

Evaluation of function, disability and participation of patients with motor neuron disease

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ABSTRACT

Aims: To objective the symptoms and estimate the necessity of technical or social aid as well as to receive parameters for treatment, this evaluation was carried out. The aim is the preparation of core sets for patients with motor neuron diseases. **Methods:** Data sources were found in PubMed: published in the last 50 years; **Languages:** German and English. After a systematic literature review, two independent reviewers scored the significance of the published studies by 14 criteria including study design, outcome measures, follow-up, data analysis and presentation. **Results:** 36 significant studies with control group: self-estimated life quality and emotion are the most frequent items which were investigated. In contrast to this frequency, the studies with reference to mobility, emotion and

activities of daily life are most significant. The result is a proposal of ICF core set by the use of different specific and general items. **Conclusion:** In literature, there does not exist any assessment or setting which distinguish the function and disability of the polio patients on the whole. So the developed ICF core set may be a possibility to objectify the motor neuron disease after its multidisciplinary confirmation.

Keywords: Disability, Evaluation, Motor neuron disease

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INTRODUCTION

Patients with motor neuron diseases often suffer from insufficient mobility, musculoskeletal pain and reduced endurance in activities of their daily living. To objective the symptoms and estimate the necessity of technical or social aid as well as to receive parameters for study evaluation, assessments are useful. The knowledge of the extent of the patients` impairment, their reduced activities

and destroyed structures are essential. In 2001, the WHO extended the international classification of disease and health by an international classification of functioning (ICF), which moreover includes environmental factors. The aim of this is a common speech of all care professions about requirements and resources of rehabilitation to improve the life quality of patients. Core sets facilitate the handling of ICF but do not exist for specific neurological diseases.

One clinical picture of affected motor neurons is the anterior acute poliomyelitis. This importance increases because new cases of polio arose for instance in southern Antwerp as well as in Nigeria. Reasons are increased travel and reduced willingness to vaccinate.

In addition, the number of patients suffering from disabilities after anterior acute poliomyelitis is indicated between 50,000 and 100,000. Multiple new disabilities can arise decades after the disease broke out, still making great demands on the health care system despite the decrease of the disease frequency. Following the recovery from anterior acute poliomyelitis with relative neuromuscular stability and possible remaining paralysis, a loss of strength of approximately one up to 15% of strength per year over a period of eight years occurs quite frequently [1]. Besides muscles obviously impaired in functionality, muscles appearing to be healthy and compensating slight functional disturbances at the beginning, are also frequently affected. Specific assessments similar to global assessments do not exist for poliomyelitis patients. The disease an international agreement is intended because of international problems of handling.

The attempt to understand the clinical picture of postpolio syndrome (PPS) offers the following questions:

- Which outcomes do polio associated symptoms estimate?
- Which specific polio assessments were developed to evaluate polio assimilated disabilities?
- Which of the global and specific outcomes and assessments are significantly tested?

The aim of the study is to find out how it is possible to describe the symptoms and functions of patients with motor neuron diseases comprehensible using the example of postpolio syndrome.

The result of the review is the proposal of a core set to evaluate problems and therapy options in patients with late effects of poliomyelitis.

MATERIALS AND METHODS

According to the following procedure all synonymic words of the disease combined with its symptoms and their possible measurements are the basis in published studies about the evaluation of long-term damages due to poliomyelitis (Figure 1). The screening resulted from PubMed published in last 50 years in German or English

language. After identification of the most important outcomes the scientific quality of these published significant studies were scored by 14 criteria including study design, outcome measures, follow-up and data analysis including presentation [2]:

1. Selection of study population
2. Description of inclusion and exclusion criteria
3. Study size
4. Follow-up ≥ 24 months
5. Drop-outs / loss to follow-up $\leq 15\%$
6. Information on patients who completed follow-up versus drop-outs and loss to follow-up
7. a: Relevance of outcome measures to the level of activities and participation
b: Relevance of outcome measures to the level of muscle strength
8. Validity of outcome measures
9. Reproducibility of outcome measures
10. Description of potential prognostic factors
11. Descriptive statistics of most important outcome measures
12. Descriptive statistics of most important prognostic factors
13. Univariate technique

Multivariate technique

Every item which was evaluated as significant in a study was estimated by two independent reviewers. They gave a number of points according to the fulfilled criteria. In dependence of the number of published studies respectively the item, their importance was proved by the following score

$$\text{Score} = \frac{\sum \text{rating points of one item}}{\sum \text{studies of this item}}$$

Likewise the evaluation of the important items occurred in correlation with the international classification of functioning.

