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Equine-Assisted Social Pedagogy Enhancing Life Management Skills of Individuals with Disabilities

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The objective of this Bachelor thesis was to study to what extent Equine-assisted social pedagogy impacted the Life Management Skills of individuals with a physical and/ or cognitive impairment. To reach out to the target group, the author contacted the instructors who work in the field around Finland by email.

Data for the study were collected quantitatively by sending an online questionnaire to the instructors. The survey included background questions about the participants and The Oxford Participation and Activities Questionnaire (Ox-PAQ). The Ox-PAQ form was filled in twice: first, the participants self-evaluated their daily Life Management Skills prior to starting with Equine-assisted social pedagogy, and secondly, the participants were asked to reflect on questions related to their Life Management Skills in the four preceding weeks. The instructors were asked to forward the e-form to their customers who belonged to the target group of the study.

The results were collected over a time period of three weeks in March 2020. Thirteen individuals responded to the survey. Even though the response rate was quite low, some conclusions could be drawn from the information provided by the participants. Statistical analysis and explanatory approaches were applied in the analysis of the results. The results indicate that attending Equine-assisted social pedagogy once or twice a week had a beneficial impact on the participants in managing their daily activities. The results lead to the conclusion that Equine-assisted social pedagogy had an uplifting effect on the emotional level of the participants. They felt less stressed, anxious, sad, and depressed when managing their daily activities.

This may demonstrate that Equine-assisted social pedagogy could be utilized as a useful tool to improve the Life Management Skills of individuals with a disability. Equine-assisted social pedagogy aims to increase social competence, social engagement and enhances the emotional well-being of individuals with a physical and/ or cognitive impairment. This in turn supports the individual's functional capacity in the functioning of his/ her daily activities.

Keywords	Equine-assisted social pedagogy, Life Management Skills, Physical and Cognitive Impairment, Oxford Participation and Activities Questionnaire (Ox-PAQ)

Contents

1 Introduction

Equine-assisted social pedagogy includes a wide range of activities at the stall environment, such as stables management; grooming a horse; taking care of the horse's equipment; doing ground-based activities with a horse; horseback riding or even carriage driving. The instructor/s, client/s, or other volunteers participate in these activities as well. (PATH Intl. 2020.)

In Finland, Equine-assisted social pedagogy is nationally also known as Social pedagogical horse activity (sosiaalipedagoginen hevostoiminta). Equine-assisted social pedagogy as a contemporary profession is a relatively new emerging field there. Nowadays, it is applied as a working method to prevent and rehabilitate socially excluded individuals. (Sosiaalipedagoginen Hevostoimintayhdistys ry 2020.)

At this time, Equine-assisted social pedagogy is not provided as a service option by the Social Insurance Institution, KELA. Unlike Equine-Assisted Therapy (EAT), Equine-assisted social pedagogy is not financially supported by them. While in EAT specific rehabilitative goals (generally physical) are set according to the client's needs (PATH International), in Equine-assisted social pedagogy, the main objective is social-emotional development (Bracher 2000), and to foster social growth (Sosiaalipedagoginen Hevostoimintayhdistys ry 2020).

The University of Eastern Finland offers a supplemental training program in collaboration with Ypäjä Equine College, which is named "Equine-assisted Social Pedagogy as a tool to prevent Social Exclusion and promote Social Rehabilitation". The main admission criterion to be admitted to the training program is an undergraduate degree in an educational-; social- or health care field, as well as competency with handling horses. (Lipponen & Vehmasto 2019, p. 8.)

In this bachelor's thesis, the author investigates how Equine-assisted social pedagogy impacts the Life Management Skills of individuals with disabilities. The Oxford Participation and Activities Questionnaire (Ox-PAQ) was electronically sent to trained Equine-assisted social pedagogy instructors throughout Finland. The Ox-PAQ included questions related to Routine Activities (fourteen items), Emotional Well-Being (five items), and

Social Engagement (four items) (Dawson, Dummett, Fitzpatrick, Jenkinson, Kelly & Morley 2013). Contact details of Equine-assisted social pedagogy practitioners were searched from an accredited web page (Hevostoiminta.net).

In Finland, data provided in the English language has been somewhat limited to this topic. Hence, the research related to this bachelor's thesis may be considered a valuable addition to this field of studies and the international community.

The author hopes that the study provides additional evidence for Equine-assisted social pedagogy to gain official recognition by Finnish authorities and is granted financial support as an effective working method for the prevention and intervention of social exclusion.

2 History of Equine-Assisted Social Pedagogy in Finland

In Finland, the initial term of Equine-assisted social pedagogy was at first referred to as “Riding Pedagogy”. The decision to rename the term was taken after the completion of a pilot study. The pilot study was named “Riding Pedagogy - a tool to prevent social exclusion of children and adolescents". In Riding Pedagogy, the emphasis lies on the horse-riding activity itself, whereas in Equine-assisted social pedagogy, the focus is more on social growth and social rehabilitation. The incentive to start the project was to search for new ways to improve the life quality of children and youngsters that were at risk of social exclusion for the better. The research project started in the year 2002 and lasted five consecutive years. The project was funded by the Ministry of Education and Culture (Opetus- ja kulttuuriministeriö), yet it was carried out by the Equestrian Federation of Finland (Suomen Ratsastajainliitto ry). (Lipponen & Vehmasto 2019, pp. 6-8.)

The long-term goal of the development project was to study the impact of Equine-assisted social pedagogy on children and adolescents, as well as to develop the education system. One of the aims throughout the project was to organize annual national seminars right from the first year of the operation. The last major national symposium was held in 2007. The national media reported extensively about the subject throughout that time. (Lipponen & Vehmasto 2019, p. 7.)

Since the first year of its operation, the project received controversial critics, while all at the same time, it had numerous supporters. From the early beginning on, The Finnish Equestrian Association was actively involved in the creation of Equine-assisted social pedagogy. The Finnish Central Union for Child Welfare (Lastensuojelun Keskusliitto ry) soon became their close networking partner, and therefore has contributed to the evolution of its establishment. (Lipponen & Vehmasto 2019, p. 7.)

The University of Easter Finland started introducing a supplemental training program in the year 2002 called “Equine-assisted social pedagogy as a tool to prevent Social Exclusion and promote Social Rehabilitation” (28cr.). (Lipponen & Vehmasto 2019, p. 8.)

2.1 Social Pedagogical Frameworks in Equine-Assisted Social Pedagogy

Social pedagogy is based on the firm conviction that it is possible to decisively impact social circumstances through education (Hämäläinen cited in Thempra 2020). Among

the basic principles of social pedagogy lies the empowerment of individuals to use their voice to change not only their own lives, but it as well teaches how to have an impact on the broader society (ThemPra 2020).

The link between Social pedagogy and Equine-assisted social pedagogy was first made in the late 1990s (Lipponen & Vehmasto 2019, p. 6). Equine-assisted social pedagogy is based on social pedagogical frameworks and it applies concepts such as Functionality, Communality and Experientiality. (Lipponen & Vehmasto 2019, p. 10).

The Equine-assisted social pedagogy instructor is responsible for ensuring that participants are accepted into the community. He distributes tasks that are most suited to the needs of clients. Activities in Equine-assisted social pedagogy are aimed to increase a person's self-awareness, enhance his physical and mental well-being. The stable environment offers numerous activities and opportunities to facilitate empowerment; it provides a safe space where failing and succeeding are a natural part of growing socially. By attending to the needs of a horse, Equine-assisted social pedagogy may teach and motivate individuals to integrate healthier lifestyle habits into one's own lives, and it may lead to improved self-care; having a regular daily rhythm; engaging in physical exercise; maintaining a balanced diet; or taking sufficient rest. (Lipponen & Vehmasto 2019, p. 13.)

The Zone of Proximal Development theory suggested by Vygotsky during the late 1920s, was progressively elaborated until he died in 1934. it claims that maximal learning takes place in a social context with other peers or another person who is more skilled in a field - who then simultaneously operates as a mentor or guide (ThemPra 2020). The concept can be seen in Equine-assisted social pedagogy when instructors, volunteers, or peers support the ones who are less experienced in an area.

The Relational Universe is a model that illustrates a relationship-centered practice (ThemPra 2020). A relationship-centered approach is essential when working with individuals who experience loneliness. In the viewpoint of the author, individuals with disabilities are at higher risk of being socially excluded from society, and as a result, may experience feelings of isolation. Equine-assisted social pedagogy implements a relationship-centered approach by fostering a sense of communality.

3 Life Management Skills

The theoretical framework of this bachelor thesis is based on the enhancement of Life Management Skills in individuals with disabilities. There are numerous approaches and definitions of Life Management Skills. As Equine-assisted social pedagogy was founded in Finland, the author would like to introduce three Finnish approaches to the concept of Life Management- as an incentive to the reader to make up his own way of the meaning of Life Management.

According to J. P. Roos, who invested his time studying the Finnish way of life, Life Management (also referred to as life control) is the skill to lead one's life towards the "correct" direction. Nevertheless, it also is a shelter against external catastrophes. He splits the concept into two categories, internal and external life control (Roos 1985, p.41; 1988, p. 132). Internal life control is the ability to adapt to life's circumstances and to try to see the positive elements in them. On the other hand, external life control is the ability to lead one's own life towards the right direction. Material and mental wellbeing are crucial elements of external life control. To seek and acquire material wealth means to seek for external life control. Besides, he distinguishes between absolute and superficial life control. Superficial life control means to uphold a facade of life control, which has become ever more prevalent in the urban lifestyle (Roos 1985, p. 42). He claims, that in today's world it is more necessary to focus on internal control, as external control is not a central issue in today's society anymore. As people's primary concern is not solely driven by economic welfare any longer, individuals experience increased levels of loneliness as a consequence of this (Roos 1985, p. 29, 42, 66, 82-83; 1987).

P. Niemelä defines life control as the ability to walk through life's difficulties and to be able to act in new situations. On his terms, internal life control means to be equipped with the skillset to cope in life. Like J. P. Roos (1991), he divides the concept into internal and external life control. By internal life control, Niemelä refers to an individual's capacity to control himself. According to him, external life control is a competency skill to manage external life risks (Niemelä 1991, p. 12, p. 17; Redistil 1995).

J. Hämäläinen's divides Life Management (life control) likewise into internal and external life control. Internal life control is when certain developmental stages have reached their full potential and when a person then is able to make decisions that lead his life towards a positive direction.

