginning of the disease physical activity is sufficient, but when the disease has progressed physiotherapy is needed. The main purpose of physiotherapy is to reduce muscle tightness, decrease pain and to maintain and improve the activities of the daily living. Swimming, aquatics and Nordic Walking are suitable forms of exercise for people with Parkinson's disease. It is however important to find a beneficial form of physical activity and the balance between rest and exercise is crucial. It is better to do for example two smaller passes instead of one long. Group exercises are usually popular among persons with Parkinson's disease. (Hiivola & Koivunen 2000, p 31-32.)

Although physiotherapy is not needed in the beginning of Parkinson's disease it is still advisable. The purpose is to maintain and improve the functional ability and the goals are set in agreement with the client. The goals of physiotherapy can be changed when necessary as the disease progresses. Shortly put the physiotherapy can be divided into five main categories. The first one is obviously the examination part that should be individual. The second part is to make an exercise program for the client that is structured according to the needs of the client. The program is altered on a regular basis because of the disease progression. The following physiotherapy concerns motor skills. The production of movement slowly becomes more difficult and thus the client easily stops trying and the movements are restricted. The physiotherapy aims to enable the client to produce qualitative movements and the exercises are therefore concentrated on that. Passive treatments are needed to some extent with for example massage and pain treatment. The fourth category is the care of complications and it basically means symptom-based treatment. The treatment should take place when the client is asymptomatic or as symptom-free as possible because the disease causes great fluctuation in the health condition. This category also involves dealing with the every day life and to overcome the difficulties. In this context family members and other health care professionals can be utilised. Family members and other persons connected with the client are of importance in the fifth category that concerns knowledge of the disease. This category deals with the education of the patient and family members and provides a foundation for coping with Parkinson’s disease. (Paltamaa 2000, p 29-30.)

A study in 2001 aimed at evaluating the effectiveness of a home physiotherapy program for persons with Parkinson’s disease. The home physiotherapy program showed to be twice as effective as a program in hospital settings. (Niewboer et al, 2001, p 270-272.) Furthermore a meta-analysis of studies concerning the effects of physiotherapy on Parkinson’s disease was made in 2001. The analysis consisted of articles published between 1966 and 1999 and they were collected from different data bases with a combination of certain keywords. The conclusion based on the meta-analysis is that physiotherapy is beneficial for persons with Parkinson’s disease. (de Goede, Keus, Kwakkel & Wagenaar 2001, p 509.) Furthermore another analysis of literature investigated the effects of physical activity on strength, mobility, balance and ADL’s to mention a few among people with Parkinson’s disease. Similarly different databases were used with a combination of different keywords. The main outcome was that physical activity is beneficial for persons with Parkinson’s disease and it showed that ADL’s and physical performance improved through exercise. Further studies need however to be taken in order to find more specific exercises for persons with Parkinson’s disease. (Crizzle & Newhouse. 2006, p 422.) Moreover a review on randomized controlled trials has been made to investigate the effectiveness of exercise on physical, social, psychological aspects as well as on quality of life. This review was made by two independent researchers and 14 randomized controlled trials with moderate reliability were included. The outcome once again supports physical activity especially in connection to physicality, strength, balance, gait speed and health-related quality of life. This analysis also states that further studies are needed to investigate dosage of exercise in different stages of the disease. (Goodwin, Richards, Taylor, Taylor & Campbel l 2008, p 631.)

One essential issue to be considered when planning physical activity for people with Parkinson’s disease is that it needs to be easy to modify. As there are many different stages of Parkinson’s disease the participants need to be able to take part according to their own current health condition. Furthermore there are no specific exercises for people with Parkinson’s disease, but as studies propose the physical activity should be symptom-based. As there is no possibility to plan individual exercises as the estimated number of participants is about 50, the exercises have been planned according to the general problems in Parkinson’s disease. The morning exercise will consist of circuit training with eleven spots with different exercises for the whole body. The exercises will be basic as there is not enough time to introduce more complex exercises. The participants will be able to do the exercises according to their own skill level and current health condition. In addition chairs will be placed at the spots in order for the participants to be able to rest if needed. In addition the spots will be circled in groups of a maximum of five persons because of the amount of participants. The small groups also work in an empowering manner because the participants can get peer support from each other. The spots contain basic muscle workout for the whole body in different starting positions. In addition balance has been introduced in some of the spots with the aid of step boards, balls, rubber bands and stepping exercises. The spots will be circled two times and there will be a short break between the sets. During the first set each spot will take 75 seconds and during the second set 60 seconds will be spent per spot and the transfers between the spots are included in these times.

