

Processes of Care in Paediatric Rehabilitation

Renate Siebes

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Processes of Care in Paediatric Rehabilitation

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Renate Christina Siebes

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1

Introduction

Although theory and effects of paediatric rehabilitation care and parent involvement in rehabilitation treatment have been described extensively in international literature, little has been written about what actually happens *in between*, *i.e.*, about how theories on care provision have been operationalized in clinical practice and what the mode and the level of parent involvement is. This thesis reflects our efforts to describe the relatively unknown clinical implementation of the paediatric rehabilitation care process in the Netherlands. To what extent are parents involved in the different stages of the paediatric rehabilitation treatment process? What is being done in treatment? Is there a clear relation between treatment activities and parent identified problems? Are parents satisfied about the services they and their child have received?

In this chapter major developments and shifts in health care in general and paediatric rehabilitation in specific are described to provide the reader with the practical background information that is needed to place our study in the correct context. The structure of paediatric rehabilitation in the Netherlands is outlined, and working models in Dutch paediatric rehabilitation are discussed. In addition, the most recent policy developments with their main themes and current paediatric rehabilitation research in the Netherlands are described. Finally, the outline of this thesis is presented.

1.1 Quality of health care

Quality of health care has become increasingly important for health care providers and is a major focus for health services research. The earliest initiatives to quality assurance in health care can be found in Hippocrates' Epidemics, Bk. 1, Sect. XI: "... As to diseases, make a habit of two things — to help, or at least to do no harm". The Roman physician Claudius Galenus of Pergamum (131 – 201 AD), writing about 500 years later on the subject, translated the phrase into Latin as "Primum non nocere" (First, do no harm). The statement defines a way of thinking which places the welfare of the patient above other concerns. This fundamental principle of medical ethics was held up from Hippocrates all the way up to Florence Nightingale in 19th century England, when she stated in her Notes on Hospitals that "It may seem a strange principle to enunciate as the very first requirement in a hospital that it should do the sick no harm".¹³⁹ One century later, Donabedian described a modern conceptual framework for evaluating quality of patient care, which is widely adopted in the working field.⁴⁷ He defined quality assurance as "all actions that are taken to establish, protect, promote, and improve the quality of health care" (p. xxiii). With Donabedian, many believe the continuous improvement of the level of quality should be the goal to be pursued ("How can we get better?").

Care provision has undergone important changes in the past decades. The most far-reaching shift to take place was the reconceptualization of the family role. In roughly half a century the role of parents in the care process evolved from being without role and control, into the role of an equal partner in the decision-making processes of treatment

and in determining the contents of their child's care.²⁰⁶

The International Classification of Functioning, Disability and Health¹³⁸ (see Figure 1.1), known more commonly as ICF, provides a standard language and framework for the description of health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities. A version of the ICF for children and youth (ICF-CY) is also available.¹¹⁵ The ICF represents a revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was first published by the World Health Organization for trial purposes in 1980. From emphasizing people's disabilities (ICIDH), the focus now is on their level of health (ICF). Moreover, within the ICF attention is not only paid to the horizontal axis (body functions and structures, activities, and participation), but also to the vertical axis, with special attention for environmental and personal factors. The ICF provides a systematic coding scheme and permits comparison of data across countries, health care disciplines, services and time.

1.2 Paediatric rehabilitation in the Netherlands

In the Netherlands, there are 23 specialized rehabilitation centres with a paediatric department. Furthermore, all medium- and large-sized hospitals have a rehabilitation department. Each year 9000 children are treated on an outpatient basis at these locations.¹⁵⁴ Paediatric rehabilitation services are directed primarily at children with a temporary or sustaining primary motor disturbance.¹³⁰ Virtually every child qualifies for treatment in a paediatric rehabilitation setting, but in practice the youngest children are mostly treated at home by private therapists, often combined with outpatient visits at the hospital's physician in paediatric rehabilitation medicine, with or without additive specialized support of the rehabilitation centre. After the initial observational and assessment period there are several options, depending on child age and the complexity of problems. Preschool children with complex problems, for instance, can visit the specialized toddler day care treatment groups where they receive multidisciplinary treatment in the rehabilitation centre. The multidisciplinary treatment for complex disabilities then shifts towards schools for children with a physical disability, which are often connected to a multidisciplinary rehabilitation team. Children in mainstream education can often do with outpatient consults combined with monodisciplinary therapy alone. Some specialized rehabilitation centres offer inpatient paediatric rehabilitation clinics for intensive treatment. Each year 300 children are temporarily admitted to such a clinic.¹⁵⁴ The upper age limit for paediatric rehabilitation is about 20 years, but in practice a young adult's social situation determines whether paediatric or adult rehabilitation is the best option.¹³⁰

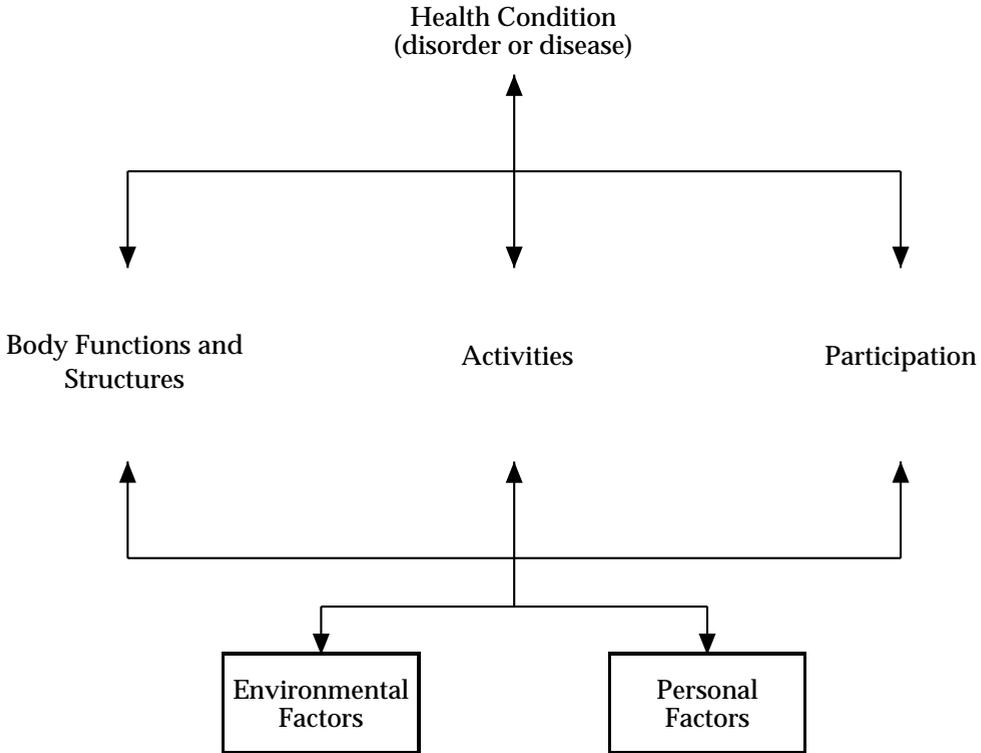


Figure 1.1 The International Classification of Functioning, Disability and Health.¹¹⁵ The ICF provides a long list of codes to describe the integrity of body functions and structures, the ability and performance of activities of daily life, the scope of the individual's social participation, and environmental factors that might facilitate or challenge functioning.

1.2.1 Working models in paediatric rehabilitation

Since the 1970's, working models were utilized in Dutch paediatric rehabilitation to systemize assessment and treatment. The SAMPC model by Bangma⁶ addresses the five areas common to daily life having a significant effect on the course of rehabilitation: somatic, activities of daily living, social, psychological, and communication. The Bangma model was used in the Netherlands as a basis for rehabilitation medicine since 1972, but is less suitable to be used in paediatric rehabilitation because the model does not address developmental and educational aspects of care, and cannot make a distinction between parent and child problems.

In 1996, the Rehabilitation Activities Profile for Children (Children's RAP), an instrument for interdisciplinary communication in paediatric rehabilitation, was implemented in the Netherlands to support the intensified interaction between parents and team members.¹⁵⁸ This framework provides team members and parents with a common language (abilities of the child and its parents) and a common reference framework (the needs of the child and its parents), which helps both parents and service providers to put the actual problems of the child into words during the mostly annual or semi-annual team conferences. Moreover, the Children's RAP serves as a checklist, which—in theory—prevents team members forgetting to report on relevant information, or from adding irrelevant information.¹⁵⁹ By formulating child and parent needs and by translating these needs into explicit treatment goals, all documented in the Children's RAP report, the transparency of the treatment process can be optimized. In this way, treatment is focused on things that are important for the child and its parents. Today, the Children's RAP is the standard instrument for team reporting and team communication in paediatric rehabilitation in the Netherlands.¹³⁰

1.2.2 Recent shifts in paediatric rehabilitation care

Parallel to changes in health care in general during the past decades, the family role in paediatric rehabilitation services changed substantially. The term family-centred care (FCC) is commonly used to describe this new way of providing care. FCC can be described as an holistic approach towards service delivery, in which the unique strengths, resources and set of needs of each child and its family form the base for a highly individualized and dynamic model of care.^{49,97,116} Parents and team members are equal partners and work together jointly, sharing aims, information, and responsibilities. Research indicates that providing FCC is associated with an increase in parents' skills and knowledge about child development, enlarged parental satisfaction with services, decreased parental stress and improved well-being,^{88,90,92,151,161} improved psychological adjustment of the child,^{112,190,191} and gains in child development and acquisition of skills.^{26,107,134} Satisfaction with services has been shown to intensify the partnership between service providers and parents.^{88,90}

1.2.3 Paediatric rehabilitation care policy

Changes in health care during the 20th century were accompanied by shifts in health care policy. Table 1.1 provides an overview of the most recent policy developments with their main themes. On the occasion of the centennial of paediatric rehabilitation in the Netherlands the report "Juggling with limitations"¹⁹⁴ (published in 2000) discussed four possible future scenarios for paediatric rehabilitation in the Netherlands. In the same year, the Association of Dutch Rehabilitation Institutions and the Association of Physicians in Rehabilitation Medicine (VRIN and VRA, nowadays Revalidatie Nederland) formally

Table 1.1 Recent policy developments with their main points

Juggling with limitations¹⁹⁴ (2000)

1. View parents as the best partners in the rehabilitation process and make them feel heard, keep them informed, and offer them necessary practical aid and psychosocial support, so that parents themselves can continue functioning as well as possible
2. Develop a corporate vision on paediatric rehabilitation, with a clear demand for and continuously fitting services as steering principles
3. Reflect on the possibilities to influence intangible things like emancipation, participation into society and the force field around that
4. Reinforce the expertise and efficiency of the deployment of rehabilitation disciplines by executing high-quality scientific research, in which multidisciplinary results are the criterion

Future perspectives on paediatric rehabilitation in the Netherlands²¹³ (2000)

1. Realization of an interdisciplinary treatment model
2. Transition from supply-driven to demand-driven care
3. Attention for both the child and its family
4. Transparency
5. Increased attention for adolescents
6. Decentralized where possible, centralized where necessary
7. Building a national rehabilitation network
8. Close cooperation with schools
9. Improvement of accessibility of services by bringing down existing walls
10. Provide a scientific foundation by performing research

Juggling with possibilities¹⁹⁵ (2001)

1. Parent and adolescent identified problems should be the starting point of treatment
2. Special attention should be paid to the switch from (early) childhood to adolescence
3. Better psychosocial support of parents and adolescents is necessary
4. The best possible integration should be pursued with the appropriate "supporters"

Joint vision on paediatric rehabilitation²¹² (2003)

1. There are more target groups who can profit from specific rehabilitation methods, for instance, children with chronically illness, mild acquired brain damage, cancer, and cardiac pathologies.
2. The child is part of the family, and as such, the family is part of the rehabilitation treatment system. It is therefore important to make time for assessment of the system and family counselling. Moreover, each family (or family member) has its own problems asking for practical support.
3. Good communication is essential for a good proceeding of the rehabilitation plan. Communicative skills of individual team members are essential for effective team communication and for a comprehensive inventory of parent identified problems of the child.
4. The overall needs of the family should be the starting point of care provision, without practical or financial limitations. Breaking down the walls between institutions, cooperation, networking, and chain care should get more attention.

National Paediatric Rehabilitation Innovation Program 2006–2010 "All hands on deck"¹⁹⁷ (2005)

1. Equipment of parents and family
2. Transition into adulthood
3. Founding of a national paediatric rehabilitation service point

reacted to the report with a new report "Future Perspectives on Paediatric Rehabilitation in the Netherlands".²¹³ As a result of the discussion about and reactions on the first report "Juggling with limitations", the Stichting Toekomstscenario's Gezondheidszorg published a second report in 2001: "Juggling with possibilities".¹⁹⁵ In 2003, the associations of physicians in rehabilitation medicine, psychologists and orthopedagogists discussed their vision on the future of paediatric rehabilitation in the Netherlands.²¹²

In 2005 the Advisory Committee Paediatric Rehabilitation selected three main themes for innovation of paediatric rehabilitation: (1) Increased attention for parents and the family and appropriate psychosocial support; (2) Increased attention for adolescents and transition into adulthood; and (3) Building a rehabilitation network and improvement of accessibility of services by bringing down existing walls.¹⁹⁷ Funds were raised and the National Innovation Program was carried out in a joint venture with parent associations and patient associations.

1.2.4 Paediatric rehabilitation research

The aforementioned care policy developments are reflected in paediatric rehabilitation research. A large inventory in the summer of 2005 revealed 23 current innovation initiatives in paediatric rehabilitation.¹⁹⁷ Another 51 scientific research projects were identified, among which the extended national PERRIN research program (**PE**diatric **R**ehabilitation **R**esearch in the Netherlands).¹⁹⁷ The various research projects did not focus solely on the child, but also included, for instance, family and environmental factors.

Today, more and more scientific research is incorporated in research networks, like the PERRIN program with six inter-related studies in paediatric rehabilitation, of which five aim to describe the development of children and adolescents with a cerebral palsy. *NetChild*, another multidisciplinary network of professionals in the field of childhood disability (rehabilitation medicine, paediatric physical therapy, and special education) that was launched in 2003 to bring together Utrecht research colleagues, focuses on three research topics: Family, Function, and Fitness.

Interviews by the National Innovation Program with people involved in paediatric rehabilitation from different perspectives provided two main themes which shaped the National Innovation Program: "Equipment of parents and family" and "Transition into adulthood". A National Paediatric Rehabilitation Service Point will coordinate the Innovation Program.¹⁹⁷ In 2005, the work field was involved in the Innovation Program with a call for innovation projects within the two themes. Finally, at the end of 2005, the National Paediatric Rehabilitation Innovation Program 2006 – 2010 was presented. As the president of the National Paediatric Rehabilitation Innovation Program phrased it: "The juggling is over, the course has been set, all hands on deck and full steam ahead!"

1.3 Outline of this thesis

This thesis describes paediatric rehabilitation care in the Netherlands with a focus on the parent perspective. Table 1.2 provides a summary of the objectives of the different studies included.

Table 1.2 Objectives of the different studies in this thesis

Chapter	Objective
2	Evaluate therapeutic motor interventions for children with cerebral palsy, review changes in the scientific quality of therapeutic intervention studies and point out trends and changes in the nature of the evaluated programs.
3	Validate the Dutch translation of the Measure of Processes of Care (MPOC), a measure of the family-centredness of services from a parent perspective.
4	Determine the one-year stability and the responsiveness to changes of the Measure of Processes of Care.
5	Validate the Dutch translation of the short Measure of Processes of Care (MPOC-20).
6	Validate the Dutch translation of the Measure of Processes of Care for Service Providers (MPOC-SP), a measure of the family-centredness of services from a service provider perspective.
7	Validate the Dutch translation of the Giving Youth a Voice Questionnaire (GYV-20), a measure of the client-centredness of services from an adolescent perspective.
8	Describe how parents experience their involvement in the paediatric rehabilitation process and determine their level of satisfaction with received services.
9	Examine whether the paediatric rehabilitation treatment activities for children with complex needs were tuned to parent identified problems and whether the treatment process was transparent for all involved.

A review study of therapeutic intervention programs for children with cerebral palsy (chapter 2) was performed to establish the best way to describe the process of care. Children with cerebral palsy represent the largest diagnose group in paediatric rehabilitation in the Netherlands¹⁵⁴ and were therefore chosen as the review subject population. We concluded that single case studies, combined with efforts to develop measures specifically for children—and families—with complex needs might make more valuable contributions to the scientific evaluation and justification of therapeutic intervention programs. These results were the framework for the remainder of our study on processes of paediatric rehabilitation care in the Netherlands.

A necessary precursor of our descriptive study was the creation of valid measurement instruments of the process of care. Chapters 3 to 7 of this thesis describe the validation of the Dutch versions of three measures of the family-centredness of services: the Measure of Processes of Care (MPOC and MPOC-20; parent perspective), the Measure of Processes of Care for Service Providers (MPOC-SP; service provider perspective), and the Giving Youth a Voice Questionnaire (GYV-20; adolescent perspective). Next, in chapter 8, the MPOC was used to measure parent satisfaction with services they and their child received. In addition, interviews with a large group of parents gave insight into how parents experience their involvement in the paediatric rehabilitation treatment process. A Quality of Care cycle, which shows how the treatment process is organized, was used to structure the results. Finally, in chapter 9, the results of an intensive observational study are presented. The aim was to examine whether the paediatric rehabilitation treatment activities of children with complex needs were tuned to parent identified problems and whether the process was transparent for all involved. A single-subject design was repeated for five school-aged, randomly selected subjects with cerebral palsy. Within a four-week time period all subjects were followed during nine regular treatment sessions (physical therapy, occupational therapy, and speech therapy, each three times), and their written reports were studied.

2

Qualitative analysis of therapeutic motor intervention programmes for children with cerebral palsy: an update

Renate C. Siebes,¹ Lex Wijnroks,¹ Adri Vermeer¹

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

This study presents a comprehensive evaluation of therapeutic motor interventions for children with or at risk for cerebral palsy (CP), examining 50 studies covering the period from 1990 to 2001. The purpose was to review noticeable changes in the scientific quality of the studies and to highlight trends and changes in the nature of the evaluated programmes. Our results were compared with those of Vermeer and Bakx²¹¹ who reviewed the period from 1980 to 1989. It was concluded that fundamental research with adequate methodology was applied more often in the study period than in the period reviewed by Vermeer and Bakx. However, these developments did not lead to a substantial improvement in the scientific foundation of the interventions under study. Single case studies, combined with efforts to develop measures specifically for children with CP and with high sensitivity, might make more valuable contributions to the scientific justification of therapeutic interventions.

2.1 Introduction

Cerebral palsy (CP) is the most common physical disability in childhood with prevalence rates ranging from 2 to 2.6 per 1000 live births in industrialized countries.^{55,69,129,155,157,189} CP can be defined as a heterogeneous group of non-progressive, but often changing, motor impairment syndromes caused by chronic brain injuries. It occurs as a result of prior perinatal events (congenital CP), or a variety of factors in the first few years of life (acquired CP).^{3,137,170} Determining motor type, distribution and severity of CP is essential for diagnosis. However, many children with the disorder have additional disabilities, such as cognitive deficits, visual, hearing, speech and language disorders, and epilepsy.

The four major subtypes of motor deficit in CP are the spastic form, the dystonic type (commonly referred to as athetoid CP), ataxia, and hypotonia, with the spastic variety being the most common. Mixed lesions combine characteristics of the spastic, dystonic, and ataxic types. Although it is generally accepted in clinical practice that the predominant motor type is identified, mixed types are now increasingly diagnosed.^{12,111,170}

Frequently used topographical classifications according to the distribution of motor involvement are hemiplegia, diplegia, and quadriplegia. True monoplegia, paraplegia, or triplegia scarcely occur, although it may appear that some children fit into these categories.¹⁷⁵ Severity is thought to be equally distributed among the mild, moderate, and severely involved categories.¹⁷⁰

Over the years several approaches to the classification of CP have been implemented and revised (e.g., Fay,⁵⁷ Minear,¹³² and Mutch *et al.*¹³⁷). Scherzer¹⁷⁰ emphasized that a modern classification of CP, which takes early developing signs and recognition of the emerging motor type into consideration, can dispel confusion regarding the diagnosis and can help provide better communication between the various professionals treating the child.

A growing range of therapeutic methods is available for managing CP in children. Neurodevelopmental treatment (NDT) as well as a number of other treatments, such as Vojta therapy, sensory integration, Temple-Fay, Rood, and Kabat can be classified as neurophysiological approaches (also referred to as neurofacilitation approaches or neuromaturational approaches) and were developed decades ago. More recently, action system approaches have provided a new way of conceptualizing motor development and control.^{84,214} Proponents of the ecological approach⁶⁴ and the dynamical systems approach^{83,200} favour the view that motor development and coordination emerge from a dynamic interaction of many subsystems in a task-specific context. Law and colleagues¹⁰⁷ and Ketelaar and coworkers⁸⁶ provide good examples of applying the action system approach.

Other frequently evaluated therapeutic methods are conductive education and bio-feedback with a central role for motor learning theories, electrical stimulation, and hippotherapy.

During the past decades several reviews of therapeutic interventions for children with or at risk for CP have been published. Table 2.1 provides an overview of reviews of such studies published between 1980 and 2001.

Twenty years ago Dunst and Rheingrover⁵¹ and Simeonsson and coworkers¹⁸⁶ both reviewed the effectiveness of interventions with infants and young children with organic impairments. They reported that all studies provided some type of documentation of outcome, but that most studies failed to meet common criteria for scientific research. Therefore, the majority of results from most of the studies could not be interpreted from a scientific point of view and did not provide sufficient evidence for the effectiveness of the interventions.

Since the publication of these two reviews, nine other review studies have been published. These studies focused on the effectiveness of NDT^{19,144,163} and other therapeutic interventions,^{22,74,149,203,207} as well as methodological aspects.^{76,211}

The overall conclusion to be drawn from these reviews is that the effectiveness and efficacy of therapeutic interventions for children with CP could not be determined owing to poor quality of research. The majority of the presented reviews report that small study groups, poor measures, difficulties with matching and the creation of control groups, and many other technical and ethical problems all contribute to the lack of experimental evidence for the efficacy and effectiveness of therapeutic intervention programmes for children with CP.

The purpose of this paper was to review possible changes in the scientific quality of therapeutic motor intervention studies on children with CP over the decade 1990 to 2001 and to highlight trends and changes in the nature of the evaluated programmes. We compared our results with those of Vermeer and Bakx,²¹¹ who reviewed the decade 1980 to 1989. This report, therefore, can be seen as an update on the scientific quality of therapeutic motor intervention research.

Table 2.1 Reviews on therapeutic intervention programs for children with or at risk for CP, 1980 – 2001

Author(s)	Year ^a	Sample ^b	n ^c	Period
Dunst and Rheingrover	1981	Interventions with organically impaired infants	49	1967 – 1980
Simeonsson <i>et al.</i>	1982	Early intervention programs for biologically impaired infants and young children	27	1975 – 1981
Hourcade and Parette	1984	Therapeutic strategies utilized with infants and young children who have cerebral palsy	18	1952 – 1982
Parette and Hourcade	1984	Therapeutic strategies utilized with infants and young children who have cerebral palsy	18	1952 – 1982
Ottenbacher <i>et al.</i>	1986	NDT used in paediatric therapy both in isolation and in combination with other developmental therapies	37	1960 – 1985
Tirosh and Rabino	1989	Physical therapy for children with cerebral palsy	9	1973 – 1988
Campbell	1990	Physical therapy in improving postural control in cerebral palsy	30	1966 – 1988
Vermeer and Bakx	1990	Intervention research literature on children with cerebral palsy	33	1978 – 1989
Royeen and DeGangi	1992	NDT-based treatment for infants, toddlers, children, and adults with neuromotor disorders	19	1980 – 1990
Turnbull	1993	Early intervention for children with or at risk for cerebral palsy	17	1973 – 1992
Hur	1995	Therapeutic interventions for children with cerebral palsy	37	1966 – 1994
Butler and Darrah	2001	NDT or NDT-based treatment for children diagnosed with cerebral palsy	16	1973 – 1997

^a Year of publication; ^b review focus; ^c number of studies in review. NDT, neurodevelopmental treatment.

2.2 Method

2.2.1 Procedure

An on-line computer search of *Index Medicus* (Medline) and *Psychological Abstracts* (PsychLIT) from January 1990 through to April 2001 using the keywords "cerebral palsy", "infantile encephalopathy", "rehabilitation", "treatment", "intervention", and "therapy" revealed 2162 hits.

The initial selection contained only original articles published in English, German, Spanish, or French in a (Social) Science Citation Index, S(S)CI, journal between January 1990 and April 2001. Participants were groups of children at risk for or diagnosed with CP and who were aged from 0 to 18 years at the start of the programme. Only studies

that used currently accepted clinically based traditional therapeutic motor intervention methods or a combination of these methods and other forms of therapy were included in the review. Adjuncts to physical therapy, such as botulinum injection therapy, intrathecal baclofen, and orthopedic devices, were not the focus of this review and were therefore excluded. In addition, articles on oral motor control (drooling, swallowing, speech and communication), surgical interventions such as rhizotomy and cerebellar implants, other pharmacotherapeutical interventions (e.g., painkillers), dental care, nutrition, acupuncture, psychotherapy, and hyperbaric oxygen therapy were excluded. Long-term follow-up studies were only included if the programme characteristics of the original study were described in sufficient detail.

After a first selection based on the abstracts, 98 non-overlapping potentially relevant articles were identified, of which 37 studies met the inclusion criteria. The other hits were letters to editors, general descriptions, parent training, or reviews.

Another 13 papers were identified by examining the reference lists of the selected articles and recent review articles^{8,19,76,163,207} and by reviewing the table of contents of 20 selected S(S)CI journals. The final 50 articles were written in English (all initial hits in German, French, and Spanish did not fulfill our inclusion criteria) and covered 49 different studies; one study was reported in more than one article.^{77,78}

2.2.2 Evaluation criteria

There are several methodological requirements that need to be met within a research programme designed to evaluate behavioural gains due to therapy. A study is considered effective when gains in target measures can be attributed to the therapy under study rather than to other causes.

The optimal design for most clinical treatment trials is the randomized controlled group trial. Alternatives are quasiexperimental designs using a control group without randomization.^{35,199}

Sellick and Over¹⁷² defined seven methodological requirements for evaluation studies, without which the results of the research are likely to be ambiguous. These requirements deal with sample size, control group prescription, definition of the population under study, assessment methods, and assessment methodology. Additionally, Sackett¹⁶⁶ summarized six rules of scientific evidence for the study of therapy.

With the above-mentioned requirements as our guideline, we formulated 15 criteria for evaluation of the studies (Table 2.2). To determine the value of the evidence available about an intervention, we applied Sackett's method for grading research¹⁶⁷ with minor modifications supported by research of the American Academy for Cerebral Palsy and Developmental Medicine.^{18,19} Table 2.3 provides an overview of Sackett's levels of evidence for grading research.

The review of Vermeer and Bakx²¹¹ was chosen as a reference base for practical and methodological reasons: we had access to the database and notes that were made dur-

Table 2.2 Evaluation criteria

Sample characteristics	Description
Size of study sample	Experimental group, control or contrast group – Not present
Age of participants	Mean, range (in months) – Unspecified
Sex of participants	M Male F Female – Sex unspecified
Medical diagnosis	++ Detailed diagnoses, type of CP specified + Limited diagnoses, only general characteristics are presented – Medical diagnosis unspecified
Psychological diagnosis	++ Detailed diagnoses + Limited diagnoses, only general characteristics are presented – Psychological diagnosis unspecified
Treatment characteristics	
Method of treatment	++ Detailed programme description + Only name or a general reference to method is stated – Method unspecified
Treatment objective	++ Clearly defined + Only a brief description of objective is presented – Treatment objective unspecified
Treatment frequency and intensity	++ Both presented + Only one of these variables has been given – Neither has been provided
Duration of treatment/programme	+ Duration specified – Duration unspecified
Methodological aspects	
Design of the study	Case, Single, Pre, Quasi (with control or contrast group, without randomization), True (with control or contrast group and randomization)
Reliability of the measures	++ Explicitly reliable: the reliability test has been published + Standardized: the measurement procedure is described – Unreliable
Internal validity: can measured effects be attributed to treatment under study?	++ High internal validity + Fair internal validity – Low internal validity Internal validity can be reduced by various study variations such as subject assignment, contamination, co-intervention and blind assessment
External validity: are results of research generalizable?	++ Generalization is plausible + Some possibilities for generalization – No information about generalization is given
Statistical evaluation	++ Detailed description of statistical methods, <i>p</i> values and <i>F</i> values are presented + Only a brief description of statistical methods is described, some values are presented – No statistical evaluation
Levels of evidence	Levels according to Sackett's method for grading research ¹⁶⁷ modified by Butler <i>et al.</i> ¹⁸ and Butler and Darrah; ¹⁹ see also Table 2.3.

–, unspecified; +, limited; ++, detailed. Pre, non-randomized trial without control participants.

Table 2.3 Levels of evidence for grading research^{18,19,167}

Level	Group research	Single individual research
I	Randomized controlled trials	$n=1$ randomized controlled trial
II	Nonrandomized controlled trials	ABABA design
	Prospective cohort studies with concurrent control group	Alternating treatments (<i>e.g.</i> , ABACA) Multiple baseline across participants
III	Case studies with control participants	ABA design
	Cohort studies with historical control group	
IV	Case series without controls	AB design
V	Case reports	Case reports
	Non-empirical methods	Non-empirical methods

ing the review process of Vermeer and Bakx but, more importantly, it was possible to establish an interrater reliability between the two reviews which was necessary for the comparison. In contrast to Vermeer and Bakx, orthopaedic research and studies that handled psychological effects were excluded from the present review. Appendices 2.A, 2.B, and 2.C present the results of the evaluation of the categories as described above.

2.3 Results

2.3.1 General characteristics

Great variability in therapies for children with CP was found in the literature. Among the 49 studies in this review, NDT, conductive education, electrical stimulation, strength training, biofeedback, hippotherapy, and saddle riding were most frequently the subject of evaluation. In addition, we found evaluation studies focusing on targeted training, physical activity, swimming programmes, Dohsa-hou (a Japanese psychorehabilitation technique), pelvic positioning, functional physical therapy, and a sibling education programme.

Of all these treatment modalities NDT, biofeedback, swimming programmes, and Vojta therapy have been of special interest during the last decades. Particularly in the last decade, we found a growing interest in functional treatment methods with a focus on daily activities (*e.g.*, functional physical therapy and conductive education), hippotherapy, electrical stimulation, and strength training. In relation to this finding, a substantial growth in the use of functional measures, such as the Gross Motor Function Measure (GMFM)¹⁶⁵ and the Pediatric Evaluation of Disability Inventory (PEDI),⁷⁰ could be observed.

The majority of the evaluated research reports provided sufficient information regarding the number, sex, and age of the participants. Group size ranged from 1 to 66 individ-

uals, but only four studies included more than 50 patients. In our study sample 57% of the participants was male. The age of participants ranged from 4 months to 21 years with a mean of 7 years. The total number of individuals in the study sample was 896.

Children with quadriplegia ($n = 239$) were the predominant participants, followed by children with hemiplegia ($n = 190$), and diplegia ($n = 186$). Of the remaining children the medical diagnosis was not specified sufficiently ($n = 281$). Most of the therapies were centre-based and carried out by a physical therapist on a one to one basis. Parent involvement was mentioned in 20 studies. The reported frequency of therapy ranged from once a week to daily sessions. The duration of the total intervention programmes ranged from only one session to more than 2 years. The duration of individual sessions ranged from 5 minutes to as long as a full school day.

The attrition rate varied from 0% to 27%, but complete data were not provided by all studies.

Of the 49 studies, 20 used control or contrast groups, and 15 used random assignment. Only six studies matched the participants and nine stratified them.

According to the levels of evidence^{18,19,167} as described in Table 2.3 and Appendix 2.C, 27% of the reviewed studies could be classified as level I. Level II evidence was provided in 39% of the studies, whereas 31% of the studies supported level IV evidence. The remaining two studies were case reports without control participants and consequently represent level V evidence.

2.3.2 Comparison between periods 1980 to 1989 and 1990 to 2001

To evaluate any noticeable changes in the scientific quality of therapeutic motor intervention research with children with CP over the past decade, the results of this review covering the period from 1990 to 2001 were compared with those of Vermeer and Bakx²¹¹ whose study is a fairly good representation of intervention research with children with CP for the period 1980 to 1989.

To compare the two periods (Table 2.4) only the 15 studies of the Vermeer and Bakx review that handled NDT and other sensori-motor methods, and 10 studies on feedback treatment and vestibular stimulation were obtained, bringing the total of studies in the sample for 1980 to 1989 to 25. The results revealed some minor differences and shifts in intervention research on children with CP between the decades 1980 to 1989 and 1990 to 2001.

The description of medical diagnoses and psychological diagnoses improved slightly. The mean number of individuals in the study sample increased by 3%. The quality of the description of treatment characteristics had not changed significantly over the years, but there was a shift in frequency, duration, and setting of the treatment. There was an increase in the intensity of treatment, especially of daily treatment. Although the majority of the studies in the sample reported total treatment duration of less than one year, there was a growing number of studies with a longer duration. There was also a shift towards

Table 2.4 Comparison of period 1980 – 1989 with 1990 – 2001^a

Variable	1980 – 1989	%	1990 – 2001	%
Sample characteristics				
Number of studies in sample	25	–	49	–
Total in sample, <i>n</i>	446	–	896	–
Mean in sample, <i>n</i>	17.8	–	18.3	–
Range <i>n</i>	1 – 100	–	1 – 66	–
Mean age <i>m</i>	Unspecified	–	87	–
Age range <i>m</i>	3 – 390	–	4 – 251	–
Medical diagnosis	–	0 0	1	2
	+	11 44	7	8
	++	14 56	41	84
Psychological diagnosis	–	17 68	20	41
	+	6 24	25	51
	++	2 8	4	8
Treatment characteristics				
Treatment objective	+	8 32	12	24
	++	17 68	37	76
Frequency/intensity	–	2 8	2	4
	+	6 24	16	33
	++	17 68	31	63
Methodological characteristics				
Studies with control/contrast group, <i>n</i>	8	32	20	41
Design	Case	1 4	5	10
	Single	13 52	15	31
	Pre	4 16	12	24
	Quasi	4 16	6	12
	True	4 16	11	22
Reliability measures	–	3 12	5	10
	+	10 40	16	33
	++	12 48	28	57
Internal validity	–	4 16	7	14
	+	18 72	24	49
	++	3 12	18	37
External validity	–	21 84	25	51
	+	4 16	12	24
	++	0 0	12	24
Statistical evaluation	–	6 23	11	23
	+	8 24	12	24
	++	11 53	26	53
Level of evidence	I	6 24	13	27
	II	2 8	19	39
	III	5 20	0	0
	IV	11 44	15	31
	V	1 4	2	4

^a See Table 2.2 for a description of the evaluation criteria. Single, case series with or without control participants; Pre, non-randomized trial without control participants; Quasi, non-randomized controlled trial; True, randomized controlled trial; –, unspecified; +, limited; ++, detailed.

home-based treatment, which could be explained partly by the growing insight into the importance of participation of parents in therapy.