External life control include factors such as economic wellbeing, human relations, work, hobbies, educational institutions, and operating systems in the society that sustain overall life quality (Hämäläinen 1999, appendix 1). J. Hämäläinen (1996, p. 11) highlights that the ability to control life does not remain a static resource, but rather fluctuates, meaning it can deteriorate for some time before one isn able to regain its full strength again. He suggests, a person may improve his life by making new constructive decisions on a daily basis (Hämäläinen 1998, p. 160).

Eventually, the author decided to base the theoretical framework of this thesis on the approach of L. Böhnisch (1992), who was a well-known social pedagogue in Germany. L. Böhnisch describes life control as a psychic and social competence, which has been given to humans as a gift by God so that man would be able to take a leading role in his life. Socialization, social integration, and 'state of life' are essential elements of life control. He explains that socialization is a process in which a person's personality evolves through his interactions with his social environment (Böhnisch 1992, p.80). Successful socialization is when a human being has accomplished to live his life in harmony with the norms and values of a society, yet is capable to remain his true authentic self (Böhnisch 1992, p. 82).

4 Therapeutic Value of Equines

According to Hallberg (2009, p. 89) there are three themes that define how the essence of horses may be of help to human beings: improved communication skills, enhanced relational skills, and personal growth through a horse-human relationship.

As a large animal, a horse evokes a feeling of respect in a person. A horse provides genuine and direct feedback, positioning him in the role of a co-educator to the human being (Lipponen & Vehmasto 2019, p. 10). Horses are big, elegant, strong, quick, naturally sensitive, and are inherently cautious of their environment. This is because, before horses have been domesticated, they lived in the wild and were constantly threatened by dangerous predators. The healing power of horses has been mystified and has been regarded as a magical wonder in the past. However, by looking at the horse's intrinsic nature, one begins to apprehend him better:

> The keen ability of horses, as of all social animals, to 'read' and correctly interpret symbolic social signals is perhaps the most important key to their surprisingly peaceful subordination to humans in the domestic relationship… The well-known

> ability of horses to 'mind read' is neither so extraordinary nor so mystical as it is often made out to be; it is hardly surprising that an animal whose entire socioecology is based on an ability to read subtle social cues can pick up on the hesitations, uncertainty, and lack of self-assurance of one rider, and the confidence and resolution of another. (Budiansky 1997, p. 93.)

When a human being understands where their sensitive nature is derived from, he starts to learn to handle a horse by understanding his actions and behaviors instead of using force upon him (Yrjölä 2011, p. 99). It is well documented that learning the skills to handle a horse instills heightened confidence levels in an individual. Once students have learned how to overcome challenges related to good horsemanship, they awaken to their own talents and strengths (Hallberg 2008, pp. 198-199).

The walking movement of the horse is three-dimensional, which is therapeutically beneficial to the horse rider. The rhythmical movement transferred from the horse to the rider cause movements in three directions: back and forth (horizontal), from side-to-side (transversal), and top to bottom (vertical). These movements lead to improved body control and awareness, as the sensory functions of the brain are ignited. It as well relaxes muscle tones, e.g. a person with multiple sclerosis or cerebral palsy experiences improved symptoms by sitting on a walking horse (Bramanti, Cacciola, Cavallaro, Milardi & Portaro 2016). Another supporting factor is that the body temperature of a horse is approximately 1,5°C higher than from humans, which leads to decreased spasticity (Karlsson & Takala, 2001, pp. 21-23). Int addition, the movements of a horse when transferred to a rider causes passive movements in his pelvis. Thereby, the position correcting mechanisms of the body is set in motion, that results in an improved body posture (Sandström, 2011, p. 64).

At the turn of the 20th century in Britain and Central Europe, researchers proved how human-horse interactions induced psychophysical rehabilitation to the human being (Lipponen & Vehmasto 2019, p. 7). A saying by Plato explains how doctors fail to cure an individual by separating the human mind from his body:

> The cure of the part should not be attempted without treatment of the whole. No attempt should be made to cure the body without the soul. Let no one persuade you to cure the head until he has first given you his soul to be cured, for this is the great error of our way, that physicians first separate the soul from the body.

All things considered it must be noted that it is the responsibility of a horse therapist to decide which horse is most suitable to a client. A horse that may be suitable to one client

may not be adequate for another. A therapy horse that is physically and mentally in a healthy condition is able tune into the needs of a horse rider. He recognizes at which point the horse rider requires support and encouragement, and on the other hand when he needs to face and recognize his limits. (Kulmala & Liikala, 2002, p. 8.)

5 Existing Research

In 2003 the Department of Social Work at the University of Exeter in the United Kingdom published results of a study which was carried out by H. Burgon. The aim of the study was to investigate further about the psychotherapeutic impacts of horseback riding. The study was conducted on a group of adults who were service users of a social service's mental health team (in South Devon). Previous scientific research studies had not looked at the psychotherapeutic benefits of horse riding yet, and therefore this investigation turned out to be of great value. H. Burgon was interested in discovering whether elevated self-esteem levels and enhanced interaction skills would be visible in the daily lives of the participants. By applying the participant observational methodology and conducting research in a case study, H. Burgon found that participants demonstrated increased confidence levels and gained psychological benefits through the support of a horse-human relationship. (Burgon 2003.)

Furthermore, A. L. Bizub (a post-doctoral researcher from Yale University School of Medicine), A. Joy (a supervisor of the Connecticut Mental Health Center's Ambulatory Rehabilitation Service) and Dr. L. Davidson (an Associate Professor of Psychiatry at Yale University School of Medicine), partnered up to conduct a research study in the year 2003. They invested their time into a research project that investigated how horses may assist individuals that suffer from a severe mental illness, and whether they could teach them to express themselves better. Five individuals who were diagnosed with a psychiatric disease participated once a week for two hours in horseback riding. After ten weeks of therapeutic horseback riding, researchers discovered notable changes in the sense of self-awareness, self-esteem, and self-efficacy in the participants. The researchers observed that participants gained a deeper understanding of interpersonal relationships as they experienced a higher level of connection with others. One of the participants, who previously showed signs of withdrawal started to participate in the daily activities of the residential facility he lived in; another of the participants was able to pursue residential and financial independence. The results indicated that horseback riding improved Participation in individuals with a psychiatric disability. (Bizup, Joy & Davidson 2003.)

One of the most fascinating research studies that has been conducted to date is a pilot study by Dr. E. Gehrke (a professor of International Business Management at the Alliant International University of San Diego). Dr. Gerhrke came to realize that horses have had an impact on her especially in her working life. She felt how they influences her in areas such as organizational management, coaching others, or how she would manage her leadership trainings. The first pilot study was titled: Horses and Humans Energetics- the study of Heart Rate Variability (HRV) between Horses and Humans. The study used electrocardiography (ECG) recorders in order to track the heart variability of humans and horses. The heart variability was monitored as they were resting, moving and interacting with one another. The ECG results showed patterns of increased coherent heart rate variabilities as the horses and humans were close to one another. HeartMath uses a mind-body approach to harness people's ability to improve their health, they suggest that the coherent HRV patterns are a result of activated brain functions and/ or positive emotional experiences. To conclude, the results suggest that when humans are in the presence of horses, they may experience a range of positive emotional states as well as increased brain functions. (Gehrke 2006.)

In another research project, ten children who were diagnosed with autism spectrum disorder (ASD) participated in Equine-Assisted Activities (EAA) for nine weeks. They were monitored throughout these nine weeks to determine whether EAA had an impact on their behavioral actions. Eight other children diagnosed with ASD participated in a non-equine intervention. The results demonstrated that the children who took part in the EAA intervention showed significant improvements in their social, physical and emotional functioning following the first six weeks. In comparison, the children who participated in the non-equine intervention showed positive improvements in their behaviors, but to a lesser degree. (Baier, Ivey-Hatz, Krenek, Lanning & Tubbs 2014.)

A recent study showcased Equine-assisted occupational therapy (OT) to be effectual in growing children diagnosed with ADHD. Frequently, children with ADHD seem to encounter challenges in their Executive Functions (EFs) and self-management. As a result, they are exposed to higher risks of social, emotional and educational challenges in their daily lives. Twenty-five young children (6-14-year-old), diagnosed with ADHD (3 girls, 22 boys), participated in Equine-assisted occupational therapy intervention for a time period of 12 weeks, whereby each session lasted 45min. Throughout the courses, immediate feedback principles in combination with a child-and family-centered strategy were integrated. Data of pre- and post-intervention was collected; measurements of Executive

Functions and occupational performances were taken. The results were analyzed by applying “The Behavior Rating Inventory of Executive Function (BRIEF)” and the “Canadian Occupational Performance Measure (COPM)”. The findings portrayed noticeable improvements in the Executive Functions (EF) of the children participating in the study. (Gilboa & Helmer 2020.)

6 Research Method

The first step of the research study was to find a relevant and existing topic that was reasonable to invest further research into in. Secondly, to gather further understanding, the author searched for theoretical literature from books, databases, newspaper articles, theses, and authorized webpages related to the field.

This study applies the Oxford Participation and Activities Questionnaire (Ox-PAQ), which was developed out of the incentive to *measure* activity and participation in a person’s daily life. It was specially created for a wide range of health conditions. With the help of Ox-PAQ improvements or deteriorations could be taken note of in the long-term, instead of going by unnoticed. The Ox-PAQ includes questions regarding to how a person manages his daily affairs, his physical, social, and emotional well-being. The Ox-PAQ was developed on the theoretical grounds of the World’s Health Organization International Classification of Functioning, Disability, and Health (ICF). The ICF defines the term participation as “involvement in life situations” and activity as “the execution of a task or action by an individual”. The ICF further classifies participation and activity into following categories: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; community, social and civic life. (Dawson, Dummett, Fitzpatrick, Jenkinson, Kelly & Morley 2013.)

In addition to the Ox-PAQ survey the author included a personal background questionnaire to find out if there were any similarities, dissimilarities, or visible patterns in the responses of the target group. Participants were asked to fill in the Ox-PAQ twice. First, the participants were asked to reflect and self-evaluate their daily Life Management Skills prior to starting with Equine-assisted social pedagogy. Secondly, the participants were asked to reflect on questions related to their Life Management Skills in the four preceding weeks. For the collection of empirical data, the author sent an email to Equine-assisted social pedagogy practitioners around Finland to politely ask for their participation and

cooperation in the research study. They were kindly requested to forward the questionnaire to their clients, who formed the target group of this study. The main criteria of the target group were participation in Equine-assisted social pedagogy sessions and characteristics of a cognitive and/ or physical impairment/s. An e-based version of the Ox-PAQ & Personal Background questionnaire was sent via Microsoft Forms to Equine-assisted social pedagogy practitioners around Finland in March 2020. The personal contact details were looked up from the official webpage of Equine-assisted social pedagogy in Finland, where practitioners have the opportunity to register officially as practicing professionals (www.hevstoiminta.net).

