

Summary



The profound increase in the number of elderly people in the Netherlands in the future, will result in an increase in number of patients in need for rehabilitation care. With ageing several physiologic functions decline and the resulting physical impairments may negatively affect the course of functional status. At older age, people may develop multiple morbidities, which have been demonstrated to be negatively associated with quality of life, and performance of activities in daily life, and, lead to a higher use of healthcare services. Cognitive impairments may also increase with age, and have been shown to impact on disability, well-being and the use of healthcare services. Physical impairments, multiple morbidities and cognitive impairments are the most important causes of limitations in functioning in the elderly. For the development of rehabilitation programs for an ageing population, knowledge of these determinants on the course of functioning is essential.

The present thesis is part of the CARPA study 'Co-morbidity and Ageing in Rehabilitation Patients: the influence on Activities'. This study investigates the course of functional status and the impact of physical impairments, co-morbidity and cognitive impairments on this course in elderly patients with late-onset sequelae of poliomyelitis, osteoarthritis and Parkinson's disease. This thesis encompasses the studies with regard to late-onset sequelae of poliomyelitis.

Although poliomyelitis has become an almost forgotten disease in the Western world after the introduction of routine vaccination in the late 1950s, there are still many individuals with polio residuals. As these people are ageing, they are confronted with new neuromuscular symptoms 30 to 40 years after the original childhood disease. These symptoms include a gradual or, less frequent, abrupt onset of progressive new weakness, abnormal muscle fatigability, with or without generalized fatigue, muscle atrophy, or pain. The denominator for these late-onset symptoms is post-polio syndrome (PPS). Taking into account that PPS is a diagnosis by exclusion and that this thesis focused on the impact of age and co-morbidity on functioning of elderly patients with a history of poliomyelitis, the more neutral term late-onset sequelae of poliomyelitis (LOSP) was preferred.

The new late-onset neuromuscular symptoms cause increasing difficulties with physical functioning, such as walking, standing, climbing stairs and other mobility-related activities of daily life. To date, studies on the course of functioning of people with a history of poliomyelitis have almost always excluded subjects above the age of 65 and subjects with co-morbidity, or co-morbidities were not assessed or not reported. Therefore, these studies may have underestimated the functional problems and rate of decline in ageing former polio patients. As the impact of age and co-morbidity on the course of functioning in patients with LOSP remains unresolved, this thesis aims to describe the course of functional status of patients aged 45 – 85 years with late-onset sequelae of poliomyelitis over a period of 5 years and to explore the impact of age and co-morbidity.

Chapter 2 systematically reviewed studies focussing on the course of functional status and muscle strength over time and prognostic factors of change in patients with LOSP based on a literature search. A computerized literature search up to July 2004 was conducted and these results were published (chapter 2.1). An unpublished update of

the literature from July 2004 to July 2009 was added in **chapter 2.2**. The original review comprised 2 studies on the course of functional status and 4 studies on the course of muscle strength with sufficient methodological quality. In **chapter 2.2**, 2 additional articles with sufficient or high quality on the course of functional status (including the 5-year longitudinal CARPA study (**chapter 6**)), and the course of muscle strength, were summarized. Adding the results of these studies to the original systematic review gave better insight in the course of functioning and muscle strength in patients with LOSP. The heterogeneity in outcome measures between studies, prevented a quantitative analysis of the decline in perceived functional status over time. Nevertheless, all studies on perceived functioning reported a deterioration over time. Walking ability, assessed with timed walking tests, deteriorates slowly, 0.2 – 0.7% per year. Muscle strength declines approximately 3 times faster (1.5 – 1.9% per year). Factors that negatively affect the decline in functioning that have been reported in high-quality studies were the severity of polio residuals and co-morbidity, while age so far has not been shown to influence the decline in functioning. In general, studies require long term follow-up periods to observe a change in functioning with a minimum between 3 and 5 years depending on the outcome measures and study population. Furthermore it was concluded that uniformity in outcome measures between prognostic studies on all levels of functioning (impairments, activities and participation) is crucial to compare studies and to gain better insight in the course of functioning over time and factors that may affect this course in polio survivors.