The relaxation part of the morning exercise will occur at the end of the session. The duration of the relaxation will be about 15 minutes and a tape will be used for this purpose. The name of the CD is “Lepohetki” (freely translated “Moment of Relaxation”) and it was made by the Finnish Parkinson Association in 2001. The name of the track used is “Pysäytä kiire rentoutumalla” (“Stop the stress by relaxation). (Suomen Parkinson-liitto 2001.) Relaxation is important in Parkinson’s disease as it can prevent the occurrence of tremor to some extent. Tremor presents itself during social events, especially during agitation, stress or anxiety and relaxation can alleviate the tremor. Relaxation has been proven effective against bradykinesia and rigidity as well. In connection with these symptoms fatigue is often experienced and relaxation contributes to the recuperation. There is a vast range of techniques that can be used for relaxation and the aim is to find the right type of relaxation. With Parkinson’s disease it is proposed that the use of visualization and mental pictures could be effective. Such relaxation that uses muscle contraction to relax different muscles is not suggested in Parkinson’s disease. In Parkinson’s disease the muscle tonus and the motor skills might be disturbed thus relaxation involving muscle contraction is not advisable. (Banks 1991, p 79-80.)

When it comes to external cueing music will be used during the warm-up and circuit training. A systemtic review was made about the effects of external cueing on gait in patients with Parkinson’s disease and in 2005. One study of high quality supported the effects of auditory cueing on walking speed, but it is uncertain whether it can affect the ADL’s. (Lim et al 2005, p 695-713.) The warm-up involves walking hence music will be played with the aim to support the exercise. Music will also be played during the circuit training in order to provide rhythm for the exercises.

3.5 Theory for Peer Support and Panel Discussion

The theory for peer support and panel discussion overlap as they are quite closely connected. Furthermore the lecture and the discussion contained similar subjects, but they were covered from different viewpoints. The lecture was basically a session about peer support and the benefits of it and other issues related to it. In addition there was some time for questions and/ or comments at the end. The panel discussion on the other hand covered issues related to life with Parkinson’s disease and peer support was in a way included throughout the discussion. This was possible because there was a panel of four persons (three with Parkinson’s disease and one carer) and one chairman that approached the topics from different viewpoints. The topics for the discussion covered quite many aspects of life with Parkinson’s disease.

A study about Parkinson’s disease and the experiences of both the sufferer and the carer was published in 2005. The study was carried out in Finland and a number of 35 persons with Parkinson’s disease and 34 carers participated. The material was compiled by theme interviews and included elderly people (65+) with Parkinson’s disease and their carers. The mean age among the sufferers was 73 years and the majority of the study population consisted of males (71%). The mean time since the onset of symptoms was 8 years and the mean time for the diagnosis 6 years. 63% were members of the Parkinson Association. When it comes to the carers the majority of them were women (82%) and the man age was 62 years. 63% of the carers were spouses to a person with Parkinson’s disease, 18% other relative and 9% other. 80% of the carers lived together with the sufferer and the others visited on regular basis, e.g. a few times per week or month. (Haapaniemi, Leino & Routasalo 2005, p. 311, 313-316.)

Prior to the diagnosis the first symptom was tremor in one hand. Other commonly experienced symptoms were overall stiffness in the body, slowness of movement and changes in balance and/ or movement. Other more vague symptoms were of a more general nature, such as fatigue and pain. The symptoms had been noticed by the carer as well. Furthermore the carers had noticed mood-related symptoms, such as depression, anxiety, jealousy and lack of initiative. Moreover problems with memory and taught blackout were noted. Both the carers and the sufferers were unable to relate the symptoms to any specific disease and there was a general belief that the symptoms were related to the normal ageing process. Both the carers and the sufferers had inadequate knowledge about Parkinson’s disease and they had a very negative approach towards the disease. The diagnosis was often made by a doctor, but the final diagnosis was made by a neurologist. At his stage it was common that the sufferers did not comprehend the situation. The sufferers were usually quite calm about the disease and factors such as peer support and knowledge about the disease facilitated this. (Haapaniemi, Leino & Routasalo 2005, p 316-317.)