7 Results

In this section, some of the data is presented as charts. In the first part, responses regarding background information of the respondents are summarized. The Background Questionnaire included questions related to the individual's sex, age, educational background, place of living, when, how, and why they chose to participate in Equine-assisted social pedagogy sessions. In the second part, responses of the Ox-PAQ are analyzed. The questionnaire included in total twenty-three questions. All the Ox-PAQ questions included multiple-choice options. Respondents had the choice to respond to each question with 1= Never, 2= Rarely, 3= Sometimes, 4= Often, or 5= Always. As priorly mentioned, the Ox-PAQ was filled in twice by the respondents. First, the participants self-evaluated their daily Life Management Skills prior to starting with Equine-assisted social pedagogy; secondly, the participants were asked to reflect on questions related to their Life Management Skills in the four preceding weeks. The responses of the pre- and post-interventive states were compared by calculating the average value of each question. Each question was looked at separately, data that pointed out a significant difference in their average value are presented in the charts. The results are showcased in the English language, the original survey was distributed in the Finnish language.

7.1 Background Questionnaire Analysis

Figure 1 illustrates that out of thirteen collected responses, nine males and four females returned the questionnaire. This breaks a well-known stereotype, that females are usually predominantly drawn to the presence of horses. It seems, in the context of Equine-assisted social pedagogy, males display their interest towards horses as well.

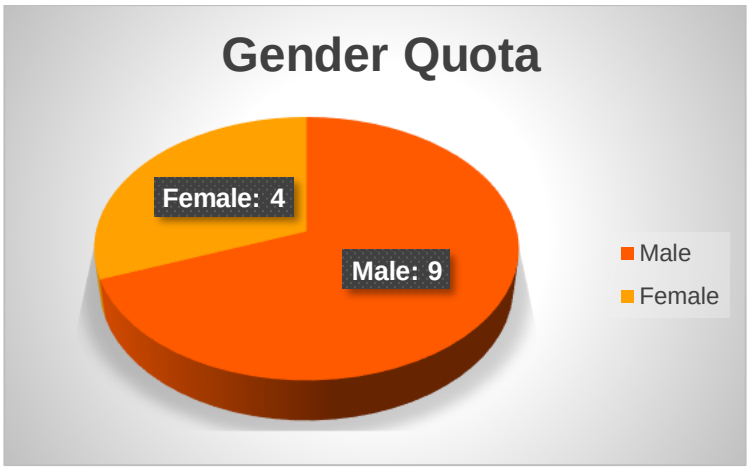


Figure 1. Gender Ratio of Returned Questionnaires.

Out of thirteen responses, the total age range of respondents was between 0-17 years old. As shown below in Figure 2, seven respondents were between 0-11 of age, and six respondents were in the age gap of 12-17 years old - the data hints to a trend that costumers of Equine-assisted social pedagogy are predominantly children and youngsters. Equine-assisted social pedagogy was initially aimed to prevent the social exclusion of children and youngsters, which the data of this study affirms. Additionally, the results of the study depict that Equine-assisted social pedagogy attracts young individuals with disabilities.

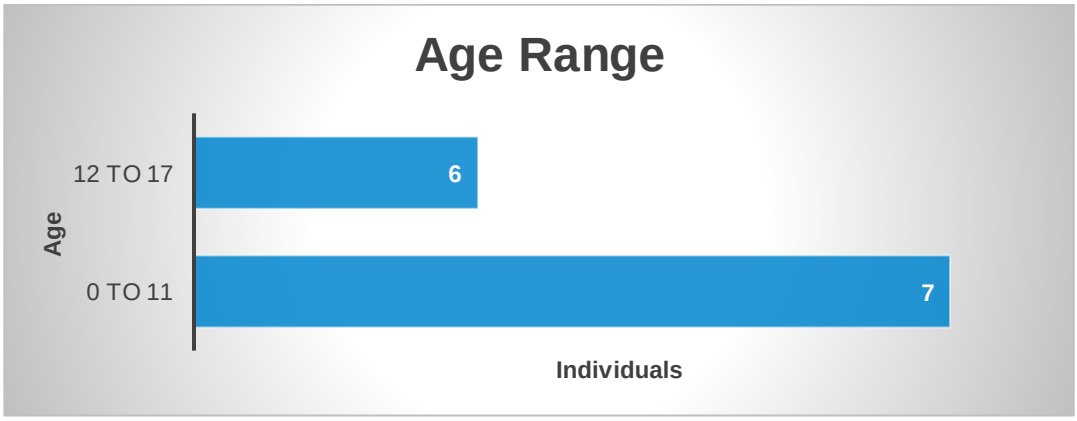


Figure 2. Age Range of Respondents.

The individuals who responded to the survey were from two different regions in Finland, North Savo, and Southwest Finland. Figure 3 below demonstrates that 67% (six individuals) were from North Savo, and 33% (3 individuals) were from southwestern Finland.

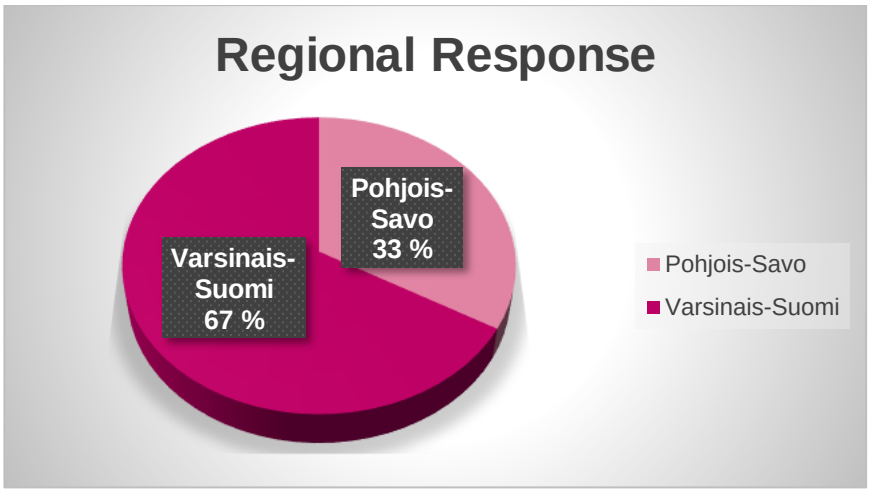


Figure 3. Regional Responses.

In Figure 4, it is seen that out of thirteen individuals who responded to the question of how frequently they participated in Equine-assisted social pedagogy, eight replied that they would attend the activity once a week regularly, while four of them partake even twice weekly. One individual stated that participation in EAA took place for ten sessions, each time lasting 2 hours.

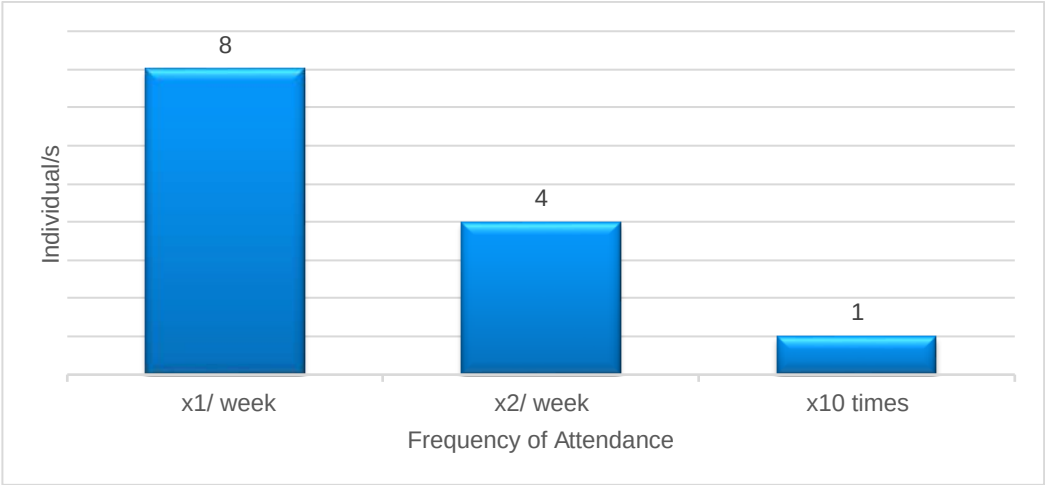


Figure 4. Equine Assisted-Social Pedagogy Attendance Frequency of Customers.

The last question of the Background Questionnaire asked individuals since when they started to take part in Equine-assisted social pedagogy. Results in Figure 5 indicate that two participants attended Equine-assisted activities (EAA) since the year 2018; one since 2017; one since 2016; four since 2015 and four since the year 2012.

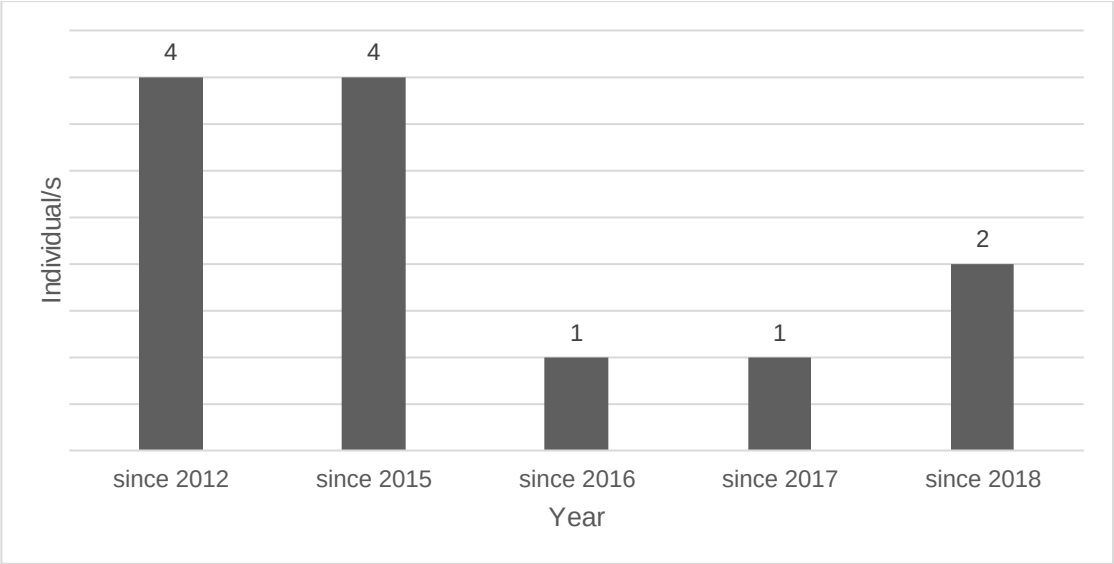


Figure 5. Time Frame Participation of Equine-Assisted Social Pedagogy.