In **chapter 3**, the baseline data of the entire CARPA study with regard to the Western Ontario and MacMasters Universities Osteoarthritis Index (WOMAC) have been used to investigate whether its physical functioning subscale can be used to assess physical functioning in patients with LOSP and in patients with Parkinson's Disease (PD). The WOMAC originally is an osteoarthritis-specific questionnaire to establish the level of physical functioning. The baseline data of the WOMAC physical functioning subscale (WOMAC-PF) of 288 patients with osteoarthritis, 200 patients with Parkinson's disease and 168 patients with LOSP have been analyzed. Unidimensionality was adequate and item fit was generally good. Differential item functioning was found to be present between the 3 diagnostic groups in 10 of 17 WOMAC-PF items. Therefore it was concluded that the WOMAC-PF is an unidimensional measure of physical functioning in patients with LOSP and PD, in addition to its established use in OA. When making cross-diagnostic comparisons of the level of physical functioning, directly comparing WOMAC-PF scores may not be adequate due to the presence of differential item functioning.

Chapter 4, 5 and 6 reported on the data derived from the 5-year follow-up study of 168 patients with late-onset sequelae of poliomyelitis, aged 45 – 85 years.

Heterogeneity in outcome measures used in studies focusing on patients with late-onset sequelae of poliomyelitis prevents summarizing the evidence in an effective way. The aim of **chapter 4** therefore was to prioritize one questionnaire and one walking test from a number of questionnaires and tests that are widely used in post-polio populations by comparing their reproducibility, measurement range and mutual associations, in order to advocate their use as core qualifiers of physical functioning in research and clinical practice.

Physical functioning subscales from Short Form-36 (SF36-PF), WOMAC and Nottingham Health Profile were compared as well as timed-up-and-go test, time needed to walk 10 meter at self-preferred and maximum speed and distance walked in 2 minutes at self-preferred speed. The results showed that the test-retest reliability of all questionnaires was sufficient to excellent. The smallest detectable changes were best for SF36-PF and WOMAC-PF and the 2-minute walking test. SF-36 physical functioning scale and 2-minute walking test showed the highest correlation. Based on these results, the SF36-PF and 2-minute walking test were recommended as core qualifiers for physical functioning, to assess the perceived physical performance and walking capacity in research and clinical practice.

In **chapter 5** functional independence and perceived physical functioning of patients with LOSP in 3 age groups (45 – 54 years, 55 – 64 years and 65 – 85 years) were compared and the impact of age and co-morbidity on these outcome measures was investigated. Elderly patients showed a lower level of functional independence, whereas no difference in perceived physical functioning was found. The co-morbidity score increased with age. Age was independently associated with functional independence, but not with perceived physical functioning. This may corroborate an age-related shift in the perception of physical limitations. The co-morbidity categories ‘cardiac’, ‘vascular’, ‘endocrine,metabolic’ and ‘muscle,bone,skin’ appeared to be associated with both functional independence and perceived physical functioning. It was concluded that co-morbidity negatively affects functional independence and perceived physical functioning. Prospective studies with unselected study populations, without exclusion of co-morbidity or elderly subjects, but including age-matched controls and measures to record co-morbidity were advised to investigate the influence of co-morbidity on the course of functioning in this population.