After the diagnosis the symptoms obviously increased as the disease progressed. The majority of the sufferers however felt that they were able to cope with the situation quite well. This was due to guided or own physical activity, regular medication and peer support. Especially supporting was the support of the spouse and empowering factors were activity, hobbies and doing things that felt good. Both the carers and the sufferers emphasized on the continuance of normal life and the slow progression rate of the disease helped in this context. There was also a mutual focus on taking one day at a time and not to worry about the future. In addition a positive mind and trust in the future helped to adapt to new situations. The major part of the peer support was from family, friends, relatives and neighbours. Also peer support from nurses and the Parkinson association was considered to be beneficial. Some sufferers however felt that there was a lack in peer support and they were not able to discuss matters enough. The carers also felt that peer support worked in an empowering manner. On the other hand there were both carers and sufferers that experienced negative emotions towards their situation. Some sufferers felt that the diagnosis caused anxiety and that the disease was not properly treated. Furthermore they had both physical and social restrictions and they felt that they were forced to give up different things (summer house, hobbies etc). Also caregivers had negative emotions concerning the disease. There were negative changes in the personality of the sufferer and the life had changed. The carers also had to take on the responsibility of household chores and they carried the responsibility for medication and assistance in ADL's. A general matter of concern was however the future and the manner the disease will progress in and further life changes related to that. A general concern was for how long a time the sufferer would manage at home and for how long the carer would be able to look after the sufferer. (Haapaniemi, Leino & Routasalo 2005, p 317, 320.)

This study is believed to be relevant and reliable, because other studies have been carried out in other countries and they have shown similar results (Haapaniemi, Leino & Routasalo 2005, p 320). The issues brought up in the study reflect on the matters brought up in both the lecture about peer support and in the panel discussion. The lecture on peer support was held by a regional worker in the Parkinson Association and this person is experienced in the field. The panel discussion also reflects on the topics brought up in the study and the discussion proceeds from the moment of the first symptoms towards life with Parkinson's disease and thoughts about the future.

3.6 Theory for Balance

Balance and co-ordination is related to postural instability and these topics are important in Parkinson’s disease. The typical problems with postural instability and balance-related issues are explained in chapter “3.2 Parkinson’s Disease” and the content of the neurologist’s lecture concerns these things. It is crucial for a person with Parkinson’s disease to be aware of the postural problems and the increased risk of falling. Even the carers can utilise this information as situations of risk can be avoided if the knowledge is good.

4 KEY COMPONENTS IN THE PROJECT

There are two main issues that have been emphasized on during the progression of the project. The first matter is the project plan and the other one is the close cooperation with the contact persons in the Pori Parkinson Association. In addition the marketing of the day has been a central issue. The aim of the Parkinson Association was also to attract new members. Furthermore it has been of great importance to plan and sort out the practical arrangements of the day to avoid problems in the implementation of the project.

4.1 Project Plan and Cooperation

The project plan and the cooperation with the Pori Parkinson Association were of great importance during the project. In May 2007 the Department of Social Services and Health Care in Satakunta University of Applied Sciences had been contacted by the Parkinson Association, thus a request about the arrangement of an Empowerment Day was forwarded to the students. I announced my interest and I took on the responsibility for the project. At that time the issue was not urgent and it was decided to continue with the project in the fall. As agreed on, I contacted the Parkinson Association in the fall and we agreed on an initial appointment where I acquainted myself with some members from the board of the

Pori Parkinson Association. An initial meeting with the chairman (Västilä) and the secretary (Isosaari) of the Pori Parkinson Association was held 31.10.2007. During the meeting the facilities of the Unit of Social Services and Health Care were shown and the date for the Empowerment Day (23.4.2008) was set. In addition the timetable of the day was discussed. When it comes to the timetable it was requested that the day would start at 10.00 and finish at 15.00. In addition Västilä and Isosaari mentioned that it would be beneficial to have some form of physical activity as the first program point. Moreover it was decided to have two lecturers and to have some form of discussion based part. At this stage the idea of a panel discussion came up and it was determined to have one chair and four members. The idea was also to make the discussion as multifaceted as possible by having both persons with and without Parkinson’s disease in order to voice different aspects of life with Parkinson’s disease. Furthermore the structure of the timetable needed to be ready before 12.12.2007, because of marketing issues. (Västilä 2007.)