Nine respondents replied to the question of why they chose to participate in Equine-assisted social pedagogy, “ADHD” being the reason for eight individuals, and “Prader-Willi syndrome (PWS)” for one individual. It appears that throughout the last years, Equine-assisted social pedagogy has become more popular among individuals with ADHD. Data in this study hints that at least nine individuals who started to participate in Equine-assisted social pedagogy attended the activity since the last 2-8 years regularly.

7.2 Ox-PAQ Analysis

Statistical Analysis was applied in the interpretation of the Ox-PAQ survey. The inspiration to apply this kind of analysis was influenced by ARTSI (Kuntoutussäätio), who teaches among other things how empirical data may be collected, analyzed and represented in charts. Each multiple-choice question was given a number 1= Never, 2= Rarely, 3= Sometimes, 4= Often, or 5= Always. These numbers were added up depending on the responses of the participants in order to find the mean value of each question that was asked.

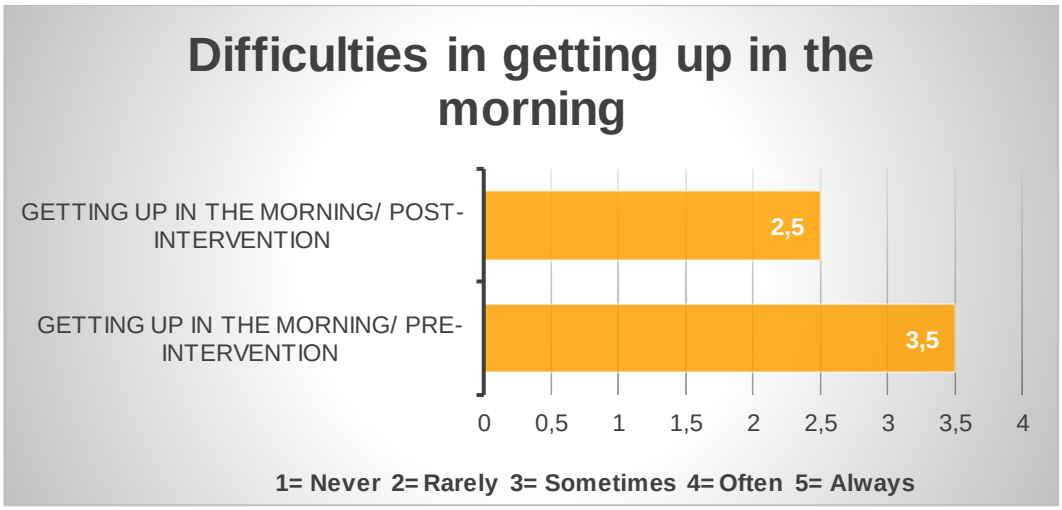


Figure 6. Ox-PAQ – Getting Up in the Morning. Pre- and Post-Intervention.

According to Figure 6, before participants started to attend Equine-assisted social pedagogy, the respondents seemed to experience difficulties when getting up in the morning (3,5). The results indicate that the respondents had sometimes-often challenges when getting out of bed in the morning in the pre-interventive state. After they started to partake in Equine-assisted social pedagogy, individuals experienced rarely-sometimes (2,5) difficulties when getting up in the morning. This may indicate that Equine-assisted social pedagogy may have an uplifting effect on the mental health level of an individual, so that he feels more motivated to get up in the morning and start the day.

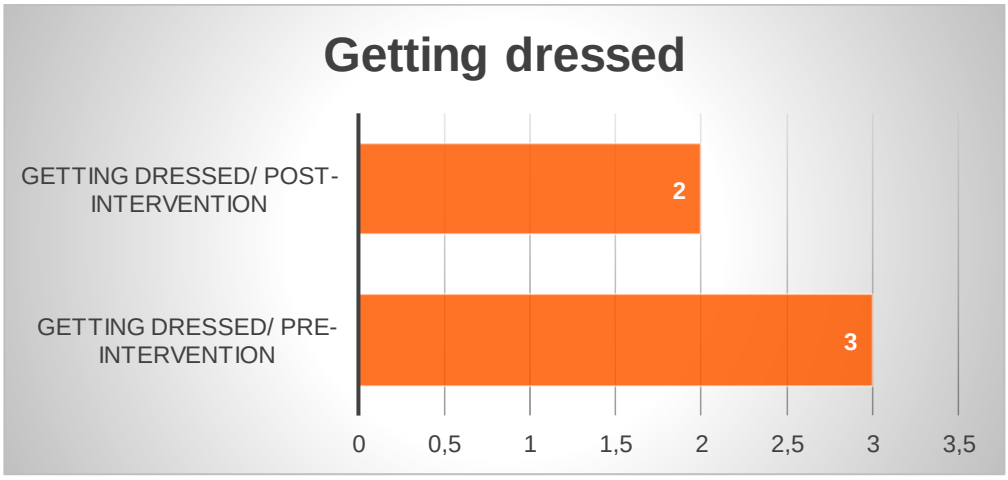


Figure 7. Ox-PAQ – Getting Dressed.

As demonstrated in Figure 7, before participation of Equine-assisted social pedagogy, respondents sometimes (3) had challenges when they were getting dressed. The level

of difficulty decreased by 1 in the post-interventive state. This means that while participants sometimes had difficulties when they were getting dressed before partaking in EAA, they rarely (2) experienced challenges in the post-interventive state.

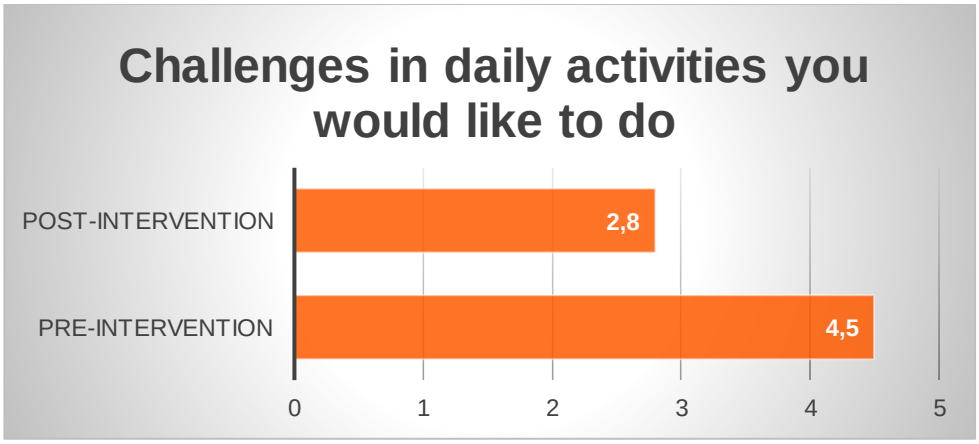


Figure 8. Ox-PAQ – Challenges in Daily Activities Participants were Fond of Doing.

The results above in Figure 8 indicate that responders often-always (4,5) had difficulties in following through with daily activities that they would have liked to engage in prior to starting with EAA. Yet, after they started participating in Equine-assisted social pedagogy, they indeed rarely-sometimes (2,8) encountered challenges in the activities that they felt like they wanted to do.

Figure 9. Ox-PAQ Challenges in Leisure Activities.

Figure 9 shows that respondents encountered sometimes-often (3,5) challenges when doing a leisure activity that they enjoyed doing in the pre-interventive state. In the post-

interventive state, individuals rarely (2) had experienced any challenges when doing an activity that they enjoyed.

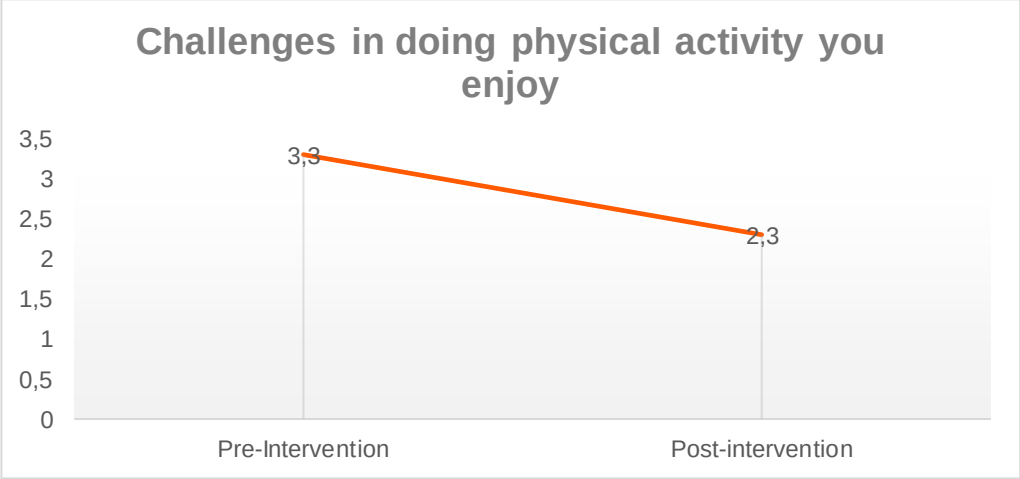


Figure 10. Ox-PAQ – Challenges in Physical Activities.

Figure 10 above demonstrates, before participating in EEA, respondents sometimes (3,3) had challenges when they were doing physical activities that they enjoyed doing. The level dropped down by one level (2,3) in the post-interventive state. This means that they rarely experienced challenges any longer when engaging in a physical activity that they enjoyed doing.