The most significant improvements concerned the methodological characteristics. According to Sackett's method for grading research, a substantial trend was found towards higher levels of evidence. In the first decade, only 32% of the interventions under study could be classified as level I and level II studies, whereas 66% of the studies in the second decade received this label. In agreement with this rise, a 9% increase in the application of control groups and contrast groups was observed. The number of single case studies halved; case reports, pre-experimental and true experimental designs were applied slightly more often in our study population (6 to 8%).

Moreover, we found an increase in the reliability and validity of the measures. Finally, the internal and external validity of the evaluation studies improved significantly.

2.4 Discussion

Previous reviews on the effectiveness and efficacy of therapeutic interventions for children with CP indicated that the studies had severe methodological problems. The overall conclusion to be drawn from these reviews was that the effectiveness and efficacy of the interventions could not be determined due to poor research quality. For example, before 1973 no study employed a control group. Since then the results of studies have been inconclusive and conflicting, despite being controlled.²⁰³ Although extensive studies into therapeutic interventions with children with CP have found no objective evidence for the effectiveness and efficacy of the programmes, intervention strategies have been increasingly implemented.^{59,149,207}

In comparison with the findings of Vermeer and Bakx²¹¹ we found that research of good methodological quality had been applied more often between 1990 and 2001. However, due to a lack of positive findings, these developments did not lead to a substantial improvement in the scientific foundation of the interventions under study. Moreover, it seems that the higher the methodological quality of the study, the less the number of reported positive results.

The lack of positive results and the deficiency in design can be attributed to several factors. It is well-documented that the growth and development of children with CP are very slow, especially in those who are severely affected physically and cognitively.⁷⁶ Therefore, it would be more realistic to expect long-term rather than immediate short-term effects of intervention. In the present review, 60% of the sample were short-term studies with a duration of less than 6 months. Another 30% had a duration of 6 to 12 months. Future research should focus on long-term effects mainly.

A significant problem in studying the effects of treatment of motor problems resulting from CP is a lack of instruments sensitive enough to detect small changes in motor ability.⁶⁰ Even minor improvements have the potential to be of major practical and psy-

chological significance for children with CP and their families.¹⁰¹ Children may have made motor progress, but the instrumentation used may not have been sensitive enough to detect those changes, thereby affecting statistical significance.¹⁴⁹ Until recently only few measures were developed and compared with normative values specifically for children with CP. The older measures were mostly generic, *e.g.*, measures for children at risk, or children with motoric or developmental delays. These measures hardly focus on limitations or skills but rather on the impairments of the child, evaluating muscle tone, muscle force, postural responses, joint mobility, *etc.* Many authors have criticized the one-sidedness of these measures and have emphasized the importance of functional assessment tools in clinical practice.⁸⁴ In the past decade, several functional assessment instruments which measure the child's performance on functional daily activities, have been developed and validated specifically for children with CP, *e.g.*, the Gross Motor Function Measure (GMFM),¹⁶⁵ the Functional Independence Measure for Children (WeeFIM),¹³⁵ and the Pediatric Evaluation of Disability (PEDI).⁷⁰ For an excellent systematic literature review of functional assessment measures for children with CP, we refer to the work of Ketelaar and colleagues.⁸⁵ With respect to responsiveness to change, only two of the 17 measures described by Ketelaar and coworkers, the GMFM and the PEDI, met criteria for reliability and validity. However, the authors concluded the methodological quality of recently developed instruments had much improved compared with previously developed instruments.

Another potential assessment difficulty may arise in working with this group of children with severe impairments. For these children the maintenance of present levels of motoric functioning (*e.g.*, the avoidance of contractures) may be a reasonable goal already,¹⁴⁹ while most measures have been developed mainly to determine progress.

Physical therapy has such an established role in primary care for children with CP that studies randomly assigning participants to a control group without treatment are considered unethical by many.²⁰³ A certain basic therapy for this group of children is essential. The results, therefore, always represent the additional value of the intervention under study, and large effects cannot be expected.

Furthermore, it may be that what occurs in terms of therapy with the child is not the actual intervention, but simply a way of reaching the parents and teaching them to cope with the abilities and limitations of their child. This could partly explain the poor results of many evaluation studies.

In the past, comparatively little research has been able to assess or evaluate the efficacy of therapeutic motor intervention programmes for children with CP. In the light of the high cost of intervention programmes, the lack of adequate evaluation of their efficacy is remarkable. Nowadays the call for evidence for the efficacy and effectiveness of the programmes is becoming increasingly strong. Insurance companies have changed their policy regarding compensation for therapy costs: a scientific failure to demonstrate the beneficial effects of therapy leads to the exclusion of the costs for such therapy in the insurance policy. Financial constraints are such that it is becoming increasingly difficult

to offer a programme which does not have some scientific backing.⁷

Conducting research with children with CP is a challenging task. The heterogeneity of the population (*i.e.*, type and severity of CP) creates a high number of variables that should be controlled.²⁰³ Moreover, sample sizes are often small. A combination of high numbers of variables with small sample sizes may result in statistical problems surrounding chance capitalization.¹⁹⁹ Bower and McLellan¹⁴ suggested using a representative series of single case studies with individual goal setting and a validated outcome measurement using randomized treatment to overcome methodological difficulties especially relevant to small group studies. This approach, combined with efforts to develop measures specifically for children with CP and with a higher sensitivity, can make more valuable contributions to the scientific justification of therapeutic motor interventions. Considering this, it is remarkable that the number of single case studies halved during the past decade.

Acknowledgments

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2.A Treatment characteristics

Author(s)	Method of treatment	Treatment objective	Frequency/intensity	Duration
Bochner <i>et al.</i> ¹¹	++ Conductive Education	+	++	+
Bower and McLellan ¹³	+ Physiotherapy	+	++	+
Bower <i>et al.</i> ¹⁵	++ Physiotherapy	+	++	+
Bower <i>et al.</i> ¹⁶	++ Physiotherapy	+	++	+
Butler ²⁰	+ Targeted Training	++	++	-
Carmick ²³	++ Electrical stimulation	++	+	-
Carmick ²⁴	++ Electrical stimulation	++	+	-
Carmick ²⁵	++ Electrical stimulation	++	+	-
Catanese <i>et al.</i> ²⁷	+ Conductive Education	+	-	+
Chakerian and Larson ²⁸	++ Strength training (NDT)	++	++	+
Colborne <i>et al.</i> ³³	+ Biofeedback and physical therapy	++	+	+
Coleman <i>et al.</i> ³⁴	+ Conductive Education	+	+	+
Craft <i>et al.</i> ³⁷	++ Sibling education program (SIBS)	+	+	+
Dadkash ³⁹	++ Dohsa-hou	++	+	-
Damiano <i>et al.</i> ⁴³	++ Strength training	++	+	+
Damiano <i>et al.</i> ⁴²	++ Strength training	++	+	+
Damiano and Abel ⁴¹	++ Strength training	++	+	+
Embrey <i>et al.</i> ⁵⁴	++ NDT	++	++	+
Fetters and Kluzik ⁶⁰	++ NDT and practice	++	++	+
Hartveld and Hegarty ⁷¹	++ Feedback	++	++	+
Hazlewood <i>et al.</i> ⁷²	++ Electrical stimulation	++	++	+
Horn <i>et al.</i> ⁷³	++ Neurobehavioral motor intervention	++	++	+
Hutzler <i>et al.</i> ^{77,78}	+ Movement and swimming program	+	++	+
Jonsdottir <i>et al.</i> ⁸²	++ NDT and practice	++	++	+
Ketelaar <i>et al.</i> ⁸⁶	++ Functional physical therapy	+	+	+
Kluzik <i>et al.</i> ⁹⁹	++ NDT	++	++	+
Kramer <i>et al.</i> ¹⁰¹	++ Biofeedback	++	++	+
Kuczyński and Slonka ¹⁰²	+ Artificial saddle riding	++	+	+
Law <i>et al.</i> ¹⁰⁶	+ NDT	++	++	+
Law <i>et al.</i> ¹⁰⁹	++ NDT	++	+	+
Lilly and Powell ¹¹³	++ NDT	+	++	+
MacKinnon <i>et al.</i> ¹¹⁷	++ Hippotherapy	++	++	+
MacPhail and Kramer ¹¹⁸	++ Strength training	++	++	+
Mayo ¹²¹	++ NDT	+	+	+
McCormack ¹²³	++ Pelvic positioning	++	++	+
McGibbon <i>et al.</i> ¹²⁴	++ Horseback riding	++	++	+
Metherall <i>et al.</i> ¹³¹	++ Biofeedback	++	++	+
O'Dwyer <i>et al.</i> ¹⁴²	++ Feedback	++	++	+
Palmer <i>et al.</i> ¹⁴⁷	+ NDT	++	+	+
Pape <i>et al.</i> ¹⁴⁸	++ Electrical stimulation	++	++	+
Quint and Toomey ¹⁵⁰	++ Saddle riding	++	++	+
Reddihough <i>et al.</i> ¹⁵²	++ Conductive Education	+	+	+
Reid ¹⁵³	++ Saddle seat	++	-	+
Rintala <i>et al.</i> ¹⁵⁶	++ Physical activity program	++	++	+
Scheker <i>et al.</i> ¹⁶⁸	++ Electrical stimulation	++	++	+
Schindl <i>et al.</i> ¹⁷¹	++ Strength training	++	++	+
Toner <i>et al.</i> ²⁰⁴	++ Biofeedback	++	++	+
Valvano and Newell ²⁰⁸	+ Feedback	++	++	+
Wright and Granat ²¹⁸	++ Electrical stimulation	++	++	+

-, unspecified; +, limited; ++, detailed. NDT, neurodevelopmental treatment.

2.B Sample characteristics

Author(s)	Total n	Exp. n	Control/ contrast n	Mean age	Age range	Sex		Medical diagnosis	Psychological diagnosis
						M	F		
Bochner et al. ¹¹	7	7	—	49	36–83	5	2	+	—
Bower and McLellan ¹³	7	7	—	93	24–150	4	3	++	+
Bower et al. ¹⁵	44	22	22	69	36–143	—	—	++	—
Bower et al. ¹⁶	56	28	28	69	36–150	31	25	++	—
Butler ²⁰	6	6	—	55	29–89	4	2	++	—
Carmick ²³	3	3	—	73	19–120	3	—	++	—
Carmick ²⁴	2	2	—	50	19–80	2	—	++	—
Carmick ²⁵	4	4	—	44	33–56	3	1	++	—
Catanese et al. ²⁷	34	17	17	—	48–85	18	16	+	+
Chakerian and Larson ²⁸	10	10	—	58	18–87	—	—	++	—
Colborne et al. ³³	7	7	—	127	96–186	4	3	++	—
Coleman et al. ³⁴	20	11	9	45	19–69	10	10	++	—
Craft et al. ³⁷	15	15	—	123	48–234	8	7	++	—
Dadkash ³⁹	7	7	—	127	96–174	7	—	++	—
Damiano et al. ⁴³	39	14	25	104	42–168	25	14	++	—
Damiano et al. ⁴²	14	14	—	109	72–174	10	4	++	—
Damiano and Abel ⁴¹	11	11	—	104	72–155	—	—	++	—
Embrey et al. ⁵⁴	1	1	—	32	32	—	1	++	—
Fettors and Kluzik ⁶⁰	8	8	—	155	120–186	6	2	++	+
Hartveld and Hegarty ⁷¹	4	4	—	123	60–203	2	2	++	+
Hazlewood et al. ⁷²	20	10	10	72	66–141	15	5	++	+
Horn et al. ⁷³	4	4	—	27	21–34	3	1	++	++
Hutzler et al. ^{77,78}	46	23	23	68	60–95	32	14	++	—
Jonsdottir et al. ⁸²	8	8	—	155	120–186	6	2	++	+
Ketelaar et al. ⁸⁶	55	28	27	55	24–95	33	22	++	+
Kluzik et al. ⁹⁹	5	5	—	110	84–155	2	3	++	+
Kramer et al. ¹⁰¹	8	4	4	84	60–126	2	6	+	+
Kuczynsky and Slonka ¹⁰²	58	25	32	75	36–131	21	37	++	—
Law et al. ¹⁰⁶	36 ^a	18	18	—	18–104	15	21	++	+
Law et al. ¹⁰⁹	50	26+24 ^d	—	33	18–48	22	28	++	+
Lilly and Powell ¹¹³	2	2	—	30	27–32	—	2	++	+
MacKinnon et al. ¹¹⁷	19	10	9	77	48–155	9	10	+	++
MacPhail and Kramer ¹¹⁸	17	17	—	189	144–251	7	10	++	+
Mayo ¹²¹	29	17	12	11	4–18	—	—	++	++
McCormack ¹²³	1	1	—	102	102	1	—	++	+
McCibbon et al. ¹²⁴	5	5	—	114	108–143	3	2	++	+
Metherall et al. ¹³¹	1	1	—	174	174	—	1	++	—

Author(s)	Total n	Exp. n	Control/ contrast n	Mean age	Age range	Sex		Medical diagnosis	Psychological diagnosis
						M	F		
O'Dwyer et al. ¹⁴²	15	8	7	—	72 – 234	—	—	—	+
Palmer et al. ¹⁴⁷	48	25	23	15	12 – 19	36	12	+	++
Pape et al. ¹⁴⁸	5	5	35	51	3 ^e – 58	2	3	++	+
Quint and Toomey ¹⁵⁰	26	13	13	—	84 – 203	—	—	—	—
Reddihough et al. ¹⁵²	66	17 ^b 15 ^c	17 ^b 17 ^c	23	12 – 36	41	25	++	+
Reid ¹⁵³	6	6	—	72	50 – 105	5	1	++	—
Rintala et al. ¹⁵⁶	8	8	—	126	84 – 138	5	3	++	+
Scheker et al. ¹⁶⁸	19	19	—	123	40 – 251	10	9	++	+
Schindl et al. ¹⁷¹	10	10	—	138	72 – 227	4	6	++	+
Toner et al. ²⁰⁴	6	6	—	—	48 – 90	3	3	++	+
Valvano and Newell ²⁰⁸	16	8	8	123	95 – 148 ^f	—	—	++	+
Wright and Granat ²¹⁸	8	8	—	126	—	5	3	++	+

^a Casting excluded; ^b randomized group; ^c non-randomized group; ^d cross over design with washout period; ^e healthy siblings (reliability check: Peabody Developmental Motor Scale); ^f CP group. —, unspecified; +, limited; ++, detailed. Ages are in months.

2.C Methodological aspects

Author(s)	Design	Reliability measures	Internal validity	External validity	Statistical evaluation	Level of evidence ^a
Bochner <i>et al.</i> ¹¹	Single	+	+	-	-	IV
Bower and McLellan ¹³	Single	++	+	-	-	IV
Bower <i>et al.</i> ¹⁵	True	++	++	++	++	I
Bower <i>et al.</i> ¹⁶	True	++	++	++	++	I
Butler ²⁰	Case	+	+	-	-	IV
Carmick ²³	Case	+	+	-	-	IV
Carmick ²⁴	Case	-	+	-	-	IV
Carmick ²⁵	Case	-	+	-	-	IV
Catanese <i>et al.</i> ²⁷	Quasi	++	++	++	++	II
Chakerian and Larson ²⁸	Pre	+	+	-	++	II
Colborne <i>et al.</i> ³³	Pre	++	+	+	+	II
Coleman <i>et al.</i> ³⁴	Quasi	++	++	++	++	II
Craft <i>et al.</i> ³⁷	Pre	+	-	+	+	II
Dadkah ³⁹	Pre	+	-	-	++	II
Damiano <i>et al.</i> ⁴³	Pre	++	++	-	++	II
Damiano <i>et al.</i> ⁴²	Pre	++	-	-	++	II
Damiano and Abel ⁴¹	Single	++	+	-	++	IV
Embrey <i>et al.</i> ⁵⁴	Single	+	++	-	-	II
Fetters and Kluzik ⁶⁰	Pre	++	+	-	++	II
Hartveld and Hegarty ⁷¹	Single	+	-	-	-	IV
Hazlewood <i>et al.</i> ⁷²	True	+	++	++	+	I
Horn <i>et al.</i> ⁷³	Single	+	+	-	-	IV
Hutzler <i>et al.</i> ^{77,78}	Quasi	++	+	++	++	II
Jonsdottir <i>et al.</i> ⁸²	Pre	+	++	-	+	II
Ketelaar <i>et al.</i> ⁸⁶	True	++	++	++	++	I
Kluzik <i>et al.</i> ⁹⁹	Single	++	+	-	++	IV
Kramer <i>et al.</i> ¹⁰¹	Pre	++	++	-	+	I
Kuczyński and Slonka ¹⁰²	Quasi	+	+	++	+	II
Law <i>et al.</i> ¹⁰⁶	True	++	++	++	++	I
Law <i>et al.</i> ¹⁰⁹	True	++	++	+	++	I
Lilly and Powell ¹¹³	Single	-	+	-	++	II
MacKinnon <i>et al.</i> ¹¹⁷	True	++	++	++	+	I
MacPhail and Kramer ¹¹⁸	Pre	++	+	+	++	II
Mayo ¹²¹	True	++	++	++	++	I
McCormack ¹²³	Single	++	+	-	++	V
McGibbon <i>et al.</i> ¹²⁴	Single	++	-	-	++	IV
Metherall <i>et al.</i> ¹³¹	Case	+	+	-	+	V
O'Dwyer <i>et al.</i> ¹⁴²	True	++	++	+	++	I
Palmer <i>et al.</i> ¹⁴⁷	True	++	++	+	++	I
Pape <i>et al.</i> ¹⁴⁸	Single	++	+	+	+	II
Quint and Toomey ¹⁵⁰	Quasi	+	++	+	+	I
Reddiough <i>et al.</i> ¹⁵²	True	++	++	++	++	I
Reid ¹⁵³	Pre	++	+	+	++	II
Rintala <i>et al.</i> ¹⁵⁶	Single	-	+	-	-	IV
Scheker <i>et al.</i> ¹⁶⁸	Single	-	-	-	-	IV
Schindl <i>et al.</i> ¹⁷¹	Pre	+	+	+	+	II
Toner <i>et al.</i> ²⁰⁴	Single	++	+	-	+	IV
Valvano and Newell ²⁰⁸	Quasi	++	+	+	++	II
Wright and Granat ²¹⁸	Single	+	-	+	++	IV

^a Lower numbers indicate higher quality.^{18,19,167} Single, case series with or without control participants; Pre, non-randomized trial without control participants; Quasi, non-randomized controlled trial; True, randomized controlled trial. -, unspecified; +, limited; ++, detailed.

3

The Measure of Processes of Care (MPOC): validation of the Dutch translation

Petra E.M. van Schie,¹ Renate C. Siebes,²
Marjolijn Ketelaar,^{3,4} Adri Vermeer²

¹VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands;

²Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ³Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands; ⁴University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Aim: The objective was to validate the Dutch translation of the Canadian Measure of Processes of Care (MPOC) questionnaire for use in paediatric rehabilitation centres in the Netherlands. The MPOC consists of 56 items (assessing five domains) and was designed to find out what parents of children with chronic health problems think of the services they and their child receive and to measure the extent to which these services are family-centred.

Methods: The Canadian validation procedures were followed, consisting of construct and concurrent validation and reliability analyses. Participants were parents of 427 children aged 1 – 18 years recruited through nine paediatric rehabilitation centres in the Netherlands.

Results: The construct validity of the Dutch translation of the MPOC (MPOC-NL) was examined with confirmative analyses of the scale structure. These analyses all supported the construct validity of the MPOC-NL. The MPOC-NL showed adequate internal consistency, with Cronbach's α ranging from .80 to .95. The intraclass correlation coefficients (ICCs) ranged from .79 to .94, which demonstrated good stability of the MPOC-NL. The Spearman correlations between MPOC-NL scores and satisfaction questions ranged from .39 to .73, and thus supported the construct validity of the MPOC-NL. Correlations between MPOC-NL scores and a question about parents' stress in relation to services received were moderately negative ($r_s = -.28$ to $-.39$).

Conclusion: The construct and concurrent validity of the MPOC-NL was shown by confirmative analyses of the original Canadian scale structure, and by modest Spearman correlations between MPOC-NL scores and satisfaction and stress variables. The MPOC-NL is internally consistent and reliable.

3.1 Introduction

Family-centred service describes a philosophy or approach to providing services for children and their families. In the broadest sense, family-centred care means welcoming the family as partners in the care of the child. Keywords are partnership, supportive and respectful treatment, and information exchange.^{92,94,161} Truly family-centred services foster the development of an equal partnership between parents and health care professionals that is beneficial to the child. They respond in a collaborative way to each family's individual and changing self-identified needs. The partners share common goals, mutual respect and responsibility for outcomes.^{36,50}

The history of family-centred care starts during the late 1970s, when a shift was made from a professionally dominated services model towards new methods of caring for hospitalized children to make health care providers more aware and responsive to the needs of children in hospitals and their families. The key elements of family-centred care according to Johnson and colleagues⁸¹ are outlined in Table 3.1. This focus is consistent with the demands of international disability movements and the UN standard rules for disability.¹⁰⁴ Although family-centred service has been discussed extensively in literature

and, over the years, has become the standard among health care professionals, many still have difficulty implementing the model. Shelton¹⁷⁴ (p. 118) describes this ongoing process as "... our journey toward articulating how family-centred care can be translated into practice."

Table 3.1 Key elements of family-centred care⁸¹ (p. 3)

1	Recognizing that the family is the constant in a child's life, whereas the service systems and personnel within those systems fluctuate
2	Facilitating family/professional collaboration at all levels of health care
3	Honouring the racial, ethnic, cultural, and socioeconomic diversity of families
4	Recognizing family strengths and individuality and respecting different methods of coping
5	Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information
6	Encouraging and facilitating family-to-family support and networking
7	Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care systems
8	Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families
9	Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs

Along with the broader implementation of family-centred care, laws and regulations have adapted to the changing relationships between parents and health care providers. For instance, in the Netherlands parents can choose from a wide range of services, either paid for directly by insurance companies, or out of a personal budget of the child that is managed by the parents. The personal budget allows parents to arrange and purchase the support the child needs in the broadest sense, which can be other support than the existing facilities offer. Furthermore, in clinical practice parents formulate their needs for services in a newly developed and implemented tool for planning programmes, the *Rehabilitation Activities Profile for Children* (Children's RAP).¹⁵⁸

In the Netherlands quality of care and parental participation in the process of rehabilitation are main topics as well in rehabilitation research as in quality management. A valid measure to ask parents for their opinion about the quality and the family-centredness of care provided by paediatric rehabilitation centres was not yet available in Dutch. In a literature search for a measure to evaluate family-centredness of rehabilitation care, the Measure of Processes of Care (MPOC)⁹⁰ was found. The MPOC consists of 56 items (assessing five domains) and was designed to find out what parents of children with chronic health problems think of the services they and their child receive and to measure the extent to which these services are family-centred.

For several reasons it was preferable to use this existing instrument in stead of developing a new measure. When an instrument is used in another language or culture other than it was originally developed in, its psychometric properties must be examined

again.⁶⁷ Therefore, the original Anglophone MPOC was translated into Dutch and the validity and reliability of this Dutch translation (MPOC-NL) were assessed following the Canadian validation study. In this way the two versions of the MPOC could be compared and similarities and differences could be discussed.

The main objective of this study was to examine the psychometric qualities, *i.e.*, the construct and concurrent validity, internal consistency and reliability of the MPOC-NL. For construct validity, the following research hypotheses were formulated: (1) The MPOC-NL has a comparable multidimensional structure as the original Canadian MPOC;⁹⁰ (2) The internal consistency of the MPOC-NL is good (Cronbach's α is between .70 and .90). For concurrent validity, the following research hypotheses were formulated: (3) MPOC-NL scale scores correlate positively with satisfaction as measured by the Client Satisfaction Questionnaire (CSQ);¹⁰³ (4) MPOC-NL scale scores correlate negatively with parent's perception of the amount of stress related to their child's rehabilitation process experienced in the past year; and (5) MPOC-NL scale scores correlate positively with parent's ratings of overall satisfaction with care provided by their rehabilitation centre. Additionally, the test-retest reliability of the MPOC-NL was examined.

3.2 Methods

3.2.1 Participants

A convenience sample of parents of children aged 1 – 18 with various diagnoses was recruited through nine paediatric rehabilitation centres in the Netherlands. The sample size was based on general guidelines requiring 5 – 10 subjects per variable or item in order to conduct the planned analyses.^{140,141} Because the MPOC has 56 items, a sample of between 280 and 560 subjects was appropriate.

Participants for the validation study were recruited en masse in response to a letter of introduction from the research group along with a letter of endorsement from the rehabilitation centre. Out of 1441 families of the initial mailing, 596 families consisting of 996 parents consented to participate in the study. These parents were mailed an MPOC-NL, a CSQ, a general questionnaire including one question to measure stress and a question to measure overall satisfaction, and a stamped return envelope. After the initial letter, two reminders were sent. All questionnaires were coded with a number, and confidentiality was guaranteed for all answers.

Of the 596 families who intended to participate, 427 (71.6%), consisting of 679 parents, returned usable questionnaires. Analysis of the reasons for not responding revealed that the majority of the families that did not return the questionnaires after intention to participate, had had no significant contacts with the rehabilitation centre over the past year. To maintain independence of cases, data of the parent who more actively attended the child's treatment programme were selected for the analyses when both parents in a family responded. Data analysis was therefore executed with data of 405 mothers and 22

fathers.

The demographic characteristics of the families and children in this study are outlined in Table 3.2 and Table 3.3, respectively. Most of the participants (89.8%) were from two-parent families, and most (94.8%) were mothers of which the majority had had high school education. The ages of the children whose parents participated in this study ranged from 1 to 18 years, with a mean of 7.9 ($sd = 4.7$) years. Most children (79.2%) were less than 13 years of age, and 60.3% were boys. A wide range of chronic, mostly neurodevelopmental, disorders were represented. Sixty-six percent of the children had more than one health or developmental problem. Just more than two-thirds (67.2%) received two or more of the major developmental therapies (*i.e.*, occupational, physical or speech therapy). On average, the children had received rehabilitation services for 4.0 ($sd = 3.6$) years. The Dutch study sample characteristics were comparable to those of the Canadian study sample.

Table 3.2 Demographic characteristics of respondents ($n = 427$): family and respondent variables

Identity of respondent	%	Family income	%
Natural mother	94.8	<€24.500	20.8
Natural father	5.2	€24.500 (modal)	14.5
		€24.500–€49.000	33.0
Family type	%	>€49.000	17.6
Single-parent family	10.1	Missing	14.1
Two-parent family	88.8	Number of children at home	%
Missing	1.1	1 child	22.5
Nationality	%	2 children	42.4
Dutch	90.2	3 children	24.6
Other	9.8	> 3 children	9.3
		Missing	1.2
Respondent's educational level	%		
Some high school	1.2		
Completed high school	34.4		
Completed college/technical training	58.7		
Completed university	5.6		

Percentages may not add to 100.0% due to rounding to one decimal place.

3.2.2 Instruments

3.2.2.1 Measure of Processes of Care

The MPOC is a 56-item questionnaire designed to find out what parents of children with chronic health problems think of the services they and their child receive and how these

Table 3.3 Demographic characteristics of respondents ($n = 427$): child variables

Age (year)	%	Number of health or development problems	%
< 2	1.4	1 problem	33.7
2 – 5	37.7	2 or 3 problems	38.9
5 – 12	40.1	≥ 4 problems	27.4
12 – 16	15.5		
≥ 16	5.3	Ambulatory status	%
Gender	%	Walks without aid, no problems at all	27.6
Male	60.3	Walks without aid, difficulty with jumping and running	23.4
Female	39.7	Always uses walking aid	6.8
		Walks with difficulty, uses wheelchair most of the time	11.0
		Always uses wheelchair	25.5
Length of time using centre	%	Still too young to walk	3.5
< 1 years	11.4	Missing	2.1
1 – 2 years	23.3		
2 – 5 years	33.7	Types of service/therapy received	%
≥ 5 years	31.6	Physical therapy	82.7
Main diagnosis	%	Occupational therapy	63.2
Cerebral palsy	31.4	Speech-language therapy	45.0
Muscle disorder	11.5	Behavioural therapy	11.7
Spina bifida/hydrocephalus	7.5	Psychological services	8.2
Syndrome	7.3	Social work	10.8
Sensomotor disorder	7.0	Number of services or therapies received	%
Acquired brain injury	5.2	1 service/therapy only	24.6
Behavioural disorder	3.3	2 services/therapies	28.2
Other disabilities	10.8	3 services/therapies	37.1
Diagnosis not known	4.2	≥ 4 services/therapies	1.9
Missing	11.9	No therapy at this moment	8.1

Percentages may not add to 100.0% due to rounding to one decimal place.

services affect psychosocial outcome. The MPOC was developed initially for use in a research programme focusing on the relationship between caregiving for children with disabilities and their families and parental psychosocial well-being. The MPOC can be used for clinical evaluation, research purposes and quality assurance.⁹⁰

Each item is presented as a question "To what extent do the people who work with your child... ", followed by an item describing a specific action or behaviour of health care professionals or rehabilitation centre staff. The final 11 questions of the MPOC ask about the centre where the child receives services, rather than about professionals in the team. The instructions ask parents to think back over the past year and choose from one of the seven response options to "indicate how much this event or situation happens to you". Three of the response options are labelled: a value of 1 corresponds with "never", 4 with "sometimes" and 7 with "to a great extent". A "not applicable" category is also included. The phrasing of the questions and response options was selected to capture both the quantitative and qualitative nature of parents' experiences rather than a mere

frequency count of occurrences. Each of the items is included in one of five scales: (1) *Enabling and Partnership* (16 items); (2) *Providing General Information* (nine items); (3) *Providing Specific Information about the Child* (five items); (4) *Coordinated and Comprehensive Care for Child and Family* (17 items); and (5) *Respectful and Supportive Care* (nine items). An MPOC scale score is calculated as the mean of the ratings for the items in the scale. As items are not weighted, a scale score can range from 1.00 to 7.00. The MPOC was developed as a discriminative measure to discern differences in parents' perceptions of service delivery and has sound psychometric properties. The participation of close to 2000 Canadian parents in various stages of the development of the MPOC, assures that aspects of care and services that are most important to parents are captured.⁹⁰

The original Canadian MPOC⁹⁰ was translated independently into Dutch by two separate individuals. The consensus version of the questionnaire was then back-translated into English by a professional translator. After some minor adjustments the research version of the MPOC-NL was approved by the *CanChild* research group. The Gunning Fog Index⁶⁸ was used to assess the level of reading difficulty of the MPOC-NL. According to the authors of this index the average person reads at the level 9 (9 – 12 is rated high school level), and anything above the level 17 is difficult for university students. The MPOC-NL was rated at level 12, which stands for fairly difficult to read. To lower the reading level, some minor adjustments were made in the instructions how to complete the questionnaire during the process.

3.2.2.2 Questions about satisfaction and stress

General satisfaction was measured with the CSQ.¹⁰³ The CSQ consists of eight items and yields a summed score of global satisfaction with care and services received. Each CSQ item has a four-point scale. The CSQ has demonstrated high internal consistency (Cronbach's $\alpha = .93$), and the authors report evidence of adequate validity. In addition, overall satisfaction was measured with a question in a general questionnaire about overall satisfaction (answer on a 10-point scale, like in the Dutch school system). Stress is measured with the same question as was used in the Canadian validation study, *i.e.*, "... the degree to which caregiving by the centre has affected the amount of stress and worry you experienced in caring for your child (in the past year or less)". The five response options range from "considerably reduced my stress and worry" to "considerably increased my stress and worry".

3.2.3 Statistics

The construct validity of the MPOC-NL was examined with confirmative analyses of the scale structure. In order to confirm the scale structure of the MPOC-NL, items must correlate significantly with the scales to which they belong. Furthermore, these correlations should be stronger than the correlations between the items and scales to which the items

do not belong. The Spearman rank correlation coefficient (r_s) was used to analyse the correlation between an item score and its scale score without that item and other scale scores, and Pearson's product-moment correlation coefficient (r) for correlations between the scales. In addition, a rotated varimax factor analysis with an a priori interest in five factors was conducted to confirm the five factor structure of the MPOC-NL.

For each of the five scales Cronbach's α was calculated as a measure of internal consistency. Alphas between .70 and .90 are generally considered good and indicate the items in that scale measure about the same aspect. Higher alphas may indicate a high level of item redundancy, which means several items ask the same question in a slightly different way.¹⁹⁶

Concurrent validity was analysed using Spearman's rank correlation coefficient for the correlations between MPOC-NL scale scores and the total score on the CSQ, and between MPOC-NL scale scores and questions about stress and overall satisfaction. Correlations above .30 are generally considered good in the psychological and measurement literature.⁹³

The test-retest reliability of the scales was determined using intraclass correlation coefficients (ICCs).¹⁷⁶ ICC values above .80 represent a good reproducibility and are generally found acceptable for clinical work.^{38,187} To examine the stability over time 39 parents who participated in the validation study were asked to complete an MPOC-NL again three weeks later. It was thought unlikely that parents could recall their responses on the 56 items three weeks later, and it was not expected that new experiences with health care professionals during these three weeks would greatly influence parents' responses.

3.3 Results

3.3.1 Construct validity

The construct validity of the MPOC-NL was assessed with confirmative analyses of the scale structure. Firstly, the 56 MPOC-NL items were correlated with their own and the other four scale scores after omission of the item under study using Spearman's rank correlation coefficient. With r_s ranging from .64 (item 47 with *Respectful and Supportive Care*) to .86 (item 54 with *Providing General Information*), all items correlated best and significantly ($p < .001$) with their own scale score. Secondly, the correlation between the MPOC-NL scales was calculated using Pearson's product-moment correlation coefficient. The correlation between the five scales is shown in Table 3.4. All scales correlated significantly with any of the other scales ($p < .001$). With r ranging from .50 to .92 the Pearson correlations were good. Finally, the MPOC-NL data were analysed using a rotated varimax factor analysis. Nine factors with eigenvalues of at least 1.0 were identified, accounting for 73.0% of the variance. Our a priori interest in five factors, like the Canadian MPOC, was extracted by oblique rotation. This solution accounted for 64.4% of the variance. Although it was expected that the Dutch factors would be approximately

the same as the Canadian factors, they differ partly. Twenty-five items loaded highest in the original Canadian factors. The remaining 31 items were placed in a different factor. Items in the factors *Enabling and Partnership* and *Respectful and Supportive Care* seemed to be inter-exchangeable, whereas *Providing General Information* remained unaltered.