The next meeting was arranged 11.12.2007 and the participants were again Västilä and Isosaari. During this meeting the structure of the timetable was displayed and accepted. The program points were discussed and we agreed on that the physical activity should consist of circuit training and relaxation. In addition we discussed the members of the panel discussion and agreed on whom to ask to participate. The practical arrangements of the day were also discussed during this meeting. We decided to put a deadline for pre-registration for the Empowerment Day one month prior to the event. The amount of participants expected was around 50, but it was still important to know the exact number of participants to be able to do the finishing touches for the day. (Västilä 2007.) The third meeting was held 18.3.2008 and the program was discussed in detail. Especially the panel discussion and the topics of it were brought up as well as how to guide the participants in the facilities. We also addressed issues such as parking, dining and coffee and we also discussed further marketing. It was decided to contact the local paper in Satakunta (Satakunnan Kansa) and market the event to members outside the Pori Parkinson Association. (Västilä 2008.) Apart from the three meetings there was a considerable amount of contact through e-mail and telephone. The cooperation with the Pori Parkinson Association lasted from October 2007 until the date for the Empowerment Day 23.4.2008.

4.2 Marketing

As mentioned the marketing was initialized with the letter about upcoming events in December 2007. In addition the contact persons said that they inform the members during other events thus reminding the members about the Empowerment Day. In addition on the International Parkinson Day (11.4.2008) there was an announcement in the local newspaper (appendix 1) and the main idea was to attract new members and make the event known to the public. This resulted in a few more registrations for the Empowerment Day. The International Parkinson Day is celebrated to the memory of James Parkinson that was the first to describe the symptoms of the disease. The expected number of participants for the Empowerment Day was 50 and exactly 50 took part in the Empowerment Day. Thus the marketing reached its target.

4.3 Practical Arrangements

The initial practical arrangement that needed to be considered was the facilities to be used. For the morning exercise the big gym in the facilities of the Department of Social Services and Health Care in Satakunta University of Applied Sciences was used as it was spacious enough. A large classroom with the technical equipment needed would be used for the other program points. The participants were able to have their lunch and coffee in the restaurant of the department. There were signs that showed the participants where to go and during the first program point they were told about the program of the day and how to find the places. A timetable with all the activities for the day was distributed to the participants. There were elevators available and I guided the participants to the right locations.

5 THE EMPOWERMENT DAY 23.4.2008

The final product of the project is an Empowerment Day for persons with Parkinson's disease and their next of kin. The Empowerment Day has been planned in cooperation with contact persons from the Parkinson Association in Pori and will be implemented in the facilities of Satakunta University of Applied Sciences. Shortly put the program is a variety of physical activity, lectures and discussion (appendix 2 and 3).

5.1 The Morning Exercise

The morning exercise is started by a brief warm-up that basically consists of walking and moving the upper extremities. The warm-up is followed by circuit training with eleven spots that the participants circulate in groups of four to five persons. The circuit training was chosen on the basis of its practicality as the estimated number of participants is around 50. The circuit training allows the participants to perform the exercises in their own pace and the small groups provide both support and encouragement. During the circuit training there will also be music to provide rhythm for the exercises. The circuit training has two rounds with a pause in between. During the first round the amount of time spent at one station is 75 seconds and during the second round 60 seconds. Thus the total amount of time spent at the circuit training is about 30 minutes. The physical activity is followed by a relaxation part that lasts for about 15 minutes. Afterwards there is a 45-minute lunch break.

5.2 The Lectures

There are two lecturers that will participate in the Empowerment Day. The first lecturer is a regional worker from the Parkinson Association and the second one is a neurologist. The first session with the regional worker is 30 minutes long and is focused on Parkinson’s disease and peer support. The second lecture is 45 minutes long and the main issue is Parkinson’s disease and balance. At the end of both sessions there will be time for questions and discussion. At the end of the second lecture there will be some pause gymnastics (appendix 4) and this session is followed by a 30-minute coffee break.

5.3 The Panel Discussion

The purpose of the panel discussion is to address issues in the life of a person with Parkinson’s disease from different view points. There will be one chairman and a panel of four that discuss different matters related to Parkinson’s disease. The discussion is lead by the chairman that addresses the matters and the persons in the panel will share their thoughts on the topic in question. The panel contains three persons that have Parkinson’s disease and one next of kin. The panel will firstly focus on the Parkinson diagnosis and life changes in relation to that. The discussion will continue with family life and social life and in addition exercise and medication will be discussed. The final issue that will be discussed is the Parkinson Association and the audience can voice their opinions at the end of the session. The duration of the panel discussion is one hour.

5.4 The Final Program Point

The final program point will take about thirty minutes. The participants can initially fill out a questionnaire about the empowerment day. The questionnaire (appendix 5 and 6) is brief and it gives the participants an opportunity to comment freely on the day as well as grading the different parts of the program. The final program point also includes a trivia as the Parkinson Association requested some kind of fun activity to end the day.