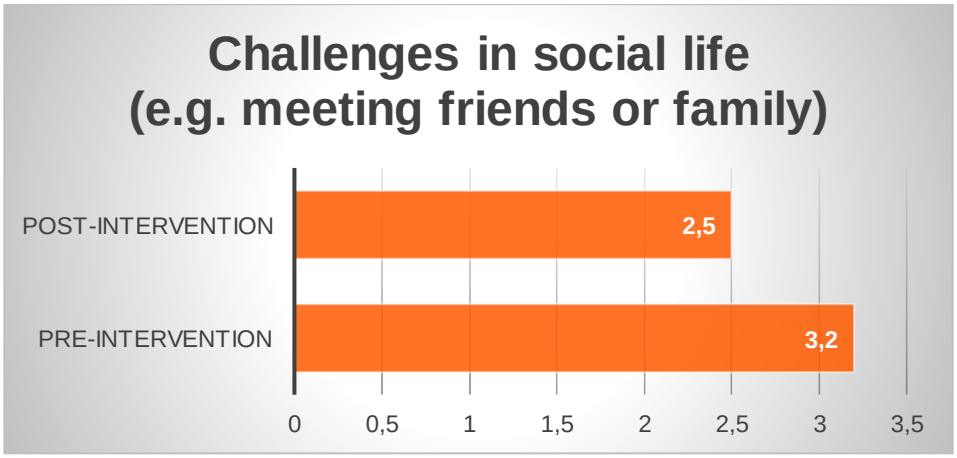


Figure 11. Ox-PAQ – Social Life Challenges.

Prior to participants' engagement in Equine-assisted social pedagogy, respondents sometimes (3,2) experienced challenges in their social life, such as meeting up with their friends or family members. The results in Figure 11 portray that the level dropped from

3,2 to 2,5 in the post-interventive condition. Participants rarely-sometimes (2,5) had difficulties while being in a social setting with their friends or families after attending EAA.

Figure 12 reveals prior to participation of Equine-assisted social pedagogy respondents had challenges in maintaining close relationships with their friends and family (3,5). After they started to take part in Equine-assisted social pedagogy, individuals experienced rarely-sometimes (2,4) challenges in maintaining close relationships. This may indicate that Equine-assisted social pedagogy may have supported them in the process of improving their social skills. The results were equal when participants were asked about how well they were able to maintain their friendships (pre-interventive state 3,5 and post-interventive state 2,4).

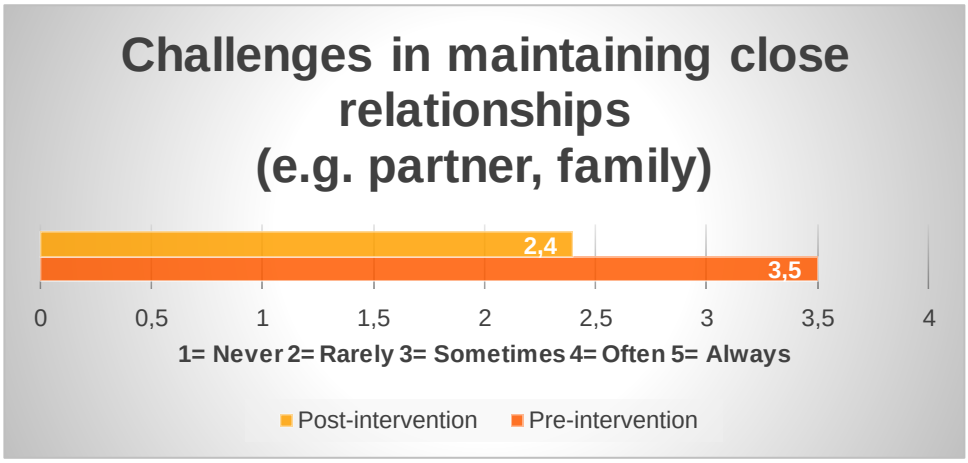


Figure 12. Ox-PAQ - Maintaining Close Relationships.

Figure 13 below summarizes multiple responses of the participants. They were asked if they had difficulties in using public transport; encountered challenges when engaging in community life; were as independent as they would like to be; and whether they engaged with other individuals when they were out in the community. A summary of the responses is presented here:

Before respondents started to be involved in Equine-assisted social pedagogy, they replied that they often (4,2) encountered challenges when they were using public transport. After engaging in EAA, however, they only sometimes (3,1) experienced challenges when using public transport.

Engaging in community life seemed to cause sometimes-often (3,5) complications before respondents engaged in EAA. After they started with Equine-assisted social pedagogy, partaking in community life caused participants rarely-sometimes (2,8) challenges. This indicates, respondents began to feel more comfortable within themselves and were able to enhance their social skills through EAA.

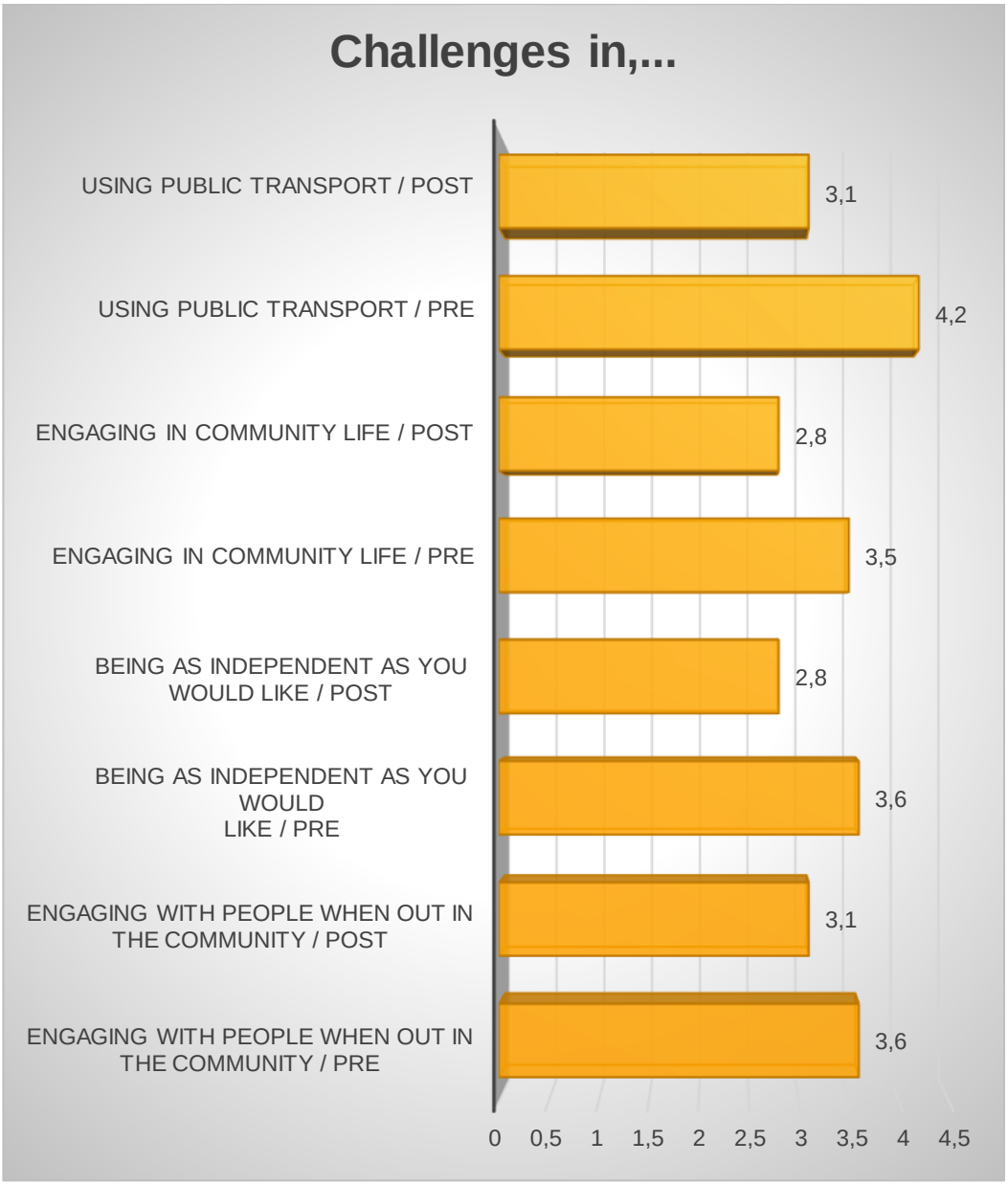
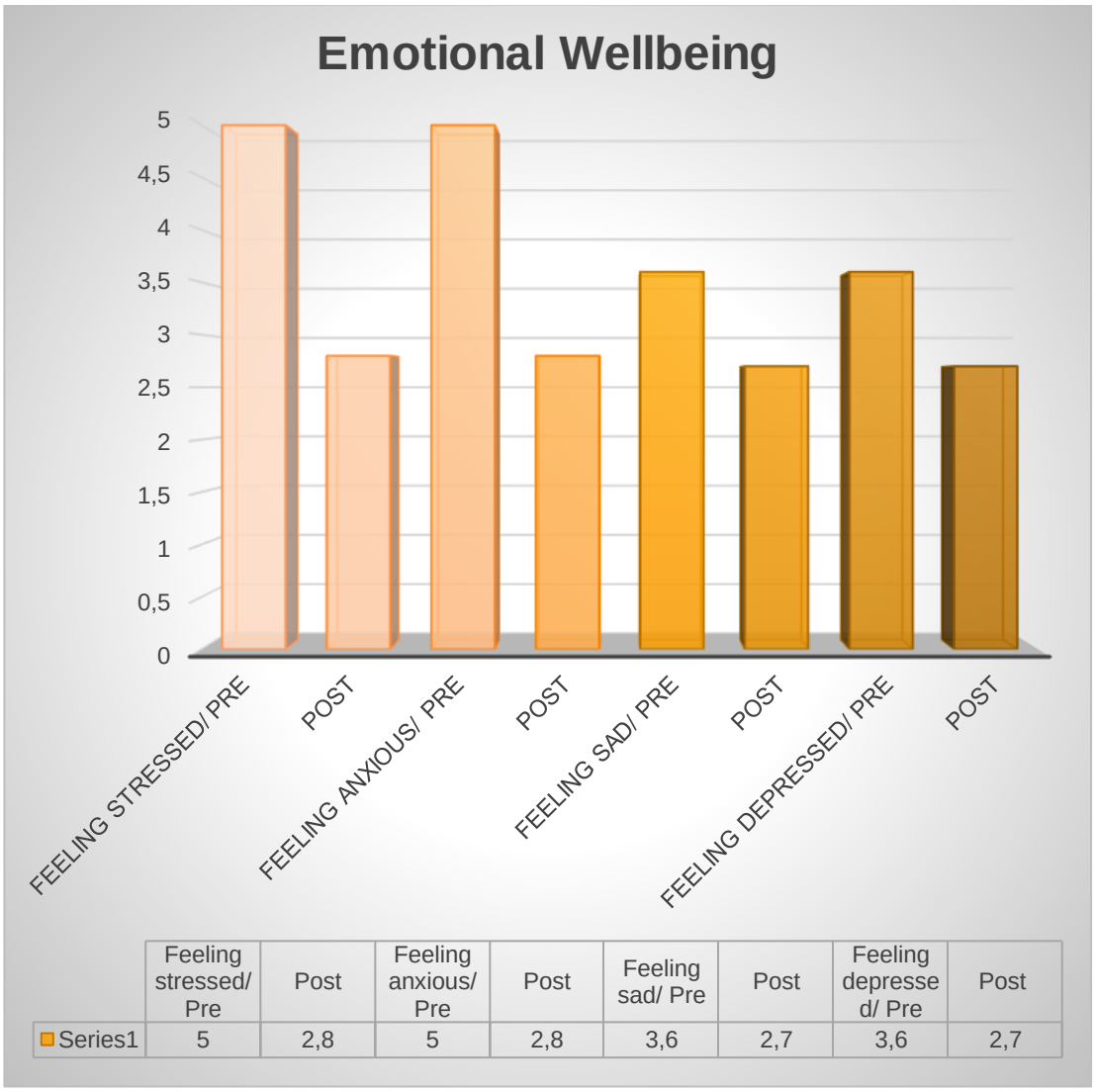


Figure 13. Ox-PAQ – Routine Activities.