Table 3.4 Correlation between the MPOC-NL scales using Pearson's product-moment correlation coefficient (r)

Scale	EP	PGI	PSI	CCC	RS
Enabling and Partnership (EP)	1	.51	.72	.92	.87
Providing General Information (PGI)		1	.53	.54	.50
Providing Specific Information about the Child (PSI)			1	.71	.65
Coordinated and Comprehensive Care for Child and Family (CCC)				1	.89
Respectful and Supportive Care (RS)					1

All correlations with $p < .001$.

3.3.2 Internal consistency

Table 3.5 presents the results of the internal consistency analysis. Cronbach's α was calculated for each of the five scales. The results demonstrated adequate internal consistency for each scale with a ranging from .80 (*Providing Specific Information about the Child*) to .95 (*Enabling and Partnership* and *Coordinated and Comprehensive Care for Child and Family*). With four out of five scales exceeding the recommendation of Streiner and Norman¹⁹⁶ of Cronbach's α between .70 and .90, the numbers may indicate a high level of similarity among the items, and plead for a reduction of these scales. The internal consistency analyses also supported the construct validity of the five scales, because they indicated that the items within each factor group together in a statistical as well as a clinically meaningful way.

Table 3.5 Mean scale scores and internal consistency

Scale	n_i	m	sd	n_s	α
Enabling and Partnership	16	5.43	1.12	279	.95
Providing General Information	9	3.71	1.58	280	.92
Providing Specific Information about the Child	5	5.39	1.21	315	.80
Coordinated and Comprehensive Care for Child and Family	17	5.41	1.10	257	.95
Respectful and Supportive Care	9	5.66	1.00	325	.90

n_i , number of items; m , mean scale scores; sd , standard deviation; n_s , number of subjects; Cronbach's α , internal consistency.

3.3.3 Concurrent validity

The concurrent validity of the MPOC-NL was examined using Spearman rank correlation coefficients for the correlations between MPOC-NL scale scores and the total score on the CSQ, and between MPOC-NL scale scores and questions about stress and overall satisfaction. The Spearman correlations between MPOC-NL scale scores and the total score on the CSQ ranged from .39 to .73 ($p < .001$). Correlations between MPOC-NL scale scores and the questions about overall satisfaction ranged from .41 to .72 ($p < .001$) for the 10-point grade (see Table 3.6). These findings are in the right direction, and consistent with the work of King and colleagues,⁹⁰ but not so strong as to make the MPOC-NL redundant. By being modest, rather than very high, the correlations suggest a related, but somewhat different issue is being measured by the MPOC-NL. With King and colleagues we therefore conclude that these correlations are also evidence of the construct validity of the MPOC and MPOC-NL.

Table 3.6 Association between the MPOC-NL scale scores and satisfaction variables

Scale	n_s	r_s CSQ	n_s	r_s OS
Enabling and Partnership	422	.73	409	.69
Providing General Information	416	.39	403	.41
Providing Specific Information about the Child	418	.56	407	.54
Coordinated and Comprehensive Care for Child and Family	422	.72	409	.72
Respectful and Supportive Care	422	.68	409	.67

n_s , number of subjects; r_s , Spearman rank correlation coefficient; CSQ, Client Satisfaction Questionnaire; OS, overall satisfaction (10-point scale). All correlations with $p < .001$.

A single question about stress was used to examine the relation between care provided by the centre and stress. The Spearman correlations between stress and all MPOC-NL scale scores were statistically significant ($-.28$ to $-.39$; $p < .001$) and in the expected direction.

3.3.4 Reliability

The test-retest reliability of the MPOC-NL was analysed using ICCs.¹⁷⁶ Complete and usable data were obtained from 33 parents. The mean time interval between the first and second administration was 24.8 ($sd = 9.39$) days, with a median of 22 days and a range of 12 – 50 days. The ICCs ranged from .79 (*Providing General Information*) to .94 (*Enabling and Partnership*), which demonstrated good stability of the MPOC-NL.

3.4 Discussion

Like the Canadian MPOC, the MPOC-NL is psychometrically strong, with good evidence of construct validity with a sound confirmation of the scale structure, internal consistency and good reliabilities. The main Dutch study sample characteristics were comparable to those of the Canadian study. Therefore, the base of both validity studies was similar. Furthermore, most results of the Canadian and Dutch study were comparable (see Table 3.7), which suggests that Canadian parents and Dutch parents have similar ideals and opinions.

Table 3.7 Comparison of Dutch (D) and Canadian (C) results

Scale	α		ICC		r CSQ		r_s stress	
	D ¹	C ²	D ³	C ⁴	D ¹	C ²	D ¹	C ²
EP	.95	.96	.94	.88	.73	.64	-.38	-.50
PGI	.92	.93	.79	.80	.40	.40	-.28	-.43
PSI	.80	.82	.85	.86	.55	.43	-.31	-.28
CCC	.95	.96	.88	.78	.73	.61	-.39	-.44
RS	.90	.92	.90	.84	.71	.52	-.39	-.43

¹Dutch validity study ($n = 423$). ²Canadian field testing study ($n = 151$). ³Dutch test-retest reliability study ($n = 33$). ⁴Canadian test-retest reliability study ($n = 29$). EP, Enabling and Partnership; PGI, Providing General Information; PSI, Providing Specific Information about the Child; CCC, Coordinated and Comprehensive Care for Child and Family; RS, Respectful and Supportive Care; Cronbach's α , internal consistency; ICC, intraclass correlation coefficient; r , Pearson product-moment correlation coefficient; r_s , Spearman rank correlation coefficient; CSQ, Client Satisfaction Questionnaire. All correlations with $p < .001$.

The factor analysis that was performed in the present study, revealed both differences and similarities in the distribution of items in the Dutch and the Canadian study. Regarding the outcome of this factor analysis some remarks must be made. For one thing, the starting points of the Canadian and the Dutch factor analyses were different. King and colleagues^{90,91} performed the analysis to reduce their 92-item MPOC. The product of the analyses was the 56-item MPOC that was used in the Dutch validation study. The factor analysis in the MPOC-NL study was exploratory and performed to confirm the factor structure of the MPOC once again, and done with 56 items in stead of 92. Nevertheless, it seemed that different clusters of items group together in the Dutch translation of the MPOC. Given the high proportion of variance that was accounted for by the first factor (48.77%; 48.37% in the MPOC-NL study), McConachie and Logan¹²² argue it is probably best to repeat the factor analysis in any new situation of use of the MPOC. However, revision of the factor structure that was found in the Canadian study should be made with great caution. In the Dutch validation study all other analyses strongly confirmed the

original factor structure. Therefore, in this case it was not evident to adopt another factor structure.

The MPOC was developed initially for use in a research programme focusing on the relationship between caregiving for children with disabilities and their families and parental psychosocial well-being. Although the MPOC was developed as a measure to ask parents about their experiences with concrete situations and actions by health care professionals, and not as a measure of parent's satisfaction as such, literature reports strong associations between aspects of caregiving and satisfaction, and it seems that respectful and supportive care may be associated with reduced stress.⁹¹ In another study by King and colleagues,⁸⁸ structural equation modelling showed significant pathways between more family-centred caregiving and three parental outcomes: more satisfaction with services, less stress and better emotional well-being. Therefore, using the MPOC as a quality assurance instrument with a focus on parent's satisfaction seems evident.

The MPOC was originally developed for use in paediatric rehabilitation centres, but the items are general enough for application of the MPOC in other settings, such as children's medical centres or private physical therapy practices. When done, additional field testing is required. Bjerre and colleagues,¹⁰ for example, validated the original MPOC-56 for the Swedish context, whereas their fellow-countrymen Granat and colleagues⁶⁶ adapted the MPOC-56 into a 28-item version for use as a national instrument for evaluation of parental participation in Sweden. Their MPOC-28 was found to be a useful analytical tool for comparisons over time and for measuring changes in parent's overall level of satisfaction with the habilitation services they received. McConachie and Logan¹²² examined the usefulness of the MPOC for the evaluation of the wide variety of services for children with disabilities and their families in the UK. They found evidence of the discriminating potential of the MPOC, and concluded the MPOC can be used as a measure of outcome for child disability services of differing organizational structures. In another study Swaine and colleagues¹⁹⁸ concluded the MPOC is an informative and applicable tool for use with parents of children hospitalized for a severe head injury in the acute setting.

In using the MPOC-NL in rehabilitation centres in the Netherlands, some practical problems arose and, therefore, some adjustments are made or suggested.

Firstly, a scale score does not correct for the value parents attribute to certain behaviours. When a value of 1 is scored, the mean scale score is lowered, whether the parent values this behaviour highly, or not at all. For example, a contact frequency of two visits to the paediatric rehabilitation centre per year brings along other needs than the parents of a child that visits centre day-care for 3 days a week have. With a lower contact frequency certain behaviours by health care professionals seem to be less relevant. Parents can score a value of 1, but have never asked for that behaviour, or have no need for it. Therefore, we believe weight scale scores should be introduced, that correct for the weight parents attribute to the behaviours that are mentioned in the MPOC. In this way a more reliable reflection of parents' perception of the services they and their child

received is established.

MPOC scale scores are calculated as the mean of the ratings for the items in the scales, and can therefore range from 1.00 to 7.00. As the Dutch school system uses grades from 1 to 10, the scale scores are difficult to interpret for health care professionals. A recalculation of the current mean scale scores on a seven-point scale into a better interpretable school-like grade on a 10-point scale, will further enlarge the practicability of the MPOC-NL.

Many Dutch parents and professionals considered the MPOC-NL too long for a self-administered questionnaire. Based on the high alphas found in the present study, indicating that many questions almost measure the same thing, there is a need for a shorter version of the MPOC-NL, like the Canadian MPOC-20 that was derived from the original 56-item MPOC.⁹⁵ The future shorter version of the MPOC-NL should preferably be based on Dutch data. These analyses will likely produce a deviant factor structure with partly different items accounting for possible variations in the focus of the Dutch rehabilitation process. Furthermore, the high Pearson correlations between MPOC-NL scales in the Dutch sample point out that parent satisfaction with care has probably one underlying dimension to which all of the scales are highly related.

Parents reported some difficulties with completing the MPOC-NL. Firstly, they said it was sometimes hard to give a mean judgement about behaviours by health care professionals, especially when there were more professionals involved, and one of them showed "extreme" behaviour. Furthermore, parents found it very difficult to distinguish between health care that was facilitated by the paediatric rehabilitation centre and other health care providers. In the Netherlands, most children with a moderate or severe limitation visit schools for special education with all health care services "on board". These children only visit the centre to see their rehabilitation specialist, or the specialist or even the whole rehabilitation team of the centre also work at the school. Children with mild limitations mostly visit the paediatric rehabilitation specialist in the centre once or twice a year, and have made other arrangements to receive therapy in their neighbourhood. As parents reported, this involvement in more than one health care setting can plausibly cause distortion of the responses.

The evaluative power of the MPOC, *i.e.*, the power to point out differences that occurred after, for example, programme interventions, is another point of interest that should be explored in future research. In addition, the differences between fathers and mothers should be analysed, to find out whether it is useful to let both parents fill out the MPOC.

3.5 Conclusion

The MPOC-NL has sound psychometric qualities. We believe the MPOC-NL is widely applicable, and will be a valuable and usable tool for various research and clinical pur-

poses, especially in the areas of programme evaluation and total quality management. Providing the users of the MPOC-NL with tools for a correction of the scale scores accounting for the weight parents attribute to the separate behaviours, and a recalculation of the mean scale scores on a seven-point scale into a better interpretable school-like grade on a 10-point scale, will further enlarge the practicability of the MPOC-NL. Furthermore, a short version of the MPOC-NL, based on the Dutch data set, should be constructed. Finally, the evaluative power of the MPOC, and the differences between fathers and mothers should be explored.

Acknowledgments

The authors wish to thank all parents and health care professionals who took part in this study for sharing their time and experiences, the support staff of participating rehabilitation centres for their assistance, Prof. Peter Rosenbaum and colleagues of the CanChild Centre for Childhood Disability Research for sharing their knowledge and making the MPOC available, and Dr. Gerard Maassen for statistical support. This project was funded by Zorg Onderzoek Nederland (ZonMw).

4

One-year stability of the Measure of Processes of Care

Renate C. Siebes,¹ Lex Wijnroks,¹ Marjolijn Ketelaar,^{2,3}
Petra E.M. van Schie,⁴ Adri Vermeer,¹ Jan Willem Gorter^{2,3}

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands; ³University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁴VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Background: The Measure of Processes of Care (MPOC) is a 56 item self-administered measure designed to examine what parents of a child with a chronic health problem think of the services they and their child receive, and to measure the extent to which these services are family-centred. Reliability and validity of the MPOC were established in prior studies. The aim of the present study was to assess the one-year stability of the MPOC to justify its use as an evaluative tool.

Methods: Nine paediatric rehabilitation centres in the Netherlands participated in this short longitudinal survey study. Subjects were 204 parents (response rate 73.9%) of children aged 1 to 18 who received care in one of the participating paediatric rehabilitation centres. All subjects filled out two MPOCs with a one-year interval.

Results: All correlations between the scale scores of the MPOC at the first and second administration were relatively high and significant (range: .443 to .609, all p 's < .001), demonstrating high inter-individual stability. However, all mean scale scores, except for *Providing General Information*, significantly reduced after one year.

Conclusions: The MPOC has a moderate one-year stability. However, due to its tendency to score lower when repeated after one year, its use as an evaluative follow-up instrument to assess the effectiveness of a programme intervention is restricted.

4.1 Introduction

In 1996, the Mc Master University *CanChild* research group developed the Measure of Processes of Care (MPOC) as a measure of parents' perception of the family-centredness of the services they and their child received.⁹⁰ The MPOC can be used for clinical evaluation, research purposes, and quality assurance. However, before the MPOC can be used to evaluate the success of an intervention (*i.e.*, in a pretest and posttest design), the long-term stability of the questionnaire should be examined, which was the aim of the present study.

The provision of paediatric rehabilitation services has undergone important changes in the past decades. The most far-reaching shift that has taken place was the reconceptualization of the role of the family. In roughly half a century the role of parents in the care process evolved from being a target for intervention without any control into the role of an equal partner in the decision-making processes of treatment and determining the contents of their child's care.²⁰⁶ The term family-centred care (FCC) is commonly used to describe this new way of providing care. FCC can be defined as placing the child's needs, in the context of their family and community, at the centre of care and devising an individualized and dynamic model of care in collaboration with the child and the family that will best meet these needs.¹¹⁶ Within FCC the emphasis is on child and family strengths and resources needed for normalized patterns of living and respectful and supportive care.^{49,97} Families are involved in their child's care and have the opportunity to learn more about their child and (options for) their child's treatment. Family members in turn

are able to share their knowledge with professionals, thus providing a more holistic picture of the child and a way to heighten awareness of the child as part of the family. FCC has been shown to contribute to parental satisfaction with services.^{49,79,88,90,92,97,110,161} There is also evidence that FCC fosters parents' emotional well-being.^{88,91,92,151,161} Reported child outcomes of FCC are developmental progress or skill development,^{26,107,134} and a better psychological adjustment.^{112,190,191}

Over the years, several measures have been developed to evaluate the family-centredness of care for children with disabilities.¹⁷⁸ The combined satisfaction data of parents, children, and service providers will provide valuable information for further improvement of the quality of rehabilitation care for children with disabilities.^{95,178} At this moment, the MPOC is the only broadly focused, valid, and reliable instrument that is available for the evaluation of the family-centredness of services from a parents' perspective.^{178,209} Although the MPOC is already being used to evaluate whether an intervention has been effective (for instance, in the Ekström Ahl⁵³ study), the MPOC's long-term stability has not been shown yet.^{94,95} The current study aims to justify the use of the MPOC as an evaluative tool by answering the question whether the MPOC scale scores are stable (rank order and mean scores) when administration is repeated after about one year.

4.2 Methods

4.2.1 Main outcome measures

4.2.1.1 Measure of Processes of Care

The MPOC is a 56-item self-administered parent questionnaire designed to find out what parents of a child with a chronic health problem think of the services they and their child receive, and to measure the extent to which these services are family-centred.⁹⁰ Parents answer on a seven-point scale ranging from "never" (1) to "to a great extent" (7), with an additional "not applicable" category. In the Dutch MPOC version all answer options have a descriptive label. These were adopted from the Canadian MPOC-20.⁹⁵ Each of the items asks the parents to what extent a certain behaviour was performed by the care providers of the centre working with their child. The items cover five scales:⁹⁰ (1) *Enabling and Partnership* (16 items); (2) *Providing General Information* (9 items); (3) *Providing Specific Information about the Child* (5 items); (4) *Coordinated and Comprehensive Care for Child and Family* (17 items); and (5) *Respectful and Supportive Care* (9 items). The 56-item Canadian MPOC was translated into Dutch and validated.²⁰⁹ Both the original Canadian and the translated Dutch MPOC have sound psychometric properties.^{90,209} After the validation of the Dutch MPOC, the utility of the measure in the Netherlands was further enlarged in two ways: (1) by asking the respondents to indicate the importance of each item, a weighted score could be calculated, and (2) an additional conversion into a grade on a scale from 1 to 10 (like the Dutch school grades) was made to increase the

interpretability of the scale scores.

4.2.1.2 Other measures of satisfaction

Besides the MPOC scores, three other variables to determine whether parents' satisfaction with received services had changed were included in the study. Firstly, parents were asked to answer the question "When you compare the current quality of care you and your child receive with the quality of care one year ago, did it: a) remain the same, b) increase, or c) decrease?". Furthermore, parents were asked to give their overall satisfaction rating for the care provided by the centre on a scale from 1 (very negative) to 10 (very positive). Finally, the Client Satisfaction Questionnaire (CSQ)¹⁰³ was used to measure general satisfaction. This measure consists of eight items with a four-point scale and yields a summed score of global satisfaction with care and services received (range 8 (lowest) to 32 points (highest)). The CSQ has demonstrated adequate validity and high internal consistency.¹⁰³

4.2.2 Participants and procedure

Between 2001 and 2004 a large project on the measurement of processes of care in the Netherlands was performed by associates of the Dutch *NetChild* research group. All participants were parents of children aged 1 to 20 years with various diagnoses treated in nine out of 23 Dutch paediatric rehabilitation centres. Of the 423 families (679 parents) that participated in the first phase of the project, 274 parents (176 mothers and 98 fathers) consented to participate in the second phase stability study. These parents received the MPOC, a general questionnaire, and a prepaid return envelope by mail. After about four weeks a reminder was sent. All questionnaires were coded with a number, thus confidentiality was guaranteed for all answers. Of the 274 parents who consented to participate, 205 parents (134 mothers and 71 fathers) returned their questionnaires (74.8%). Most of the parents who did not respond reported they had not had enough contact with the paediatric rehabilitation centre over the past year to fill out the questionnaires meaningfully. The mean time interval between the first and the second phase was 314.6 days. The demographic characteristics of the families and children of the second phase are outlined in Table 4.1 and Table 4.2.

4.2.3 Data analyses

To assess stability of the rank order of the parents' judgement of the quality of the care process, Pearson correlations were calculated. To examine changes in the mean scores across time MANOVA analyses for repeated measures were conducted, with the scale scores at phase one and phase two as the within-subject variables. Paired samples *t*-tests (2-tailed) were performed to examine whether the mean grades for the overall quality of care and the CSQ sum scores were stable over time.

Table 4.1 Characteristics population second phase of the project on the measurement of processes of care ($n = 205$): family and respondent variables

Identity of respondent	%	Family income	%
Natural mother	65.4	< €14.000	6.8
Natural father	34.6	€14.000 – €24.500	13.2
		€24.500 (modal)	14.6
Family type	%	€24.500 – €49.000	35.1
Single-parent family	8.8	> €49.000	19.0
Two-parent family	91.2	Missing	11.2
Nationality	%	Number of children at home	%
Dutch	92.2	1 child	21.0
Other	7.8	2 children	42.9
Missing	1.5	3 children	24.4
		≥ 4 children	11.8
Respondents' educational level	%		
Some high school	2.0		
Completed high school	27.8		
Completed college/technical training	33.9		
Bachelor degree	25.9		
Master degree	10.7		

Percentages may not add to 100.0% due to rounding to one decimal place.

4.3 Results

4.3.1 MPOC's one-year stability

First, it was examined whether the MPOC scale scores were stable when the administration was repeated after about one year. The inter-individual stability was determined with Pearson's correlation coefficient r . The correlations ranged from .443 (*Providing Specific Information about the Child*) to .609 (*Respectful and Supportive Care*) and were all significant (all p 's < .001), meaning that parents kept about the same rank order in the group at the second phase compared to the first phase. Next, a MANOVA for repeated measures showed a significant overall decrease of the mean scale scores between the first and the second phase ($F(1, 184) = 33.09, p < .001$). Separate MANOVA analyses of variance for repeated measures demonstrated that only the scale *Providing General Information* was stable over time (see Table 4.3).

4.3.2 Possible explanations for the decrease

One obvious explanation for the overall decrease in the scale scores may be that the quality of the care process of the paediatric rehabilitation centres had decreased between the first and second administration. To test this hypothesis, the school grades that were given for the overall quality of care at the first and the second phase were compared. That is,

Table 4.2 Characteristics population second phase of the project on the measurement of processes of care ($n=205$): child variables

Child's age	%	Types of service/therapy received	%
< 2 years	1.0	Physical therapy	85.9
2 – 5 years	28.8	Occupational therapy	62.9
5 – 12 years	43.9	Speech-language therapy	43.4
12 – 16 years	20.6	Psychological services	23.0
≥ 16 years	6.0	Social work	6.8
Child's gender	%	Number of services or therapies received	%
Male	67.3	1 service/therapy only	29.3
Female	32.7	2 services/therapies	25.9
		3 services/therapies	35.1
		≥ 4 services/therapies	2.9
Diagnosis	%	No therapy at this moment	6.8
Cerebral palsy	47.5	Number of health or development problems	%
Neuromuscular disorders	16.7	1 problem	32.7
Spina bifida/hydrocephalus	5.9	2 or 3 problems	38.1
Acquired brain injury	6.4	≥ 4 problems	29.2
Sensomotor developmental disorder	6.9		
Other disabilities	16.6		
Length of time using centre	%		
1 – 2 years	32.2		
2 – 5 years	38.2		
≥ 5 years	29.6		

Percentages may not add to 100.0% due to rounding to one decimal place.

Table 4.3 Mean MPOC scale scores at the first and second phase of the project on the measurement of processes of care

Scale	First phase			Second phase			$F(1, 185)$	p
	n	m	sd	n	m	sd		
EP	190	5.40	1.06	190	4.95	.98	47.764	.000
PGI	187	3.90	1.52	187	3.73	1.28	3.021	.084
PSI	188	5.31	1.24	188	4.87	1.01	24.912	.000
CCC	190	5.40	1.03	190	5.05	.93	27.704	.000
RS	191	5.68	.93	191	5.30	.87	43.668	.000

EP, Enabling and Partnership; PGI, Providing General Information; PSI, Providing Specific Information about the Child; CCC, Coordinated and Comprehensive Care for Child and Family; RS, Respectful and Supportive Care; n , number of participants; m , mean scale score; sd , standard deviation. $n = 187 - 191$.

when the quality of the care process had deteriorated, it should be reflected in a reduction of the grades parents gave for the overall quality of care. For a similar reason, we compared the sum scores of the Client Satisfaction Questionnaire that was completed at the first and the second phase. Finally, we calculated the mean MPOC scale scores of the first and the second phase of parents who reported that the quality of received care had not changed during the past year. If nothing had been changed according to the parents, then their mean scale scores should have remained stable between the first and second administration.

Paired samples *t*-tests were performed to compare parents' school grades for the overall quality of care and the sum scores of the CSQ at the first and the second phase administration. The mean school grades for the overall quality of care at the first phase and the second phase slightly reduced, (7.69, *sd* = 1.12, and 7.58, *sd* = .97, at the first and second phase respectively), but the difference was not significant ($t = -1.368$, $df = 132$, $p = .174$). The sum score of the CSQ, on the other hand, increased slightly from 22.85 (*sd* = 3.46) at the first phase, to 23.12 (*sd* = 3.87) at the second phase, but this raise was also not significant ($t = 1.112$, $df = 188$, $p = .268$). Further, the majority of the parents ($n = 157$) reported no changes in the quality of care between the first and second phase, which contradicts our finding that the MPOC scale scores showed a significant decrease. Moreover, a separate MANOVA analysis of variance for repeated measures showed that the mean MPOC scale scores of this group still decreased significantly ($F(1, 156) = 31.74$, $p < .0001$). Figure 4.1 shows the overall decrease of mean scale scores for the three groups of parents: parents who reported an increase in the quality of care they and their child received ($n = 16$), parents who reported no changes ($n = 157$), and parents who reported a decrease of the quality of received care ($n = 11$). In sum, reduction in the mean scale scores in a one-year period could neither be explained by changes in the parents' overall judgement of the quality of the care process, nor by the parents' report of the changes in the quality of care in the same period.

There are some other possible explanations for the overall decrease in the MPOC scale scores. One possible explanation might be that the overall decrease in the scale scores can be attributed to a major change in one of the participating centres during the year, for instance, due to internal reorganizations. A MANOVA for repeated measures with centre as a between-subject factor and the scale scores at phase one and two as the within-subject factor did not show a significant main effect for centre ($F(8, 176) = .646$, $p = .738$).

Another explanation might be that the overall decrease was caused by changes in expectations of parents of younger children. These parents may have high expectations about the progress their children will make at the beginning of the care process, but soon they must correct their unrealistic expectations to more realistic ones. It is possible that it has influenced their judgment of the care process negatively. Parents of older children may already have realistic expectations and will demonstrate more stable MPOC-scores over time. To test this explanation, subjects were divided into three groups on the basis of the child's age: 0 to 4 years ($n = 61$), 5 to 12 years ($n = 101$), and 13 years and

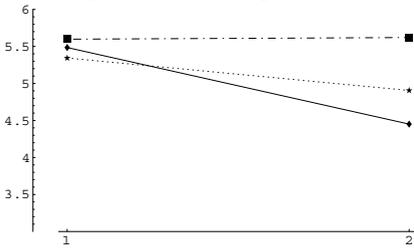
up ($n = 43$). A MANOVA analysis of variance for repeated measures with age group as a between-subject factor and the scale scores at phase one and two as the within-subject factor, demonstrated a significant main effect for child age ($F(2, 182) = 4.340$, $p = .014$), but no significant age group by time interaction ($F(2, 182) = .31$, NS). This final result indicates that our hypothesis was not confirmed by the data. In addition, post hoc tests (Bonferroni) showed that the youngest age group (0 – 4 years) had significantly ($p = .012$) higher scale scores than the oldest age group (13 years and older).

Still, another but similar explanation might be that the more parents become familiar with the centre the more they become critical about the care process and therefore tend to score lower on the MPOC when it is filled out again after one year. That is, parents who have contact with the centre for a relatively short time, will become more and more critical, while parents who are very experienced with the centre will not change their opinion very likely. In other words, the former group should be mainly responsible for the reduction in the mean scale scores across time. Parents were divided into four groups according to their number of years of experience with the centre at phase one: parents who had less than one year experience ($n = 45$), parents who had about one year of experience ($n = 35$), parents who had 1.5 to 3.5 years experience ($n = 40$), and parents who had 4 or more years of experience with the centre ($n = 105$). A MANOVA analysis of repeated measures, with groups differing in number of years experience with the centre as a between-subject factor, revealed a significant main effect of experience ($F(3, 181) = 4.47$, $p = .005$), and an experience by time interaction effect ($F(3, 181) = 4.79$, $p = .003$). Post hoc tests (Bonferroni) indicated first, that in line with our expectations, the mean scores were lower when parents were more familiar with the centre. Second, contrary to our prediction, the scale scores of parents who had one year or less experience with the centre remained stable after one year, and the scale scores of parents who had more than one year experience reduced significantly.

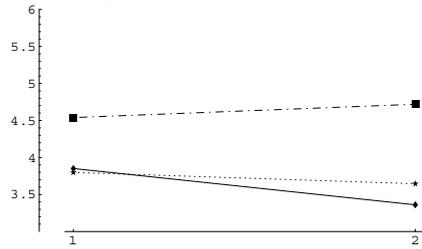
4.4 Discussion

The aim of the present study was to examine the MPOC's one-year stability. The analyses showed sufficient inter-individual stability, but also an overall decrease of the mean scale scores at the second phase. At first, reduction in the mean scale scores could not be easily explained as the parents' overall satisfaction (CSQ) and their judgement of the quality of the rehabilitation centre had not changed. Additional analyses showed that parents who had more experience with the centre were more critical, and tended to become even more critical at the long run than parents who had less experience. This is in line with some other results. Literature suggests that parents of children with frequent and regular contacts with paediatric hospital care were significantly more critical compared with parents with fewer hospital contacts.²¹⁹ In another study by our research group, which comprehended the third phase of our large project on the measurement of processes of

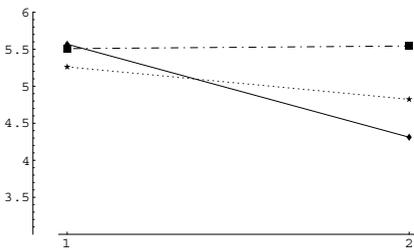
Enabling and Partnership



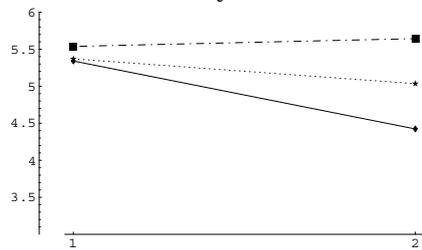
Providing General Information



Providing Specific Information about the Child



Coordinated and Comprehensive Care for Child and Family



Respectful and Supportive Care

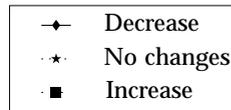
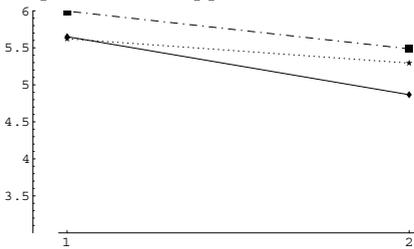


Figure 4.1 Mean MPOC scale scores (vertical axis) at the first and the second phase (horizontal axis) for parents who reported a decrease, no changes, or an increase in the quality of care and their child received in the paediatric rehabilitation centre.

care in the Netherlands, 75 parents who had all filled out the Dutch MPOC were interviewed. Twenty-nine parents (38.7%) stated their participation in the study had changed their view on the process of care. They told they had become more conscious of the caregiving process during the study (21.3%) and that they had developed a more critical view on their child's process of care (26.7%). Another 14.7% of the interviewed parents reported they no longer perceived the caregiving process as a matter of course. Filling out the MPOC functioned as an eye opener for them. These findings may partly explain

the overall decrease of MPOC scale scores at the second phase.

The overall decrease of the scale scores could not be explained by a regression to mean effect, since we found no evidence that parents who scored high at the first assessment tended to score lower the second time after one year.

Because of the low number of parents in the decrease and increase groups (16 and 11, respectively), and because we had no grip on the changes that had occurred in the centre and in treatment during the in-between year, we were not able to determine the responsiveness to changes of the MPOC. Figure 4.1 shows that the mean scale scores of parents who reported the quality of care had increased are highest, and the scores of parents who reported a decrease are lowest, but these findings should be confirmed in an intervention study with a larger study sample and a pretest-posttest design.

The positive skew of the scale scores, which are common for health care questionnaires in Western societies, makes the area where changes occur smaller than the seven-point scale. It is very hard to detect any improvement, or to distinguish among various grades of excellence.¹⁹⁶ Moreover, a statistically significant mean decrease of .36 on a seven-point scale in the present study, which is one third of the distance between two answer options, may not be a clinically relevant decrease.

The MPOC was developed originally to measure a certain group of parents' satisfaction—at a certain time—about the services they and their child receive, and to measure the extent to which these services are family-centred. In daily practice, the MPOC is being used more and more as an evaluative measure of parents' satisfaction with received services over time. The main message of the present paper is that MPOC scale scores should be interpreted with caution when the measure is used as an evaluative follow-up instrument, for instance, to evaluate a programme intervention. The MPOC is responsive to changes, but due to its tendency to score lower when repeated after some time, individual scale scores cannot be used to evaluate the effectiveness of the treatment. When using the MPOC as an instrument to assess the effectiveness of a group intervention longitudinally, correction of the scores should be considered.

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5

Quality of paediatric care from the parent perspective: validation of the short Measure of Processes of Care in the Netherlands

Renate C. Siebes,¹ Gerard H. Maassen,² Lex Wijnroks,¹ Marjolijn Ketelaar,^{3,4}
Petra E.M. van Schie,⁵ Jan Willem Gorter,^{3,4} Adri Vermeer¹

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Utrecht University, Department of Methodology and Statistics, Utrecht, the Netherlands; ³Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands; ⁴University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁵VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Objective: In the present study we aim to assess the reliability and validity of the 20-item version of the Dutch Measure of Processes of Care (MPOC), an instrument developed by the McMaster University *CanChild* research group to evaluate the family-centredness of paediatric rehabilitation services from a parent perspective.

Design: The reliability, concurrent validity, predictive validity, and construct validity of the Dutch MPOC-20 were determined in a large Dutch MPOC database.

Subjects: Participants were 405 mothers and 22 fathers of children aged 1 to 18 years recruited through nine paediatric rehabilitation centres in the Netherlands.

Main measures: The participants filled out the MPOC-20 items, the Client Satisfaction Questionnaire (CSQ), and two additional questions about satisfaction with services and the amount of stress they experienced.

Results: The internal consistency analyses (α .75 to .87) and the test-retest analyses (ICC .78 to .91) showed that the Dutch MPOC-20 is a reliable tool. The concurrent validity of the Dutch MPOC-20 was confirmed by positive correlations between MPOC-20 scale scores and the CSQ (r .39 to .69), and between MPOC-20 scale scores and an overall satisfaction variable (r_s .36 to .62). The predictive validity of the Dutch MPOC-20 was supported by moderately negative correlations between MPOC-20 scores and a stress variable (r_s -.26 to -.40). The construct validity of the Dutch MPOC-20 was confirmed by significant scale inter-correlations (r .41 to .84) and a factor analysis.

Conclusions: The 20-item version of the MPOC (Dutch MPOC-20) is a reliable and valid measure of the family-centredness of paediatric rehabilitation. The MPOC-20 with a low respondent burden of only 5 to 10 minutes is the measure of first choice in a survey or annual assessment of quality of care along with other instruments.