6 IMPLEMENTATION, FUNDING AND ETHICS

The empowerment day was implemented 23.4.2008 in the facilities of Satakunta University of Applied Sciences at the department of Social Services and Health Care in Pori. The time reserved for the empowerment day was from 10.00 to 15.00 and it was free off charge for the participants. A total of 50 persons participated in the empowerment day. The only part that needed funding was the neurologist's lecture (160 €) and it was financed by Satakunta University of Applied Sciences.

When it comes to the ethical issues of the day both the anonymity of the participants as well as the lecturers was taken into consideration. No names have been mentioned in this work and I have not received any contact information about the participants. The enrolments have been given directly to the Pori Parkinson Association and I have merely received the final number of participants. Photos were taken during the day with oral consent. There was however no agreement in writing and hence the decision to exclude photos was taken.

7 EVALUATION

The evaluation of the Empowerment Day is based on questionnaires filled out by the participants. 50 persons participated in the day and a total of 38 persons returned the questionnaires. One questionnaire was excluded as it was not readable. The questionnaires were interpreted by taking the mean value of all answers received from a particular question. The numbers used in the assessment were from 4-10. 4-5 responds to unsatisfactory, 6-7 equals satisfactory, 8-9 means good and 10 is excellent. The participants could also comment freely on the day at the end of the questionnaires.

7.1 The mean values and number of responses

The first question concerned the amount of persons with and without Parkinson’s disease that participated in the Empowerment Day. The 37 questionnaires included showed that 22 persons have Parkinson’s disease, 11 do not have Parkinson’s disease and 4 persons did not respond to the question. Table 5 is a summary of the questionnaires and represents the mean values and number of responses to each question. Table 1 initially shows the morning exercise and the five questions concerning it. The warm-up had the lowest mean value of 7,9 with 32 responses and the relaxation and the entirety had the highest mean value of 8, 3 with 34 responses each. The table continues with the lectures and it was obvious that the balance lecture was more popular than the one on peer support. The entirety of the peer support lecture got the mean value 7,8, (36 responses) while the entirety of the balance lecture scored 8,8 (37 responses). The pause gymnastics had a mean value of 7, 8 with 35 responses.

The following representation in table 1 is the panel discussion and the three questions concerning it. The topicality of the subjects received a mean value of 8, 4 and how interesting the discussion was 8, 3. The entirety of the discussion got 8, 3. The number of responses to all three questions was 36. The final part of table 1 represents the overall grades for the day. There were three questions and 37 responses to each of them. The first question was if the participants felt empowered and the mean value was 8, 3. The length of the day received a mean value of 8, 4 and the overall grade for the empowerment day was 8, 3.

Table 5. Representation of the mean values of the questionnaires and number of responses concerning the different program points.

	x	n
MORNING EXERCISE		
The warm-up	7,9	32
The circuit training	8,1	34
The relaxation	8,3	34
The music	8	35
The entirety of the morning exercise	8,3	34
PEER SUPPORT LECTURE		
The content	7,9	36
The length	7,8	36
The entirety	7,8	36
BALANCE LECTURE		
The content	8,7	37
The length	8,7	37
The entirety	8,8	37
PAUSE GYMNASTICS		
How refreshing were the pause gymnastics?	7,8	35
PANEL DISCUSSION		
The topicality of the subjects	8,4	36
How interesting were the subjects?	8,3	36
The entirety of the discussion	8,3	36
OVERALL QUESTIONS		
Do You feel empowered?	8,3	37
The length of the day	8,4	37
The overall grade	8,3	37

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7.2 Comments by the participants

When it comes to the morning exercise one comment was that it was slightly too demanding for persons with more severe symptoms and that the form of exercise was untypical for persons with Parkinson’s disease. In addition someone wrote that the physical activity part could have been longer. There were no comments on the lecture on peer support, but there was one on the balance lecture and it was that it could have been longer.

In relation to the panel discussion participants had some problems hearing the discussion. There was also a wish that there should have been some more time to deal with the topics and further engagement in the discussions. The program was also too tight and the breaks should have been longer. Someone also wished that there should have been more information about the Parkinson association and its activities. There were also comments on how pleasant the day had been and that the entirety of it was good and wishes that it would be arranged again.

8 DISCUSSION

The aim of the project was to arrange an Empowerment Day for persons with Parkinson's disease and the aim was reached. There was however a considerable amount of work that needed to be done before the implementation of the day was possible. The work load was to some extent shared with the Parkinson association in Pori. The cooperation with the organization was crucial in order to create an empowerment day that both persons with Parkinson's disease and their next of kin would be able to extract the most of.