When participants were asked about how often they felt they had challenges in being as independent as they would like to be, the mean value in the pre-interventive state was

3,6 - indicating they sometimes-often experienced the feeling of not being as independent they would like to be. Later, as they started to partake in EAA, the mean value decreased to 2,8, which demonstrated, that after engaging in EAA, participants only sometimes felt they had challenges in being as independent they would like to be.



	Feeling stressed/ Pre	Post	Feeling anxious/ Pre	Post	Feeling sad/ Pre	Post	Feeling depressed/ Pre	Post
Series1	5	2,8	5	2,8	3,6	2,7	3,6	2,7

Figure 14. Ox-PAQ – Emotional Wellbeing Questions.

The results above in Figure 14 are striking, when participants were asked about how frequently they felt stressed and anxious on a day-to-day basis, the participants responded with always (5) in the pre-interventive state. Both stress levels, as well as anxiety levels declined after regularly attending EAA. In the post-interventive state, participants claimed they only rarely-sometimes (2,8) suffered from anxiety and stress in their daily routine.

Before the time participants took part in Equine-assisted social pedagogy, they replied, they sometimes-often (3,6) felt sad and depressed. After engaging in EAA, they rarely-sometimes (2,6) experienced a feeling of depression and sadness in their everyday life.

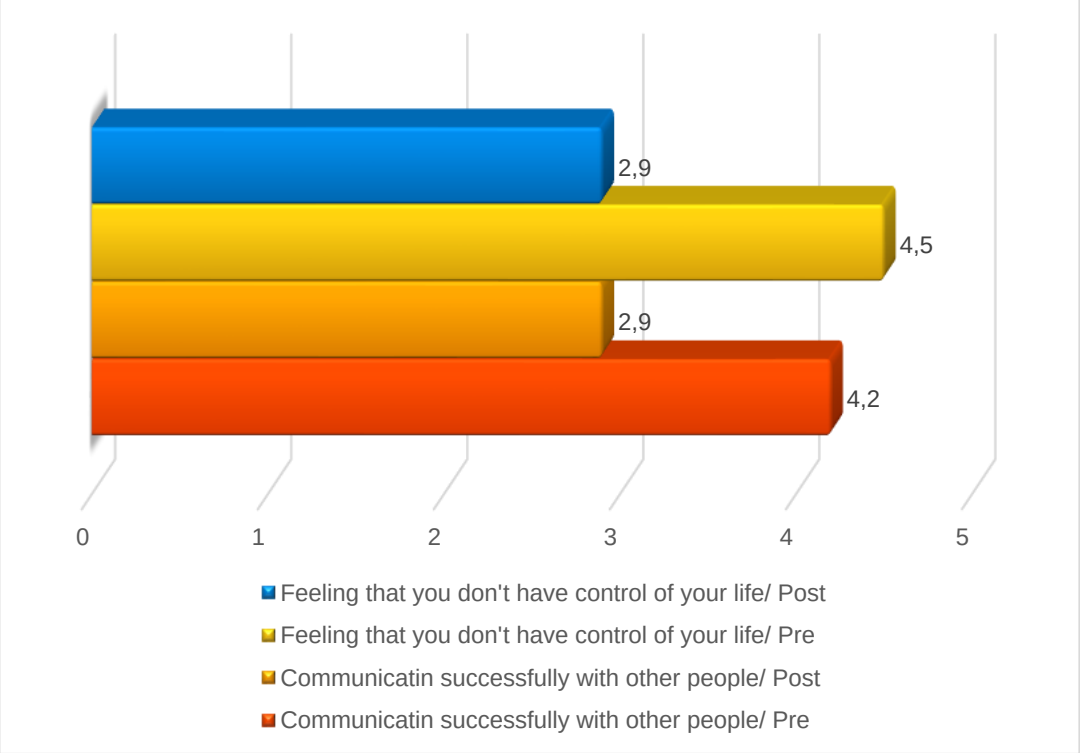


Figure 15. Ox-PAQ - Emotional Wellbeing.

Figure 15 illustrates, before participation in EAA, respondents often (4,2) felt they had challenges in communicating successfully with others. As they started to be involved in Equine-assisted social pedagogy, individuals felt they sometimes (2,9) faced challenges when communicating successfully with other people.

As respondents were asked how often they felt not having control of their own life, their response in the pre-interventive state was, they often-always (4,5) thought they did not have control over their own life. However, when they started to participate in EAA, individuals only sometimes (2,9) sensed they had no control over their own lives. This indicates that Equine-assisted social pedagogy may have supported them in the process of improving their Life Management Skills (life control).

8 Reliability, Validity and Ethics

The data of the research study was collected throughout the time when the COVID-19 virus started to spread in Finland. Also, the time frame of the data collection was rather short (three weeks). Both factors may have led to a low response rate of the questionnaire. The author exclusively gathered empirical data via electronic communication, if phone calls were included as a motivator or reminder to participate in the study, the response rate might have been higher.

The questions in the Ox-PAQ are based on Patient-reported outcome measures (PROMs), which means that a person is asked to self-assess his health levels and overall life quality. Hence, the nature of this type of data collection is structured on subjective viewpoints (Subjectivity). This has been carefully considered in the interpretations of the results.

Data of this Bachelor thesis was collected through an electronic survey, which was gathered from Equine-assisted social pedagogy instructors and their clientele. At first, the question of whether it would be ethical to collect data from individuals in the working field, as well as collecting data from minorities (individuals below the age of 15) was raised. Nevertheless, the issue was resolved by leaving personal data questions entirely out and by incorporating multiple-choice questions. Individuals below the age of fifteen were asked to fill in the questionnaire together with their guardian. This step ensured compliance of ethical guidelines.

9 Conclusion

The data of the survey provided useful information and delivered a comprehensible basis to move forward. When it comes to interpreting empirical data, one must consider that the data is based on subjective opinions. It is essential to take under consideration that the questions asked in this survey may be interpreted in multiple ways by the responder; depending on the way he chooses to interpret the question/s. Even though the response rate of the study was quite low, it provided valuable information. Up to this date, research conducted in the field of Equine-assisted social pedagogy has not been much scientifically researched about in Finland**.** The results of this research may be considered as a part of the developing the field.

The objective of this research study was to gain more understanding whether Equine-assisted Social Pedagogy affected the Life Management Skills of individuals with disabilities. The theoretical framework of this thesis is based on L. Böhnisch's approach of life control. According to him, life control is made up of the psychic and social competency of an individual. This would mean that if one would be able to increase his psychic (mental) and social competency, one's life skills would be enhanced as a result. The results of this study indicated that Equine-assisted social pedagogy did have an impact on the person's mental and social competency for the better, and that Life Management Skills of the participants were enhanced through this form of intervention method. Therefore, Böhnisch's theory of life control seems to be truthful here.

The empirical data of the study demonstrated improved mental health levels in participants after they participanted in EAA. Anxiety and stress levels significantly decreased in the post-interventive state; participants' depression levels were lowered. Not only did individuals feel more socially competent in their interactions with others after attending EEA, but they reportedly felt socially more integrated in the society. The children and youngsters participating in this study felt they had fewer difficulties getting up in the morning and with getting dressed after engaging in EAA. Participants demonstrated significant improvements in the participation of their hobbies and other activities that they enjoyed doing daily. Their ability to engage in physical activities was enhanced. When managing relationships, they improved their skills by learning how to maintain close relationships. Participants were able to use public transport better and engaged more in community life as a result of attending EEA. Their overall sense of life control significantly improved as a result of this intervention method.

To conclude, Equine-assisted social pedagogy enhances Life Management Skills of individuals with disabilities by improving the person's emotional wellbeing, social skills, and social participation.

9.1 Recommendations for Future Research

The author highly recommends future research related to this topic, but on a broader scale. If all Equine-assisted social pedagogy practitioners in Finland were participating in a larger-scale research study, which would turn out to be an effective tool to improve social exclusion, there would be a higher possibility that Equine-assisted social pedagogy would receive higher accreditation by Finnish authorities.

9.2 Acknowledgement

The author would like to give thanks to everyone who participated in this research; without the support of the Equine-assisted social pedagogy instructors, this research study would not have been possible.

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Participation Invitation Letter

Hello!

I am a third-year student of Social Services at Metropolia University of Applied Sciences and as part of my Bachelor's thesis I carry out a survey to increase our current understanding of Social pedagogical horse activity (EAA) and how it could impact Life Management Skills of individuals with a physical and/ or cognitive impairment.

The survey is conducted in collaboration with Oxford University Innovation's Clinical Outcomes Evaluation Team, using the Oxford Participation and Activity Questionnaire (Ox-PAQ), which has been developed by experienced expert physicians.

Your responses to the questions will be kept confidential. There is no compensation for participating in this study. However, your participation will be a valuable addition and findings could lead to greater public understanding of the power of the healing power that horses have on humans.

The questionnaire is to be filled in by the clients themselves, or if needed together with the therapist/ guardian. Individuals below 15 years of age are asked to fill out the form together with their guardian.

The first part of the questionnaire includes background questions about the participant. The Oxford Participation and Activities Questionnaire (Ox-PAQ) is filled in twice: first, the participants self-evaluate their daily Life Management Skills prior to starting with EAA, and secondly, the participant is asked to reflect on questions related to their Life Management Skills in the four preceding weeks.

https://forms.office.com/Pages/ResponsePage.aspx?id=12EaTaW2ZE-Hh_B0-HAT7tsEJNNnIyJEoanXuNXL7xJUM0xaUkJRNkw3Uk1FT0FFODBIT0pQRU5ERS4u

Please complete the form by March 20th, 2020.