5.1 Introduction

Quality assurance ("Are we doing OK?") and quality improvement ("Are we getting better?") of paediatric rehabilitation care and parental participation in the process of rehabilitation are main topics in rehabilitation research as well as in quality management in the Netherlands. In order to be able to assess the quality of care, over the years several measures were developed to evaluate the provided care from the perspectives of all involved, *i.e.*, clients, parents, and service providers, thus providing a holistic picture of the quality of care.¹⁷⁸ Even so, a valid Dutch questionnaire asking parents for their opinion about the quality and the family-centredness of care provided by paediatric rehabilitation settings was unavailable at the start of a large project on the measurement of processes of care, that was executed by associates of the *NetChild* research group. To fulfil the need for such a questionnaire in the Netherlands, the Canadian Measure of Processes of Care (MPOC) was translated into Dutch and validated.²⁰⁹ The present study was carried out to provide the Dutch paediatric rehabilitation field with a validated shorter version of the MPOC, with a lower respondent burden.

The measurement of parent satisfaction with their child's care has been the subject of a small, yet raising, number of studies.^{88,90,92,100,126} In research on children, parents generally report on and evaluate the care. They may be the best or only source of information for assessing the personal aspects of care and to integrate information across settings, service providers, and time periods.^{44,125} In their literature search for sound measures of the process of care-giving, King and co-workers⁹⁶ identified several measures, but all of these showed significant weaknesses or drawbacks and were unsuitable for studying the process of care on a behavioural level, *i.e.*, they did not lend themselves to evaluate actual behaviour. In order to meet the need for a methodologically sound measure of parent's perceptions of the care they and their children receive, with proven psychometric properties, the *CanChild* research group at McMaster University developed the Measure of Processes of Care (MPOC), which was first published in 1996.⁹⁰ This self-administered parent questionnaire has good reliability and validity and consists of five different scales addressing all the aspects of care-giving that were valued most by parents during the MPOC development.⁹⁰ To improve the utility of the MPOC and the ability to discriminate between programs with different service delivery models, the *CanChild* research group shortened and refined the 56-item MPOC to become MPOC-20, with 20 items divided over the same five scales.⁹⁵

When the 56-item MPOC was made available in the Netherlands, we received many inquiries from scientific researchers, quality control workers, and parents about a shorter version of the questionnaire, with a lower respondent burden. Furthermore, the high alphas (.80 to .95) that were found in the Dutch MPOC validation study²⁰⁹ indicate that multiple questions may measure the same aspect in the Dutch version, and can therefore be skipped. Hence, there were both practical and psychometric reasons to provide the Dutch paediatric rehabilitation field with a shorter MPOC. The objective of the present study was to examine the psychometric qualities, or more specific, the reliability, concurrent validity, predictive validity, and the construct validity of the 20-item version of the MPOC in the Netherlands (Dutch MPOC-20), which was a direct translation of the Canadian MPOC-20.

5.2 Methods

5.2.1 Procedure

In the present Dutch MPOC-20 validation study, the data of the earlier Dutch MPOC validation study were used.²⁰⁹ The participants for the Dutch MPOC validation study were recruited en masse in response to a letter of introduction from the research group along with a letter of endorsement from the rehabilitation centre. The 996 parents (596 families) who consented to participate were mailed an MPOC, a CSQ, and a general questionnaire including one question to measure stress and a question to measure overall satisfaction. To improve the response rate, maximum two reminders were sent. Of the families who

intended to participate, 427 families (71.6%), consisting of 679 parents, returned usable questionnaires. To maintain independence of cases, data of the parent who more actively attended the child's treatment program were selected for the analyses when both parents in a family responded. The analyses were therefore performed with data of 427 parents. Thirty families participated in the test-retest study and filled out another MPOC after about four weeks ($mean = 24.8$ days; $sd = 9.39$). The fill out time of the Dutch MPOC-20 was checked in a small sample of 10 respondents, who additionally filled out the actual Dutch MPOC-20. In this small sample the same fill out time interval was found as in the Canadian MPOC-20 study, being 5 to 10 minutes.

5.2.2 Participants

Participants were 405 mothers and 22 fathers of children aged 1 to 18 years ($mean = 7.9$ years; $sd = 4.7$) recruited through nine paediatric rehabilitation settings. Most of the participants (89.8%) were from two-parent families and the majority had had high school education. Most of the children (79.2%) whose parents participated were less than 13 years of age, and 60.3% were boys. A wide range of chronic, mostly neurodevelopmental, disorders were represented. Two-thirds of the children had more than one major health or developmental problem, and two-thirds had two or more of the major developmental therapies (*i.e.*, physical, occupational, or speech therapy). On average, the children had received rehabilitation services for 4.0 ($sd = 3.6$) years. The Dutch study sample characteristics (summarized in Table 5.1) were comparable to those of the Canadian study sample.

5.2.3 Instruments

5.2.3.1 Measure of Processes of Care

The Dutch MPOC-20 is a direct translation of the original MPOC-20 published by King et al.⁹⁵ The MPOC-20 consists of 20 items and was based on the 56-item MPOC. The Appendix lists the 56 MPOC items and shows which items are included in the MPOC-20. In the shortening process, the Canadian authors selected the best exemplars of the scales by examining the frequency distributions of the items, the item importance ratings, and item correlations.⁹⁵ This yielded 35 items, which could be narrowed down to 20 items after internal consistency analyses and a principal component analysis with oblique rotation. In the MPOC-20 the original five scales were kept by the authors because they made conceptual sense and represent essential aspects of family-centred services. The authors reported good psychometric properties of the MPOC-20.⁹⁵

The 20 items are answered on a seven-point scale ranging from "never" (1) to "to a great extent" (7), with an additional "not applicable" category. A higher score corresponds with a more favourable judgement of the care process. Each of the items asks the parents to what extent a certain behaviour was performed by the care providers of

Table 5.1 Demographic characteristics of respondents ($n = 427$): respondent and child variables²⁰⁹

Respondent gender	%
Male	5.2
Female	94.8
Child gender	%
Male	60.3
Female	39.7
Age range children	
1 – 18 ($m = 7.9$; $sd = 4.7$)	
Number of years of received services	
$m = 4.0$; $sd = 3.6$	
Diagnosis	%
Cerebral palsy	31.4
Neuromuscular disorders	11.5
Spina bifida/hydrocephalus	7.5
Syndrome	7.3
Sensomotor developmental disorder	7.0
Acquired brain injury	5.2
Behaviour disorder	3.3
Other	10.8
Diagnosis not known	4.2
Missing	11.9

n , number of respondents; m , mean; sd , standard deviation. Percentages may not add to 100.0% due to rounding to one decimal place.

the centre working with their child in the previous 12 months. The 20 items cover five scales:⁹⁵ (1) *Enabling and Partnership*; (2) *Providing General Information*; (3) *Providing Specific Information about the Child*; (4) *Coordinated and Comprehensive Care for Child and Family*; and (5) *Respectful and Supportive Care*.

In the Dutch MPOC, parents were also asked to rate the importance of each item on a scale from 0 (not at all important) to 4 (very important), with a neutral middle category (2). The mean importance ratings ranged from 2.27 to 3.85 ($m = 3.27$), showing that parents believe that each MPOC item reflects an important aspect of their child's rehabilitation process.

5.2.3.2 Questions about satisfaction and stress

The Client Satisfaction Questionnaire (CSQ)¹⁰³ consists of eight items and yields a summed score of global satisfaction with care and services received. The CSQ has demonstrated adequate validity and high internal consistency.¹⁰³ General satisfaction was also

measured on a five-point scale with answers ranging from "very satisfied" to "not at all satisfied". In addition, for predictive validity, stress was measured with the same question as was used in the Canadian validation study,⁹⁰ *i.e.*, "...the degree to which caregiving by the centre has affected the amount of stress and worry you experienced in caring for your child (in the past year or less)". The five response options ranged from "considerably reduced my stress and worry" to "considerably increased my stress and worry".

5.2.4 Statistics

To determine whether parametric statistics could be performed in the validation process, the skewness and kurtosis of the items were examined at face value. In Western societies, the health care system is rated more favourable than the middle response option.^{10,94,122,198,209} Therefore, the scale scores in the present study were expected to be negatively skewed, because they pile up toward the higher end of the scale.

Cronbach's α coefficient was calculated for each of the five scales as a measure of internal consistency. Alphas between .70 and .90 were considered "good" according to the criterion set by Streiner and Norman.¹⁹⁶ Intraclass correlation coefficients (ICCs)¹⁷⁶ were used to examine the test-retest reliability of the Dutch MPOC-20 and were calculated for the 30 families whose test-retest data were available. ICCs above .80 are generally found acceptable for clinical work.^{38,187}

To examine the concurrent validity, Pearson's product-moment correlation coefficient (r) was calculated for the correlations between MPOC-20 scale scores and the total score on the CSQ. Coefficients between .20 and .80 are generally found acceptable for clinical work.¹⁹⁶ Higher correlations would indicate that the correlations are almost perfect and that separate factors can not be distinguished any longer. On the other hand, lower correlations could be a sign that the factors are that distinguished that they might not represent the same construct anymore. Concurrent validity was also analysed using Spearman's rank correlation coefficient (r_s) for the correlations between MPOC-20 scale scores and the overall satisfaction variable.

Predictive validity was analysed using Spearman's rank correlation coefficient (r_s) for the correlations between MPOC-20 scale scores and a stress variable. It was hypothesized that parents with a high satisfaction score would have a low stress score.⁸⁸

The construct validity of the MPOC-20 was examined by calculating the inter-correlations among the five scale scores using Pearson's product-moment correlation coefficient (r). A confirmative factor analysis with varimax rotation was conducted to examine the clustering of the 20 items in the Dutch study sample.

5.3 Results

The analyses were performed with data of 427 respondents, but due to missing items, the numbers of respondents in the analyses differed. First, descriptive statistics of the MPOC-20 were calculated (see Table 5.2). As expected, four of the five mean scale scores tended toward the higher end of the scale's range ($mean = 5.32 - 5.65$), but the distributions were not found to be severely skewed. Furthermore, the analyses showed no peaks in the item score distribution.¹⁹³ Therefore, analysis of the ordinal data of the MPOC-20 with parametric statistics was allowed.^{196,201}

Table 5.2 Mean scale scores, internal consistency, and test-retest reliability Dutch MPOC-20

Scale	<i>n</i>	<i>m</i>	<i>sd</i>	α	<i>n</i>	ICC
Enabling and Partnership	379	5.37	1.23	.75	30	.91
Providing General Information	308	3.76	1.61	.87	30	.82
Providing Specific Information about the Child	354	5.32	1.36	.78	30	.78
Coordinated and Comprehensive Care for Child and Family	387	5.65	1.10	.82	30	.79
Respectful and Supportive Care	348	5.45	1.18	.86	30	.83

n, number of respondents; *m*, mean scale scores; *sd*, standard deviation; Cronbach's α , internal consistency; ICC, intraclass correlation coefficient.

5.3.1 Reliability: internal consistency and test-retest reliability

For each of the five scales Cronbach's α was calculated as a measure of internal consistency. As is illustrated in Table 5.2, all alphas of the Dutch MPOC-20 were between .70 and .90, representing a good internal consistency according to the Streiner and Norman criterion.¹⁹⁶ Table 5.2 also shows that two of the Dutch MPOC-20 scales had ICCs just below .80 (*Providing Specific Information about the Child*: .78; *Coordinated and Comprehensive Care for Child and Family*: .79). The ICCs of the remaining scales were good, ranging from .82 to .91. The overall test-retest reliability was satisfactory.

5.3.2 Concurrent validity

Table 5.3 shows that the Pearson's product-moment correlation coefficients between the MPOC-20 scale scores, on the one hand, and the total score on the Client Satisfaction Questionnaire, on the other, were all significant, ranging from .39 to .69 ($p < .001$). Spearman's rank correlation coefficients (r_s) for the correlations between MPOC-20 scale scores and the overall satisfaction variable all satisfied the criterion that was chosen for good correlations (see Table 5.3).

Table 5.3 Association between scale scores Dutch MPOC-20 and satisfaction and stress variables

Scale	<i>n</i>	<i>r</i> CSQ	<i>n</i>	<i>r_s</i> OS	<i>n</i> Stress	<i>r_s</i>
EP	422	.64	411	.59	392	-.33
PGI	415	.39	403	.36	386	-.26
PSI	414	.50	403	.50	386	-.30
CCC	422	.69	410	.62	392	-.36
RS	422	.69	410	.59	392	-.40

EP, Enabling and Partnership; PGI, Providing General Information; PSI, Providing Specific Information about the Child; CCC, Coordinated and Comprehensive Care for Child and Family; RS, Respectful and Supportive Care; *n*, number of respondents; *r*, Pearson's correlation coefficient; CSQ, Client Satisfaction Questionnaire;¹⁰³ *r_s*, Spearman's correlation coefficient; OS, overall satisfaction variable; Stress, stress variable. All correlations with $p < .001$ (2-tailed).

5.3.3 Predictive validity

Spearman's rank correlation coefficient (*r_s*) demonstrated statistically significant correlations between MPOC-20 scale scores and a stress variable in the expected direction (*r_s* -.26 to -.40; $p < .001$).

5.3.4 Construct validity

The inter-correlations among the five Dutch MPOC-20 scale scores ranged from .41 (moderate) to .84 (high) (see Table 5.4), which indicated some overlap between the scales.

Table 5.4 Correlation between scales Dutch MPOC-20 using Pearson's product-moment correlation coefficient (*r*)

Scale	EP	PGI	PSI	CCC	RS
Enabling and Partnership (EP)	1	.41	.57	.73	.74
Providing General Information (PGI)		1	.44	.46	.50
Providing Specific Information about the Child (PSI)			1	.57	.58
Coordinated and Comprehensive Care for Child and Family (CCC)				1	.84
Respectful and Supportive Care (RS)					1

All correlations with $p < .001$ (2-tailed).

Conducting a factor analysis with varimax rotation we examined to what extent the Canadian factor structure also underlies the Dutch dataset. This analysis revealed three factors with eigenvalues larger than 1.0, explaining 63% of the variance. The five factor solution (explaining 70% of the variance) could partly confirm the original Canadian

factor structure (oblimin rotation revealed similar results). All items of *Respectful and Supportive Care* and *Providing Specific Information about the Child* loaded highest in these consecutive factors in the Dutch sample as well. Two out of the three *Enabling and Partnership* items were placed in this factor again. The *Coordinated and Comprehensive Care for Child and Family* items were divided over *Respectful and Supportive Care* and *Enabling and Partnership*. Finally, the five items of *Providing General Information* were designated to two separate general information scales.

5.4 Discussion

The Dutch MPOC-20 appeared to be a short, reliable and valid instrument to evaluate the family-centredness of paediatric rehabilitation services from a parent's perspective.

In the Netherlands, researchers, professionals, and parents requested for a shorter version of the validated Dutch MPOC-56. In this study, we chose to translate and validate the original Canadian MPOC-20. There are, however, other methods to shorten a measure. According to the guidelines proposed by Guillemin, Bombardier, and Beaton,⁶⁷ a shorter version of a questionnaire should always be based on analyses of a relevant dataset in order to reach optimal validity of the shortened measure. Theoretically, we could have used the Dutch MPOC dataset to create a new short measure with a very strong clinical applicability for the dataset population. However, a shorter MPOC already exists,⁹⁵ and by creating a new short version the international commensurability of results will be lost.

A Swedish research group chose for another option and modified the original MPOC-20 to become MPOC-28; five more questions were kept from the MPOC-56, and three new were added.⁶⁶ Obviously, the clinical applicability of this new instrument is strong in Sweden, but by adding extra items, the ability to compare their results with those of other international research groups has decreased significantly.

In this study a relatively high response rate was accomplished. Addressing parents' concerns fits with the societal trend to be more responsive to consumers and to provide services that meet their needs.⁹⁵ To fulfil these needs for as many parents as possible it is important to obtain high response rates of the MPOC survey. Numerous strategies have been described to improve response rates, and thus the quality of the results of a study.^{2,52,196,215} These strategies include, for instance, repeated mailing of the questionnaire, an attractive format of the questionnaire, inclusion of a request to explain nonparticipation in the first mailing, follow-up of nonresponders with a repeated mailing of the questionnaire, a catching covering letter, giving a token of appreciation for participation, a guaranty of anonymity, personalization, and the enclosing of a stamped, self-addressed return envelope. Most of these techniques have already been applied in the MPOC validation study and are passed on to the Dutch MPOC users. Another important strategy to improve response rates is the reduction of the length of the questionnaire. An additional option to raise the response rate is to lower the reading difficulty of the MPOC. In the

earlier MPOC validation study²⁰⁹ the Gunning Fog Index⁶⁸ was used to determine the level of reading difficulty of the Dutch MPOC. According to the authors of this index the average person reads at the level 9 (9 – 12 is rated high school level), and anything above the level 17 is difficult for university students. After some adjustments, the Dutch MPOC was rated at level 12, which stands for fairly difficult to read. With an improved reading ease, more respondents with a lower educational level can probably complete the MPOC as well. Future studies could examine the possibilities to further improve the MPOC's reading ease.

Table 5.5 Comparison of the ranges of the statistics of the two Dutch Measures of Processes of Care

	MPOC-56	MPOC-20
Range mean scale scores	3.71–5.66	3.76–5.65
Range <i>sds</i> of mean scale scores	1.00–1.58	1.10–1.61
Median	3.71–5.81	3.80–6.00
Cronbach's α	.80–.95	.75–.87
ICC	.79–.94	.78–.91
r_s scales with Stress	–.39–.28	–.40–.26
r scales with CSQ	.40–.73	.39–.69
r between scales	.50–.92	.41–.84

sd, standard deviation; ICC, intraclass correlation coefficient. r_s , Spearman's correlation coefficient; Stress, stress variable; r , Pearson's correlation coefficient; CSQ, Client Satisfaction Questionnaire.¹⁰³

Table 5.6 Use of the MPOC-56 versus the MPOC-20

	MPOC-56	MPOC-20
Characteristics		
International comparability of results ^a	++	+
Respondent burden ^b	–	++
Utility^c		
Use for clinical purposes	++	+
Use for research purposes	++	+
Use for program evaluation and quality control	++	+
Use to formulate topics for quality improvement	++	–

^a +, intermediate comparability; ++, good comparability. The MPOC-20 has been developed recently. It will take some time before foreign research groups report on their MPOC-20 findings. Until then, the MPOC-20 results can be compared with MPOC-56 results. ^b –, high burden, 15 to 20 minutes; ++, low burden, 5 to 10 minutes. ^c –, low utility; +, intermediate utility; ++, good utility.

In the Netherlands, two Measures of Processes of Care are now available to evaluate the family-centredness of paediatric rehabilitation services in a parent perspective: the 56-item MPOC and the 20-item shortened MPOC. Table 5.5 compares the psychometric properties of the two Dutch MPOCs and shows that the alphas and correlation coefficients are good for both measures. Except for the expected decreases of alphas and inter-correlations, the values of the long and short MPOC are comparable. We agree with King *et al.*⁹⁵ that the 56-item MPOC is particularly good for research purposes and is the most informative measure on the item level. However, with a fill-out time of 15 to 20 minutes, the respondent burden may be too high. The MPOC-20 has a low respondent burden (5 to 10 minutes), but is less detailed at the item level since it has only 20 items. MPOC-20 data can be examined on a scale level to determine areas of relative strength and areas needing improvement within and across programs or organizations, but with less detail than the MPOC-56.⁹⁵ When the MPOC is used in a survey or annual assessment of quality of care along with other instruments, the MPOC-20 with a reduced respondent burden of only 5 to 10 minutes is the measure of first choice. Table 5.6 summarizes the advantages and disadvantages of the use of the 56-item MPOC and the 20-item MPOC. Although we have no reason to doubt the use of the MPOC to pinpoint specific areas of improvement on an item level, it should be noted that this specific application has not been examined yet.

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5.A Items and scaling of the 56-item Measure of Processes of Care

Item description ¹	In MPOC-20?
Enabling and Partnership	
Fully explain treatment choices to you?	Y
Offer you positive feedback or encouragement (e.g., in carrying out a home program)?	N
Tell about options for treatment or services for your child (e.g., equipment, school, therapy)?	N
Trust you as the "expert" on your child?	N
Anticipate your concerns by offering information even before you ask?	N
Make sure you have a chance during visits to the centre to say what is important to you?	N
Let you choose when to receive information and the type of information you want?	Y
Tell you about the reason for treatment or equipment?	N
Provide opportunities for you to make decisions about treatment?	Y
Answer your questions completely?	N
Recognize that your family has the final say when making decisions about your child's treatment?	N
Consult with you when discussing equipment or services?	N
Tell you about details about your child's services, such as the reasons for them, the type of therapies and length of time?	N
Make sure you have opportunities to explain what you think are important treatment goals?	N
Make you feel like a partner in your child's care?	N
Listen to what you have to say about your child's needs for equipment, services, etc.?	N
Providing General Information	
Have information available to you in various forms, such as a booklet, kit, video, etc.?	Y
Give you information about the types of services offered at the organization or in your community?	Y
Promote family-to-family gatherings for social, information or shared experiences?	N
Provide opportunities for special guests to speak to parents on topics of interest?	N
Provide support to help cope with the impact of childhood disability (e.g., by advocating on your behalf or informing you of assistance programs)?	N
Have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	Y
Provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	Y
Provide opportunities for the entire family to obtain information?	Y
Have general information available about different concerns (e.g., financial costs or assistance, genetic counseling, dating, sexuality)?	N
Providing Specific Information about the Child	
Explain what they are doing when you are watching your child in therapy?	N
Tell you about the results from assessments?	Y
Provide you with written information about what your child is doing in therapy?	Y
Provide you with written information about your child's progress?	Y
Notify you about the reasons for upcoming case conferences, meetings, etc. about your child?	N

(continued on next page)

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Item description ¹	In MPOC-20?
Coordinated and Comprehensive Care for Child and Family	
Suggest therapy plans that fit with your family's needs and lifestyle?	N
Explain things to your child in a way that your child understands?	N
Take the time to establish rapport with you or your child when changes occur in your services?	N
Discuss with you everyone's expectations for your child, so that all agree on what is best?	N
Make sure that your child's skills are known to all persons working with your child, so the skills are carried across services and service providers?	N
Provide ideas to help you work with the health care "system"?	N
Recognize the demands of caring for a child with special needs?	N
Look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at the physical needs?	Y
Show sensitivity to your family's feelings about having a child with special needs (e.g., your worries about your child's health or function)?	N
Follow up at the next appointment on any concerns you discussed at the previous one?	N
Make sure that at least one team member is someone who works with you and your family over a long period of time?	Y
Develop both short-term and long-term goals for your child?	N
Plan together so they are all working in the same direction?	Y
Make sure you are informed ahead of time about any changes in your child's care (e.g., therapists, programs, equipment)?	N
Seem aware of your child's changing needs as he/she grows?	N
Make themselves available to you as a resource (e.g., emotional support, advocacy, information)?	N
Give you information about your child that is consistent from person to person	Y
Respectful and Supportive Care	
Accept you and your family in a nonjudgmental way?	N
Remember personal details about your child or family when speaking to you?	N
Provide a caring atmosphere rather than just give you information?	Y
Treat you as an individual rather than as a "typical" parent of a child with a disability?	Y
Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	Y
Help you to feel competent as a parent?	Y
Provide enough time to talk to you so you don't feel rushed?	Y
Treat you and your family as people rather than as a "case" (e.g., by not referring to you by diagnosis, such as "the spastic diplegic")?	N
Have support staff that are polite and courteous to you and your family?	N

¹ Each item begins, "To what extent do the people who work with your child...", or, where applicable, "To what extent does the centre where you receive services...". Published with consent of the authors. © King, Rosenbaum & King, *CanChild* Centre for Childhood Disability Research, December, 1998, McMaster University, Hamilton, ON Canada.

6

Family-centred services in the Netherlands: validating a self-report measure for paediatric service providers

Renate C. Siebes¹, Marjolijn Ketelaar^{2,3}, Lex Wijnroks¹,
Petra E.M. van Schie⁴, Bianca J.G. Nijhuis⁵, Adri Vermeer¹, Jan Willem Gorter^{2,3}

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands; ³University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁴VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands; ⁵Center for Rehabilitation, University Medical Center Groningen, University of Groningen, Groningen, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Objective: The objective was to validate the Dutch translation of the Canadian Measure of Processes of Care for Service Providers questionnaire (MPOC-SP) for use in paediatric rehabilitation settings in the Netherlands.

Design: The construct validity, content validity, face validity, and reliability of the Dutch MPOC-SP were determined.

Subjects: The 163 service providers that participated in the validation study represented seven paediatric rehabilitation centres and affiliated schools in the Netherlands (overall response rate 55.6%). In this sample 19 disciplines were represented.

Main measures: The MPOC-SP consists of 27 items (assessing four domains) and was designed to examine how service providers think about the quality of care they provide and to assess the extent to which these services are family-centred. Fifty-three service providers filled out an additional face validity questionnaire.

Results: All items correlated best and significantly with their own scale score (r_s .48 to .82, $p < .001$). The Pearson's correlation coefficients were all significant and confirmed that the four scales measure different aspects of a same construct, namely family-centred service. The content validity and the face validity of the Dutch MPOC-SP were good, indicating the questionnaire measures relevant aspects of family-centred service delivery in paediatric rehabilitation settings in the Netherlands. The test-retest analyses (ICC .83 to .89) and the internal consistency analyses (α .65 to .84) showed that the Dutch MPOC-SP is a reliable tool.

Conclusions: The Dutch MPOC-SP is a reliable and valid instrument to measure the family-centredness of service delivery.

6.1 Introduction

Today, the concept of family-centred service dominates the service delivery in paediatric rehabilitation. In order to be able to evaluate the family-centredness of the care for children with disabilities, over the years several measures have been developed to evaluate the provided care from the perspectives of all who are involved, *i.e.*, clients, parents, and service providers.

The concept of family-centred service first came into use in the 1950s, when Carl Rogers¹⁶⁰ introduced an approach that gave control to the client as opposed to the service provider. Also in this decade, Scherz¹⁶⁹ and Birt⁹ used the term to describe family-centred ways of service delivery to children and their families. In the 1960s the "client-centred" approach was first adopted in the care for children with disabilities and their families. By the end of the 1970s practice and research had learned professionals working with children with disabilities that the most effective services focus on the family rather than the professional-child diad. Since then, families are involved in their child's care and have the opportunity to learn more about their child and (options for) their child's treatment. Family members in turn are able to share their knowledge with professionals, which provides a more holistic picture of the child and a way to heighten awareness of

the child as part of the family. Since the shift towards family involvement in paediatric care, the concepts of family-centred care and family-centred service have been researched and described thoroughly.^{1,205}

Family-centred service is offered and available to all family members and is characterized by an equal partnership between families and service providers, respectful and supportive care, and an emphasis on child and family strengths and resources needed for normalized patterns of living.^{4,36,49,58,61,79,90,97,110,120,161,173} With the family unit as the primary and principal context for promotion of child health and well-being, family-centred service has been shown to contribute to parents' emotional well-being.^{88,91,92,161} There is also evidence that family-centred service fosters parental satisfaction with services.^{49,79,88,90,92,97,110,161}

Table 6.1 Instruments used to evaluate family-centred service

Instrument	Year	Scope	Respondent
• Family-Focused Intervention Scale	1990	EIP	Parent questionnaire
• Brass Tacks: A self-rating of family-centred practice in early intervention	1991	EIP	Service provider questionnaire
• FOCAS: Family Orientation of Community and Agency Services	1993	CAS	Service provider questionnaire
• Issues in early intervention	1993	EIP	Service provider questionnaire
• FamPRS: Family-Centred Program Rating Scale	1995	EIP	Service provider questionnaire
• MPOC: Measure of Processes of Care	1996	CDS	Parent questionnaire
• Family-Provider Interaction Analysis	2000	EIP	Analysis of verbal behavior between parent and service provider
• MPOC-SP: Measure of Processes of Care for Service Providers	2001	CDS	Service provider questionnaire
• MBP-FCS: Measure of Beliefs about Participation in Family-Centred Service	2003	CDS	Parent and service provider questionnaire
• GYV-20: Giving Youth a Voice Questionnaire	2003	CDS	Adolescent questionnaire

EIP, early intervention program(s); CAS, community and agency services; CDS, childhood disability services.

To date, several measures have been developed to evaluate the family-centredness of services for children with disabilities.^{5,63,65,75,87,90,119,128,136,216} The measures either choose the care recipients' perspective, the service providers' perspective or the child's perspective to evaluate the family-centredness of the services. Most instruments are somewhat narrow in their scope because they only include certain age groups, diagnoses, disciplines, or behaviours. Table 6.1 shows the results of our literature search for valid and reliable measures that are available to evaluate the degree of family-centredness of intervention programs. The majority of these measures come from the early intervention field. Only in the last decade, family-centred service has been applied to the whole field of paediatric rehabilitation, resulting in new instruments with a broader scope.^{63,87,90,216}

Of these measures, the Measure of Processes of Care (MPOC)⁹⁰ is the most widely used measure to capture the family-centredness of service delivery from a parent's perspective. To date, the MPOC has been translated into five languages (French, Dutch, Swedish, Finnish, and German), and has been distributed to 23 countries around the world.⁹⁵

At the present time the Measure of Processes of Care for Service Providers (MPOC-SP)²¹⁶ is the only broadly focused, valid, and reliable instrument that is available for the evaluation of family-centred service by service professionals. Other instruments that have been designed to address family-centred perceptions of service providers only investigate professional beliefs and attitudes, not reported practices. This self-assessment measure of family-centred service equips professionals with a tool that can give them information about how family-centred their way of working is, and may thereby lend valuable insights into the practice of family-centred service and make service providers more aware of the family-centred ideal.^{97,110} Since family-centred service is gaining ground in the Netherlands, those were important arguments to validate a Dutch translation of the MPOC-SP. The main objective of the present study was to examine the psychometric qualities, or more specifically, the construct validity, the content validity, the face validity, the internal consistency, and the reliability of the Dutch version of the MPOC-SP.

6.2 Methods

6.2.1 Instruments

6.2.1.1 The Measure of Processes of Care

The MPOC is a 56-item self-administered questionnaire for parents to quantify the extent to which they experience family-centredness in the care for their children.⁹⁰ Each of the MPOC items is included in one of five scales derived by factor analyses: (1) *Enabling and Partnership* (16 items); (2) *Providing General Information* (nine items); (3) *Providing Specific Information about the Child* (five items); (4) *Coordinated and Comprehensive Care for Child and Family* (17 items); and (5) *Respectful and Supportive Care* (nine items). The MPOC was developed as a discriminative measure to discern differences in parents' perceptions of service delivery. Close to 2000 Canadian parents participated in a series of qualitative and quantitative studies which accompanied the various stages of the development of the MPOC. The result was a well-validated measure of parents' perceptions of the caregiving process, which tapped all aspects of care that are most important to parents.⁹⁰

6.2.1.2 The Measure of Processes of Care for Service Providers

The MPOC-SP was designed to measure the family-centred behaviours of health professionals working with children with chronic health or developmental problems in a systematic way. This four-scale 27-item measure was based on the 56-item MPOC, of

which 18 items were altered or eliminated because they addressed attitudes and beliefs, which were considered not appropriate for a self-assessment tool that seeks to quantify behaviours, rather than beliefs and attitudes. After a factor analysis ($n = 324$) another 11 items were eliminated because their factor loadings did not meet the statistical criterion that was set.²¹⁶

The items are arranged according to four scales:

- *Showing Interpersonal Sensitivity* (SIS; 10 items): items describe care that actively involves parents in their child's care
- *Providing General Information* (PGI; 5 items): consists of items that meet the general information needs of parents
- *Communicating Specific Information about the Child* (CSI; 3 items): items reflect behaviours through which parents obtain information about their own child
- *Treating People Respectfully* (TPR; 9 items): items reflect care in which all family members are treated with respect

Items are not weighted, therefore scale scores can be calculated as the mean of the ratings for the items in the scale. Since the response options range from 1 ("never") to 7 ("to a great extent"), scale scores can range from 1.00 to 7.00. The service providers are asked to think back over the past year and choose one of the seven response options to indicate how much this event or situation happened to them. All response options are labelled, and a "not applicable" category is also included. The phrasing of items and response options captures both the quantitative and qualitative nature of service providers' experiences, rather than a mere frequency count of occurrences.

The original Canadian MPOC-SP was translated into Dutch separately by two individuals. The consensus version of the Dutch questionnaire was then back-translated into English by an independent professional translator, compared with the original, and approved. In the MPOC-SP, service providers indicate how much the events did happen to them in the past year. In the Dutch research version the professionals additionally rated how important they found the events or situations on a five-point scale from 0 (not at all important) to 4 (very important) in order to check the content validity of the Dutch MPOC-SP.

6.2.1.3 Face validity questionnaire

This 26-item questionnaire was designed to assess the face validity and content validity of the Dutch MPOC-SP. Questions about the contents of the MPOC-SP and what the MPOC-SP purports to measure were asked. Service providers could add or omit topics and indicate which items they found most or least important. Also, questions were asked about the applicability of the MPOC-SP in Dutch paediatric rehabilitation settings.

6.2.2 Participants

In the present study, service providers of seven centres and affiliated schools participated. These centres were of different size and were situated in different parts of the Netherlands, covering both rural and urban areas.

The MPOC-SP questionnaires were distributed together with a letter with information about the study. All questionnaires were returned directly and anonymously to the researchers at Utrecht University. No reminders were sent. The sample size was based on general guidelines requiring five to ten subjects per variable or item in order to conduct the planned analyses,^{140,141} which means at least 135 respondents had to be recruited for the validation of the Dutch MPOC-SP.

In order to obtain retest information, one centre was asked to keep a list of names and respondent numbers at the first mailing. At subsequently four weeks, three months, and six months after the initial mailing all service providers of that list received another MPOC-SP with their unique identification number and a request to participate in the stability study. Of the three time samples, the first sample at four weeks after the baseline represents the test-retest reliability. It was not expected that respondents could recall their answers four weeks later. Similarly, it was thought unlikely that new experiences during these four weeks would have a great influence on the responses. The follow-up at about three months and at about six months represent the stability of the Dutch MPOC over a longer period of time.

All service providers of this centre were also asked at the initial mailing to fill out an additional 26-item questionnaire that was designed in order to collect information about the face validity of the Dutch MPOC-SP and the applicability of the MPOC-SP in the Netherlands. Service providers who worked at this centre were given time to fill out both the MPOC-SP and the face validity questionnaire —individually— during a team conference meeting. The face validity data represent a sample of service providers of one paediatric rehabilitation setting, but still are a comparatively good reflection of most of the disciplines who work in multidisciplinary teams in paediatric rehabilitation settings in the Netherlands.

6.2.3 Statistical analyses

First of all, the skewness and kurtosis of the items had to be examined to determine whether parametric statistics could be performed.

The construct validity of the Dutch MPOC-SP was explored using two different analyses. Spearman's rank correlation coefficient (r_s) was used to confirm the original factor structure and examined the correlation between an item score and its scale score without that item and other scale scores. Pearson's product-moment correlation coefficient (r) was used to analyze the correlations between the scales. The content validity and the face validity of the Dutch MPOC-SP were examined with qualitative and quantitative analyses of data derived from the additional 26-item questionnaire that was filled out by

a representative sample across professional disciplines in one of the participating centres ($n = 53$) and importance ratings of the MPOC-SP items ($n = 163$).