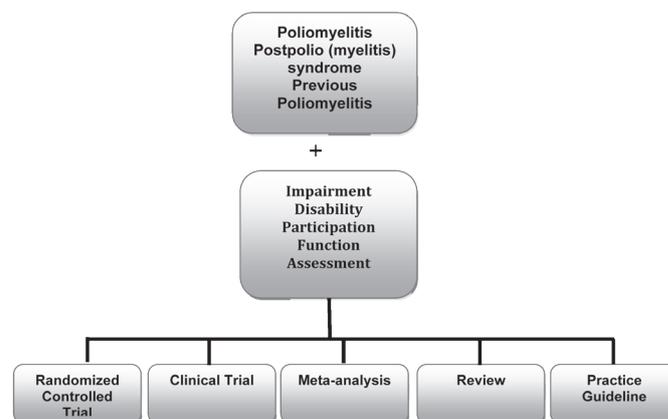


Figure 1: Combination of study search.

RESULTS

Four hundred twenty-five articles fulfilled the review criteria. Within 85 articles with significant results, 36 significant studies with randomized control groups were shown in Figure 2.

Five of them evaluate treatment in polio patients and others describe the health status of the disease population and try to objective specific outcomes.

Table 1 documents all discovered assessments to estimate general health and specific disturbances in polio patients [1, 3–30]. Specific health assessments as well as general health assessments are included. It can be seen that life quality and emotion is a frequently item that was investigated. The table reviews the quality of publications which evaluate one or more items. The last column sums up the positive marks. The studies with reference to mobility, emotion and activities of daily living are most significant, the studies relating to life quality and pain have a smaller methodological quality. Four papers do not fulfill the quality criteria regarding useful assessments to include in our preparation of core sets. Reliable and valid instruments to evaluate the leading symptoms of polio patients are the timed up and go test and the six minute walk test, additionally the fatigue severity scale with nine questions assessed by one until seven points. Pain is a possible objective by means of multidimensional pain inventory with three-question complexes consisting of 61 items; more precise is the visual analogue scale (VAS) for pain and for other body functions. Manual muscle testing is standard in every clinical examination of patients with motor neuron diseases.

The general quality of life was often assigned by using the short form of 36 (SF 36) questions about quality of life. This includes parameters for physical and psychological domains. The seven items give information on physical functioning, physical and mental roles, bodily pain, mental health, vitality and general health. Furthermore, a general evaluation of carrying out a daily routine is the known Barthel index.

To objective bodily function and to control the possibility as well as the efficacy of a therapy especially exercise training, technical outcomes extend the validation of specific activities. Specific devices or test batteries are used to measure the efficiency of the cardiopulmonary system, muscle activity and gait.

The frequency and distribution of significant domains in the 32 randomized controlled trials are illustrated in Figure 3. Activities of daily living as well as mental more than physical functions are of superficial interest. The evaluation of mobility has the most important statistical significance according to the calculated score. These described domains receive the following proposal for an ICF Core set given in Table 2. In column one, poliomyelitis relevant functions are listed whereas the assessments concerning bodily function and structures, activities and