If you have any questions, please do not hesitate to ask!

Best Regards,
Samira Yassamani

Clinical Outcomes

Background Questionnaire (English & Finnish)

Questionnaire (English)

i. Your gender?

Man
Woman

ii. Which of the following age groups do you belong to?

0-11 years
12-17
18-30 years
31-40
41-50 years
51-64 v.
65 years of age or older

iii. Province in which you live:

iv. What is your education?

Still at school (primary school, upper secondary school, vocational school or course, college)
Primary school
Primary school
Vocational school or course
High school or high school student
College level vocational training
University of Applied Sciences
University, bachelor's degree
College, postgraduate degree
None of these

v. When did you start social pedagogical horse work and what differences do you notice about yourself?

vi. How often do you participate in the activity?

vii. Why do you participate in Equine-Assisted Activities?

Questionnaire (Finnish)

i. Sukupuolesi?

Mies
Nainen

ii. Mihin seuraavista ikäryhmistä kuulut?

0-11 v.
12-17 v.
18-30 v.
31-40 v.
41-50 v.
51-64 v.
65 vuotta täyttäneet

iii. Maakunta, jonka alueella asut:

iv. Mikä on koulutuksesi?

Vielä koulussa (peruskoulu, lukio, ammattikoulu tai -kurssi, opisto)
Kansakoulu
Peruskoulu
Ammattikoulu tai -kurssi
Lukio tai ylioppilas
Opistotason ammatillinen koulutus
Ammattikorkeakoulu
Korkeakoulu, alemman asteen tutkinto
Korkeakoulu, ylemmän asteen tutkinto
Ei mitään näistä

v. Milloin olet aloittanut sosiaalipedagogisen hevostoiminnan ja mitä eroja huomaat itsestäsi?

vi. Kuinka usein osallistut toimintaan?

vii. Minkä vuoksi osallistut hevosavusteiseen toimintaan?

Validation of the Oxford Participation and Activities Questionnaire

Authors Morley D, Dummett S, Kelly L, Dawson J, Fitzpatrick R, Jenkinson C
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Peer reviewer comments 3
Editor who approved publication: Dr Robert Howland

Purpose: There is growing interest in the management of long-term conditions and in keeping people active and participating in the community. Testing the effectiveness of interventions that aim to affect activities and participation can be challenging without a well-developed, valid, and reliable instrument. This study therefore aims to develop a patient-reported outcome measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ), which is theoretically grounded in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) and fully compliant with current best practice guidelines.

Methods: Questionnaire items generated from patient interviews and based on the nine chapters of the ICF were administered by postal survey to 386 people with three neurological conditions: motor neuron disease, multiple sclerosis, and Parkinson's disease. Participants also completed the Medical Outcomes Study (MOS) 36-Item Short Form Health Survey (SF-36) and EQ-5D-5L.

Results: Thus, 334 participants completed the survey, a response rate of 86.5%. Factor analysis techniques identified three Ox-PAQ domains, consisting of 23 items, accounting for 72.8% of variance. Internal reliability for the three domains was high (Cronbach's α: 0.81–0.96), as was test–retest reliability (intraclass correlation: 0.83–0.92). Concurrent validity was demonstrated through highly significant relationships with relevant domains of the MOS SF-36 and the EQ-5D-5L. Assessment of known-groups validity identified significant differences in Ox-PAQ scores among the three conditions included in the survey.

Conclusion: Results suggest that the Ox-PAQ is a valid and reliable measure of participation and activity. The measure will now be validated in a range of further conditions, and additional properties, such as responsiveness, will also be assessed in the next phase of the instrument's development.

Keywords: activity, participation, PROM, patient-reported outcome measure, questionnaire, FDA, ICF, validity, reliability

Introduction

The Oxford Participation and Activities Questionnaire (Ox-PAQ) is a newly developed patient-reported outcome measure, theoretically grounded in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF).[1] It is intended for generic use with patients experiencing a broad range of health conditions. The background and rationale for the measure have previously been published in a study protocol,[2] which readers may wish to refer to. In brief, however, current measures of participation and activity lack theoretical underpinning and are largely disability and rehabilitation focused.[3-8] Additionally, there is no measure of participation and activity for generic use, which fully meets current standards set by regulatory bodies such as the US Food and Drug Administration[9] and the European Medicines Agency.[10]

The item generation process and pretesting procedures for the Ox-PAQ have been extensively reported elsewhere.[11-13] In summary, semistructured interviews were conducted with 37 people experiencing a range of conditions, including arthritis, cancer, chronic back pain, diabetes, motor neuron disease (MND), multiple sclerosis (MS), Parkinson's disease (PD), and spinal cord injury. These interviews generated a preliminary pool of 222 items, which was subsequently reduced to 24 items via an iterative process in meetings between the authors. The resulting items were pretested through an expert review panel, a translatability assessment, and a series of 13 cognitive interviews. The pretesting procedures led to minor changes to a number of items and the addition of four new questions, resulting in a draft measure of 28 items, answerable on a five-point Likert scale, for validation in a large-scale survey.

The aim of this study is to make the first psychometric assessment of the Ox-PAQ through its administration to people with one of three neurological conditions: MND,

MS, and PD. MND is a chronic degenerative neurological condition characterized by progressive degeneration of the upper and lower motor neurons in the brain and spinal cord, resulting in rapid and severe disability. The majority of people with MND die of respiratory muscle weakness <3 years from the onset of symptoms.[14] MS is a chronic condition generally characterized by recurrent relapses followed by remissions, although ~20% of patients experience a chronic progressive form. People with MS (PwMS) can experience both physical and emotional symptoms, including chronic fatigue and depression, with a significant proportion requiring assistance with walking within 15 years of onset.[15–17] PD is a chronic progressive condition characterized by tremor, bradykinesia, and rigidity. People with PD (PwP) are susceptible to psychiatric symptoms such as depression, hallucinations, and confusion, as well as the likelihood of falls and freezing of gait as the condition progresses.[18,19] Considering the clinical characteristics of the conditions outlined, all three clearly have the potential to have a significant impact on participation and activity in a number of distinct ways, rendering them ideal candidates with which to test the Ox-PAQ.

The specific aims of this study are threefold. First, we aim to identify the underlying factor structure of the Ox-PAQ through the use of factor analysis techniques. Second, we aim to make an assessment of both the internal and external reliability levels of the new measure. Finally, we test the validity of the Ox-PAQ by assessing the magnitude of association with other similarly related constructs alongside an assessment of groups hypothesized to differ; specifically, considering the disparate nature of the disease groups outlined earlier (MND, MS, and PD), it is hypothesized that there will be significant differences in the Ox-PAQ scores between the three conditions.

Methods

Ethical approval for this stage of the Ox-PAQ study was granted by the Medical Sciences Inter Divisional Research Ethics Committee of the University of Oxford (reference MSD-IDREC-C1-2014-089).

Participants

Recruitment of participants was undertaken over a period of 6 months with the assistance of three patient support organizations: the Motor Neuron Disease Association, MS Society, and Parkinson's UK. The organizations advertised the study through various means, including social media, Web sites, print and electronic publications,

research bulletin boards, and emails, inviting potential participants to contact the research team to express their interest in taking part.

Inclusion/exclusion criteria

Participants were required to have a confirmed diagnosis of MND, MS, or PD, as well as the ability to complete the survey independently. Participants were also required to be competent in the use of English, be aged ≥18 years, and be living in the UK.

Materials

A survey booklet consisting of four sections was administered; demographic data (sex, age, age at diagnosis, marital status, and ethnic origin), the Ox-PAQ (as detailed earlier), and two further instruments for the purpose of evaluating its validity.

MOS 36-Item Short Form Health Survey

The MOS SF-36[20,21] is a 36-item questionnaire comprising eight domains of health: Physical Functioning, Role Physical, Role Emotional, Social Functioning, Mental Health, Energy/Vitality, Pain, and General Health Perception. Response options vary across items, from a simple dichotomous yes/no response to a six-point Likert scale. Raw scores for each health domain are transformed to obtain a range from zero to 100, with higher scores indicating superior health status. The measure has been widely adopted in numerous research studies and demonstrates excellent psychometric properties.[22]

EQ-5D-5L

EQ-5D-5L[23,24] is a five-item generic measure assessing mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Initially developed with questions answered on a three-point Likert scale, a revised version of the measure now incorporates a five-point Likert scale. The EQ-5D-5L includes a visual analog scale to indicate general health, with a score of zero reflecting worst health status and 100 indicating the best possible health status. Recent studies[25–29] suggest that the updated measure is both valid and reliable.

Procedure

After contacting the research team by telephone or email, participants were sent the booklet of questionnaires and a written consent form for completion and return. A

follow-up email or letter was sent to nonresponders after 2 weeks. Participants who agreed to take part in a test–retest procedure were sent the Ox-PAQ again 2 weeks after receipt of their original questionnaire booklet.

Statistical analysis

Data were checked for normality of distribution and presence of outliers prior to statistical analysis. Missing values, as well as floor and ceiling effects, were calculated for each item of the Ox-PAQ. Raw scores were transformed to a range from zero to 100, with higher scores indicative of inferior functioning. Principal components analysis (PCA) with varimax rotation was performed to identify the underlying construct of the measure. The internal reliability of identified domains was assessed via corrected item–total correlations (ITCs) and Cronbach's alpha.[30] Test–retest reliability was calculated using the single-measures (two-way mixed-effects model) intraclass correlation coefficient (ICC).[31] Concurrent validity was determined through calculation of Pearson correlations[32] between the Ox-PAQ and the two instruments MOS SF-36[20,21] and EQ-5D-5L.[23,24] Known-groups validity was assessed through calculation of one-way analysis of variance (ANOVA) and Tukey's post hoc tests. Data were analyzed using SPSS Version 20 (IBM Corporation, Armonk, NY, USA).[33]

Results

A total of 334 participants completed the postal survey, with a response rate of 86.5%. Mean age was 60.06 years (standard deviation [SD]: 12.10 years; range: 24–88 years), mean age at diagnosis was 52.82 years (SD: 14.50 years; range: 18–87 years), and mean disease duration was 7.31 years (SD: 7.52 years; range: 0–50 years). The sample comprised 162 males (48.5%) and 172 females (51.5%). Further sample characteristics by disease group can be viewed in Table 1.

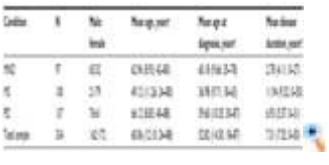


Table 1 Sample characteristics by disease group

Note: [a]The values are represented as mean (standard deviation; range).