The test-retest reliability and the stability of the Dutch MPOC-SP were examined at three follow-up moments using intraclass correlation coefficients (ICCs).¹⁷⁶ To determine the stability, only the questionnaires of service providers who reported nothing had changed during the past three months were used. ICC values above .80 represent a good reproducibility and are generally found acceptable for clinical work.^{38,187} For each of the four scales Cronbach's α coefficient was calculated as a measure of internal consistency. Alphas between .70 and .90 are generally considered good and show that the items of that scale measure about the same aspect. Higher alphas may indicate a high level of item redundancy, which means that some of the items measure the same aspect in a slightly different way.¹⁹⁶

6.3 Results

Of the 293 MPOC-SP questionnaires that were sent out, 164 were returned and analyzed (response rate varying from 39.3% to 83.3% between settings, with a mean of 64.0%). Table 6.2 displays the scale means, standard deviations, and other descriptive statistics, including internal consistency reliabilities (Cronbach's α).

Table 6.2 Descriptive statistics for the MPOC-SP

Scale	n_i	n	m	sd	Min	Max	Range	α	n_α
SIS	10	163	4.56	.80	1.13	7.00	5.87	.74	117
PGI	5	160	4.06	1.08	1.00	6.40	5.40	.84	133
CSI	3	160	5.15	1.02	1.00	7.00	6.00	.65	136
TPR	9	162	5.59	.61	2.50	6.67	4.17	.66	150

SIS, Showing Interpersonal Sensitivity; PGI, Providing General Information; CSI, Communicating Specific Information about the Child; TPR, Treating People Respectfully; n_i , number of items; n , number of subjects; m , mean scale scores; sd , standard deviations; Cronbach's α , internal consistency; n_α , number of subjects in internal consistency analyses. n varies due to missing data.

In the study sample 19 disciplines were represented, among which physical therapists (20.9%), occupational therapists (20.2%), teachers (12.3%), speech therapists (10.4%), and physicians in paediatric rehabilitation medicine (9.8%) were the largest respondent groups (73.6% of total group). Analyses of variance of the non-response did not reveal significant differences in the response pattern of the five largest disciplines in our study sample, which represented almost three quarters of the total study sample ($F(4, 157) = 1.046$; $p = .386$).

Of the 113 service providers that received the face validity questionnaire, 53 were completed and returned (response rate 46.9%). There were three retest moments, at four weeks ($n = 13$), at three months ($n = 20$), and at six month ($n = 22$). The second, third, and fourth administration took place after a mean of 30 ($sd = 9.7$), 103 ($sd = 14.2$), and 186 days ($sd = 9.3$), respectively.

Firstly, the distributions of the scores were examined to determine the skewness and kurtosis of the scale scores. Twenty-two items used the full range of the response options. Item 23 ("promote family-to-family connections") had the lowest mean item score (3.70, $sd = 1.40$), whereas item 22 ("treat children and their families as people rather than as 'cases'") had the highest mean score (5.98, $sd = 1.14$). The distributions were not found to be severely skewed, even though all items scored above the mean and some of the mean scores tended toward the higher end of the scale's range. The vertical distribution of the item scores had three peaks (above 4.5), but the overall kurtosis was not deviant. Therefore, it was considered permissible to analyze the ordinal data of the MPOC-SP with parametric statistics.^{196,201}

Various analyses were performed to assess the construct validity of the MPOC-SP. To confirm the factor structure, items were correlated with their own and the other three scale scores (using Spearman's rank correlation coefficient). With r_s ranging from .48 (item 18 with *Treating People Respectfully*) to .82 (items 24 and 26 with *Providing General Information*), all items correlated best and significantly with their own scale score ($p < .001$). Further, Pearson's product-moment correlation coefficients were calculated. The Pearson correlation coefficients showed that all scales correlated significantly with each of the other scales (Table 6.3).

Table 6.3 Correlation between the MPOC-SP scales using Pearson's product-moment correlation coefficient (r)

Scale	SIS	PGI	CSI	TPR
Showing Interpersonal Sensitivity (SIS)	1	.596**	.398**	.319**
Providing General Information (PGI)		1	.464**	.315**
Communicating Specific Information about the Child(CSI)			1	.184*
Treating People Respectfully (TPR)				1

*Correlations with $p < .05$ (2-tailed); **correlations with $p < .01$ (2-tailed).

All service providers were asked to rate the importance of the separate items on a five-point scale with a range from 0 (not important) to 4 (very important) in order to check the content validity of the Dutch MPOC-SP. All mean importance ratings of the items were above 2.5. Item 22 ("treat children and their families as people rather than as 'cases'") had the highest mean score ($mean = 3.45$, $sd = .61$), and item 9 ("anticipate parents' concerns by offering information even before they ask") was found to be least important by Dutch service providers ($mean = 2.61$, $sd = .67$).

In the face validity questionnaire the service providers were asked to describe what the MPOC-SP purports to measure. All answers to this question contained elements of the definition of family-centred service delivery. When asked directly, Dutch service providers rated the ability of the MPOC-SP to measure the family-centredness of services with 7.13 ($sd = 1.33$) on a scale of 1 to 10. These findings support the face validity of the Dutch MPOC-SP.

Table 6.4 provides the mean scale scores and standard deviations of the four waves. The data demonstrate that the scale scores fluctuate randomly and do not show a biased change between the four waves. The test-retest reliability and the stability of the Dutch MPOC-SP were examined using ICCs. The ICCs of the time interval between the first and the second administration, testing the test-retest reliability, were good and ranged from .83 (*Showing Interpersonal Sensitivity*) to .89 (*Treating People Respectfully*). The stability scores of the third and the fourth administration of the MPOC-SP, measured against the first administration, were moderate (see Table 6.5).

Table 6.4 Mean scale scores and standard deviations of the four MPOC-SP waves

Scale	Baseline			Retest at 4 weeks			Retest at 3 months			Retest at 6 months		
	<i>m</i>	<i>sd</i>	<i>n</i>	<i>m</i>	<i>sd</i>	<i>n</i>	<i>m</i>	<i>sd</i>	<i>n</i>	<i>m</i>	<i>sd</i>	<i>n</i>
SIS	4.56	.80	163	5.07	.55	13	4.76	.60	20	5.27	.72	22
PGI	4.06	1.08	160	3.87	1.30	13	4.31	1.11	20	4.34	1.16	21
CSI	5.15	1.02	160	5.21	1.14	13	4.91	1.48	20	5.06	1.61	22
TPR	5.56	.61	162	5.93	.48	13	5.68	.68	20	5.82	.86	22

SIS, Showing Interpersonal Sensitivity; PGI, Providing General Information; CSI, Communicating Specific Information about the Child; TPR, Treating People Respectfully; *m*, mean scale score; *sd*, standard deviation; *n*, number of subjects. *n* varies due to missing data.

Table 6.5 Test-retest reliability and stability of the MPOC-SP (ICCs)

Scale	Retest at 4 weeks		Retest at 3 months		Retest at 6 months	
	ICC	<i>n</i>	ICC	<i>n</i>	ICC	<i>n</i>
Showing Interpersonal Sensitivity	.83	13	.84	20	.88	22
Providing General Information	.89	13	.51	20	.52	21
Communicating Specific Information about the Child	.86	13	.79	20	.68	22
Treating People Respectfully	.83	13	.65	19	.85	21

ICC, intraclass correlation coefficient; *n*, number of subjects. The scores of the second, third, and fourth wave were compared with the scores of the first wave. *n* varies due to missing data.

For each of the four scales Cronbach's α was calculated to assess the homogeneity of the scales (last column Table 6.2). Two scales (*Showing Interpersonal Sensitivity* and *Providing General Information*) showed good internal consistency with alphas of .75 and .84, respectively. The other two scales had lower, yet still adequate, alphas (.65 and .66 for *Communicating Specific Information about the Child* and *Treating People Respectfully*). The internal consistency data also provide evidence for the construct validity of the measure and demonstrate the homogeneity of each scale's content.

6.3.1 Applicability of the MPOC-SP

To determine the applicability of the Dutch MPOC-SP, 53 service providers gave their meaning about various aspects of the use of the MPOC-SP in daily practice. A vast majority of the respondents evaluated the length and the phrasing of the Dutch MPOC-SP as satisfactory. Some service providers found the questions suggestive, or had difficulties to reflect their actual behaviour instead of desired behaviour. Further, they remarked the 27 items are not universally applicable to all professions. The respondents believe the MPOC-SP can be filled out by physical therapists, occupational therapists, speech therapists, social workers, teachers, physicians in paediatric rehabilitation medicine, psychologists, and group leaders. The items 6 ("accept parents and their family in a nonjudgmental way"), and 5 ("tell parents about options for services or treatments for their child"), respectively, were judged most important for family-centred care, whereas the items 13 ("answer parents' questions completely"), and 19 ("make sure parents had opportunities to explain their treatment goals and needs") were valued least important. *Treating People Respectfully* (43.8%) and *Showing Interpersonal Sensitivity* (35.4%) were seen as the most important scales for family-centred service. Both the discriminative power of the MPOC-SP and the power to measure changes over time were rated "good". More than 90% of the service providers responded the MPOC-SP can be used to evaluate the quality of care. The quality or research coordinator of the centre, or the head of the team, should take the initiative to distribute the questionnaires, and specialized analysts, preferably external, should report the results.

6.4 Discussion

When a questionnaire is translated into another language, the validity and reliability of the translated measure should be determined once again. The main goal of the present study was to examine the validity and reliability of the Dutch version of the MPOC-SP. Like the Canadian MPOC-SP, the Dutch MPOC-SP is a psychometrically strong instrument, with good evidence of content and construct validity with a sound confirmation of the scale structure, internal consistency and moderate to good reliabilities. Nevertheless, some remarks must be made.

In the present study, the response rate was rather low (163 out of 293 questionnaires, 55.6%). Two factors may have contributed to this moderate response rate. First, in the current study, all service providers actively involved in the care for children, including teacher assistants, group leaders, nurses, and care managers, received an MPOC-SP questionnaire. Some of the non-respondents decided the MPOC-SP was not applicable to their profession. For the greater part these were professionals who had parent contacts in a very low frequency, partly due to their role in the caregiving process. Second, not all centres were able to make some time available for the service providers to fill out the MPOC-SP. This might have lowered the response rate, because the service providers have very tight working schedules. Centres that made filling out MPOC-SP part of the team conference had higher response rates. Centres that were involved in a national rehabilitation research program (PERRIN) had the highest response rates of about 70%. These respondents were probably more interested in the subject because of their active participation in the national research program. Since analyses of variance of the non-response did not reveal significant differences in the response pattern of the five largest disciplines in our study sample, which represented almost three quarter of the total study sample, the data were not considered to be severely biased by an unequal non-response among the disciplines.

The analyses of the scale structure showed that the items within each scale group together in a statistically as well as a clinically meaningful way. Moreover, the Pearson's product-moment correlation coefficients confirmed that the four scales measure different aspects of a same construct, *i.e.*, family-centred service. All mean importance ratings of the items were above 2.5 on a five-point scale. This indicates that the aspects of family-centred service delivery that are captured in the MPOC-SP are just as valid for Dutch family-centred services as they are for Canadian family-centred services.

The results also supported the hypothesis that the Dutch MPOC-SP scale scores are consistent over four weeks of time, and thus have a good test-retest reliability, yet the evidence for the long-term stability of the MPOC-SP was not conclusive. Similar to the results of the Dutch MPOC validity study,²⁰⁹ *Providing General Information* has the lowest stability score. After six months, *Showing Interpersonal Sensitivity* and *Treating People Respectfully* still have high ICCs, whereas the other scales have lower ICCs. This finding may be explained from the fact that *Showing Interpersonal Sensitivity* and *Treating People Respectfully* for the most part measure stable character traits. The responses to the items in *Communicating Specific Information about the Child* may be influenced by recent events, such as team conference meetings or another meeting with parents.

The Cronbach's α for the four scales ranged from .65 to .84, where the Canadian reliability study reported a range of .76 to .88. Although two of the values did not exceed the minimum α of .70 for "good internal consistency" in our study, all were still adequate.

When the MPOC-SP is being used in daily practice the issue of measurement bias should be noticed by the interpreters of the questionnaires. As is the case with all other self-evaluative measurement tools, it remains unclear whether the respondents reflected

on actual or on desired behaviour, both consciously or unconsciously. Moreover, the service providers' perception of the provided care may deviate from the perceptions of the receivers of the care. We therefore believe it is always best, especially when evaluating family-centred services, to ask all who are involved for their opinion about the topic. To get a holistic picture of the quality of family-centred services, for instance, parents can fill out the MPOC, the MPOC-SP is available for service providers, and the Giving Youth a Voice Questionnaire (GYV-20),⁶³ which is based on the MPOC, can be completed by youngsters.

The MPOC-SP purports to measure whether service providers behave in a family-centred way, but does not ask them for their reason to do so, or not. All contextual factors, such as individual differences, administrative restrictions, contradictory values and beliefs, or a combination of these, are left out of account in the MPOC-SP.²¹⁶ Consequently, it is probably not sufficient to use solely the MPOC-SP to determine weaknesses and strengths of a program. The *CanChild* research group developed the Measure of Beliefs about Participation in Family-Centred Service (MBP-FCS)⁸⁷ for this purpose. The MBP-FCS measures the individual's beliefs about family-centred service, and is appropriate for use with parents and service providers. By combining the scores of the MPOC-SP with MPOC and GYV-20 scores and results of the MBP-FCS, the perceptions of and beliefs about family-centred service of parents, youngsters, and service providers can be examined.

Service providers reported that it was not always meaningful to give a mean rating for a certain behaviour. Sometimes families or children asked for an opposite approach, for instance, because of their cultural background, or because of the specific diagnosis of the child. When the MPOC-SP is being used to improve the family-centred service delivery to a certain small group, or to a specific child or family, it would seem evident to let each team member fill out one MPOC-SP for each family. The combined scores of the family-bound MPOC-SPs that were filled out for one family, may provide a more meaningful view on the service delivery to this family. Research is needed to determine whether the MPOC-SP can be used in this way. Furthermore, it would be interesting to investigate the applicability of the MPOC-SP in other settings, such as hospitals and residential long term care institutes.

The Dutch version of the MPOC-SP, which was validated with the present study, can be used to compare programs or teams, pinpointing their strengths and weaknesses. We believe the MPOC-SP will be a valuable tool for research and clinical purposes, especially on the domains of total quality management and program evaluation in paediatric rehabilitation settings in the Netherlands, providing that service professionals are given scheduled time to fill out the questionnaire.

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7

Validation of the Dutch Giving Youth a Voice Questionnaire (GYV-20): a measure of the client-centredness of rehabilitation services from an adolescent perspective

Renate C. Siebes,¹ Lex Wijnroks,¹ Marjolijn Ketelaar,^{2,3}
Petra E.M. van Schie,⁴ Adri Vermeer,¹ Jan Willem Gorter^{2,3}

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands;

³University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁴VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Aim: The objective was to validate the Dutch translation of the Canadian Giving Youth a Voice Questionnaire (GYV-20) for use in paediatric rehabilitation settings in the Netherlands. The GYV-20 consists of 20 items (assessing four domains) and was designed to evaluate the client-centredness of rehabilitation services from an adolescent perspective.

Methods: The construct validity, concurrent validity, and reliability of the Dutch GYV-20 were determined. Participants were 116 youngsters aged 11 to 21 years ($mean = 15.9$; $sd = 2.1$) recruited through six paediatric rehabilitation settings in the Netherlands.

Results: Correlations between the GYV-20 scale scores were positive ($r = .69 - .78$). The GYV-20 showed adequate internal consistency, with Cronbach's α ranging from .76 to .81. The ICCs of test-retest reliability ranged from .82 to .92, which demonstrated good stability of the GYV-20. Dutch adolescents judged the GYV-20 as a valuable and useful tool to evaluate rehabilitation services in the Netherlands.

Conclusion: The Dutch GYV-20 showed sufficient evidence of construct validity and good reliabilities. The Dutch GYV-20 offers users a useful measurement option for various research and clinical purposes.

7.1 Introduction

Today, the concept of family-centred service has become increasingly important in paediatric rehabilitation services. The topic has been examined and described extensively in literature.^{36,62,104,116,161} However, the majority of this research has focused on parents' or adults' perceptions of service delivery, without taking into account the unique views of adolescents and young adults. As youngsters may have a very different view about what is helpful or not helpful, the evaluation of services is incomplete when the young person's perspective is not taken into account. Such data may give valuable information for improving the quality of health care to adolescents and young adults. The present study was carried out to provide the Dutch paediatric rehabilitation field with a validated measure of the client-centredness of services from an adolescent perspective, in the present paper also referred to as teen-centredness of services.

Family-centred service can be described as an holistic approach towards service delivery, in which the unique strengths, resources and set of needs of each child and its family form the base for a highly individualized and dynamic model of care.^{49,97,116} Parents and team members are equal partners and work together jointly, sharing aims, information, and responsibilities. In the treatment of the young child the problems parents encounter are valued most, but when the child gets older, the issues the child brings in itself will form an increasingly important base of the treatment plan. As the adolescent ages, he will grow more and more independent and care will gradually become a good mix of family-centredness and client-centredness of services. In the Netherlands, adolescents

may attend their own team conference meeting when they turn 16 years.

Research indicates that providing family-centred service is associated with an increase in parent skills and knowledge about child development, enlarged parent satisfaction with services, decreased parental stress and improved well-being,^{88,90,92,151,161} improved children's psychological adjustment,^{112,190,191} and child developmental gains and skill acquisition.^{26,107,134} Satisfaction with services has been shown to increase the partnership between service providers and parents.^{88,90}

Over the years, several measures have been developed to evaluate satisfaction with the family-centredness of services for children and youngsters with disabilities.¹⁷⁸ Of these measures, the Measure of Processes of Care (MPOC)⁹⁰ is the most widely used measure to capture the satisfaction with service delivery from a parent viewpoint. The only measure to evaluate satisfaction with services from an adolescent or young adult perspective we found in literature was a reference to the Canadian Giving Youth a Voice Questionnaire (GYV-20)⁶³ developed by Gan, Campbell, Snider, and Hubbard in 2003, who used the MPOC as a starting point (personal communication). The authors of the GYV-20 presented their preliminary data on the reliability and validity of the instrument on a poster in 2003 and concluded that the GYV-20 has potential utility for program evaluation and quality management.²¹ Together with the MPOC⁹⁰ (parent viewpoint) and the Measure of Processes of Care for Service Providers (MPOC-SP; perception of service providers)²¹⁶ the GYV-20 will form a comprehensive test battery to evaluate the family-centredness and client-centredness of services from a viewpoint of all who are involved in the process of care.

In the Netherlands, the MPOC²⁰⁹ and the MPOC-SP¹⁷⁸ were made available recently, but a valid measure to ask for the adolescent's or young adult's view on the process of care was not available yet. Since one of the official aims for future paediatric rehabilitation in the Netherlands is to pay more attention to youth,²¹³ such a measure has a high clinical relevance. The objective of the current study was to examine the psychometric qualities, or more specifically, the construct validity, the concurrent validity, the internal consistency, and the test-retest reliability of the Dutch translation of the GYV-20.

7.2 Methods

7.2.1 Instruments

7.2.1.1 Giving Youth a Voice Questionnaire

The GYV-20 was developed by the Canadian Bloorview McMillan Children's Centre (Toronto, Ontario) to assess the teen-centredness of paediatric rehabilitation care as perceived by adolescents and young adults. Focus groups which were held with adolescents and young adults identified four major themes within teen-centred services: (1) *Supportive and Respectful Relationships*; (2) *Information Sharing and Communication*; (3) *Sup-*

porting Independence; and (4) *Teen-Centred Services*. MPOC items that fit into one of the four themes were taken over and adapted. Additional items were generated from the focus group interviews. The 76-item questionnaire was then reviewed by researchers, managers, clinicians, and adolescent clients and brought back to a 56-item questionnaire, which was named the MPOC-A. This measure was filled out by 104 respondents to determine the validity and reliability of the instrument. The authors reported first evidence of good reliability and validity of the 56-item MPOC-A in an abstract.²¹ To increase the user-friendliness of the MPOC-A, the questionnaire was shortened. This resulted in a 20-item measure with the items equally divided over four scales covering the four identified themes. Some sample items are presented in Table 7.1. The measure was renamed the Giving Youth a Voice Questionnaire (GYV-20), because the contents had evolved considerably from the original MPOC.

Table 7.1 Sample items GYV-20⁶³

Scale	Sample item
	How much do the people who work with you...
Supportive and Respectful Relationships	... Explain when they are late or there are delays?
Information Sharing and Communication	... Make sure you have a chance to say what is important to you?
Supporting Independence	... Give you information to prepare you for living on your own?
Teen-Centred Services	... Offer groups for young people to talk about shared experiences?

Published with consent of the authors.

Each GYV-20 item is presented as a question "How much do the people who work with you...", followed by an item describing a specific action or behaviour of health-care professionals. The instructions ask the respondents to think back over the past year and choose from one of the seven response options to "indicate how much this event or situation happened to you". Three of the response options are labelled: a value of 1 corresponds with "never", 4 with "sometimes", and 7 with "a lot". A "not applicable" category is also included. The phrasing of the questions and response options was selected to capture both the quantitative and qualitative nature of adolescents' experiences rather than a mere frequency count of occurrences. Items are not weighted; therefore scale scores can be calculated as the mean of the ratings for the items in the scale. Since the response options range from 1 to 7, scale scores can range from 1.00 to 7.00.

The original Canadian GYV-20 was translated into Dutch independently by two members of our research group. The consensus version of the questionnaire was then back-translated into English by a professional translator. The research version of the Dutch GYV-20 was approved by the Canadian authors.

7.2.1.2 General questionnaire

Extra questions in a separate questionnaire gathered background information about the respondents (age, gender, disability, and type of care), asked about experiences filling out the GYV-20 (opinion about length, ease, and instructions), and assessed the participants' overall satisfaction about the care provided to them by the centre during the past year on a five-point scale which ranged from "not at all satisfied" to "very satisfied". The most obvious choice to determine the GYV-20's concurrent validity would be to include the Client Satisfaction Questionnaire (CSQ)¹⁰³ in our study. However, this questionnaire is not suitable to be filled out by adolescents, and by altering the contents, the questionnaire would have to be validated once again. The aforementioned variable, that correlated highly with CSQ scores in a previous study,²⁰⁹ was therefore chosen to determine the concurrent validity.

7.2.1.3 Interview

An additional interview contained ten questions about taking part in our study and filling out the GYV-20. For example, the interviewees were asked as to whether they thought it is important that adolescents and young adults are asked for their opinion, and whether the GYV-20 is a good way to do so.

7.2.2 Participants

A convenience sample of adolescents and young adults with various diagnoses was recruited through six paediatric rehabilitation settings in the Netherlands. The physicians in paediatric rehabilitation medicine of the participating centres selected all youngsters who were treated by service providers of the paediatric rehabilitation department regularly either on an inpatient or outpatient basis, and who were considered to be able to understand the questions and fill out the GYV-20. Moreover, to draw respondents, advertisements about the study were placed in relevant journals and on several websites, and posters and flyers were sent to all Dutch high schools for adolescents with special needs. The sample size was based on general guidelines requiring five to ten subjects per variable or item in order to conduct the planned analyses.^{140,141} Since the GYV-20 has 20 items, a sample of between 100 and 200 subjects was considered appropriate.

Adolescents and young adults who were approached via their rehabilitation centre received a letter of endorsement from this centre, an information leaflet, an informed consent form, the GYV-20, and a stamped return envelope. Out of 403 adolescents and young adults of the initial mailing, 116 (41.4% male, 58.6% female) participated in the study (overall response rate: 28.8%; range 13.5 – 48.3% among the six participating centres). Only one adolescent responded to our advertisements. Seventeen respondents consented with an interview. The ages of the respondents ranged from 11 to 21 years, with a mean of 15.9 years ($sd = 2.1$). Figure 7.1 shows the age distribution. Initially, we

had set 12 years as the lower inclusion limit and 18 years as the upper inclusion limit, but it soon appeared that being treated actively by the paediatric rehabilitation department was a better criterion, because not all young adults moved on to adult rehabilitation at age 18, and some of the 11-years-old were already treated by an adolescent rehabilitation team. A wide range of disorders and functional limitations were represented in the study sample. The demographic characteristics of the respondents are displayed in Table 7.2.

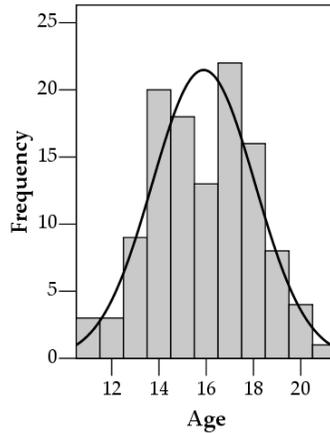


Figure 7.1 Age distribution respondents

Two of the participating rehabilitation centres consented with a reminder after about eight weeks, which was then sent out to all youngsters of the initial mailing ($n = 60$). In this second mailing we asked the youth who did not respond to send back a form on which they could indicate their reason for not responding. Of the 35 non-responders in these two centres, only eight sent back the non-response form. It appeared that these youngsters should not have been selected to participate in our study in the first place, because they had, for instance, no significant contacts with the rehabilitation centre over the past year, or had severe multiple disabilities with cognitive limitations. The reasons for not responding of the remaining adolescents and young adults (97.2%) remain unknown. In this second mailing, we invited the adolescents and young adults who did fill out the GYV-20 to participate in a short interview by telephone. Youngsters of the four other centres were approached by e-mail.

On the informed consent form, respondents could indicate whether they agreed to fill out another questionnaire four weeks later. According to general guidelines,¹⁹⁶ at least 10% of the minimum number of 100 respondents should fill out a second GYV-20 to be able to examine the test-retest reliability. All youth who gave their permission ($n = 91$) received a second GYV-20. Of this group, 61 responded and filled out a second GYV-20 (response rate 67.0%). It was thought unlikely that the youngsters could recall their responses on the 20 items four weeks later, and it was not expected that new experiences

Table 7.2 Demographic characteristics of the respondents ($n = 116$)

Gender	%
Male	41.4
Female	58.6
 Age range	 11 – 21 ($m = 15.9$; $sd = 2.1$)
Diagnose	%
Neuromuscular disorders	19.4
CRPS ¹ I or post-traumatic dystrophia	13.9
Cerebral palsy	12.0
Chronic fatigue syndrome	12.0
Congenital limb deficiency	7.4
Spina bifida/hydrocephalus	5.6
Acquired brain injury	5.6
Sensomotor developmental disorder	0.9
Other	23.1

¹ Chronic Regional Pain Syndrome. Percentages may not add to 100.0% due to rounding to one decimal place.

with health-care professionals during these four weeks would greatly influence their responses.

7.2.3 Statistical analyses

To determine whether parametric statistics could be performed in the validation process, the skewness and kurtosis of the GYV-20 items were examined at face value. In Western societies, the health care system is rated more favourable than the middle response option.^{10,94,122,198,209} Therefore, the scale scores in the present study were expected to be negatively skewed, because they pile up toward the higher end of the scale.

The construct validity of the Dutch GYV-20 was explored using two different analyses. Spearman's rank correlation coefficient (r_s) was used to confirm the original scale structure and examined the correlation between an item score and its scale score without that item and other scale scores. All items should correlate significantly and best with their own scale score. Further, Pearson's product-moment correlation coefficient (r) was used to analyze the correlations between the scale scores. The concurrent validity was examined using Pearson's product-moment correlation coefficient for the correlations between GYV-20 scale scores and a question about overall satisfaction with received services on a five-point scale. Coefficients between .20 and .80 are generally found acceptable for clinical work.¹⁹⁶ Higher correlations would indicate that the correlations are almost perfect and that separate factors can not be distinguished any longer. On the other hand, lower correlations could be a sign that the factors are that distinguished that they

might not represent the same construct anymore. For each of the four scales Cronbach's α was calculated as a measure of internal consistency. Alphas between .70 and .90 are generally considered good and indicate that the items in that scale measure about the same aspect.¹⁹⁶ The test-retest reliability of the Dutch GYV-20 was determined using intraclass correlation coefficients (ICCs).¹⁷⁶ ICC values above .80 represent a good reproducibility and are generally found acceptable for clinical work.^{38,187} Finally, the interviews were labelled and analyzed qualitatively.

7.3 Results

In the analyses 116 questionnaires of 48 boys and 68 girls were included. All the mean scale scores of adolescents younger than 16 years ($n = 51$) were higher than the mean scale scores of youngsters of 16 years and up ($n = 63$), but ANOVA's did not reach significance.

7.3.1 Skewness and kurtosis

Firstly, the distributions of the scores were examined at face value to determine the skewness and kurtosis of the scale scores. Fourteen items used the full range of the response options. The three labelled options were chosen most frequently. Item 5 ("talk to you honestly") had the highest mean item score ($mean = 6.11$; $sd = 1.17$), whereas item 11 ("inform you of how treatments might harm you or help you") had the lowest mean score ($mean = 5.35$; $sd = 1.52$). As expected, all four mean scale scores tended toward the higher end of the scale's range ($mean = 5.58 - 5.81$, see Table 7.3). Consequently, the central point of the distribution moved up to the higher end of the scale. From this regard the distributions were not very severely skewed. Further, the analyses did not show peaks in the distribution of the item scores.¹⁹³ Therefore, it was considered permissible to analyze the ordinal data of the GYV-20 with parametric statistics.^{196,201}

Table 7.3 Mean scale scores, reliability, and internal consistency of the Dutch GYV-20

Scale	n_i	n_s	m	sd	n_s	α	n_s	ICC
Supportive and Respectful Relationships	5	114	5.58	.99	99	.81	60	.87
Information Sharing and Communication	5	114	5.81	.96	94	.79	60	.82
Supporting Independence	5	114	5.69	1.06	103	.76	60	.91
Teen-Centred Services	5	114	5.71	1.07	99	.79	60	.92

n_i , number of items; n_s , number of subjects; m , mean scale scores; sd , standard deviations; Cronbach's α , internal consistency; ICC, intraclass correlation coefficient.

7.3.2 Construct validity

Various analyses were performed to assess the construct validity of the Dutch GYV-20. To confirm the scale structure, items were correlated with their own and the other three scale scores. With r_s ranging from .61 (item 5 with *Information Ssharing and Communication*) to .80 (item 15 with *Teen-Centred Services*), all items correlated best and significantly with their own scale score (all p 's < .001). Further, the Pearson correlation coefficients showed that all scales correlated significantly with each of the other scales (Table 7.4). Although the scales are theoretically distinct, the moderate size of the correlations showed that there is considerable overlap between the scales.

Table 7.4 Correlation between the GYV-20 scales using Pearson's product-moment correlation coefficient (r)

Scale	SRR	ISC	SI	TCS
Supportive and Respectful Relationships (SRR)	1	.75	.78	.74
Information Sharing and Communication (ISC)		1	.72	.69
Supporting Independence (SI)			1	.75
Teen-Centred Services (TCS)				1

All correlations with $p < 0.001$. $n = 114$.

7.3.3 Concurrent validity

The concurrent validity of the Dutch GYV-20 was examined using Pearson's correlation coefficients for the correlations between GYV-20 scale scores and a five-point scale overall satisfaction variable. Table 7.5 displays the correlations between the mean scale scores and the question about overall satisfaction, which ranged from .52 to .61 (all p 's < .001). By being modest, rather than very high, the correlations suggest a related, but somewhat different issue is being measured by the GYV-20.

Table 7.5 Association between the GYV-20 scale scores and a five-point scale overall satisfaction variable

Scale	r OS
Supportive and Respectful Relationships	.54
Information Sharing and Communication	.52
Supporting Independence	.52
Teen-Centred Services	.61

n , number of subjects; r , Pearson's product-moment correlation coefficient; OS, overall satisfaction. All correlations with $p < 0.001$. $n = 112$.

7.3.4 Reliability

For each of the four scales Cronbach's α was calculated to assess the homogeneity of the scales. The results of the internal consistency analysis are presented in Table 7.3 and demonstrate adequate internal consistency for each scale with α ranging from .76 (*Supporting Independence*) to .81 (*Supportive and Respectful Relationships*). The internal consistency data also provide evidence for the construct validity of the measure and demonstrate the homogeneity of each scale's content.

Sixty-one adolescents and young adults participated in the test-retest reliability study. The mean time interval between the first and the second administration was 30 days ($sd = 5.38$), with a range of 24 to 48 days. The ICCs of the test-retest reliability analyses, were good and ranged from .82 (*Information Sharing and Communication*) to .92 (*Teen-Centred Services*), as is shown in Table 7.3 (last column).

7.3.5 Adolescents' judgement about the GYV-20

All adolescents in our study sample completed four questions about the length and the ease of the Dutch GYV-20 and the instructions. Moreover, to determine the applicability of the Dutch GYV-20, 16 adolescents were interviewed by telephone about various aspects of the use of the GYV-20 in daily practice. The interview lasted about five minutes and the responses were quite unanimous.

Most of the respondents (82%) had understood all the GYV-20 questions, and 92% thought the instructions were clear. The items 11 ("inform you of how treatments might harm you or help you") and 13 ("treat you as an individual rather than like all other youth with a disability") were named most frequently as items that were difficult to understand. Almost three quarter of the youngsters considered the length of the questionnaire appropriate. A surprising 25% responded the questionnaire could have been longer. One third of the adolescents had help with reading, writing, or clarification of the questions while completing the GYV-20. Some of the respondents reported it was sometimes hard to give a mean judgement about all their health-care professionals, especially when one of them acted "extremely".

The interviewees all greatly appreciated that the GYV-20 gave them the opportunity to express their opinion about the care process. Only three of them had filled out an evaluation form in the past, but the remaining adolescents had never completed a questionnaire which asked them for their opinion about the provided care. They believed they were the best to judge their own care process because they were in the middle of it and had all the inside information. They assumed that their parents probably may have experienced and perceived the process differently. The 16 interviewed adolescents thought the GYV-20 could be a very useful tool in paediatric rehabilitation because it demonstrates "how they are doing", and shows what adolescents and young adults find important issues. Feedback of the results was considered important; the adolescents would like to be informed in what way the centre will use their ratings and remarks to improve the teen-

centredness of the care process. By filling out the GYV-20, the youngsters hoped to reach an equally good or even better treatment for the youngsters that will visit the centre after them.

7.4 Discussion

The goal of the present study was to examine the validity and reliability of the Dutch translation of a measure to evaluate the client-centredness of rehabilitation services from an adolescent's perspective: the Giving Youth a Voice Questionnaire (GYV-20). The Dutch GYV-20 is psychometrically strong, with sufficient evidence of construct validity and good reliabilities. Due to the lack of a validated indicator of overall satisfaction with rehabilitation services in adolescents we could only provide preliminary evidence of concurrent validity of the Dutch GYV-20. Dutch youngsters greatly valued the GYV-20 as a means to express their opinion about the teen-centredness of their care process. In our opinion the Dutch GYV-20 offers the user a valuable and usable measurement option for various research and clinical purposes, especially in the areas of program evaluation and total quality management.