The frame for the day was somewhat clear already during the first meeting with the contact persons from the Pori Parkinson Association. The lecturers had already been contacted and a date for the empowerment day was decided based on their schedules. In addition the hopes for the day were to have some kind of physical activity and some kind of discussion based program point. In addition the contact persons wished some kind of lighter activity that would end the whole day.

The initial meeting with the contact persons from the Pori Parkinson Association was held in the autumn 2007. During that meeting we decided to implement the Empowerment Day 23.4.2008. The timetable for the day however needed to be finished before the 12.12.2007, because of the marketing to the members of the Parkinson Association. Hence the initial marketing was initiated because a letter about the upcoming activities was sent to all the members.

The cooperation obviously continued with the Parkinson Association throughout the whole planning process and we had a few meetings and we also had contact via e-mail and telephone whenever necessary. The day was implemented as planned 23.4.2008. When it comes to the morning gymnastics the challenge was to plan some kind of physical activity for a large target group with individuals with varying health conditions. Thus circuit training was considered to be a good physical activity as it can be done in small groups, yet in an individual pace. The small groups would also provide encouragement and support if needed. In retrospect one round of the circuit training might have been enough as some of the participants were not interested in physical activity and some did not have enough strength for two rounds. The relaxation was successful, but the timing of the morning exercise was too tight and it would also have been beneficial to have a few assistants.

During the circuit training music was played and it was obvious that the majority of the participants found it supporting for the physical activity. One issue that was not taken into consideration was that music could cause problems for persons with hearing devices. Thus the music had to be played on a relatively low volume and was no longer that supportive for the circuit training.

The lectures went well although the timetable was too tight. The main reason for the failure in the timetable was that some participants were late for the first lecture and we decided to wait until all the participants were present. The delay in the timetable affected the rest of the day and it was necessary to remove the final program of the day, e.g. the trivia. There was a break after the lectures and some participants were late for the panel discussion as well thus the only choice was to leave out the trivia to gain some additional time for the panel discussion. In this context it is crucial to have enough time in the schedule, because some activities might take longer than expected and it is always better to have too much time than too little time. Another issue that should be seriously taken into consideration prior to an event is the audibility. During the Empowerment Day there were some problems during the panel discussion as some of the panel members’ voices were low because of the Parkinson’s disease. There was a microphone, but the persons that needed it avoided to speak right into it thus there was no clear amplification of the speech.

The Empowerment Day was good according to the questionnaires. There were of course some things that could have been improved and those issues have been addressed previous in this discussion part. It was nice to have an opportunity to work together with the Pori Parkinson Association to achieve a mutual goal e.g. the implementation of the Empowerment Day. A project like this equals a great work load and careful planning, but it has been very educational to work in this manner.

When it comes to the theoretical framework for the Empowerment Day, it was of initial interest to get acquainted with the target audience, hence the information about the Parkinson Association and Parkinson’s disease. In this context I found it important to include studies about the quality of life of people with Parkinson’s disease and to place the Empowerment Day in the ICF concept. It was fairly easy to find material and the challenge was to compile the material to provide an overall picture of the quality of life among persons with Parkinson’s disease. I was not able to find any reliable studies about empowerment in direct relation to Parkinson’s disease, but the concept of some kind of empowerment was covered in some of the articles. The article “Parkinsonin tautiin sairastuneen ja hänen omaisensa kokemuksia sairauden eri vaiheissa” (freely translated as “The Experiences of the Person with Parkinson’s Disease and the Carer in the Different stages of the Disease”) in particular was of great value in the theoretical framework. The article gave insight in life with Parkinson’s disease on many levels and provides a good support for the Empowerment Day as it is directed to both people with Parkinson’s disease and their next of kin. Furthermore there were a number of studies about Parkinson’s disease and physical activity-related issues. Furthermore it was easy to find information about peer support and its importance in Parkinson’s disease. I think that my theoretical framework supports the programme of the day.