Chapter 6 presented the results of the 5-year observational cohort study with regard to the course of functioning and muscle strength and the impact of age and co-morbidity on the course of functional independence and perceived physical functioning. Disability, measured as functional independence, walking capacity and perceived physical functioning, declined little. The rate of decline in functioning was in line with other studies on polio survivors. Muscle strength, assessed as maximal quadriceps strength on a fixed dynamometer, decreased somewhat more. Unfortunately selective drop-out, resulting in a functionally better group with less co-morbidity, must be assumed at the fifth measurement due to temporary malfunction of the dynamometer. Judging from the decline in muscle strength at the 3-year follow-up, the 5-year measurements probably underestimate the real decline in muscle strength and the decline measured at 3-year follow-up may better reflect the true decline in ageing polio survivors. Co-morbidity increased over the years and a higher level of co-morbidity correlated with a lower score in functional independence and faster decrease in functional independence. For functional independence and perceived physical functioning prognostic models were constructed. Legs strength sum score and co-morbidity total score were prognostic factors for functional independence, whereas age was not. The prognostic model for perceived physical functioning included gender, age, legs strength sum score and co-morbidity total score, but no prognostic determinants were identified. To our surprise, age did not impact on functioning and future long-term follow-up studies should be

conducted with age-matched controls to compare the rate of decline in subjects with and without a history of poliomyelitis. Long-term follow-up with a sensitive outcome measure for musculoskeletal co-morbidities should determine whether the impact of co-morbidity will increase over the years.

Finally, chapter 7 discussed the main findings and clinical implications, critically focused on the methodology and gave recommendations for future research.

Four imaginary patients who differ in age, gender, extent of paresis of the legs and rate of co-morbidity were discussed to give some idea of the difference in the progression of disability in terms of functional independence between patients and the importance to consider age, co-morbidity and paresis for the functional prognosis of individuals with LOSP.

The longitudinal data showed that walking measured with walking tests deteriorates slowly, whereas muscle strength declined faster. Furthermore 2 studies, including our own, reported that the severity of polio residuals was a prognostic factor of functioning. The difference in deterioration rate between walking capacity and muscle strength supports the concept of 'overuse' of muscles in daily life. To maintain functioning over the years, patients are forced to use their weakening muscles at increasing relative loads.

In rehabilitation therapy, 2 approaches, that can be complementary to each other, can be distinguished: (1) preservation or improvement of muscular capacity and (2) the reduction of physical demands of daily life activities. Especially patients with relative good functional prognosis and muscle strength should be considered to use preservation of muscular capacity as an appropriate mean of therapy, because these patients still have a muscle status that can be trained. Patients with a worse functional prognosis should be considered to benefit from multidisciplinary treatment programs focusing on the reduction of physical demands, necessitating life style changes, because these patients are likely less able to train their limited and overused muscles.

An important methodological limitation to this study is the fact that sampling bias and selective drop-out might have occurred in our cohort. Therefore, an underestimation of the increase in disability and decline in muscle strength cannot be excluded and should be considered in especially the older subjects.

In future research this cohort should be followed further to gain insight in the long-term course of functioning and the impact of prognostic factors. The challenge will be to assure complete data collection with regard to the different outcome measures, especially muscle strength. Age-matched controls must be included to separate LOSP-related decline in functioning from age-related decline. A comprehensive measure of co-morbidities of the musculoskeletal system should be added to the outcome measures. Based on new insights, questionnaires on fatigue, activity monitoring and the collection of blood samples to assess the level of cytokines are to be added to the measurements.

The goal for the future with respect to rehabilitation must be that the millions of polio survivors can retain their functioning at the highest achievable levels as they age.

Post-Polio Research at AMC Amsterdam

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The research on post-polio syndrome in Amsterdam started in 1989 and was initiated by professor Marianne de Visser, neurologist. From that time on increasing numbers of Dutch patients with post-polio syndrome came to the AMC Amsterdam. Post-polio research has continued in Amsterdam, led by Marianne de Visser, Anita Beelen and Frans Nollet, resulting in 29 peer reviewed scientific papers up till now. PhD theses were written by Barbara Ivanyi in 1999, Frans Nollet in 2002, Herwin Horemans in 2005, Merel Brehm in 2007, and Janneke Stolwijk-Swüste in 2009.

At present 4 PhD students in the Dept of Rehabilitation are doing research in the field of polio.