The small overall response rate ($mean = 28.8\%$) in this study is a cause for concern. Numerous strategies have been described in literature to improve response rates, and thus the quality of the results of a study.^{2,52,196,215} These strategies include, for instance, follow-up of non-responders with a repeated mailing of the questionnaire, an attractive format of the questionnaire, reduction of the length of the questionnaire, a catching personalized covering letter, giving a token of appreciation for participation, a guaranty of anonymity, and the enclosing of a stamped, self-addressed return envelope. Most of these techniques have already been applied in the GYV-20 validation study. Reduction of the length of the questionnaire was not an option. Since sufficient efforts were made to increase the response rates, it may be that, contrary to our expectations, youngsters who did not respond had no interest in sharing their opinion about the teen-centredness of the services they received. Many other possible explanations can be given for the low response rates, varying from a too complicated procedure to participate in the study (including filling out the consent form with an additional signature of one of the parents), to the time of year the questionnaires were sent out (early spring to summer), to the reading difficulty of the GYV-20 not matching the adolescent's cognitive level. These and other hypotheses that can explain the low response rates should be tested in future research.

In using the GYV-20 in rehabilitation settings in the Netherlands, some practical problems arose. Therefore two future adjustments of the questionnaire are suggested here, which were addressed in related studies.^{95,178,209} Firstly, a GYV-20 scale score does not correct for the value adolescents and young adults attribute to certain acts. When a value of 1 is scored, meaning that the behaviour never occurred, the mean scale score is lowered, but it does not tell us anything about whether the youngster values this behaviour

highly, or not at all. Therefore, we suggest to introduce weight scale scores that correct for the weight adolescents and young adults attribute to the behaviours that are mentioned in the GYV-20. In this way a more valid reflection of their perception of the services they have received can be established. A possible hazard of this addition may be that the questionnaire becomes more complicated to fill out. Secondly, in the GYV-20, responses are made using a seven-point scale, with three of the points labelled as "a lot" (7), "sometimes" (4), and "never" (1). To make finer distinctions in the upper range of the scale and to reduce the uncertainty of unlabeled options—in our study the three labelled options were chosen most frequently—, we advise to label each of the seven response options. This is one of the adjustments King and colleagues made when they refined the MPOC.⁹⁵

Currently, the Dutch GYV-20 is the first and only measure with reported construct validity and reliability to evaluate the client-centredness of the services from an adolescent or young adult perspective systematically. Together with the MPOC and the MPOC-SP, the translated Dutch GYV-20 will form a comprehensive test battery to evaluate the family-centredness and teen-centredness of services from a viewpoint of all who are involved in the process of care. It would be interesting to explore in future research how the MPOC, the MPOC-SP, and the GYV-20 are interrelated.

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8

Parent participation in paediatric rehabilitation treatment centres in the Netherlands: a parents' viewpoint

Renate C. Siebes,¹ Lex Wijnroks,¹ Marjolijn Ketelaar,^{2,3}
Petra E.M. van Schie,⁴ Jan Willem Gorter,^{2,3} Adri Vermeer¹

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands;

³University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁴VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Aim: The importance of family-centred care and services has been increasingly emphasized in paediatric rehabilitation. One aspect of family-centred care is parent involvement in their child's treatment. The aims of this study were (1) to describe how, and to what extent parents are involved in the paediatric rehabilitation treatment process in the Netherlands; (2) to determine the level of parents' satisfaction about the services they and their child have received; and (3) to describe what ideas parents have to enhance their involvement in the treatment process.

Methods: 679 parents of children aged 1 to 20 years participated in our longitudinal study on family-centred care in the Netherlands. The children had various diagnoses and were treated in nine out of 23 Dutch paediatric rehabilitation centres. In the third phase of our study, a random sample of 75 parents was interviewed within four weeks after completion of the Measure of Processes of Care and the Client Satisfaction Questionnaire. A Quality of Care cycle with six stages was used to structure the evaluation.

Results: The data showed that parents are involved in all stages of their child's rehabilitation process in various ways. The average level of parents' satisfaction about the services received was high. According to the interviewed parents, the communication between professionals and parents, parent involvement in goal setting, and parent involvement in treatment could be improved upon.

Conclusion: Parents are to a large extent involved in all stages of the treatment process in Dutch paediatric rehabilitation settings. Although parents valued the services received, they suggested various ways to enhance parent participation.

8.1 Introduction

The provision of paediatric rehabilitation services has changed substantially in the past decades. The most far-reaching shift that has taken place was the reconceptualization of the role of the family. In roughly half a century the role of parents in the care process evolved from being a target for intervention without any control into the role of an equal partner in the decision-making processes of treatment and determining the contents of their child's care.²⁰⁶ The terms family-centred care and family-centred services are commonly used to describe this new way of providing care. Although the terms are meant to reflect different elaborations of the family-centred philosophy, they are often used interchangeably.⁶² The concepts they represent have been increasingly emphasized in child healthcare settings. Little is known, however, about one specific aspect of family-centred care and services: the level and mode of parents' involvement in the rehabilitation treatment process. In what way are they involved in their child's treatment, and do they feel they are involved enough? Are parents satisfied about the services they receive? These questions will be addressed in this study. For simplicity we will use the term family-centred care (FCC) in this paper to encompass the concepts of family-centred care and services.

FCC can be described as placing the child's needs within the context of their family and community, and at the centre of care. An individualized and dynamic model of care is devised in collaboration with the child and family that will best meet these needs.¹¹⁶ Within FCC, the emphasis is on child and family strengths and resources needed for normalized patterns of living and respectful and supportive care.^{49,97} Families are involved in their child's care and have the opportunity to learn more about their child and (options for) their child's treatment. Family members in turn are able to share their knowledge with professionals, and this provides a more holistic picture of the child and a way to heighten awareness of the child as part of the family. With the family unit as the primary and principal context for promotion of child health and well-being, FCC has been shown to contribute to parents' emotional well-being.^{88,91,92,151,161} There is also evidence that FCC fosters parental satisfaction with services.^{49,79,88,91,92,97,110,161} Reported child outcomes of FCC are developmental progress or skill development,^{26,107,134} and a better psychological adjustment.^{112,190,191}

8.1.1 Paediatric rehabilitation in the Netherlands

In the Netherlands, all medium-sized and large hospitals have a rehabilitation department. Further, there are 23 specialized rehabilitation centres with a paediatric department. Each year 9000 children are treated on an outpatient basis, either in a rehabilitation centre or at the rehabilitation department of a hospital.¹⁵⁴ Paediatric rehabilitation services are directed primarily at children with a temporary or sustaining primary motor disturbance.¹³⁰ Essentially, every child may qualify for treatment in a paediatric rehabilitation setting, but in practice the youngest children are mostly treated at home by private therapists, often combined with outpatient visits with the hospital's physician in paediatric rehabilitation medicine, with or without additive specialized support of the rehabilitation centre. After the initial treatment period there are several options, depending on the complexity of the problems and the child's age. Pre-school children with complex problems, for instance, can visit the specialized toddler day care treatment groups where they receive multidisciplinary treatment in the rehabilitation centre. The multidisciplinary treatment for complex disabilities then shifts towards schools for children with a physical disability, which are often connected to a multidisciplinary rehabilitation team. Children in mainstream education can often do with outpatient consults combined with monodisciplinary therapy alone. Some specialized rehabilitation centres offer inpatient paediatric rehabilitation clinics for intensive treatment. Each year 300 children are temporarily admitted to such a clinic.¹⁵⁴ The upper age limit for paediatric rehabilitation is about 20 years, but in practice a young adult's social situation determines whether paediatric or adult rehabilitation is the best option.¹³⁰

FCC has become widely accepted as part of the philosophy of treatment in paediatric rehabilitation settings in the Netherlands.¹³⁰ In particular, in the last decade there have been two important developments: the development and implementation of the Rehabil-

itation Activities Profile for Children, which provides team members in a rehabilitation treatment centre with a common language (abilities of the child and his or her parents) and a common reference framework (the needs of the child and his or her parents)¹⁵⁸ and the introduction of the functional treatment approach with an emphasis on problematic daily-life activities and the role of the environment.⁸⁶ These developments both fit with the 2000 report on "Future perspectives for paediatric rehabilitation in the Netherlands",²¹³ in which several long-term aims for paediatric rehabilitation in the Netherlands are described: (1) realization of an interdisciplinary treatment model; (2) shift from offer-aimed towards request-aimed care; (3) attention for both the child and its family; (4) transparency; and (5) increased attention for adolescents.

Between 2001 and 2004, a longitudinal project on the measurement of processes of care in the Netherlands was performed by associates of the *NetChild* research group. The project included three phases (see Table 8.1), of which the present study comprised the third phase. This study was a mixed-methods design, using interviews and questionnaires, which is an appropriate method for addressing a complex issue such as FCC. It was carried out to collect detailed information about parent involvement in the paediatric rehabilitation process in the Netherlands. More specifically, the aims of the current study were (1) to describe how, and to what extent parents are involved in different stages of the paediatric rehabilitation treatment process in the Netherlands; (2) to determine the level of parents' satisfaction about the services they and their child have received; and (3) to describe what ideas parents have to enhance their involvement in the process of care.

Table 8.1 Description of the three phases of the longitudinal project on the measurement of processes of care

Phase	Period	Method	<i>n</i>
1	January 2002–July 2003	<ul style="list-style-type: none"> • Measure of Processes of Care⁹⁰ • Client Satisfaction Questionnaire¹⁰³ • General Questionnaire 	679
2	May–July 2003	<ul style="list-style-type: none"> • Measure of Processes of Care • Follow-up questionnaire 	205
3	September 2003–February 2004	<ul style="list-style-type: none"> • Measure of Processes of Care • Client Satisfaction Questionnaire • Interview 	75

n, number of respondents.

Table 8.2 Sample characteristics third phase

<i>n</i>	75
Two-parent families	90.7%
Mothers	88.0%
Mean age respondents	39.1 (<i>sd</i> = 6.6)
Mean age children	7.8 (<i>sd</i> = 4.5)
Boys	64.0%
Family income	%
< €24.500	22.7
€24.500 (modal)	12.0
€24.500–€49.000	32.0
> €49.000	22.7
Missing	10.7
Diagnosis	%
Cerebral palsy	54.1
Neuromuscular disorders	13.5
Sensomotor developmental disorder	6.8
Acquired brain injury	5.4
Spina bifida/hydrocephalus	4.1
Behaviour disorder	2.7
Syndrome	1.4
Other disabilities	8.1
Diagnosis not known	4.1
Mean number of health problems	2.6 (<i>sd</i> = 1.9)
Mean number of involved disciplines	1.9 (<i>sd</i> = 1.1)
Mean number of years at centre	4.0 (<i>sd</i> = 3.7)
Children's mobility	%
Walks without aid, no problems	17.6
Walks without aid, running and jumping are difficult	21.6
Uses walking aid	14.9
Uses wheelchair most of the time	10.8
Always uses wheelchair	31.1
Too young to walk	4.1

n, number of respondents; *sd*, standard deviation. Percentages may not add to 100.0% due to rounding to one decimal place.

8.2 Methods

8.2.1 Sample

All participants ($n = 679$) were parents of children aged 1 to 20 years with various diagnoses treated in nine out of 23 Dutch paediatric rehabilitation centres. Within each family ($n = 427$), the parent who was involved most in the child's treatment process

was invited to participate in this study. A total of 187 parents (43.8%) gave their consent for an interview. Because of the large response, we chose to only include parents with complete data in the first and second phase. Out of this group ($n = 143$), 75 parents were selected randomly for enrolment in the third phase of our longitudinal study. The sample characteristics for the 75 parents who participated in phase 3 are displayed in Table 8.2.

8.2.2 Processes of care

The process of care can be described as all necessary and consecutive steps in the treatment process, starting with the referral to the treatment institution to treatment conclusion. These steps can be described in a Quality of Care cycle (visualized in Figure 8.1), which was adopted from Ketelaar and colleagues⁸⁶ to structure our study. The cycle covers six distinguishable stages.

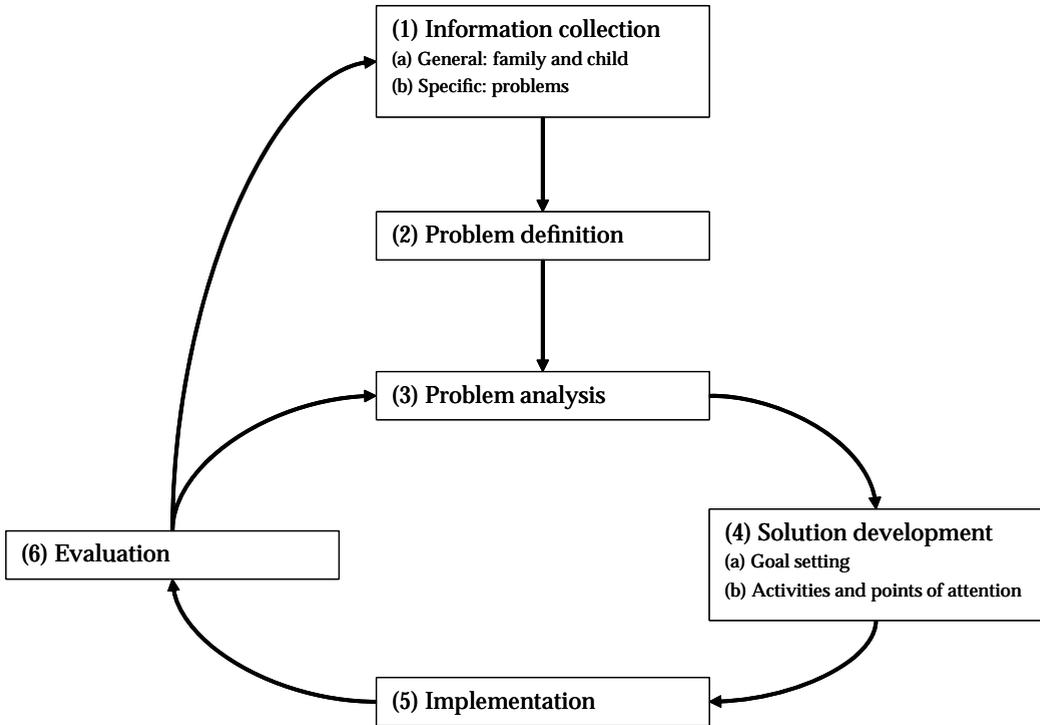


Figure 8.1 Quality of Care cycle⁸⁶

- 1. Information collection** The aim of the first stage of the quality cycle is to get an overall picture of, for instance, the child's daily life, living conditions, strengths and needs of the family, expectations and priorities of the parents and their view on their own role in their child's programme.⁸⁶ In the first stage information about the child and the family in general (stage 1a) and about specific problems (1b) is collected.
- 2. Problem definition** At the second stage, the main problems are defined and listed in order of importance by using the information gathered in stage 1.
- 3. Problem analysis** In this stage of the quality cycle, each problem that is defined in stage two is analysed individually. Using the information gathered at stage one, the constraints and enablers are identified. These may be recognized in the child (for instance, motivation, muscle strength), the task (for instance, use of aids for communication or transportation) or the environment (for instance, floor surface, gravity). Another important issue at this stage is to determine whether or not the expectations of the parents are realistic. At the end of this stage, expectations for the child of all persons involved are discussed, so that all participants in the treatment process can agree about what will be best for the child and the child's family.
- 4. Solution development** At the fourth stage, the solutions to the previously defined problems are worked out in two distinguished aspects: goal setting and activities/points of attention. Before the activities can be determined, practical constraints, such as limited availability of a parent, or living in a rural area away from certain services, are considered. When these conditions are clear, parents and professionals agree upon specific activities to achieve the goals.
- 5. Implementation** During the implementation stage, the goals and activities agreed upon in the previous stages are practiced.
- 6. Evaluation** In the final stage of the Quality of Care cycle, the treatment goals are evaluated. When goals are evaluated, the quality cycle starts again, starting with the collection of problematic activities (halfway stage 1), assuming that no significant changes took place with respect to family functioning.

8.2.3 Instruments

Four instruments were used to fulfil the research aims: the Measure of Processes of Care,⁹⁰ the Client Satisfaction Questionnaire,¹⁰³ a follow-up questionnaire (completed at the second phase) and a telephone interview. All separate questions of the interview and the follow-up questionnaire that were used in the analyses are given in Appendix 8.A arranged by the stages of the Quality of Care cycle.

Table 8.3 Formulas for converting MPOC scale scores or MPOC item scores into (weighted) scores and grades

$$g_u = (1\frac{1}{2}m) - \frac{1}{2}$$

$$s_w = \frac{1}{8} (b(-7 + m) + 4(7 + m))$$

$$g_w = \frac{3}{2}s_w - \frac{1}{2}$$

g_u , unweighted MPOC grade for scale or item (scale: 1 – 10); m , unweighted MPOC scale score or item score (scale: 1-7); s_w , weighted MPOC scale score or item score (scale: 1 – 7); b , score for the importance of a scale or individual items according to the respondents, with 0 = not at all important, 1 = not very important, 2 = neutral, 3 = important and 4 = very important; g_w , weighted MPOC grade for scale or item (scale: 1 – 10). MPOC, Measure of Processes of Care.

8.2.3.1 Measure of Processes of Care

The Measure of Processes of Care (MPOC) is a 56-item questionnaire designed to find out what parents of children with chronic health problems think of the services they and their child receive. The MPOC can be used for clinical evaluation, research purposes, and quality assurance.⁹⁰ Each of the 56 items is included in one of five scales: (1) *Enabling and Partnership* (16 items); (2) *Providing General Information* (9 items); (3) *Providing Specific Information about the Child* (5 items); (4) *Coordinated and Comprehensive Care for Child and Family* (17 items); and (5) *Respectful and Supportive Care* (9 items). An MPOC scale score can range from 1 to 7 and is calculated as the mean of the ratings for the items in the scale.

The original Canadian MPOC was translated into Dutch and validated.²⁰⁹ Both the original Canadian and the translated Dutch MPOC have sound psychometric properties.^{90,209}

In the Dutch MPOC, two additional scores can be calculated to improve the clinical utility of the measure in paediatric rehabilitation centres in the Netherlands: (1) a weighted score, using the respondent's ratings of item importance, and (2) a weighted or unweighted grade on a scale from 1 to 10 (like the Dutch school grades). In this study the weighted score was used to calculate the grades (see Table 8.3 for formulas).

8.2.3.2 Client Satisfaction Questionnaire

Parents' general satisfaction was measured with the Client Satisfaction Questionnaire.¹⁰³ The Client Satisfaction Questionnaire consists of eight items and yields a summed score of global satisfaction with care and services received. Each item has a four-point scale. The Client Satisfaction Questionnaire has demonstrated high internal consistency (Cronbach's $\alpha = .93$), and the authors report evidence of adequate validity.

8.2.3.3 Follow-up questionnaire

Our follow-up questionnaire asked about parent roles in the process of care, satisfaction of parents with the care provided by the centre, contacts with the centre, and aspects of team conference meetings and treatment reports.

8.2.3.4 Interviews

The structured telephone interviews had a general section, a section with questions about participating in our study, a section about contacts with the centre, a section with questions about treatment aspects and taking part in the care process, and, finally, some questions about the team conference meetings. For an overview of all interview questions we used in the analyses, refer to Appendix 8.A. The interview was constructed in a way that (parts of) sections could be skipped when the questions were not applicable to the family. The interviews lasted 25 to 105 minutes ($m = 52.2$; $sd = 18.7$). After a training period, the inter-interviewer reliability was established by a comparison (at face value) of simultaneously worked-up interviews.

8.2.4 Data collection and analysis

All parents ($n = 75$) filled out another MPOC and CSQ and, within four weeks maximum after completion, they were interviewed by one of our three interviewers. All data of the third phase (MPOC, CSQ, and interview data) were used in the analyses, as well as the baseline demographic data gathered in the first phase, and data from the follow-up questionnaire filled out at the second phase. The time interval between the second and the third phase was six months maximum, which was considered acceptable regarding possible changes in parents' views on the process of care.

The parent answers were transcribed literally during the interview. Next, each interview transcript was labelled independently by two interviewers using a priori developed categories. During the process of content analysis new categories were added to the list. The interviewers reached a 100% agreement on the labelling. The interviews were then entered into the WinMAX program (now called MAXqda) and categorized. This program provides a qualitative method to process user-coded text segments. Some interview variables could be analysed quantitatively and were therefore entered into SPSS.

All selected variables (see Appendix 8.A) were attached to one of the stages of the Quality of Care cycle described earlier. For an overall view of parents' satisfaction with paediatric care, the five mean weighted MPOC scale scores were computed, and converted into a grade on a scale from one to 10 for a better interpretability. The MPOC scores of this particular group did not differ significantly from the MPOC scores of the larger sample.

8.3 Results

8.3.1 Parent involvement

Our first aim was to describe how, and to what extent parents are involved in all stages of the paediatric rehabilitation process in the Netherlands. The data showed that parents are involved in all stages of their child's rehabilitation process in various ways. Table 8.4 summarizes all empirically derived aspects of parent involvement from a parents' perspective answering the question *how* parents are involved in their child's treatment process. Next, we will describe *to what extent* these characteristics can be found in paediatric rehabilitation in the Netherlands.

8.3.1.1 Stage 1: Information collection

The first live contact with the centre, usually the intake interview, took place after a mean waiting period of eight weeks. Three-quarters of the parents recalled that the physician in paediatric rehabilitation medicine had the interview with them. The majority of these parents retained good memories of this first centre contact. They remembered this phase as the period during which the care professionals could make more than enough time for them. Parents were able to tell their story (45%), felt they were taken seriously by the care professionals (35%), were comforted (21%), were informed about the centre and treatment procedures, and, as far as possible, about the clinical picture of their child (32%). More than 90% felt they had had the opportunity to explain what they believed to be problematic skills and important goals for their child. Eight parents (11%) felt the initial information was not sufficient. Other negative remarks about the first contact with the centre were incidental. Only 3% of the parents had had a home visit as part of the intake procedure.

8.3.1.2 Stage 2: Problem definition

Two-thirds of the parents whose children were actively treated in a centre were asked to list the problematic activities in order of importance, usually together with the team members. The activities at the top of their list were usually identified as the key problems. Ninety-one percent of the parents had been involved in formulating the key problems, and most of these parents could recall the current key problems of their child.

8.3.1.3 Stage 3: Problem analysis

Eighty percent of the parents reported that their initial expectations were more or less fulfilled. Of the remaining parents, some mentioned they had overestimated the amount of progress their child could make. Other parents reported that the ongoing uncertainty about the diagnosis of their child did not lead to satisfaction of their expectations, partly

Table 8.4 Summary of empirically derived aspects of parent involvement in paediatric rehabilitation treatment arranged by treatment stage

Stage 1: Information collection

- Parents share information about their child with healthcare professionals
- Parents explain what they believe are problematic skills and important goals for their child

Stage 2: Problem definition

- Parents list the problematic activities in order of importance with the help of healthcare professionals
- Parents formulate key problems together with healthcare professionals

Stage 3: Problem analysis

- Parents discuss their expectations for their child with healthcare professionals
- Parents and healthcare professionals check whether the key problems are realistic goals

Stage 4A: Solution development, goal setting

- Parents formulate treatment goals together with healthcare professionals

Stage 4B: Solution development, activities/points of attention

- Parents talk about their and their family's limitations regarding the treatment goals (for instance, limited time to assist their child doing activities at home)

Stage 5: Implementation

- Parents accompany their child to treatment sessions once in a while
- If relevant, parents perform activities at home
- Parents assist healthcare professionals in their search for the aids that are best for their child
- Parents share their thoughts with healthcare professionals

Stage 6: Evaluation

- Parents read reports about their child's progress
- Parents attend their child's team conference meetings, are a full conversation partner
- Parents read the notes of their child's team conference meeting

due to the complexity of the syndrome, partly because of a lack of knowledge in the centre.

8.3.1.4 Stage 4: Solution development

A vast majority of the parents had been involved in the setting of treatment goals and could either recall short-term goals or long-term goals, or both. Only 2% reported they had never had a voice in the goal setting. More than 95% of the interviewees reported that the treatment goals closely resembled the problematic skills they encountered in

daily life. With regard to the problematic skills, 88% of the parents told that all or most of the problematic skills they mentioned had been transformed into treatment goals. Sixty percent of the parents reported that the home situation was considered in the treatment of their child (for instance, their child's hobbies, involvement of siblings or other family members, living conditions).

8.3.1.5 Stage 5: Implementation

More than half of the parents (53%) never or rarely were present at a treatment session of their child. Nevertheless, 91% of the interviewed parents was familiar with the current treatment activities of their child. One third of the children performed treatment activities at home on a regular basis. The home programme intensity ranged from 4 minutes to 700 minutes per week ($m = 149.7$; $sd = 192.2$). Parents often remarked that "...every day is one big exercise from getting up to going to bed". Most of the parents (96%) told that they were actively involved when aids, such as a wheelchair, walking aids, or a speech computer, were ordered.

8.3.1.6 Stage 6: Evaluation

Eighty-nine percent of the parents attended the team conference meetings. During the team conference meeting, a vast majority of these parents (97%) were involved in the evaluation of treatment goals, at least to a certain extent. Concerning their role in the meeting, parents recalled "asking questions", "giving their opinion", "listening", "suggesting alternatives", and "bringing up agenda items".

Parents received a report prior to each meeting (12%), or minutes after the meeting (27%), or both (57%). Only three parents reported they had never received reports or minutes. One third of the parents had a meeting with, for instance, the social worker or the physician in paediatric rehabilitation medicine prior to the team conference meeting to talk about the report and the upcoming meeting.

8.3.2 Satisfaction

Our second aim was to determine the level of parents' satisfaction about the services they had received. Table 8.5 shows the mean unweighted MPOC scale scores and the weighted MPOC grades ($m = 7.1$, on a scale from 1 to 10; $sd = 1.1$) parents gave for the care provided by their centre. The Client Satisfaction Questionnaire revealed about the same overall satisfaction score ($m = 22.7$; $sd = 3.80$; $m = 7.7$ when the mean sum score is converted into a grade on a scale from 1 to 10). More than 90% of the parents reported that the contacts with the centre were satisfactory, and that they would probably or definitely choose their centre again if they had the choice. The majority (80%) reported that the centre did fulfil their expectations, or even performed better than expected.

Table 8.5 Mean unweighted MPOC scores and weighted MPOC grades by scale

Scale	<i>n</i>	<i>m^a</i>	<i>sd</i>	<i>m^b</i>	<i>sd</i>
Enabling and Partnership	74	4.96	.93	7.3	1.2
Providing General Information	73	3.70	1.38	5.9	1.8
Providing Specific Information about the Child	74	4.80	1.18	7.1	1.5
Coordinated and Comprehensive Care for Child and Family	74	5.00	.92	7.3	1.2
Respectful and Supportive Care	74	5.31	.85	7.8	1.1
Mean	74	4.76	.89	7.1	1.1

^a Original MPOC scale scores (unweighted) on a scale from 1 to 7. ^b Respondent's ratings of item importance were used to calculate weighted MPOC grades on a scale from 1 to 10. See Table 8.3 for formulas. MPOC, Measure of Processes of Care; *n*, number of respondents; *m*, mean grades on a scale from 1 to 10; *sd*, standard deviation.

8.3.3 Ideas for enhancement of parent involvement

The final question of each interview asked parents for their ideas to enhance their involvement in the process of care. The answers focused on three topics: the improvement of communication between professionals and parents, enlargement of parent involvement in goal setting, and enlargement of parent involvement in treatment. Regarding better communication between parents and the team members, parents requested timely reporting of test results and the team conference meetings. When there are treatment changes, for instance, a change in therapy frequency or therapist, parents would like to be informed ahead. Further, if the date of the team conference meeting is set in consultation with parents, the attendance of *both* parents to the meeting is likely to improve. Parents would greatly appreciate a follow-up on current issues on the involved providers' initiative.

Parents emphasized two significant effects of an enlarged involvement of parents in goal setting: there would be a better fit with practical difficulties encountered by their children in daily life, and services would be more "in-tune" with the family's limitations and strengths. Finally, according to parents their involvement in treatment can be enhanced by offering a wider range of opportunities to attend treatment sessions and by explaining the purpose and key elements of therapy to parents.

8.4 Discussion

Today, both nationally and internationally, family-centred care and service have become the standard among healthcare professionals. In the present study we aimed to describe how parents perceive their involvement in the paediatric rehabilitation treatment process in the Netherlands. We adopted a Quality of Care cycle to structure our data collection and analysis of three research questions: (1) how, and to what extent are parents involved

in all stages of the paediatric rehabilitation process in the Netherlands, (2) what is the level of parents' satisfaction about the services they have received, and (3) what ideas do parents have to enhance their involvement in the process of care.

This study addressed one aspect of family-centred care and services from one perspective, *i.e.*, parents' perception of their involvement in their child's care. Future research should add the viewpoint of other parties in the care process, such as service providers, children and adolescents, and managers. Further, the presence of other aspects of FCC in paediatric rehabilitation in the Netherlands, for example, whether the uniqueness of each family is acknowledged by offering individualized services, should be addressed.

The average level of parents' satisfaction about the received services was high. Unfortunately, the interviews and questionnaires did not provide sufficient information to report on satisfaction by stage. Also, the interviews did not collect adequate data whether parents are playing the role they want to play, or the role they are expected to play. MacKean and colleagues¹¹⁶ did collect satisfactory information on this topic and concluded that the degree of role and decision making around the implementation of their child's care and care management may be different than it was 30 years ago, but that health professionals are still often unilaterally defining the role that parents are to play. It is only when each family has the opportunity to decide the level of involvement they wish in decision making for their child, and to decide what kind of family-professional relationship they prefer, that services are truly family-centred.

Although our sample was rather extensive with regard to the mixed-methods data collection, *i.e.*, structured interviews and questionnaires, the sample representativeness can be questioned. In the Netherlands, about 10.000 children are currently treated in paediatric rehabilitation facilities with a wide range of diagnoses, severity of disability, and type and intensity of treatment.¹⁵⁴ We recognize that all parents of these children have a unique story to tell. However, only 75 parents of these children were interviewed. Nevertheless, concerning the diagnosis, type and intensity of treatment, the sample reflects the national population of children treated in paediatric rehabilitation.¹⁵⁴ Moreover, the MPOC scores of this particular group did not differ significantly from the MPOC scores of the larger sample. Furthermore, by selecting the 75 interviewees randomly out of respondents with complete data and a consent for the interview, we tried to eliminate a self-selection bias as much as possible. Finally, our data are not coloured by socially desirable responses. During the first phases of the full project, parents' anonymity was guarded closely; therefore, they felt they could speak freely in the interview.

Although FCC is a common principle nowadays in paediatric rehabilitation centres, and the parents rated the services they and their child received good to very good, there is still room for improvement when we look at the different stages of the treatment process in detail. Although there are many differences between families, none of the interviewed parents reported on full involvement in all consecutive treatment stages. Parents should have the opportunity to be involved in all stages of the treatment cycle and should have the choice to be actively involved. When asked for, parents suggested various ways to

enhance parent participation in paediatric rehabilitation in the Netherlands.

The innovation of paediatric rehabilitation in the Netherlands is ongoing. Recently, the National Paediatric Rehabilitation Innovation Program 2006 – 2010 was presented,¹⁹⁷ with "Equipment of parents and family" as one of the three main themes of the corporate future vision. Several projects have already been developed within this theme. One of them, the "Family in Sight" project, will be carried out shortly to improve the family-centredness of services in paediatric rehabilitation centres. The current study provides a valuable baseline for this new project and the other future initiatives.

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8.A Overview of the analysed variables

<i>Item</i>	<i>Stage^a</i>	<i>Measure</i>
• Was there a waiting list for the intake interview?	1	I
• With whom did you have your very first interview in the paediatric treatment facility?	1	I
• Could you tell how this interview went along?	1	I
• Were you visited by therapists of the centre? How often?	1	F
• Did you have a voice in the decision which problems or goals were to be handled first?	2	I
• In what way have you been involved in setting the key problems or general treatment goals?	2	I
• Can you describe the key problems and general treatment goals that have been set during the last team conference meeting?	2	I
• Can you describe your initial expectations for your child's progress, when you first attended the centre?	3	I
• Did you have to adjust your expectations? Due to what?	3	I
• Did you have a voice in setting the treatment goals?	4A	I
• Can you describe the current treatment goals (for each therapy)?	4A	I
• Do you feel the treatment goals closely resembled the problems your child encountered in daily life?	4A	I
• During the last 12 months, to what extent have the services the centre provided to you met your needs?	4A	F
• Was your home situation considered in the treatment of your child?	4B	I
• During the last 12 months, how often did you attend treatment sessions of your child?	5	F
• Can you tell what a treatment session is like, in general?	5	I
• During the last 12 months, how often did your child have to practice at home?	5	I/F
• Have you been able to assist your child doing treatment activities at home?	5	F
• How long did it take you to do the exercises at home with your child?	5	I
• Did you have a say when aids were ordered?	5	F
• During the last 12 months, how often have you been invited for a team conference meeting?	6	F
• Did the centre consult your schedule when they were planning a team conference meeting?	6	F
• During the last 12 months, how often did you attend team conference meetings?	6	F
• During the last 12 months, have you received reports about your child and minutes of the team conference meetings?	6	I
• Can you describe your role during the team conference meeting?	6	I
• Have you been involved in the evaluation of treatment goals of your child?	6	F
• Afterwards, did you feel you had had the opportunity to say what you wanted in a meeting?	6	F
• Did you understand what was being said during a meeting?	6	F
• Did you feel at ease when you attended a team conference meeting?	6	F
• How would you rate (scale 1 – 10) the services provided to you by the centre in an overall general sense?	OS	F

(continued on next page)

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<i>Item</i>	<i>Stage^a</i>	<i>Measure</i>
• In an overall sense, how satisfied were you with the treatment of your child during the last 12 months?	OS	F
• If you had the choice, would you choose this paediatric rehabilitation centre again for the treatment or counselling of your child?	OS	F
• What is the frequency and the mode of the contacts you have with the treatment centre?	OS	I
• If you would have the opportunity, would you like to change your attendance to team conference meetings?	OS	F
• If you would have the opportunity, would you like to change your attendance to treatment sessions?	OS	F
• Would you like to be involved more in the treatment of your child?	OS	F
• Would you like to be involved in setting the treatment goals for your child in a different way?	OS	I
• What can the centre do to enhance your involvement in the process of care?	OS	I

^a See Figure 8.1. I, interviews; F, follow-up questionnaire; OS, overall satisfaction.