9 CONCLUSION

To plan and to implement a day with a certain theme equals hard work and many learning experiences. The main aim of the project was to plan and implement an Empowerment Day. In this context a project plan is crucial. In addition if there is a cooperation agency involved it is of great importance to be reliable, flexible and hard working. The main aim was reached in this case and the overall grade was good. The day was carefully planned but in retrospect there is of course issues that could have been improved or done differently. The number of participants was in this case quite big for only one person to handle and the whole process, particularly the implementation would have been easier if there had been another student involved If that had been the case there would have been someone to consult and share the experience with. I am still content with my own input and it has been educational to cooperate with the Parkinson Association. It can furthermore be concluded that this kind of theme day is beneficial for persons with Parkinson’s disease and their next of kin. It involves members of the Parkinson Association as well as their next of kin and they have an opportunity to take part in a varying program. They also have a chance to receive peer support and to exchange thoughts and ideas and they can engage in discussion. The idea of an Empowerment Day for persons with Parkinson’s disease is very good and both persons with and without Parkinson’s disease benefit from the day. Thus it would be good if similar events would be arranged in the future as well. According to the outcome of the questionnaires they too support the theory that persons with Parkinson’s disease enjoy these kinds of activities.

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LIST OF APPENDICES

Parkinson-päivä 11.4.

Tänään 11.4. vietetään Euroopassa kansainvälistä Parkinson-päivää. Parkinsonin tauti on etenevä neurologinen sairaus, jonka syytä ei tiedetä. Aivoissa tapahtunut muutos mustassa tumakkeessa johtaa dopamiinin vähenemiseen. Tämä vuorostaan aiheuttaa lukuisia oireita kuten liikkeiden hitaus, lepovapina, lihasjäykkyys ja tasapaino-ongelmia. Sairautta ei voida parantaa, vain sen oireet lievitetään lääkkeillä ja kuntoutuksella.

Porin seudun Parkinson-yhdistys järjestää keskiviikkona 23.4. klo.10.00- 15.00 voimavarapäivän Satakunnan Ammattikorkeakoulussa. Ohjelmasta löytyy mm. kevyt liikuntatuokio, kaksi asiantuntijaluentoa ja mielenkiintoinen paneelikeskustelu. Ilmoittatumiset ennen 16.4. Kauko Västilälle.
(Satakunnan Kansa. 11.4.2008)

English Translation

Parkinson Day 11.4

Today 11.4 we are celebrating the World Parkinson Day in Europe. Parkinson's disease is a progressive neurological disease, which cause is unknown. Changes in the substantia nigra in the brain cause a lack of dopamine. Hence it causes several symptoms such as slowness of movement, tremor at rest, rigidity and balance problems. There is no cure for the disease, but the symptoms can be alleviated with medication and rehabilitation.

The Pori Parkinson Association arranges an Empowerment for persons with Parkinson's disease at Satakunta University of Applied Sciences 23.4.2008 from 10.00 to 15.00. The program consists of light physical activity, 2 expert lectures and an interesting panel discussion. Preregistrations to Kauko Västilä before 16.4.

PORIN VOIMAVARAPÄIVÄ

23.4.2008
Satakunnan Ammattikorkeakoulu
Sosiaali- ja terveysala
Maamiehenkatu 10
28500 Pori

OHJELMA

10.00-11.00 AAMUJUMPPA

- tietoa päivän ohjelmasta, ruokailusta ja tiloista
- verryttely, kuntopiiri ja rentoutus

11.00-12.00 LOUNAS

12.00-12.20 VERTAISTUKI LUENTO

- Aluetyöntekijän pitämä luento vertaistuesta

12.20-13.00 TASAPAINO LUENTO

- Neurologin pitämä luento tasapainosta

13.00-13.30 TAUKOJUMPPA & KAHVITAUKO

13.30-14.30 PANEL DISCUSSION

- Paneelikeskustelu Parkinsonin tautiin liittyvistä asioista
- Paneelissa on yksi johtaja ja neljä jäsentä

14.30-15.00 LOPPUKEVENNYS

- Kyselylomakkeiden täyttäminen
- Tietovisa

EMPOWERMENT DAY IN PORI
23.4.2008

Satakunta University of Applied Sciences
Maamiehenkatu 10
28500 Pori

PROGRAM

10.00-11.00 MORNING EXERCISE

- Information about the program, facilities and dining
- Warm-up, circuit training and relaxation

11.00-12.00 LUNCH

12.00-12.20 PEER SUPPORT LECTURE

- Lecture on peer support held by a regional worker from the Parkinson Association

12.20-13.00 BALANCE LECTURE

-Lecture about balance held by a neurologist

13.00-13.30 PAUSE GYMNASTICS & COFFEE

13.30-14.30 PANEL DISCUSSION

- Panel discussion about Parkinson-related issues
- One chairmen and four members

14.30-15.00 FINAL PROGRAM POINT

- Questionnaires
- Trivia

APPENDIX 4

PAUSE GYMNASTICS

1. ELEVATION AND DEPRESSION OF SHOULDERS
2. ROTATE SHOULDERS FORWARDS, THEN BACKWARDS
3. OPEN THE CHEST, THEN HUG YOURSELF
4. STRETCH THE NECK, ROLL FROM SIDE TO SIDE
5. MAKE A FIST, RELAX
6. CONTRACTION OF THE GLUTEAL MUSCLES, RELAX
7. CONTRACTION OF ALL FACIAL MUSCLES, OPEN MOUTH
8. FINISH BY SMILING!