Abbreviations: MND, motor neuron disease; MS, multiple sclerosis; PD, Parkinson's disease.

Percentages of missing responses, as well as floor and ceiling effects, for each of the 28 items of the Ox-PAQ are presented in Table 2. Missing data were minimal, ranging

between 0% and 1.8%. Items 2, 21, and 22 (highlighted with asterisk) were subsequently removed from further analysis due to floor effects >40%. A preliminary PCA of the remaining 25 Ox-PAQ items was performed as a means of identifying the underlying construct (scale structure) of the measure. Based on inspection of factors by two of the authors (DM and CJ), two further items, relating to making small movements with hands and coping with pain, were removed due to lack of relevance with the factor onto which they loaded. A further PCA of the remaining 23 Ox-PAQ items resulted in a three-factor solution, explaining 72.7% of variance. Item factor loadings and percentage of explained variance by factor can be viewed in Table 3. Factor 1, Routine Activities (14 items), assesses individuals' capacity to engage in regular activities that form the basis of daily life. Factor 2, Emotional Well-Being (five items), provides a snapshot of current mental health status. Factor 3, Social Engagement (four items), reflects how well, or otherwise, individuals are able to maintain relationships, both personal and from a wider community perspective.

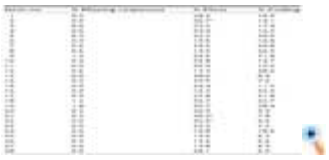


Table 2 Percentage of missing data and floor/ceiling effects by Ox-PAQ item

Note: [a]Item removed.

Abbreviation: Ox-PAQ, Oxford Participation and Activities Questionnaire.

Table 3 PCA solution, factor loadings, and percentage of explained variance for the Ox-PAQ

Abbreviations: Ox-PAQ, Oxford Participation and Activities Questionnaire; PCA, principal components analysis.

Reliability

Internal reliability

Corrected ITCs and Cronbach's alpha values for each domain can be viewed in Table 4. ITCs ranged from 0.87 to 0.60, with Cronbach's alpha values for the three identified domains ranging from 0.81 to 0.96.

Table 4 Ox-PAQ item–total correlations, Cronbach's alpha values,
and domain mean scores

Abbreviations: ITC, item–total correlation; Ox-PAQ, Oxford Participation and Activities Questionnaire; SD, standard deviation.

External reliability

Test–retest reliability was assessed in 127 participants who indicated no change in health status when completing the Ox-PAQ 2 weeks after their first completion. ICCs were calculated at 0.96 for Routine Activities, 0.83 for Emotional Well-Being, and 0.83 for Social Engagement.

Validity

Concurrent validity

Pearson correlations between the Ox-PAQ and MOS SF-36 are presented in Table 5. Correlations ranged from –0.41 to –0.87, all being highly statistically significant. Domains of the MOS SF-36 deemed most similar to those of the Ox-PAQ correlated more highly, e.g., Physical Function and Routine Activities (r=–0.87, P<0.001), Emotional Well-Being and Emotional Well-Being (r=–0.81, P<0.001) and Social Function and Social Engagement (r=–0.71, P<0.001).

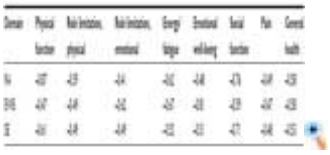


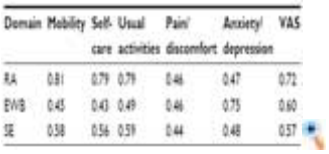
Table 5 Pearson correlations between domains of the Ox-PAQ and MOS SF-36

Note: All correlations significant at P<0.001.

Abbreviations: EWB, Emotional Well-Being; MOS SF-36, Medical Outcomes Study 36-Item Short Form Health Survey; Ox-PAQ, Oxford Participation and Activities Questionnaire; RA, Routine Activities; SE, Social Engagement.

Pearson correlations between the Ox-PAQ and EQ-5D-5L are presented in Table 6. Correlations range from 0.43 to 0.81, all being highly statistically significant. As with the MOS SF-36, those EQ-5D-5L items deemed most similar to those of the Ox-PAQ correlated more highly, eg, Mobility and Routine Activities (r=0.81, P<0.001), Usual Activities and Routine Activities (r=0.79, P<0.001) and Anxiety/Depression and Emotional Well-Being (r=0.75, P<0.001).

Known-groups validity



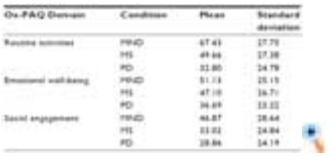
Domain	Mobility	Self-care	Usual activities	Pain/ discomfort	Anxiety/ depression	VAS
RA	0.81	0.79	0.79	0.46	0.47	0.72
EWB	0.45	0.43	0.49	0.46	0.75	0.60
SE	0.58	0.56	0.59	0.44	0.48	0.57

Table 6 Pearson correlations between domains of the Ox-PAQ and the EQ-5D-5L

Note: All correlations significant at *P*<0.001.

Abbreviations: EWB, Emotional Well-Being; MOS SF-36, Medical Outcomes Study 36-Item Short Form Health Survey; Ox-PAQ, Oxford Participation and Activities Questionnaire; RA, Routine Activities; SE, Social Engagement; VAS, visual analog scale.

Mean Ox-PAQ domain scores and standard deviations by disease group are given in Table 7. ANOVA results indicate statistically significant differences among the three conditions for all three domains: Routine Activities: $F(2,311)=45.66$, $P<0.001$; Emotional Well-Being: $F(2,330)=10.64$, $P<0.001$; Social Engagement: $F(2,326)=14.16$, $P<0.001$. Post hoc tests (Tukey's honest significant difference) at the 0.05 level of significance confirm significantly inferior scores in Routine Activities for people with MND when compared to PwMS ($P<0.001$) and PwP ($P<0.001$), alongside significantly inferior scores for PwMS compared to PwP ($P<0.001$). For Emotional Well-Being, significantly inferior scores are evident when comparing those with MND and PwP ($P<0.001$), as well as PwMS and PwP($P<0.001$). Assessment of Social Engagement identifies significantly inferior scores for people with MND compared to PwMS ($P<0.001$) and PwP ($P<0.001$).



Ox-PAQ Domain	Condition	Mean	Standard deviation
Routine activities	MND	67.43	17.73
	MS	49.66	17.38
	PD	52.80	14.78
Emotional well-being	MND	51.13	15.15
	MS	47.10	16.71
	PD	36.69	13.33
Social engagement	MND	66.87	18.64
	MS	53.02	14.84
	PD	59.84	14.19

Table 7 Mean Ox-PAQ scores and standard deviations by disease group

Abbreviations: MND, motor neuron disease; MS, multiple sclerosis; Ox-PAQ, Oxford Participation and Activities Questionnaire; PD, Parkinson's disease.

Discussion

This study has presented the first psychometric evaluation of the newly developed Ox-PAQ. Before identifying the underlying factor structure of the new measure, the percentages of missing responses, as well as the floor and ceiling effects, for the original 28 items were inspected. Percentage of missing data by item was low, with

no item exceeding 2%, indicating a high level of acceptability to respondents. Analysis of floor and ceiling effects led to the removal of three items, due to floor effects exceeding 40%, a criterion incorporated in the validation of previous measures.[34,35] Following a preliminary PCA, two further items were removed due to a lack of relevance with the factor onto which they loaded. Twenty-three items were subsequently included in a further PCA to confirm the factor structure of the Ox-PAQ, resulting in a three-factor solution. All factor loadings were in excess of the 0.55 level regarded as good, with the majority higher than the 0.71 level regarded as excellent.[36]

Reliability of the Ox-PAQ is demonstrated through a number of analyses. The internal reliability of the measure is confirmed through ITCs, which are in excess of previously defined criteria,[37] confirming that item scores within each domain are related to the overall domain score. Further evidence is provided by the Cronbach's alpha values, which lie between 0.81 and 0.96 for the three Ox-PAQ domains, indicating good-to-excellent internal reliability.[38] ICCs that fall between 0.83 and 0.92 for the three Ox-PAQ domains indicate excellent external reliability and are significantly greater than the recommended level of 0.60.[39]

Validity of the Ox-PAQ is demonstrated via assessment of concurrent and known-groups validity. Correlations with the MOS SF-36 and EQ-5D-5L indicate strong concurrent validity. The majority of correlations between Ox-PAQ domains and those of the MOS SF-36 and EQ-5D-5L fall in the 0.40–0.60 range typically observed, with the most similarly related domains in excess of the 0.60 level, representing a high degree of concurrent validity.[40] Assessment of known-groups validity is made where there are good reasons to hypothesize that scores on a measure of interest will differ between groups,[41] as has been incorporated in previous research.[42-44] Previous studies have made comparisons between PwMS and PwP,[45,46] with results reported here largely confirming this previous research; MS can have a significantly greater impact on physical functioning and emotional well-being than PD. Although no study appears to have compared MND with other neurological conditions, considering its clinical characteristics (as outlined in the "Introduction" section), it would seem reasonable to hypothesize that scores are likely to be significantly inferior to the scores of PwMS and PwP. Results from the study would seem to confirm this, with people with MND reporting significantly greater problems as measured by all three domains of the Ox-PAQ when compared to PwMS and PwP.

A number of limitations of this study are acknowledged. First, the reported analyses are confined to three neurological conditions, namely, MND, MS, and PD. Further assessment and validation in alternative disease groups is required to facilitate wider use of the new measure. Additionally, current analyses are confined to traditional psychometric techniques. Further investigation into the operating characteristics of the Ox-PAQ using modern techniques such as Rasch analysis[47–49] may be beneficial in due course. Finally, it is recognized that the method of recruitment for the study was self-selecting in nature, and the sample may not therefore be fully representative of the disease groups that participated.

Conclusion

In conclusion, results from this first psychometric analysis of the Ox-PAQ are promising, with results indicating that the instrument is a valid and reliable measure of participation and activity. The next phase of the instrument's development will involve migration of the Ox-PAQ to an e-based format, alongside validation in a range of further conditions and an assessment of the responsiveness of the measure. Further details regarding the development and validation of the Ox-PAQ can be found at the University of Oxford Health Services Research Unit Web site http://www.ndph.ox.ac.uk/research/health-services-research-unit-hsru/research/oxpaq-initiative. Information regarding the use of the Ox-PAQ can be obtained from the authors DM or CJ.

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Disclosure

The authors report no conflicts of interest in this work.

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