9

Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs

Renate C. Siebes,¹ Marjolijn Ketelaar,^{2,3} Jan Willem Gorter,^{2,3} Lex Wijnroks,¹
Aleida C.E. de Blécourt,⁴ Heleen A. Reinders-Messelink,⁵
Petra E.M. van Schie,⁶ Adri Vermeer¹

¹Utrecht University, Langeveld Institute for the Study of Education and Development in Childhood and Adolescence*, Utrecht, the Netherlands; ²Rehabilitation Centre De Hoogstraat*, Utrecht, the Netherlands; ³University Medical Centre, Department of Rehabilitation, Rudolf Magnus Institute of Neuroscience, Utrecht, the Netherlands; ⁴University Medical Center Groningen, Center for Rehabilitation, University of Groningen, Haren, the Netherlands; ⁵Rehabilitation Centre "Revalidatie Friesland", Beetsterzwaag, the Netherlands; ⁶VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands

*Partner of *NetChild*, Network for Childhood Disability Research in the Netherlands

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Abstract

Purpose: The aim of the present study was to examine whether the paediatric rehabilitation treatment goals and activities of children with complex needs were tuned to parent identified problems and whether the needs and treatment goals were transparent for all involved.

Method: Five school-aged, randomly selected subjects with cerebral palsy classified by means of the Gross Motor Function Classification System (GMFCS) as level II ($n = 1$), level III ($n = 1$), and level V ($n = 3$) were observed in detail during physical, occupational, and speech therapy, and their written reports were studied. Parent identified problems, treatment goals, and treatment activities were linked to the ICF components, domains and categories, and the amount of agreement was determined by code comparison.

Results: For only two children a sum of six parent identified problems were documented. Forty-five treatment goals were identified and 72 treatment activities were observed. The analyses indicated some tuning of parent identified problems, goals and activities in all subjects, but only four of the treatment activities were perfectly tuned to treatment goals as well as to parent identified problems.

Conclusions: The tuning and transparency of the paediatric rehabilitation process described in the present study could be improved substantially. Several options are discussed.

9.1 Introduction

Since children in paediatric rehabilitation are involved in a developmental process as well as in an educational process, rehabilitation professionals are faced with a diversity of problems in and around the child. Because of the complexity of the care process and the interference with parents' and children's daily life, paediatric rehabilitation should fit within the family's lifestyle and be as comprehensive as possible.¹⁸⁸

As far as we could determine, only general descriptions of comprehensive care are provided in literature. In the present paper comprehensive care is defined as a demand-driven, transparent, and tuned care-process; parent identified problems of the child form the base for treatment activities, and there must be a clear link between treatment activities, treatment goals and the child's problems. Comprehensive care is all-inclusive and meets the often long-term medical, educational, mental, and social needs of children with chronic health conditions and their families.^{56,127,130,133,210} Comprehensive care is one of the key elements of family-centred services, a holistic approach towards service delivery, in which the unique strengths, resources, and set of needs of each child and its family form the basis for a highly individualized and dynamic model of care.^{49,97,116}

To meet the complex needs of the child and its parents, specialists from several disciplines are involved in the rehabilitation process, working together in a team.²⁰² The team is responsible for the provision of treatment that ideally is tuned to the needs and

capacities of the child and its parents.^{17,45,46,108,161,202} In addition to tuning, transparency of the treatment process is another important aspect of comprehensive care, comprising both openness and accountability. The treatment process should be driven by clarity about what clients want and a strong sense of responsibility and dedication to providing it.³² It should be clear to all who are involved in the child's treatment process, including the child, what is being done in treatment and why. In other words, the link between treatment goals and treatment activities and the child's problems in daily life should be visible to all persons involved.¹⁶² This helps to focus treatment activities and simplifies the transfer of treatment activities to the home situation.⁸⁶

Comprehensive care was shown to have a positive effect on children with chronic health conditions and their families. Recent literature suggests that a comprehensive approach benefits parent satisfaction with health services, decreases health needs, and improves child and maternal adjustment.^{48,56,80,114,145,192}

Although ideas over and possible effects of comprehensive care have been described extensively in literature, little is known about what actually happens *in between*, *i.e.*, about how comprehensive care is operationalized in clinical practice. What is being done in treatment? Is there a clear relation between treatment activities and parent identified problems? To know what actually happens during treatment might provide insight in the quality of paediatric rehabilitation care. In this study we aimed to describe the relatively unknown clinical implementation of the paediatric care process in the Netherlands, by observing the treatment process of five randomly selected children with complex needs. More specific, our focus was the tuning of treatment goals and treatment activities to child and parent needs and transparency of the rehabilitation process for all involved.

9.1.1 Paediatric rehabilitation care in the Netherlands

Over the years, comprehensive care has been described both in care policy as well as rehabilitation treatment guidelines. In 2000, the report "Future perspectives for paediatric rehabilitation in the Netherlands" was drawn up,²¹³ in which several long-term aims for paediatric rehabilitation in the Netherlands were described: (1) Realization of an interdisciplinary treatment model; (2) Transition from supply-driven to demand-driven care; (3) Attention for both the child and its family; (4) Transparency; and (5) Increased attention for adolescents. This year, the National Paediatric Rehabilitation Innovation Program 2006 – 2010 was presented, with "Equipment of parents and family" as one of the three main themes of the corporate future vision.¹⁹⁷

Recently, the Rehabilitation Activities Profile for Children (Children's RAP), an instrument for interdisciplinary communication in paediatric rehabilitation, was implemented in the Netherlands to support the intensified interaction between parents and team members.¹⁵⁸ This framework provides team members and parents with a common language (abilities of the child and its parents) and a common reference framework (the needs of the child and its parents), which helps both parents and service providers to put the

actual problems of the child into words during the mostly annual or semi-annual team conferences. Moreover, the Children's RAP serves as a checklist, which—in theory—prevents team members forgetting to report on relevant information, or from adding irrelevant information.¹⁵⁹ By formulating child and parent needs and by translating these needs into explicit treatment goals, all documented in the Children's RAP report, the transparency of the treatment process can be optimized. In this way, treatment is focused on things that are important for the child and its parents.

The aim of the present study was to examine, in a sample of children with cerebral palsy and complex needs, whether the rehabilitation process was tuned to the child's and parents' needs and whether the process was transparent for all involved. We judged the process to be transparent when parent identified problems and treatment goals were documented, either in the child's dossier or in the Children's RAP report.

To categorize parent identified problems, treatment goals, and treatment activities, and to be able to study how these were tuned to each other, the International Classification of Functioning, Disability and Health (ICF)²¹⁷ was used. The ICF provides an extensive and well-defined universally applicable framework for interdisciplinary disability research and for making results of research comparable, both for activity levels and overall levels of participation, in basic areas and roles of social life.^{162,217} Dahl discussed the potential impact of the ICF on rehabilitation services and research. She emphasized that use of common terms within the team allows proper formulation of identifiable and meaningful goals for rehabilitation, and enables professionals to record interventions and outcomes in a standardized professional language within a uniform framework.⁴⁰ Recently, some studies successfully linked the ICF to diagnoses of children with disabilities¹⁴³ and to health status measurements.^{29,31}

Eventually, all parent identified problems, treatment goals, and treatment activities were linked individually to the ICF components, domains and categories. Finally, the tuning of these aspects of the rehabilitation process was determined by comparison of the linked ICF codes.

9.2 Method

9.2.1 Subjects

Five children were selected randomly from a population of children with cerebral palsy attending a school for special education in the northern part of the Netherlands. They were all patients at the adjacent paediatric rehabilitation centre. This rehabilitation setting was judged to be a good representative of paediatric rehabilitation centres in the Netherlands. The children satisfied the following criteria: between 4 and 10 years of age; diagnosis of cerebral palsy; treatment by a multidisciplinary team comprising treatment on an outpatient basis by at least a physician in paediatric rehabilitation medicine, physical therapy, occupational therapy, and speech therapy. Subjects (Table 9.1) were three

boys and two girls with spastic CP (bilateral or unilateral) aged 5 to 10 years ($m = 7.1$ years). The GMFCS classifications¹⁴⁶ ranged from level II (uses walking aid for longer distances) to level V (dependent in self-mobility). Subjects A and B were dizygotic twins.

Table 9.1 Subject characteristics

Subjects	Sex	Age	Type of cerebral palsy	GMFCS ¹
A	M	7;3	Spastic Bilateral	V
B	M	7;3	Spastic Unilateral	III
C	M	5;9	Spastic Bilateral	II
D	F	10;2	Spastic Bilateral	V
E	F	5;3	Spastic/dyskinetic Bilateral	V

¹ Subject's level on the Gross Motor Function Classification System.¹⁴⁶

Informed consent was obtained from a responsible family member for each child and the ten service providers involved. The service providers had been working in the participating treatment team for 3 to 23 years ($m = 13.3$ years) and had been working in their present discipline for 5 to 29 years ($m = 17.6$ years).

9.2.2 Instruments

To obtain unbiased information, which was needed to fulfil the research aims, existing written sources were consulted and observations of treatment sessions were performed. Interference with the usual pace of matter was reduced as much as possible to maximize the data neutrality.

9.2.2.1 Written reports

Of each of the participating children a copy of the report of the most recent team conference meeting was analyzed. These reports were structured according to the Children's RAP¹⁵⁸ framework and described the actual problems and treatment goals of the child. Further, the discipline dossiers of physical, occupational, and speech therapy of all subjects were scanned for present treatment goals. Two observers studied the written reports independently and marked parent identified problems and treatment goals.

9.2.2.2 Observations

A single-subject design was repeated for five subjects. Within a four-week time period all subjects were followed during nine regular treatment sessions: physical therapy (three times), occupational therapy (three times), and speech therapy (three times). Forty sessions (the subjects A, B, and C received two (B) or three (A, C) group physical therapy sessions) were video-taped and transcribed and coded. According to the service providers, all video-taped sessions were a representative illustration of the usual treatment. Of each session, and for each child for group sessions, a transcript was made with an accurate description of all treatment activities, both verbal and non-verbal. To acquire reliable and comprehensive transcripts, all tapes were transcribed by two observers independently, and subsequently brought together in a consensus transcript.

When describing treatment, providing insight into the weight of the various session activities is important. The time-sampling method was utilized in the present study to accurately reflect the contribution of each of the activities to the total treatment time. This method yielded a list for each subject with the different observed treatment activities and their exact duration in seconds.

9.2.2.3 Linking the data to the ICF

As illustrated in Table 9.2, the ICF has two parts, each containing two separate components: (1) Body functions (b) and Structure (s), and Activities and participation (d), and (2) Environmental (e) and personal factors. The components of the ICF are structured in domains and categories. The ICF provides a long list of codes to describe the integrity of body functions and structures, the ability and performance of activities of daily life, the scope of the individual's social participation, and environmental factors that might facilitate or challenge functioning. Each ICF code starts with a letter (b, s, d, or e) which refers to the component of the classification, followed by a numeric code that starts with the chapter number (single digit), followed by the second level (two digits), and the third and the fourth level (one digit each). For instance, a goal "learn to take off his socks" can be coded as d5403, in which "d" stands for Activities and participation, 5 for the Self-care chapter, 40 stands for "dressing", and 3 for "taking off footwear". All data, including parent identified problems, treatment goals, and observed treatment activities, were linked to the ICF components, domains and categories (all three digit codes). The linking rules were based on the rules published by Cieza *et al.*,^{29,30} which were developed for linking health-status measures to the ICF. In an observational pilot study of a nine year old girl with cerebral palsy (GMFCS level V) during three different treatment sessions, the Cieza rules were adapted to make them functional for linking problems, goals and treatment activities to the ICF codes. Whenever the existing rules did not enable treatment goals or activities to be linked to the ICF in a specific and precise manner, a new rule was created and/or the existing rules were reworded. At the end of the development process, seven rules were available (see Appendix 9.A).

All marked parent identified problems and treatment goals, and the observed treatment activities of the five subjects were then linked to the ICF domains and categories. This was done independently by the two coders. Without discussion 100.0% of the parent identified problems, 76.6% of the treatment goals, and 80.6% of the treatment activities were coded similarly. Afterwards, differences were discussed until consensus was reached. The final result of the linking process was a list for each subject with parent identified problems, treatment goals, and treatment activities, all linked to ICF-codes.

9.3 Results

9.3.1 Parent identified problems

Only for two of the five subjects a sum of six (two plus four) parent identified problems were found in the Children's RAP reports. Thus, for the other three children the parent identified problems were not reported. Even analyses of the subject dossiers did not provide additional parent identified problems.

One problem could be linked to Body functions ("Diminish the drooling", b5). The other five parent identified problems could be linked to the Activities chapters of the ICF, that is to Communication ("Practice speaking through the Wizard, a communication aid", d3), Mobility ("Practice driving in a powered wheelchair", d4), and Self-care ("Learn to drink from a cup" and "Learn to get dressed and undressed", d5).

9.3.2 Treatment goals

Treatment goals identified in the Children's RAP reports could be divided into three types of goals: (1) long-lasting goals reflecting the developmental perspective of the child, (2) intermediate goals: concrete long-term goals on the levels of activities and participation, and (3) short-term goals, mostly on a discipline level and in terms of functions/structures. Long-lasting developmental goals could not be assigned to a specific ICF chapter, and were therefore not coded.

Forty-five intermediate and short-term treatment goals (range 6 to 13 goals per subject; see Table 9.3) were documented. These treatment goals were not phrased very SMART (specific, measurable, acceptable, realistic, and time-bound). The responsible physician in paediatric rehabilitation medicine of the team confirmed that the identified treatment goals were all of current interest and comprehensive. Analyses of the subject dossiers did not reveal additional treatment goals.

Of the reported treatment goals 48.9% could be linked to Body functions (b), and 42.2% to Activities and participation (d). The remainder of the goals (8.9%) were linked to Environmental factors (e). All subjects had "Enlarge the ability to do things independently" as long-lasting developmental goal.

Table 9.2 The International Classification of Functioning, Disability and Health²¹⁷

Components	Part 1: Functioning and Disability		Part 2: Contextual Factors		
	Body functions (b) and structures (s)	Activities and participation (d)	Environmental factors (e)	Personal factors	
Domains	Body functions	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability	
Categories	<ul style="list-style-type: none"> • Mental functions (b1) • Sensory functions and pain (b2) • Voice and speech functions (b3) • Functions of the cardiovascular, haematological, immunological and respiratory systems (b4) • Functions of the digestive, metabolic and endocrine systems (b5) • Genitourinary and reproductive functions (b6) • Neuromusculoskeletal and movement-related functions (b7) • Functions of the skin and related structures (b8) 	<ul style="list-style-type: none"> • Learning and applying knowledge (d1) • General tasks and demands (d2) • Communication (d3) • Mobility (d4) • Self-care (d5) • Domestic life (d6) • Interpersonal interactions and relationships (d7) • Major life areas (d8) • Community, social and civic life (d9) 	<ul style="list-style-type: none"> • Products and technology (e1) • Natural environment and human-made changes to environment (e2) • Support and relationships (e3) • Attitudes (e4) • Services, systems and policies (e5) 	<ul style="list-style-type: none"> • Structure of the nervous system (s1) • The eye, ear and related structures (s2) • Structures involved in voice and speech (s3) • Structures of the cardiovascular, immunological and respiratory systems (s4) • Structures related to the digestive, metabolic and endocrine systems (s5) • Structures related to genitourinary and reproductive systems (s6) • Structures related to movement (s7) • Skin and related structures (s8) 	<ul style="list-style-type: none"> • Not classified in ICF

Table 9.3 Parent identified problems and treatment goals identified in the Children's RAP reports, linked to the ICF domains

ICF domain	Number of parent identified problems	Number of treatment goals
Body functions		
Mental functions (b1)	1 (16.7%)	22 (48.9%)
Sensory functions and pain (b2)		1 (2.2%)
Voice and speech functions (b3)		4 (8.9%)
Functions of the digestive, metabolic and endocrine system (b5)		4 (8.9%)
Neuromusculoskeletal and movement-related functions (b7)	1 (16.7%)	3 (6.7%)
		10 (22.2%)
Activities and participation	5 (83.3%)	19 (42.2%)
Learning and applying knowledge (d1)		2 (4.4%)
Communication (d3)	1 (16.7%)	3 (6.7%)
Mobility (d4)	1 (16.7%)	10 (22.2%)
Self-care (d5)	3 (50.0%)	4 (8.9%)
Environmental factors		4 (8.9%)
Products and technology (e1)		4 (8.9%)

9.3.3 Treatment activities

All video-taped treatment sessions were transcribed, and the observed treatment activities were linked to ICF codes. Sixty different treatment activities (13, 17, and 30 activities for speech therapy, occupational therapy, and physical therapy, respectively) were observed. In total, the children received 1470 minutes of therapy, of which 920 minutes could be linked to ICF codes. The remainder of the session minutes was filled with activities that were not part of the actual treatment (see Appendix 9.A, seventh linking rule). Table 9.4 provides an overview of the time-sampled weight of the observed treatment activities arranged by the ICF domains for each of the five subjects. Of the observed "real" treatment activities, being all observed activities without the activities that were described in the seventh linking rule, 23.4% could be linked to Body functions (b). The majority of these observed activities were linked to b7 (Neuromusculoskeletal and movement-related functions: 10.4%) and b3 (Voice and speech functions: 7.0%). The majority of the observed treatment activities, 70.5%, was linked to Activities and participation (d). Activities in the Mobility domain (d4) were observed most frequently (d410–d460: 47.1%), followed by Self-care activities (d5: 9.8%), such as getting dressed (d5400) and undressed (d5401), eating (d550), and drinking (d560). Another 6.1% of the treatment activities, mostly adjustments of a wheelchair or a walking aid, were linked to Environmental factors (e).

For each subject and discipline the proportions of the real treatment time that could be linked to Body functions (b), Activities and participation (d), and Environmental factors

Table 9.4 Linked time (time-sampled proportions) of observed treatment activities for each subject divided by the total linked time arranged by the ICF domains

ICF domain	Subject A (%)	Subject B (%)	Subject C (%)	Subject D (%)	Subject E (%)	<i>m</i> (%)
Body functions (b)						23.4
Mental functions (b1)	9.5					2.1
Sensory functions and pain (b2)	3.6		3.0			1.4
Voice and speech functions (b3)	15.0	13.3		2.8		7.0
Functions of the cardiovascular, haematological, immunological and respiratory systems (b4)	0.3	0.5	1.7			0.5
Functions of the digestive, metabolic and endocrine system (b5)		4.0		6.1		2.0
Neuromusculoskeletal and movement-related functions (b7)	2.1	14.3	1.5	23.1	13.7	10.4
Activities and participation (d)						70.5
Learning and applying knowledge (d1)	5.0	7.5	1.1	6.3	1.6	4.4
Communication (d3)				15.2	13.1	4.8
Mobility (d4)	55.5	22.5	64.0	44.2	55.1	47.1
Self-care (d5)	2.5	5.2	26.1		16.1	9.8
Domestic life (d6)			0.7			0.1
Community, social and civic life (d9)	6.5	9.9	2.0			4.3
Environmental factors (e)						6.1
Products and technology (e1)		22.8		2.4	0.5	6.1

m, sum of the subjects' linked treatment time by domain divided by the total linked treatment time. Percentages may not add to 100.0% due to rounding to one decimal place.

(e) are provided in Table 9.5. As expected, occupational therapy activities were linked to Activities and participation (d) the most (*mean* = 88.3%; *median* = 62.3%), followed by physical therapy activities (*mean* = 64.8%; *median* = 97.6%) and speech therapy activities (*mean* = 61.2%; *median* = 75.2%). The observed physical therapy activities for subject D were mainly on the level of Body functions (b: 69.1%): this girl just had a botulinum toxin treatment. For subject B, one sixty-minute occupational therapy session was dedicated to the adjustment of his old and new wheelchair (e: 48.6%). In speech therapy, there were some characteristic 'd' activities, such as using communication devices and techniques (d360), and eating (d550) and drinking (d560), and activities that were linked to the ICF's 'b' section, such as articulation functions (b320) and ingestion functions (b510). In contrast to the other disciplines, these 'd' and 'b' activities were not mixed much in the speech therapy sessions, causing the somewhat extreme percentages.

Table 9.5 Proportions of the observed treatment sessions (mean of the three sessions) that were linked to the domains of Body functions (b), Activities and participation (d), and Environmental factors (e) split by discipline

Subject	Physical therapy			Occupational therapy			Speech therapy		
	b (%)	d (%)	e (%)	b (%)	d (%)	e (%)	b (%)	d (%)	e (%)
A	11.8	88.2	0.0	2.0	98.0	0.0	82.3	17.7	0.0
B	37.7	62.3	0.0	0.0	51.4	48.6	87.1	12.9	0.0
C	11.1	88.9	0.0	0.0	100.0	0.0	0.0	100.0	0.0
D	69.1	26.9	4.0	0.0	97.6	2.4	24.4	75.2	0.4
E	42.2	57.7	0.0	4.4	94.3	1.3	0.0	100.0	0.0

9.3.4 Matching of ICF codes

Figure 9.1 illustrates that there was some agreement of parent identified problems, treatment goals, and treatment activities in all subjects. Only four out of 72 ICF codes (two each for subjects C and D) were fully tuned, meaning that four treatment activities were code-related to treatment goals, and that these treatment goals were code-related to parent identified problems.

Figure 9.2 shows the overall two-way agreement of parent identified problems, treatment goals and treatment activities. Of the sum of 72 treatment activities (60 different activities were identified and some in more than one subject), 31 (43.1%) were tuned to treatment goals. Reversely, 31 out of 45 treatment goals (68.9%) were linked to treatment activities. Of the 45 treatment goals, only five (11.1%) were tuned to parent identified problems, but these were very low in numbers. Reversely, of the six parent identified problems, four were linked to treatment goals and treatment activities, and one to treatment goals alone (total agreement 83.3%).

9.4 Discussion

The current study is the very first that reported on transparency and tuning of the treatment process in detail. Only for two of the five children parent identified problems were found in the written reports. Of the other parents the identified problems were not documented. Because of this, we were not confident that the 45 identified treatment goals were all of current interest and comprehensively documented and asked the responsible physician in paediatric rehabilitation medicine of the team for a confirmation.

It is striking that in our study only four of the 72 treatment activities were related to treatment goals as well as to parent identified problems. However, we have no insight in oral communication between service providers and between service providers and parents. It may well be that parent identified problems and treatment goals that were not explicitly documented, were implicitly represented in treatment. Moreover, by using the

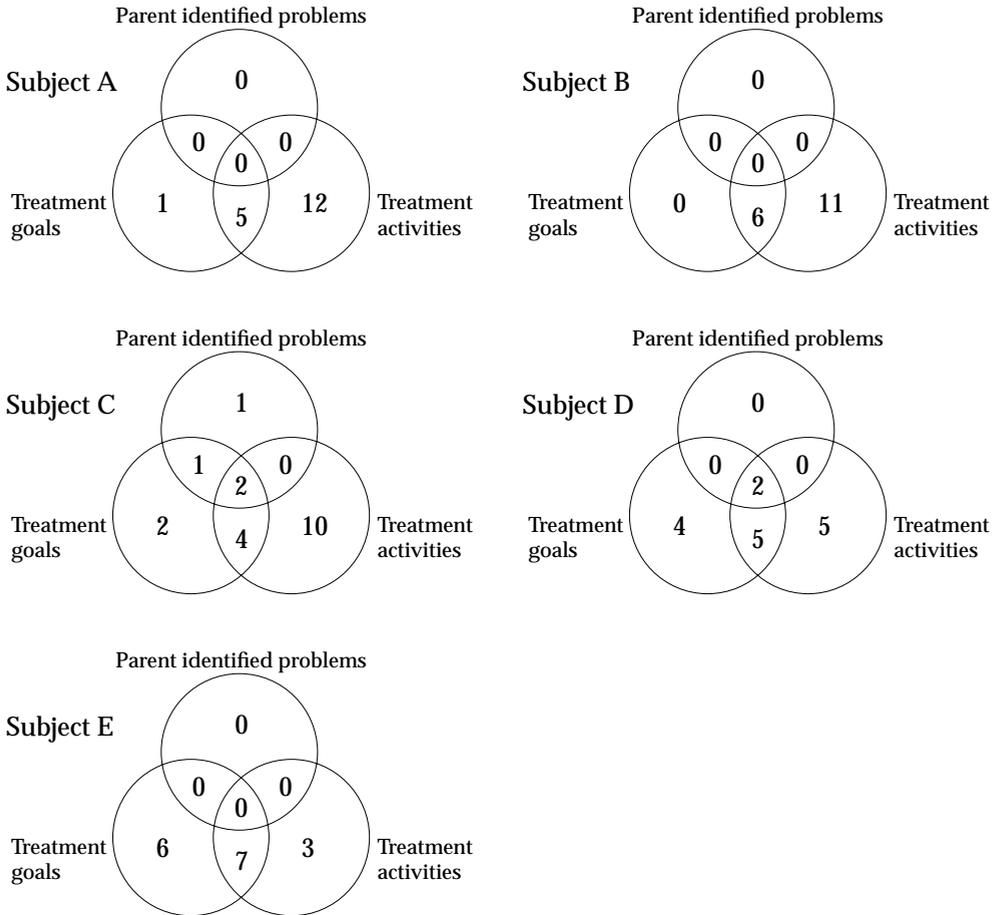


Figure 9.1 Agreement of parent identified problems, treatment goals, and treatment activities. For each subject the shared area of the circles represents the number of ICF coded parent identified problems, treatment goals, and treatment activities that corresponded.

ICF as our classification system, the link between preconditions, which are often on the Body functions level to facilitate activities of daily life, and the eventual activity, is not always visible. It may be that treatment activities and treatment goals do not match by ICF code, but in fact do have a relation. Although the tuning of the observed treatment process may therefore be better in reality, the transparency of the process remains very poor because parent identified problems and treatment goals were not documented comprehensively, either in the child’s dossier or in the Children’s RAP report.

Three findings were rather unexpected: the relative absence of parent identified prob-

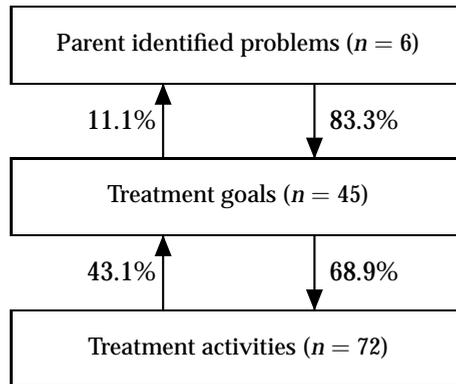


Figure 9.2 Proportions of the two-way tuning of parent identified problems, treatment goals, and treatment activities.

lems in the reports, the lack of SMART phrased goals, and the ineffective use of the Children's RAP framework. To improve these relative weaknesses, several recommendations can be made.

A very useful tool to help parents list what they believe to be important treatment goals is the Canadian Occupational Performance Measure (COPM).¹⁰⁵ Although the COPM is designed for use by occupational therapists because the domain of concern is occupation, multidisciplinary teams can use the COPM to identify child and family needs and priorities by expanding the nature of the interview to focus on other issues as well. Furthermore, the Goal Attainment Scaling (GAS) tool⁹⁸ may help to phrase treatment goals in a SMART way. A SMART phrasing of the goals will considerably improve the transparency of the treatment process. The GAS is designed to be used in situations where specific goals are set jointly between the team and the child and its parents. The expected outcome is defined, then the "more than expected" outcomes and "less than expected" outcomes, and a time period for review of achievement towards each goal is set. Although setting SMART goals may sometimes seem futile, especially where children with complex disabilities are involved, the SMART phrasing is necessary to make the treatment activities interpretable for the child and its parents. They should know what goals are set and why, know the steps to reach the goals, and know how and when the goals will be evaluated. When goals are not reached within the designated time, reporting may help to analyze why they were not reached. Finally, the use of the Children's RAP communication report forms could be optimized by filling out the reports in a structured (fixed moments) and uniform way, with clear directives for what should be reported and by whom.

It appeared that a large proportion of the available treatment time was used for non-treatment activities, such as transfers, toilet stops, picking the child up from the classroom

or a colleague and bringing the child back, cleaning up, and reading and writing in the child's communication cahier. To increase the actual treatment time and decrease time spent outside the classroom, treatment sessions and duration should be more scheduled according to the needs of the individual child. Our data suggest that a standard treatment time of 30 minutes is based on a "one size fits all" basis and is not appropriate for children with complex needs in particular.

In the present study, the ICF proved to be a valuable framework and classification system to categorize parent identified problems, treatment goals, and treatment activities. A demerit of our observation method is that not all the observed treatment activities were related to treatment. In treatment, more is happening than just the goal-related activities. For instance, when the subject was drinking juice, washing his hands, or went to the bathroom, these activities were linked by us to the Activities and participation domain, but these activities were not necessarily goal-related. Logically, it should be expected that goal-related treatment activities would fill a larger part of the treatment time than non-related activities, but in the present study it was not possible to make the distinction. Nevertheless, the linking proportion of activities and goals in Figures 1 and 2 should probably have been higher. We could have asked the service provider to indicate during the observations when the subject was actually performing a goal-related activity, but that would have disturbed the plain treatment and our objective view of treatment. Another possibility to determine which activities are goal-related is to show the session tapes to the service provider just after closure of the observations and ask the provider to indicate the goal-related treatment activities. Because of the high burden for the participating service providers, this was not an option in the present study, but it is to be recommended for future research.

Although the present study describes current paediatric rehabilitation practice in only one treatment team, we assume that the key issues will be acknowledged by other paediatric rehabilitation teams working with children with cerebral palsy inside and outside of the Netherlands. The results may serve as an eye-opener, may initiate projects to further improve the treatment chain, and may provide a valuable baseline for future projects to equip parents and families in paediatric rehabilitation, for example, in the National Paediatric Rehabilitation Innovation Program in the Netherlands.

Acknowledgments

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9.A Rules for linking parent identified problems, treatment goals, and treatment activities to ICF codes

Number	Rule	Example
1	Before one links treatment goals and treatment activities to the ICF codes, one should have acquired good knowledge of the conceptual and taxonomical fundamentals of the ICF, as well as of the components, domains and categories of the detailed classification, including definitions.	
2	Each treatment goal and each treatment activity should be linked to the most precise ICF category.	Treatment activity: "Playing with a marble track" is linked to d440 "Fine hand use" and not to d920 "Recreation and leisure".
3	If a treatment goal or treatment activity encompasses different constructs, the information in each construct should be linked to the appropriate ICF code.	Treatment goal: "Preservation of joint mobility (b710) and normalisation of muscle tone (b735)".
4	If the content of a treatment goal or a treatment activity is more general than the corresponding ICF category, then the code of the higher level is linked.	Treatment goal: "Improvement of mouth motor functions" (b51).
5	If the content of a treatment goal or a treatment activity is more general than any corresponding ICF category, then the treatment goal or the treatment activity is linked to the chapter.	Treatment activity: "Play symmetrical with both hands in a prone position" (b7).
6	If the content of a treatment goal reflects a long-term developmental perspective, the goal is not coded.	Treatment goal: "Enlarge the ability to do things independently".
7	Only activities that are evidently part of the treatment will be linked.	Transfers, toilet stops, picking the child up from the classroom or a colleague and bringing the child back, cleaning up, and reading and writing in the child's communication cahier are not part of treatment, unless the child has an active role in the activity.

10

General discussion



In Dutch clinical practice, there still is a large need for clear and univocal background information on family-centred care. Moreover, directives to bring family-centred care into practice are required to guide service providers to successful implementation of family-centred care. Such guidelines are already available in English through the *CanChild* 18-part fact sheets series on family-centred service.¹⁰⁸ These fact sheets provide parents, service providers, and organizations with structured information on diverse topics related to family-centred care.

Within family-centred care the unique strengths, resources, and set of needs of each child and its family form the basis for a highly individualized and dynamic model of care.^{49,97,116} Family-centred care should therefore be like jointly baking a "family pie". The centre provides parents with all the ingredients required, kitchen tools, and an oven to bake the pie. Parents and their children are chefs de cuisine and decide on what pie they would like to bake and what kind of help they want baking the pie and when. Parents must not be forced into a family-centred harness; they should be free to decide on their personal role in their child's rehabilitation process and should have the opportunity to decide the level of involvement they wish in decision-making for their child. Some parents may only need a recipe, or need help to make their *mise en place*, and parents who are not queens of the kitchen may need a cook to bake their family pie, either because of *can't* or *won't*. The complex care process is in constant competition with the child's and family's daily life and should therefore fit with the family's lifestyle to decrease the high family burden as much as possible.

The objective of this thesis is to describe the paediatric rehabilitation treatment process in the Netherlands with a focus on the parents' perspective. To what extent are parents involved in the different stages of the paediatric rehabilitation treatment process? What is being done in treatment? Is there a clear relation between treatment activities and parent identified problems? Are parents satisfied about the services they and their child have received? Knowing how theories about care provision have been operationalized in clinical practice will help to sharpen guidelines regarding family-centred care and will help to further improve the quality of paediatric rehabilitation care.

This thesis provides the paediatric rehabilitation field with three valid and reliable measures of the family-centredness and client-centredness of services: the Measure of Processes of Care (MPOC), the Measure of Processes of Care for Service Providers (MPOC-SP), and the Giving Youth a Voice Questionnaire (GYV-20) (chapters 3, 4, 5, 6, and 7). In chapter 8, the MPOC is used to describe parent satisfaction with received rehabilitation services, and additional interviews with 75 parents provide detailed information on their involvement in the care process. Parents' suggestions to improve parent involvement in paediatric rehabilitation care are also included in this chapter. Finally, a single case observational study in five children with complex needs is carried out to collect information about tuning and transparency of the treatment process (chapter 9). The key messages from each chapter are listed in Table 10.1. The three main topics within this thesis, development of valid measures of the family-centredness of care, parent involvement in the

care process, and tuning and transparency of care, strongly support a successful implementation of family-centred care in the Netherlands. Nevertheless, a lot of the work still has to be done.

Table 10.1 Key messages from this thesis

The higher the methodological quality of the study, the lower the number of reported positive results. (Chapter 2)

The use of single case studies, combined with the development of measures with a high sensitivity designed specifically for children with cerebral palsy, will make valuable contributions to the scientific justification of therapeutic interventions. (Chapter 2)

The Dutch Measure of Processes of Care (MPOC), short Measure of Processes of Care (MPOC-20), Measure of Processes of Care for Service Providers (MPOC-SP), and Giving Youth a Voice Questionnaire (GYV-20) are valid and reliable instruments to measure the family-centredness or teen-centredness of service delivery. (Chapters 3, 5, 6, and 7)

Dutch parents, service providers, and adolescents judged the practical applicability of the MPOC, MPOC-SP, and GYV-20 in daily practice positively. (Chapters 3, 6, and 7)

The use of the MPOC as an evaluative follow-up instrument to assess the effectiveness of a program intervention is restricted owing to its tendency to give lower scores when repeated after one year. MPOC scale scores should therefore be interpreted with caution when the measure is used as an evaluative follow-up instrument, for instance, to evaluate program interventions. (Chapter 4)

When considering the use of the short MPOC-20 or the longer MPOC-56, the eventual goal of the assessment is of decisive importance. (Chapter 5)

The average level of parent satisfaction about the services received was high, but there is always room for improvement. None of the interviewed parents had been fully involved in all consecutive treatment stages and the interviewees suggested various ways to enhance parent participation in paediatric rehabilitation. (Chapter 8)

Measures and other tools should be used to improve the transparency and tuning of the paediatric treatment process, and to facilitate truly family-centred care with the precise amount of involvement that parents desire. (Chapter 9)

10.1 Directions for future research

To give a comprehensive answer on the questions *what is being done in treatment* and *how the paediatric rehabilitation treatment process is organized* in the Netherlands, larger groups of children should be observed in future studies, with various diagnoses, and in different centres and treatment teams.