- a couple of repetitions of all the exercises, apart from number eight.

APPENDIX 5

Kyselylomake
Porin Voimavarapäivä
23.4.2008

1. Rastikaa ruutu

a) Sairastan Parkinsonin tautia ☐
b) Olen omainen/ muu ☐

Antakaa arvosana seuraaviin kohteisiin (kysymyksiin 2-7) mielenne mukaan. Arvosanat ovat niin sanottuja ”kouluarvosanoja”, eli 4-10.

10= kiitettävä
8-9= hyvä
6-7= tyydyttävä
4-5= huono

2. Aamujumppa
a) lämmitys 4 5 6 7 8 9 10
b) kuntopiiri 4 5 6 7 8 9 10
c) rentoutus 4 5 6 7 8 9 10
d) musiikki 4 5 6 7 8 9 10
e) aamujumpan kokonaisuus 4 5 6 7 8 9 10

3. Vertaistukiluento
a) luennon sisältö 4 5 6 7 8 9 10
b) luennon pituus 4 5 6 7 8 9 10
c) luennon kokonaisuus 4 5 6 7 8 9 10

4. Tasapainoluento
a) luennon sisältö 4 5 6 7 8 9 10
b) luennon pituus 4 5 6 7 8 9 10
c) luennon kokonaisuus 4 5 6 7 8 9 10

5. Taukojumppa
a) kuinka virkistävää taukojumppa oli? 4 5 6 7 8 9 10

6. Paneelikeskustelu
a) olivatko aiheet hyviä? 4 5 6 7 8 9 10
b) oliko keskustelu mielenkiintoinen? 4 5 6 7 8 9 10
c) paneelikeskustelun kokonaisuus 4 5 6 7 8 9 10

7. Voimavarapäivän kokonaisuus
a) oletteko saaneet lisää voimia tästä päivästä? 4 5 6 7 8 9 10
b) oliko päivä sopivan mittainen? 4 5 6 7 8 9 10
c) kokonaisarvosana voimavarapäivästä? 4 5 6 7 8 9 10

8. Kirjoittakaa kommenttinne vapaasti ja antakaa vinkkejä voimavarapäivän parantamiseksi.

KIITOS OSALLISTUMISESTANNE!!!

APPENDIX 6

Questionnaire
Empowerment Day
23.4.2008

1. Cross suitable alternative

a) I have Parkinson’s disease ☐
b) I am a next of kin/ other ☐

Give grades to the following questions (2-7) according to your own opinions. The grades are “school grades” from 4 to 10.

10= excellent
8-9= good
6-7= satisfactory
4-5= poor

2. Morning Exercise

a)Warm-up	4 5 6 7 8 9 10
b)Circuit Training	4 5 6 7 8 9 10
c)Relaxation	4 5 6 7 8 9 10
d)Music	4 5 6 7 8 9 10
eT)he Entirety of the Morning Exercise	4 5 6 7 8 9 10

3. Peer Support Lecture

a) Content	4 5 6 7 8 9 10
b) Length	4 5 6 7 8 9 10
c) Entirety	4 5 6 7 8 9 10

4. Balance Lecture

a) Content	4 5 6 7 8 9 10
b) Length	4 5 6 7 8 9 10
c) Entirety	4 5 6 7 8 9 10

5. Pause Gymnastics

a) How refreshing was it?	4 5 6 7 8 9 10

6. Panel Discussion

a) Topicality	4 5 6 7 8 9 10
b) Was the discussion interesting?	4 5 6 7 8 9 10
c) The entirety of the Discussion	4 5 6 7 8 9 10

7. The Entirety of the Empowerment Day

a) Do you feel empowered?	4 5 6 7 8 9 10
b) Was the length of the day suitable?	4 5 6 7 8 9 10
c) Overall grade for the day	4 5 6 7 8 9 10

8. Write your comments freely and give tips on how to improve the day.

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THANK YOU FOR YOUR PARTICIPATION!!!