Research focuses on clinical studies. Some results are summarized and can be categorized as:

- I Epidemiological and longitudinal studies
- II Diagnostic studies
- III Physiological studies
- IV Intervention studies
- V Methodological studies

Epidemiological and longitudinal studies

Polio victims from the last large epidemic in The Netherlands in 1956 with almost 1800 cases were studied 39 years later. In this population-based study among 260 respondents almost 60% experienced signs of new weakness, increased disabilities and handicaps and diminished health-related quality of life. The use of devices and adaptations had increased.(8,12)

A cohort of 103 polio patients was followed for six years. 27 of them had stable polio and 76 post-polio syndrome.(7,14) It appeared that health-related quality of life of the patients with PPS was lower compared to the stable functioning polio individuals. Over the years physical functioning did not change much. However, it appeared that the severity of paresis at baseline was a prognostic factor for decline in physical functioning in six years. These results supported the concept of overuse, that a (slow) decline in muscle mass, as a late effect of polio, may lead to a decline in physical functioning as the reduced muscle capacity becomes less able to meet the demands of daily physical activities.

In a systematic review of the literature we concluded that so far no conclusions can be drawn from the literature with regard to the functional course or prognostic factors in late-onset polio sequelae.(23) The rate of decline in muscle strength is slow, and prognostic factors have not yet been identified. Long-term follow-up studies with unselected study populations and age-matched controls are needed, with specific focus on prognostic factors.

Therefore we are presently conducting the CARPA-Polio study (Comorbidity and Aging Effects in Rehabilitation Populations on Activities). The longitudinal CARPA study focuses on the effects of aging and co-morbidity on functioning over time in 3 patient groups: Polio, M Parkinson, hip and knee osteoarthritis. The CARPA-Polio cohort includes 168 polio individuals.(26) Individuals range in age between 45 and 85 years and in contrast with many other studies, co-morbidities are not excluded but its influence on the time course is studied to reflect what happens in reality with aging. At the moment the participants in the study have been followed for 5 years. Some results have been published and included in the thesis by Janneke Stolwijk-Swüste. Age and co-morbidities were found to be negatively associated with physical functioning and physical independence. The influence of these factors on the changes over time is limited.(31) More

publications from this cohort-study will follow in the next years. At this moment the 8-years measurements are underway.

Diagnostic studies

The value of muscle computed tomography (CT) was studied. It was shown that muscles of post-polio patients experiencing new muscle weakness showed significantly more CT scan abnormalities compared with stable post-polio patients.(5) Muscle CT scan evaluation was considered a useful adjunct to muscle strength assessment and is now routine procedure in clinical practice. Furthermore, sleep complaints were inventoried. It appeared that up to half of post-polio patients reported complaints of disordered sleep, which was likely to influence daytime functioning. This was not further analyzed.(4) In the CARPA-study we have investigated respiration further in collaboration with pulmonologists from the Center for Home Ventilation in Utrecht. A paper is in preparation.

Physiological studies

Aspects of muscle function and exercise capacity were studied. It appeared that exercise capacity of polio individuals was mainly determined by the available muscle mass. No convincing evidence was found for a poor cardio respiratory condition. Results were comparable to normally active healthy controls.(11) We confirmed reports from others that polio individuals, especially those with post-polio syndrome may have difficulty with activating their muscles and are thus not fully able to recruit the available capacity.(13, 19) A clinical relevant finding is that the energy cost of walking is directly related to the severity of polio residuals.(24) This implicates that in case of two severely affected legs walking may cost twice (or even more) energy as compared to healthy people. Together with a reduced muscle mass this implies that 'one has to do more with less' substantiating the concept of overuse as a major cause of post-polio complaints. However, it appeared that only those individuals with severely reduced walking ability, reduced their walking activity in daily life.(22)

Intervention studies

In 2003 we reported a study on the effects of pyridostigmine (a drug that improves neuromuscular transmission) on fatigue, muscle strength and functioning in post-polio syndrome.(15) Unfortunately, we found no effect, which was in line with the results published earlier by Trojan et al. Our hope was that an effect could be found with different outcomes in selected polio individuals, those with proven neuromuscular transmission disturbances.(10) However, this was not the case. Since, some limited effects were found on 2 minutes walking distance, a potential benefit of pyridostigmine can not entirely be ruled out. However, that would require another study, accounting for individual differences in drug uptake. At present no such study is undertaken.