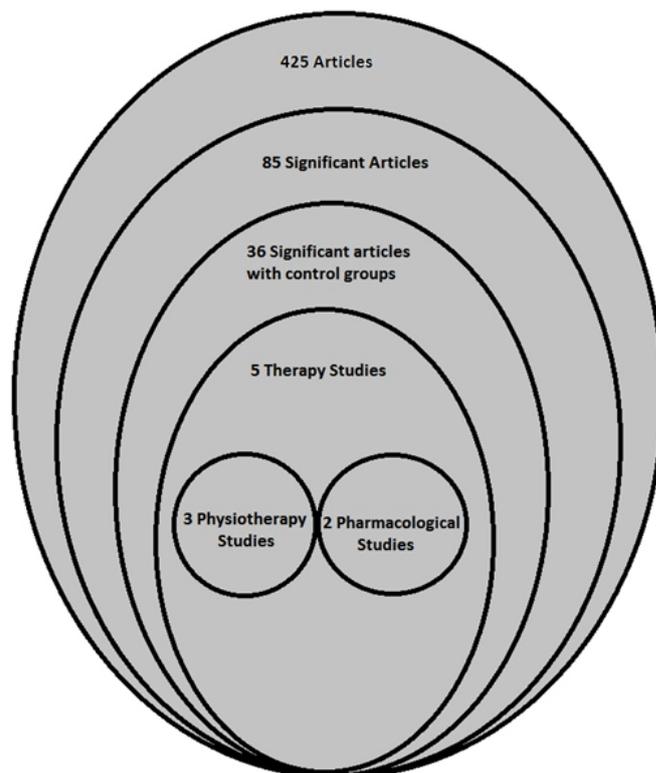


Figure 2: Review criteria associated articles.

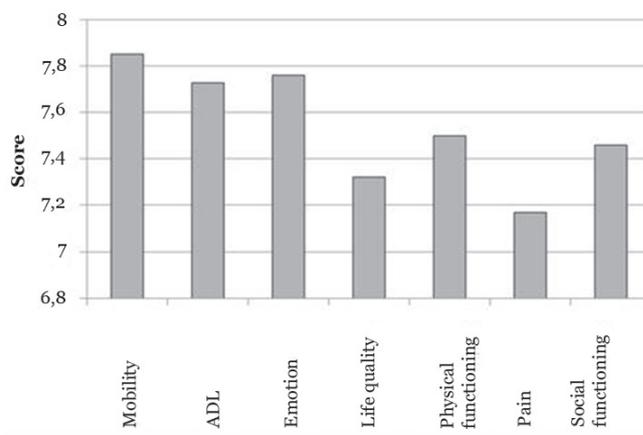


Figure 3: Frequency and distribution of significant domains.

participation as well as environmental factors named in column two.

DISCUSSION

Examination methods using instruments should complement the clinical examination and generate the basis of a differentiated treatment complex together with supplementary specialized assessments. In the beginning of the disease, the psychological stability of postpolio syndrome patients mislead over the physical functional deficits. Therefore, professional committees should

Table 1: Scientific quality of evaluation of assessments to estimate general health and specific disturbances in polio patients.

| | Score of quality criteria | | | | | | | | | | | | | | Σ | |
|--|---------------------------|---|---|---|---|---|----|----|---|---|----|----|----|----|---|----|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7a | 7b | 8 | 9 | 10 | 11 | 12 | 13 | | 14 |
| Six-minute walk test [3] | + | + | + | - | - | - | + | - | + | + | - | + | - | - | + | 8 |
| Activity card sort (ACS): Participation in activities of daily living [4] | + | + | + | - | - | - | - | + | + | + | - | + | - | + | + | 9 |
| Laboratory measurement of postural balance, Tinetti: stance/gait, Timed up and Go Test [5] | - | - | - | - | - | - | - | - | + | - | - | - | - | - | + | 2 |
| Beck depression Inventory, CAGE (cutting down, annoyance by criticism, guilty feeling, Eye-openers) questionnaire [6] | + | + | - | - | - | - | - | + | + | + | - | + | - | - | - | 6 |
| Pulmonary vital capacity, manual muscle testing [7] | + | + | - | - | - | - | - | + | - | - | + | + | - | - | + | 6 |
| Walking speed, lower extremity muscle strength sum, energy cost of walking [8] | + | + | + | - | - | - | + | + | + | + | - | - | - | + | + | 9 |
| Life satisfaction questionnaire, quality of life questionnaire [9] | + | - | + | - | - | - | - | - | + | + | + | + | + | + | - | 8 |
| Fatigue scale [10] | - | + | - | - | - | - | - | + | + | + | + | + | - | + | - | 7 |
| Maximum voluntary contraction (thumb) [11] | + | - | + | - | - | - | + | - | - | + | - | - | - | + | - | 5 |
| Questionnaire on ambulatory status, list of respiratory symptoms (environmental modification, orthoses, respiratory aids) [12] | + | - | + | - | - | - | + | + | + | + | - | + | - | + | + | 9 |
| Manual muscle testing, electromyography (EMG), Life quality [13] | + | + | + | - | + | - | + | + | + | + | - | + | - | + | - | 10 |
| Spirometry (Vpi max, Vpe max), respiratory muscle EMG [14] | + | - | + | - | + | - | + | - | + | + | + | + | - | + | - | 9 |
| International classification of functioning [15] | + | - | + | + | + | - | + | + | + | + | + | + | + | + | + | 13 |
| Degree of mobility, handicap, manual muscle testing, dynamometer (of knee muscle strength) [16] | + | - | + | - | - | - | + | - | + | + | + | + | - | | | 7 |
| CAGE (cutting down, annoyance by criticism, guilty feeling, eye-openers) questionnaire [17] | + | + | + | - | - | - | + | - | - | + | + | - | - | + | - | 7 |
| Questionnaire of social factors, general health [18] | + | + | + | - | - | - | + | - | + | + | + | + | - | - | + | 9 |
| Muscle strength (Medical Research council sum score), Fatigue severity scale, multidimensional fatigue inventory [19] | + | + | + | - | - | - | + | + | + | + | - | + | - | - | + | 9 |
| Maximal voluntary force of muscle, maximal isometric elbow flexion [20] | + | + | - | - | - | - | + | - | + | + | - | + | - | - | + | 7 |
| Fatigue impact scale, ACS, personal wellbeing index [21] | + | + | + | - | - | - | + | - | + | + | + | + | - | + | + | 10 |
| Balance, sleep quality, multidimensional fatigue inventory, physical activity scale of elderly (PASE), Short form questionnaire (SF 36), manual muscle strength test, six minute Walk Test, Timed up and Go, VAS pain [22] | - | - | + | - | - | - | + | - | - | - | - | + | - | + | + | 5 |
| Manual muscle testing, EMG [1] | + | - | + | - | - | - | + | + | - | - | - | + | - | + | - | 6 |

| | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|----|
| Personal activities in daily living: Katz ADL-Index, ICF, Nottingham Health Profile (NHP) [23] | + | + | - | - | - | - | + | - | - | - | - | + | - | + | - | 5 |
| National Rehabilitation Hospital (NRH) for limb classification [24] | + | + | - | - | - | - | + | - | + | + | - | + | - | + | - | 7 |
| Hare fatigue scale, modified Barthel index for activities of daily living, modified Klingman mobility index [25] | + | + | + | + | + | - | - | + | + | - | - | + | - | | | 8 |
| Multidimensional pain inventory [26] | + | + | - | - | - | - | + | - | + | - | + | + | - | - | + | 7 |
| Self administered upper limb questionnaire, use of mobility aids [27] | + | + | - | - | - | - | + | + | + | + | + | + | - | + | - | 9 |
| Fatigue severity scale [28] | + | - | - | - | - | - | + | - | + | + | + | + | - | + | - | 9 |
| Review about care modalities and persons [29] | + | + | + | - | - | - | + | + | + | + | + | + | - | + | - | 10 |
| Nottingham health profile, manual muscle testing, hand held dynamometer, life satisfaction, Heart rate questionnaire, polio problem list (sleep, energy, pain, social isolation, mobility) [30] | - | - | + | - | - | - | - | - | + | - | - | - | - | - | - | 2 |

Table 2: Proposal for ICF core sets for postpolio syndrome

| Body functions Outcomes | |
|---|--|
| B130 energy and drive functions | Fatigue (severity) scale, multidimensional fatigue scale, fatigue impact scale, Hare fatigue scale, Nottingham health profile, Beck depression scale, heart rate questionnaire |
| B134 sleep function | Sleep qualities, Nottingham health profile, polio problem list, CAGE, life satisfaction questionnaire, quality of life questionnaire, general health, personal wellbeing index |
| B140 attention function | |
| B152 mental role | |
| B280 sensation of pain | Visual analog scale (VAS), multidimensional pain inventory, polio problem list, pain and muscular weakness disability index, pain qualities |
| B445 respiratory muscle functions | Spiroergometry, measurement of vital capacity (Vpi max, Vpe max), respiratory muscle EMG, blood gas measurement, list of respiratory symptoms |
| B730 muscle power function | Dynamometer testing, MUAP und MUE, EMG, lower extremity muscle strength sum, maximum voluntary (contraction) force |
| B735 muscle tone function | |
| B740 muscle endurance function | Pain and muscular weakness disability index Energy cost of walking |
| B770 gait pattern function | Tinetti test, timed up and Go test, laboratory measurement of postural balance |
| B760 control of voluntary movement function | |
| Body structures | |
| S730 structure of upper extremity | Manual muscle testing, National Rehabilitation Hospital classification |
| S750 structure of lower extremity | balance testing |
| S760 structure of trunk | |
| Activities and Participation | |
| D230 carrying out daily routine | SF-36, Barthel index, activity card sort, anamnestic degree of handicap, Katz ADL Index , Nottingham health profile, modified Klingman mobility index |
| D410 changing basic body position | Timed up and go test, |
| D420 transferring oneself | Nottingham health profile, SF-36 Questionnaire |
| D430 lifting and carrying objects | SF-36 Questionnaire |

| | |
|--|---|
| D445 hand and arm use | Hand held dynamometer testing |
| D450 walking | Walking speed, timed up and go test, six-minute walk test, tinetti test, anamnestic functional loss during walking and exertion, degree of mobility, |
| D460 moving around in different locations | |
| D465 moving around using equipment | |
| D510 washing oneself | Barthel Index |
| D520 caring for body parts | |
| D530 toileting | |
| D540 dressing | |
| D610 acquiring a place to life | Physical activity for the elderly scale, SF-36, polio problem list |
| D620 acquisition of goods and services | |
| D640 doing housework | |
| D730 relating with strangers | |
| D850 remunerative employment | |
| D910 community life | Socio-professional activities, questionnaire of social factors |
| Environmental factors | |
| E115 Products and technology for personal use in daily living | Review about care modalities and persons upper limb questionnaire: use of mobility aids questionnaire of ambulatory status (environmental modification, orthosis, respiratory aids) |
| E120 Products and technology for personal indoor and outdoor mobility and transportation | |
| E340 personal care providers and personal assistants | |
| E355 health professionals | |
| E360 other professionals | |
| E530 utilities services, systems and policies | |
| E540 transportation services, systems and policies | |
| E570 social security services, systems and policies | |

estimate the grade of disability resulting in the definition of a potential nursing care level.

Assessments with subjective items are difficult to evaluate. Single functions of activities in daily living and participation are reproduced more significant by special questions about one different body function, investigation of structure and environmental factors. The practicability of a defined ICF core set in the heterogeneous disease pattern of poliomyelitis was often discussed. Many specific assessments developed for other diseases are suited fractional to objective special symptoms of poliomyelitis such as fatigue severity scale for multiple sclerosis. On the other hand, assessments like multidimensional pain inventory exceed the necessity of pain rating. The polio problem list is the assessment which reproduces all important life sectors of the polio patients; nevertheless the list allows only quantitative but no differentiated qualitative evaluation. Additionally, the existence of a publication bias is possibly caused by a loss of publications in other databases or by the selection of studies with positive or significant results. Another limitation in using the introduced score is the different number of considered paper per item. In practice, the discussion of the ICF core set proposal and assessment proposals with experts are necessary and important for analysis in polio clinics. After new discussions on the possibility and relevance of assessments their reliability, validity and sufficient sensitivity have been proved.

Benefits are the initiation of a sufficient therapy including the support by technical aids and social

support valences. In the case of the ability to work, part-time employment, workplace changes as well as general disability pension procedures could be considered as significant assessments.

There is a lack of multidisciplinary assessments of polio associated impairment. So ICF core sets are proposed by the use of different specific and general item estimation. After the evaluation and revision of this core sets by a panel of experts, their practice should be analyzed in polio clinics.

Subsequently to a new discussion about possibility and relevance, study of reliability, validity and sufficient sensitivity have to be proved in further studies.

Author Contributions

Barbara Bocker – Substantial contributions to conception and design, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Norman Best – Substantial contributions to conception and design, Revising it critically for important intellectual content, Final approval of the version to be published

Constanze Schueler – Acquisition of data, Analysis and interpretation of data, Drafting the article, Final approval of the version to be published

Ulrich Smolenski – Substantial contributions to conception and design, Revising it critically for important

intellectual content, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

Authors declare no conflict of interest.

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