Another area of interventions is innovation and biomechanical optimization of custom-made leg braces. We demonstrated that the energy cost of walking can be reduced substantially by improving braces.(27) A chapter on state-of-the-art carbon composite orthoses for post-polio syndrome was written for the latest edition of the Atlas of Orthoses and Assistive Devices by the American Association of Orthopedic Surgery issued in 2008.(28) At the moment, a grant from the national health council has been obtained to write a clinical prescription guideline. Research on the innovation of braces is ongoing in collaboration with orthopedic technicians and industry.

Methodological studies

In scientific research it is important to investigate the measurement properties of the instruments that are applied: questionnaires, time scored tests, strength tests, (electro)physiological measurements and so on. A number of papers have been published in this area. It appears that strength measurements with a hand-dynamometer, but also in a fixed chair-dynamometer show large variations and are not very sensitive to detect small changes over time in individuals.(9,19) This implies that it is not easily possible to conclude that strength has really declined in evaluating a person with post-polio syndrome over time. It appears that walking

tests and measurements of energy consumption are better able to detect individual changes, although the sensitivity to detect change is less in polio individuals than in healthy controls.(21,24) In a recent paper, we recommended the Medical Outcomes Study Short Form 36 scale Physical Functioning and a 2-min walk test at self-selected speed to be used as core qualifiers for physical functioning, the major increasing disability in late-onset sequelae of poliomyelitis, to assess perceived physical performance and walking capacity in research and clinical practice.(29)

Research in progress

CARPA-continued

At present we are following up the CARPA cohort that is focusing on aging and co-morbidity. The 8-years measurements are presently being conducted. Within these data several aspects are being studies among others fatigue.

PhD student: Irene Tersteeg, MD

Funding: The Netherlands Organisation for Health Research and Development (ZonMW)

FACTS2PPS

A multi-center intervention study to reduce fatigue and improve functioning. Two different strategies are being investigated physical exercise and a cognitive behavioral approach. The FACTS2PPS study (30) is part of a larger project FACTS2NMD coordinated by AMC and involving also other neuromuscular disorders (FACTS2MND, FACTS2FSHD). The Total FACTS2NMD consortium involves 5 PhD students, one of them fully dedicated to patients perspectives.

PhD Students: Fieke Koopman, MD and Eric Voorn, MSc

Funding: the Prinses Beatrix Fonds (PBF); The Dutch Public Fund for Neuromuscular Disorders and The Netherlands Organisation for Health Research and Development (ZonMW).

Trial Register: <http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=1371>

MUPPET

Muscle and motor Unit changes in Post-Polio syndrome Evaluated after Ten years.

In this study the patient group that was involved in the pyridostigmine trial (15) is reinvestigated after 10 years in comparison with healthy controls focusing on changes in muscle strength and motor-unit characteristics.

PhD Student: Alice Bickerstaffe, MD

Funding: the Prinses Beatrix Fonds (PBF); The Dutch Public Fund for Neuromuscular Disorders.

ORTHOTIC PRESCRIPTION GUIDELINE PPS

In this project a guideline is developed for polio based on evidence and expert opinions including clinicians from different disciplines (rehabilitation medicine, orthopedics, neurology, physical therapy), orthotists, biomechanical engineers, insurance representatives and patients. Based on the 'Process Description for Devices' all steps in the prescription process are being described. The guideline will be formatted as a handbook.

Project leader: Merel Brehm, PhD

Funding: The Netherlands Organisation for Health Research and Development (ZonMW), The National Health Council.

Senior-researchers involved: Anita Beelen, PhD, Merel Brehm, PhD, Carine van Schie, PhD.

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Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

- The objective of the study was to describe the course of functional status of patients aged 45 to 85 years with late-onset sequelae of poliomyelitis (LOSP) over five years and to explore the impact of age and comorbidity on this course.

- The speaker provided information on the baseline data, longitudinal data and the research method involved in the study.
- Started the study because in 2050 it is expected that 24.5% of the population of the Netherlands will be older than 65 years. Insight into how ageing affects functioning is required.

Questions:

- Were those in the study recruited from the clinic?
 - The subjects included in the study came to a specialist in the Netherlands. All were seen in polio clinics in Amsterdam, most with PPS.
- Amazing there was so much decline in function.
 - Looking at the decline, the first question is what happens to muscle strength? Used a decline range of three years; had a large dropout of subjects. Decline was 9% in three years and less in five years.
 - Looking at the functional independence measure, they were in the high range and only declined 2% in three years.
 - SF-36 – 9% in five years. It is quite considerable. SF-36 is a subjective measure. Take into account the instrument used.
- During the five years, when you looked at performance in the beginning and end, was data on each of the subjects?
 - Used all the collected data and analyzed the incomplete data based on individual assessment.
 - Any studies where patients are followed, other affecters that may affect the cause are excluded. Wanted to include an older group also and there was an increase in comorbidity but no effect of age so far.
 - From data, it doesn't progress more rapidly in older people. But SF-36 is a subjective measure. Also looked at strength and walking test.
- What was the age of the cohort at the time of onset of polio? How many people in your study had polio as children or adults?
 - Cohort ranged from newborns to 27 years.
- How many people in the cohort are working or had been working or applied for disability and considered unable to work?
 - Those results were not published. Study looked at impacts of fatigue and socioeconomic factors.
- In relation to medications individuals are taking, there are some medications that can have an effect in increasing weakness and others may increase the condition. That would be important to address the issue of medications people are taking.
 - Medications are on file but they were not analyzed. Medication use is very limited in this cohort.
- In these patients, did you detect any significant difference brought about by bracing one or both legs...whether the use of braces had an influence?
 - No, not in the analysis collected; had to limit ourselves. Made sure people used the same orthotics for the walking test.
 - One-half of PP patients complained of disordered sleep. This was not further analyzed.
- Do you have any idea as to whether sleep disturbances led to further fatigue when you tested them? Was the same applied to respiratory muscle weakness or scoliosis which could have affected some of the results?

- There was an association between sleep problems and fatigue in two different subjects in the cohort. Looking at this cohort with lung function test as to why people had sleep apnea. That was a very limited number.
- Relationship of men to women?
 - 67 males and 101 females.
- If there was an effect of gender it might be related to occupation.
 - There was a difference between men and women with functional scores.
- At what age do people in the Netherlands go into full retirement?
 - 65 but in a few years, 67.
 - Subjects in the oldest age group are all retired. In the two younger age groups (aged 45-65) it will be quite mixed.
- How many participated in physical exercise thinking it may build up their muscles?
 - About one in three is doing some physiotherapy. A number are swimming – limited to less than 20%.
- With regard to comorbidity, have you looked at individual comorbidity – individuals with diabetes – are these comorbidities associated with a steeper decline in functionality?
 - Looked at different categories of comorbidity based on different parts of the body, i.e. cardio respiratory. It did not impact on the course of function.
 - On the longitudinal data, a total score was used, not the categories themselves. Specific comorbidities could not be separated, e.g. cardio respiratory could be emphysema or angina.
 - In the future, a instrument is needed to measure comorbidity in greater detail
- Is there any data about the progression of normal controls in the different instruments that were used? Any data in the literature?
 - The longitudinal studies mostly describe 2-3% decline per year.
 - It is remarkable the number of studies of changes over time is still limited.
- In June there will be a publication from Dr. Kristian Borg. We are still in need of much larger scale longitudinal studies to get a better understanding of what is happening over time and to inform our patients.
- The European Polio Union and the Danish Society of Polio and Accident Victims will hold a conference from August 31 – September 2, 2011 in Copenhagen entitled "Post Polio Syndrome – a challenge of today".