In our observational study (chapter 9) we chose for a mixed-method design of observations and studying of the subjects' written reports. In other words, we concentrated on materials that were already available (written reports), and the actual treatment (observations). We did not use additional measures, nor did we have an interview with people involved in the care process, *i.e.*, service providers, parents, and children. It turned out that our mixed-method design was not the optimal choice for a comprehensive description of the tuning and transparency of the treatment process, because a lot of the information we thought to find was not committed to paper. We therefore advise to add interviews and measures of the family-centredness of services, such as the MPOC and MPOC-SP, to the instruments in future studies.

When a larger group is being observed in a future study, the MPOC, MPOC-SP, and perhaps the GYV-20 for children above 12, can be utilized for an overall and standardized view on the family-centredness of the care process. Together, they will form a comprehensive test battery to evaluate the family-centeredness and teen-centredness of services from a viewpoint of all involved in the process of care. It would be very interesting to examine—in a larger study sample—whether the MPOC, MPOC-SP, and the GYV-20 data are inter-related.

Within the framework of individualized care, we provided some preliminary results on a family-bound use of the MPOC-SP.¹⁸⁰ A family-bound MPOC-SP is filled out by all team members involved in the care for a particular family. In this way, the MPOC-SP can be utilized for individual program evaluation and quality control and to formulate topics for family-related quality improvement, for instance, to improve a problematic relationship of a family and the treatment team when it is not clear where the actual problem lies, or to coordinate a family's particular care process ("Who does what?"). This target shift of the MPOC-SP towards individual families away from general clients closely resembles the basic principles of FCS, in which the uniqueness of each child and its family is acknowledged by an individual and dynamic approach. Further research is needed to fully examine the use of the MPOC-SP as a family-bound measure.

For a comprehensive view on parent involvement in the treatment process, the visions of other parties in the care process, for instance, service providers, children, and managers, should be added to our data. Furthermore, in our interviews (chapter 8) only one aspect, *i.e.*, parent involvement in their child's treatment, of family-centred care was examined. Other aspects of family-centred care in paediatric rehabilitation in the Netherlands should be addressed in future research, for instance, whether the uniqueness of each family is acknowledged by offering individualized services.

10.2 Implications for practice, research, and policy

The study described in this thesis leaves us optimistic about the future of paediatric rehabilitation in the Netherlands. A lot of work has been done and is being done to improve the rehabilitation process for children. Not only university researchers are working on the topic, but an increasing amount of "in-house" research in paediatric rehabilitation centres of high quality are carried out, and more importantly, carried over. Moreover, clinical workers and researchers increasingly join forces to carry out research projects, which obviously has large advantages for all parties involved.

The need for valid and reliable instruments for the evaluation of paediatric rehabilitation services appeared to be larger than initially expected, because, right after the start of our project, paediatric rehabilitation research in the Netherlands accelerated, for instance, through the extended PERRIN research program (**PE**diatric **R**ehabilitation **R**esearch in the Netherlands). While our research group worked on the validation and implementation of the "family-centred" MPOC, MPOC-20, MPOC-SP, and GYV-20, other Dutch researchers and research groups were validating and implementing various other instruments and tools that can be utilized in paediatric rehabilitation, for instance, the Gross Motor Function Measure (GMFM),¹⁶⁴ the Gross Motor Function Classification System (GMFCS),¹⁴⁶ the Pediatric Evaluation of Disability Inventory (PEDI),⁷⁰ the Goal Attainment Scaling (GAS),⁹⁸ the Canadian Occupational Performance Measure (COPM),¹⁰⁵ and the Children's Assessment of Participation and Enjoyment (CAPE).⁸⁹ We should be vigilant in spotting any needs for additional instruments in clinical practice and rehabilitation research in a local as well as an international context.

Validating existing measures may not be purely advantageous: you will have to settle with the measure available, while you would probably have done things slightly different when developing the instrument yourself. For us, the international commensurability of results is an important issue and led us to choose a direct translation and validation of the original measures. This was supported by the fact that the Canadian and the Dutch rehabilitation systems have comparable organization, and by Canadian and Dutch parents, service providers, and adolescents having similar ideas about important aspects of the care-giving process. Therefore, the content validity of the Dutch MPOC, MPOC-SP, and GYV-20 are very strong. If the rehabilitation systems and the views on important aspects of the systems would have been less similar, we should have had to make a choice between international commensurability of results, and an instrument with a strong clinical applicability by adapting the original measure, foregoing international comparability.

Of course, some adaptations can always be made when validating a translated measure, as long as the actual contents of the questionnaire remain unaltered. In the Dutch MPOC, MPOC-SP, and GYV-20 version, for instance, we adjusted the explanation how to fill out the questionnaire to the Dutch care system and added some examples. Furthermore, in the MPOC and MPOC-SP, parents and service providers additionally indicate the importance of each of the items for their situation, which makes it possible to calculate

a corrected scale score accounting for the weight parents and service providers attribute to the separate behaviours (see chapter 8 for formulas). For instance, when a mean value of 1 is scored, the mean score is lowered, whether the behaviour is valued highly, or not at all. By correcting the scores for the weight attributed to the behaviours, a more reliable reflection of the perception of services is established. To further enlarge the practicability of the Dutch MPOC, we provided a formula for recalculation of mean scale scores (from a 7-point scale) into a better interpretable school-like grade (on a 10-point scale, like in the Dutch school system).

After the instrument validation procedure, potential users should be assisted in the implementation of the tool. For the GMFM,¹⁶⁴ GMFCS,¹⁴⁶ and PEDI,⁷⁰ for example, courses are already available in the Netherlands for a guided implementation.

The results of our observational study may serve as an eye-opener for other paediatric rehabilitation teams working with children with complex needs. Together with the parent interview results (chapter 8) they provide a valuable baseline for future projects to equip parents and families in paediatric rehabilitation, and may initiate projects to further improve the treatment chain. These two chapters (8 and 9) provide various tips and tricks to look at and to structure the paediatric treatment process. For example, the empirically derived aspects of parent involvement by treatment stage in chapter 8 may serve as a checklist to evaluate parent involvement in centres. Parents themselves sum up their three main ideas for enhancement of parent involvement, *i.e.*, improvement of communication between professionals and parents, enlargement of parent involvement in goal setting, and enlargement of parent involvement in treatment.

In chapter 9 the International Classification of Functioning, Disability and Health (ICF) is used as a framework and classification system to categorize parent identified problems, treatment goals, and treatment activities. The ICF provides an extensive and well-defined universally applicable framework for interdisciplinary research and for making research results comparable. Use of the ICF within the team allows proper formulation of identifiable and meaningful goals for rehabilitation, and enables professionals to record interventions and outcomes in a standardized professional language within a uniform framework, and facilitates and simplifies a regular check whether treatment activities are tuned to treatment goals and parent identified problems.

To conclude, we strongly believe parent participation in their child's care process can be enhanced, and that the tuning and transparency of the paediatric rehabilitation treatment process can improve much when limiting conditions —of which time and money are most important— are removed, when the right tools are provided with a guided implementation, and when scientific research provides the working field with a scientific justification for interventions, preferably in cooperation with clinical workers.

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Summary



In the Introduction (chapter 1), major developments and shifts in health care in general and paediatric rehabilitation in specific are described to provide the reader with the background information needed to place this thesis in the correct context. Next, the structure of paediatric rehabilitation in the Netherlands is outlined, and working models in Dutch paediatric rehabilitation are described in chronological order. Finally, the most recent policy developments with their main themes are discussed.

Chapter 2 provides a comprehensive evaluation of therapeutic motor interventions for children with or at risk for cerebral palsy. Our purpose was to review noticeable changes in the scientific quality of the studies and to highlight trends and changes in the nature of the evaluated programs. Fifty studies covering the period 1990 to 2001 were examined. We compared our results with those of Vermeer and Bakx, who reviewed the decade 1980 to 1989. We concluded that fundamental research with an adequate methodology was applied more often in our study period than in the period reviewed by Vermeer and Bakx. However, due to a lack of positive findings these developments did not lead to a substantial improvement in the scientific foundation of the interventions under study. Moreover, it seems that the higher the methodological quality of the study, the lower the number of reported positive results. Single case studies, combined with efforts to develop measures with a high sensitivity and specifically for children with cerebral palsy, can make more valuable contributions to the scientific justification of therapeutic interventions.

These findings were the impetus for our study on processes of care in paediatric rehabilitation. Chapters 3 to 7 of this thesis describe the validation of the Dutch versions of three measures of the family-centredness of services: the Measure of Processes of Care (MPOC and MPOC-20; parent perspective), the Measure of Processes of Care for Service Providers (MPOC-SP; service provider perspective), and the Giving Youth a Voice Questionnaire (GYV-20; adolescent perspective). Next, in chapter 8, the MPOC is used to measure parent satisfaction with services they and their child received.

Although quality of care and parent involvement in the rehabilitation treatment process are main topics in rehabilitation research as well as in quality management, a valid measure to ask parents for their opinion about the quality and the family-centredness of care provided by paediatric rehabilitation centres was not yet available in Dutch. Chapter 3 describes the procedure to make the MPOC available in the Netherlands. The Anglophone MPOC, developed by the McMaster University *CanChild* research group, is a 56-item self-administered questionnaire and was designed to find out what parents of children with chronic health problems think of the services they and their child receive, and to measure the extent to which these services are family-centred.

The MPOC was translated into Dutch and the validity and reliability of the Dutch version were assessed analogously to the Canadian validation study. In this way, the two MPOC versions could be compared and similarities and differences could be discussed. Participants were parents (response rate 71.6%) of 427 children aged 1 to 18 years recruited through nine paediatric rehabilitation centres in the Netherlands. These parents

filled out an MPOC, a Client Satisfaction Questionnaire (CSQ), and a general questionnaire. Like the Canadian MPOC, the Dutch translation showed to be psychometrically strong, with good evidence of construct validity and internal consistency, and good reliabilities.

At this moment, the MPOC is the only broadly focused, valid, and reliable instrument available for the evaluation of the family-centredness of services from a parent perspective. Although the MPOC's responsiveness to changes was not shown yet, in daily practice the instrument is being used more and more to evaluate the effectiveness of interventions. It was also not known yet whether MPOC scores are stable when administration is repeated after about one year. These issues are addressed in chapter 4. Our analyses of the data of a large study sample ($n = 427$) showed sufficient inter-individual stability, but also an overall decrease of the mean scale scores when administration was repeated after about one year. Furthermore, the MPOC showed some responsiveness to changes, but owing to the lower repeat scores, individual scale scores are hard to interpret when the instrument is used in an evaluative follow-up study, for instance, for evaluating a program intervention. In sum, when the MPOC is being used to assess the effectiveness of a group intervention longitudinally, scale scores should be interpreted with caution, and score correction should be considered.

When the 56-item MPOC was made available in the Netherlands, we received many requests from researchers, quality control workers, and parents for a shorter version of the questionnaire, with a decreased respondent burden. Furthermore, the high alphas we found in the Dutch MPOC validation study indicated that some questions might be redundant. One could base the shortening on a Dutch dataset to ensure maximal clinical applicability for our population, however, we chose for international commensurability and translated and validated the original Canadian MPOC-20. The results of this study are outlined in chapter 5. The Dutch MPOC-20 showed good reliabilities and good validity. Compared to the complete MPOC-56, the questionnaire fill out time is halved.

In the Netherlands, two Measures of Processes of Care are now available: the 56-item MPOC and the 20-item shortened MPOC-20. The advantages and disadvantages of both MPOC versions were discussed at the end of chapter 5. We conclude that the eventual goal of the assessment is of decisive importance when deciding on which MPOC version should be used.

After the development of the MPOC, the McMaster University *CanChild* research group developed a service provider version of the questionnaire: the MPOC-SP. This 27-item measure of family-centred service equips professionals with a tool giving information about how family-centred their way of working is, and may thereby lend valuable insights into the practice of family-centred service, as well as make service providers more aware of the family-centred ideal. Chapter 6 describes the procedure to make the MPOC-SP available in the Netherlands. The original Canadian MPOC-SP was translated into Dutch and the validity and reliability of the Dutch version were assessed. To be able to compare results, the Canadian validation procedures were copied. The 163 service

providers that participated in the validation study represented seven paediatric rehabilitation centres and affiliated schools in the Netherlands (overall response rate 55.6%). The Dutch MPOC-SP proved to be a reliable and valid instrument to measure the family-centredness of service delivery. Dutch service providers judged the practical applicability of the MPOC-SP in daily practice positively.

Now that the MPOC (parent viewpoint) and MPOC-SP (service provider viewpoint) were made available in the Netherlands, we looked for a comparable measure of the client-centredness of services from an adolescent perspective. One instrument was found in literature, the Canadian Giving Youth a Voice Questionnaire (GYV-20), developed by Gan and colleagues of the Bloorview MacMillan Children's Centre, who used the MPOC as a starting point. The original Canadian 20-item GYV-20 was translated into Dutch and the validity and reliability of the Dutch version examined. The results of this study are presented in chapter 7. Participants were 116 youngsters (response rate only 28.8%) aged 11 to 21 years recruited through six paediatric settings in the Netherlands, who all filled out a GYV-20 and a general questionnaire. Sixteen adolescents participated in an additional telephone interview about various aspects of the use of the GYV-20 in daily practice. The GYV-20 showed sufficient evidence of construct validity and good reliabilities. Dutch adolescents judged the GYV-20 as a valuable and useful tool to evaluate paediatric rehabilitation services in the Netherlands.

Family-centred care has become widely accepted as part of the philosophy of treatment in paediatric rehabilitation in the Netherlands. Little was known, however, about one specific aspect: the level and mode of parent involvement in the rehabilitation treatment process. This issue is addressed in chapter 8. Seventy-five parents of children treated in paediatric rehabilitation were interviewed about their contacts with the centre, treatment aspects, and taking part in the care process. In addition, they provided information about their satisfaction with received services by filling out the MPOC and the CSQ. A Quality of Care cycle with six stages was used to structure the evaluation. The average level of parent satisfaction with services received was sufficient (mean MPOC scale means 7.1 on a 10-point scale; mean CSQ score 7.7 on a 10-point scale). The data showed that parents were involved in all stages of their child's rehabilitation process in various ways. However, none of the interviewed parents reported on full involvement in all consecutive treatment stages. They suggested various ways to enhance parent participation. According to the interviewed parents the communication between professionals and parents, parent involvement in goal setting, and parent involvement in treatment could be improved.

To know what actually happens during treatment will provide insight in the quality of paediatric rehabilitation care. Chapter 8 describes the paediatric rehabilitation process from one perspective, *i.e.*, how parents perceive their child's treatment process. Since parents are not frequently present during treatment, they are not an optimal source of information for treatment process description. In chapter 9 we describe the relatively unknown clinical implementation of the paediatric rehabilitation care process in the Nether-

lands, by *observing* the treatment process of five children with cerebral palsy and complex needs. Our focus was the tuning of treatment goals and treatment activities to the child's and parents' needs and transparency of the rehabilitation process for all involved. The International Classification of Functioning, Disability and Health (ICF) was used to categorize parent identified problems, treatment goals, and treatment activities, and to be able to study how these were tuned to each other.

The five subjects, all diagnosed with cerebral palsy (GMFCS level II to V), were observed during treatment (physical therapy, occupational therapy, and speech therapy) and their written reports studied. Six parent identified problems, 45 treatment goals, and 72 treatment activities were identified and linked to the ICF components, domains and categories. The amount of agreement was determined by code comparison. The analyses indicated some agreement of parent identified problems, goals and activities in all subjects, but only four of the 72 treatment activities were perfectly tuned to treatment goals as well as to parent identified problems. Several options are discussed to improve the tuning and transparency of the paediatric rehabilitation process substantially. Measures (for instance, the MPOC), and other tools (for instance, the COPM and GAS), should be used to improve the transparency and tuning of the paediatric treatment process, and to facilitate truly family-centred care with the precise amount of involvement that parents desire.

In the General discussion (chapter 10) a list with key messages from this thesis is provided. We are optimistic about the future of paediatric rehabilitation in the Netherlands. A lot of work has been done and is being done to improve the rehabilitation process for children. Not only university researchers are working on the topic, but an increasing amount of "in-house" studies in paediatric rehabilitation centres of high quality are carried out, and more importantly, carried over. Moreover, clinical workers and researchers increasingly join forces to carry out research projects, which obviously has large advantages for all parties involved. We strongly believe the process of care in Dutch paediatric rehabilitation can get better when limiting conditions —of which time and money are most important— are removed, when the right tools are provided with a guided implementation, and when scientific research provides the working field with a scientific justification of interventions, preferably in cooperation with clinical workers.

Samenvatting



Om dit proefschrift in de juiste context te kunnen plaatsen is enige achtergrondinformatie noodzakelijk. Om de lezer hierin te voorzien wordt in de Inleiding (hoofdstuk 1) een overzicht gegeven van grote ontwikkelingen en verschuivingen in de gezondheidszorg in het algemeen en in de kinderrevalidatie in het bijzonder. Hierna worden de structuur van de kinderrevalidatie in Nederland en de diverse werkmogelijkheden die in de loop der tijd in de kinderrevalidatie gebruikt zijn beschreven. Aan het eind van dit hoofdstuk worden de belangrijkste ontwikkelingen op beleids- en onderzoeksgebied besproken.

Hoofdstuk 2 doet verslag van een uitgebreide reviewstudie naar motorische interventieprogramma's voor kinderen met een cerebrale parese. Ons doel was om te bepalen of de wetenschappelijke kwaliteit van de studies wezenlijk veranderd was in de loop van twee decennia en om trends en grote veranderingen in de aard van de programma's te beschrijven. Vijftig studies uit de periode 1990 tot 2001 werden beoordeeld. De resultaten werden vergeleken met de resultaten van Vermeer en Bakx die het decennium 1980 tot 1989 hadden beschreven. We concludeerden dat in onze reviewperiode fundamenteel onderzoek met een adequate methodologie vaker wordt toegepast dan in de periode die door Vermeer en Bakx beoordeeld werd. Door een gebrek aan positieve resultaten hebben deze ontwikkelingen echter niet geleid tot een substantiële verbetering van de wetenschappelijke onderbouwing van de beoordeelde interventiestudies. Er leek sprake van een omgekeerd effect: hoe hoger de methodologische kwaliteit van een onderzoek, hoe minder positieve resultaten er gerapporteerd worden. Single case studies, in combinatie met de ontwikkeling van instrumenten met een hoge sensitiviteit die specifiek geschikt zijn voor kinderen met een cerebrale parese, zullen waarschijnlijk een goede bijdrage kunnen leveren aan de wetenschappelijke verantwoording van therapeutische interventies.

Onze studie naar zorgprocessen in de kinderrevalidatie bouwt voort op deze twee bevindingen. In Hoofdstuk 3 tot en met 7 van dit proefschrift wordt de validatie van de Nederlandstalige versies van vragenlijsten beschreven die de gezinsgerichtheid van de zorg in kaart kunnen brengen: de Measure of Processes of Care (MPOC en MPOC-20; in het Nederlands vertaald als "Vragenlijst Ervaringen van Ouders met het Zorgproces"; instrument voor de mening van ouders over het zorgproces), de Measure of Processes of Care for Service Providers (MPOC-SP; in het Nederlands vertaald als "Vragenlijst Ervaringen van Zorgverleners met het Zorgproces"; instrument voor de mening van zorgverleners over het zorgproces) en de Giving Youth a Voice Questionnaire (GYV-20; in het Nederlands vertaald als "Ervaringen van Jongeren met het Zorgproces"; instrument voor de mening van jongeren over het zorgproces). In hoofdstuk 8 wordt de MPOC gebruikt om de tevredenheid van ouders over de ontvangen zorg te bepalen.

Alhoewel kwaliteit van zorg en de betrokkenheid van ouders bij de revalidatiebehandeling speerpunten zijn in revalidatieonderzoek en kwaliteitsmanagement, was er nog geen valide instrument beschikbaar waarmee ouders naar hun mening over de kwaliteit en de gezinsgerichtheid van kinderrevalidatiezorg gevraagd konden worden. Hoofd-

stuk 3 beschrijft de procedure die gevolgd werd om de MPOC beschikbaar te maken in Nederland. De Engelstalige MPOC, die ontwikkeld is door de *CanChild* onderzoeksgroep van de McMaster Universiteit in Hamilton, Canada, is een vragenlijst met 56 items die door ouders zelf ingevuld wordt. De vragenlijst is ontwikkeld om in kaart te kunnen brengen hoe ouders van kinderen met chronische gezondheidsproblemen denken over zorg die zij en hun kind ontvangen en om te bepalen in welke mate deze zorg gezinsgericht is.

De MPOC werd vertaald naar het Nederlands en de validiteit en betrouwbaarheid van de Nederlandstalige versie werden onderzocht zoals in de Canadese validiteitsstudie, waardoor de resultaten van de beide validiteitsstudies vergeleken konden worden. Aan de Nederlandse validiteitsstudie namen ouders (respons 71.6%) van 427 kinderen deel in de leeftijd van 1 tot 18 jaar. Ze werden geworven in negen kinderrevalidatiecentra in Nederland. De ouders vulden een MPOC, een Client Satisfaction Questionnaire (CSQ) en een algemene vragenlijst in. Net als de Engelstalige MPOC bleek de Nederlandse vertaling van de vragenlijst sterke psychometrische eigenschappen te hebben, met een goede constructvaliditeit, interne consistentie en goede betrouwbaarheid.

Op dit moment is de MPOC het enige valide en betrouwbare instrument dat gebruikt kan worden voor de evaluatie van de gezinsgerichtheid van zorg vanuit het perspectief van ouders. Alhoewel de responsiviteit van de MPOC voor veranderingen nog niet bepaald is, wordt de vragenlijst in de praktijk steeds vaker gebruikt om de effectiviteit van interventies te evalueren. Daarnaast is nog niet bekend of MPOC-scores stabiel zijn bij herhaalde meting na ongeveer een jaar. Deze punten worden behandeld in hoofdstuk 4. Onze analyses van de data van een grote onderzoeksgroep ($n = 427$) toonden voldoende inter-individuele stabiliteit aan, maar ook een algehele afname van gemiddelde schaalscores bij herhaalde meting na ongeveer een jaar. De MPOC scores bleken gevoelig voor verandering maar door de algehele afname van scores bij herhaalde meting is het moeilijk om de individuele schaalscores te beoordelen wanneer de vragenlijst gebruikt wordt in een evaluatieve follow-up-studie, bijvoorbeeld voor de evaluatie van een interventie. Als de MPOC *toch* wordt gebruikt om de longitudinale effectiviteit van een groepsinterventie te onderzoeken, moeten de schaalscores "met verstand" geïnterpreteerd worden. Voor een betere interpretatie van scores kan correctie van de schaalscores op het tweede meetmoment overwogen worden.

Toen de Nederlandstalige MPOC met 56 items beschikbaar was gemaakt, kregen we veel vragen van onderzoekers, kwaliteitsmedewerkers en ouders of er niet een kortere MPOC beschikbaar was. Een kortere invultijd van de MPOC zou een eventuele drempel om de vragenlijst in te vullen aanzienlijk kunnen verlagen. De hoge alpha's die we vonden in de validatiestudie van de Nederlandstalige MPOC duiden er al op dat een aantal MPOC-items weggelaten zou kunnen worden. Voor een verkorting van de MPOC met een maximale klinische toepasbaarheid zou de Nederlandse MPOC dataset als uitgangspunt moeten dienen. Wij kozen echter voor internationale vergelijkbaarheid van MPOC-resultaten en vertaalden en valideerden de originele Engelstalige verkorte

MPOC-20. De resultaten van deze validatiestudie worden beschreven in hoofdstuk 5. De Nederlandstalige MPOC-20 heeft een goede betrouwbaarheid en validiteit. Vergeleken met de MPOC met 56 items is de invultijd gehalveerd. In Nederland zijn nu twee Measures of Processes of Care beschikbaar: de MPOC met 56 items en de verkorte MPOC-20 met 20 items. De voordelen en nadelen van het gebruik van beide MPOC's worden besproken aan het eind van hoofdstuk 5. We concluderen dat bij de keuze voor de verkorte MPOC-20 of de originele MPOC met 56 items het uiteindelijke doel van de meting van doorslaggevend belang is.

Na de ontwikkeling en validatie van de MPOC ontwikkelde de *CanChild* onderzoeksgroep van de McMaster Universiteit in Canada een versie van de vragenlijst voor zorgverleners: de MPOC-SP. Zorgverleners worden met deze vragenlijst (met 27 items) toegerust met een instrument dat informatie geeft over hoe gezinsgericht ze *zelf* te werk gaan. Op deze wijze kan inzicht verkregen worden in de praktijk van gezinsgerichte zorgverlening en worden zorgverleners zich mogelijk bewuster van de gezinsgerichte idealen. Hoofdstuk 6 beschrijft de procedure die gevolgd werd om de MPOC-SP beschikbaar te maken in Nederland. De originele Engelstalige MPOC-SP werd vertaald naar het Nederlands en de validiteit en betrouwbaarheid van de Nederlandstalige versie werden onderzocht. Om de resultaten te kunnen vergelijken werd de Canadese validatieprocedure nagevolgd. Aan de validatiestudie namen 163 zorgverleners (respons 55,6%) deel die tezamen zeven Nederlandse kinderrevalidatiecentra en aangrenzende scholen vertegenwoordigden. We toonden aan dat de MPOC-SP een betrouwbaar en valide instrument is om de gezinsgerichtheid van zorg in kaart te brengen vanuit het gezichtspunt van zorgverleners. Nederlandse zorgverleners vonden de praktische toepasbaarheid van de MPOC-SP in de dagelijkse praktijk goed.

Nu de MPOC (perceptie van ouders) en de MPOC-SP (perceptie van zorgverleners) beschikbaar waren in Nederland, gingen we op zoek naar een vergelijkbaar instrument voor de cliëntgerichtheid van de zorg vanuit het perspectief van adolescenten. In de literatuur vonden we één instrument, de Canadese Giving Youth a Voice Questionnaire (GYV-20), dat ontwikkeld was door Gan en collega's van het Bloorview McMillan Children's Centre. De MPOC werd bij de ontwikkeling van de GYV-20 als uitgangspunt gebruikt. We vertaalden de originele Engelstalige GYV-20 (met 20 items) naar het Nederlands en bepaalden de validiteit en betrouwbaarheid. De resultaten van deze studie worden beschreven in hoofdstuk 7. Honderd zestien jongeren (respons slechts 28,8%) in de leeftijd van 11 tot 21 jaar namen deel. Ze werden geworven in zes kinderrevalidatiesettings in Nederland. Alle deelnemers vulden een GYV-20 en een algemene vragenlijst in. Zestien jongeren verleenden bovendien hun medewerking aan een telefonisch interview over verscheidene aspecten van het gebruik van de GYV-20 in de dagelijkse praktijk. De GYV-20 heeft een goede constructvaliditeit en betrouwbaarheid. Nederlandse jongeren vinden de GYV-20 een goed instrument om de kinderrevalidatiezorg in Nederland te evalueren.

Gezinsgerichte zorg is inmiddels breed geaccepteerd als onderdeel van de behan-

delfilosofie in de kinderrevalidatie in Nederland. Er was echter nog maar weinig bekend over één specifiek aspect: de *mate waarin* ouders betrokken worden in het revalidatiebehandelproces en de *manier waarop* ze hierin betrokken worden. Dit vraagstuk wordt behandeld in hoofdstuk 8. Vijfenzeventig ouders van kinderen die behandeld worden in de kinderrevalidatie werden geïnterviewd over hun contacten met het centrum, behandelaspecten en hun deelname aan het zorgproces. Daarnaast vulden ze de MPOC en de CSQ in om informatie te verschaffen over hoe tevreden ze waren over de ontvangen zorg. Een Kwaliteit van Zorg-cyclus met zes fases werd gebruikt om de evaluatie te structureren. De gemiddelde tevredenheid van ouders over de ontvangen zorg was voldoende (gemiddelde MPOC schaalscores 7.1 op een schaal van 1 tot 10; gemiddelde CSQ-score 7.7 op een schaal van 1 tot 10). De data lieten zien dat ouders in alle fases en op verschillende manieren betrokken worden bij het revalidatieproces van hun kind. Niemand van de geïnterviewde ouders werd echter volledig betrokken bij alle fases van het behandelproces. Ouders deden verschillende suggesties om ouderparticipatie in de kinderrevalidatie te verbeteren. De belangrijkste verbeterpunten die ouders aandroegen betroffen de communicatie tussen zorgprofessionals en ouders, betrokkenheid van ouders bij het stellen van behandeldoelen en de betrokkenheid van ouders in de behandeling zelf.

Als bekend zou zijn wat er precies in de behandeling gebeurt, zou dat een beter inzicht geven in de kwaliteit van de kinderrevalidatie. Hoofdstuk 8 beschrijft het kinderrevalidatieproces vanuit één perspectief: dat van de ouders. Doordat ouders niet altijd bij de behandeling aanwezig zijn, zijn zij mogelijk niet de beste informatiebron voor een beschrijving van het behandelproces. In hoofdstuk 9 beschrijven we hoe het behandelproces er uitziet in de kinderrevalidatie in Nederland door middel van *observaties* van het behandelproces van vijf kinderen met een cerebrale parese en een complexe zorgbehoefte. We richten ons met name op de afstemming van behandeldoelen en behandelactiviteiten op de hulpvraag van ouders en kind en op de transparantie van het revalidatieproces voor alle betrokkenen. Het ICF (International Classification of Functioning, Disability and Health) werd gebruikt om de hulpvraag, behandeldoelen en behandelactiviteiten te categoriseren en om te kunnen bepalen in welke mate hulpvraag, doelen en activiteiten op elkaar afgestemd waren. De vijf deelnemers (allen gediagnosticeerd met een cerebrale parese; GMFCS level II tot V) werden geobserveerd tijdens de behandeling (fysiotherapie, ergotherapie en logopedie) en hun verslagen werden bestudeerd. Zes hulpvragen, 45 behandeldoelen en 72 behandelactiviteiten werden onderscheiden en gekoppeld aan de componenten, domeinen en categorieën van het ICF. De mate van overeenstemming werd bepaald door vergelijking van de toegekende ICF-codes.

Uit de analyses bleek dat er voor alle deelnemers enige overeenstemming was tussen codes van hulpvragen, doelen en activiteiten, maar slechts vier van de 72 behandelactiviteiten waren volledig afgestemd op behandeldoelen *en* hulpvragen. Een aantal mogelijkheden wordt besproken om de inhoudelijke afstemming en transparantie van het kinderrevalidatieproces aanzienlijk te verbeteren. Vragenlijsten (bijvoorbeeld de MPOC) en andere instrumenten (bijvoorbeeld de COPM en GAS) zouden gebruikt kunnen wor-

den om de transparantie van het behandelproces en de afstemming van de behandeling op de hulpvraag van ouders en kind te verbeteren. Op deze manier wordt *werkelijk* gezinsgerichte zorg gefaciliteerd met een mate van betrokkenheid die ouders *zelf* willen.

In de Algemene discussie (hoofdstuk 10) wordt een overzicht gegeven met de belangrijkste boodschappen uit dit proefschrift. We zijn optimistisch over de toekomst van de kinderrevalidatie in Nederland. Er is al veel werk verzet en er worden op dit moment veel initiatieven ontwikkeld om het kinderrevalidatieproces te verbeteren. Niet alleen aan universiteiten wordt onderzoek gedaan naar dit onderwerp, maar ook een groeiend aantal revalidatiecentra voert zelf onderzoek uit en, nog veel belangrijker, deelt de onderzoeksresultaten met andere centra. Zorgprofessionals uit de praktijk en onderzoekers slaan bovendien steeds vaker de handen ineen om gezamenlijk een onderzoeksproject uit te voeren. Dit heeft uiteraard grote voordelen voor alle betrokkenen.

We zijn ervan overtuigd dat het zorgproces in de kinderrevalidatie in Nederland nog verder kan verbeteren als beperkende condities —waarvan tijd en geld de twee belangrijkste zijn— worden aangepakt, als de juiste instrumenten (met een begeleide implementatie) worden aangedragen en als wetenschappelijk onderzoek de praktijk van wetenschappelijke onderbouwingen blijft voorzien, bij voorkeur in samenwerking met zorgprofessionals uit de praktijk.

Dankwoord



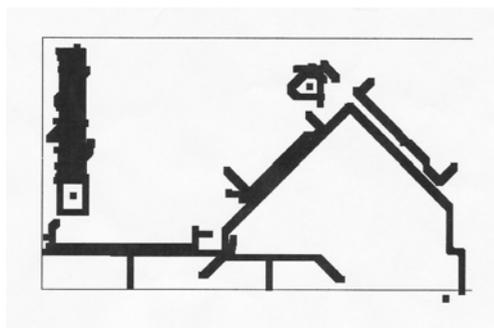
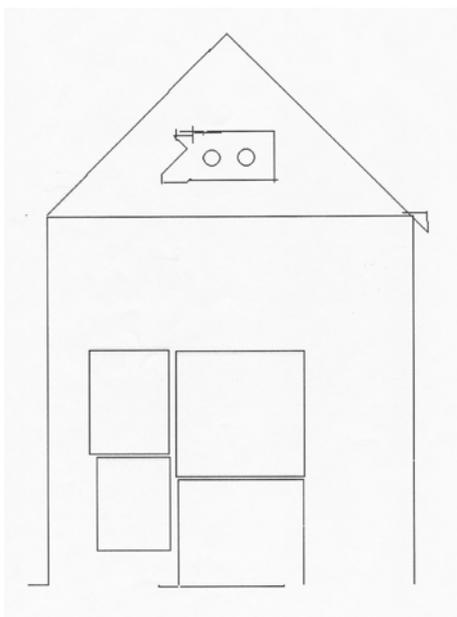
Dit dankwoord is dan wel het laatste deel van mijn proefschrift, maar wel één van de belangrijkste delen! Niet in de laatste plaats omdat het dankwoord het meest gelezen blijkt, maar zeker ook omdat dit de plek in het proefschrift is waar ik mijn waardering kan uiten voor diegenen die onmisbaar waren bij het tot stand komen ervan. Sterker gezegd: zonder onderstaanden was dit proefschrift niet eens werkelijkheid geworden...

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Krista Konijntje tussen de bloemen en het gras

Achter de schermen van dit proefschrift was van het prille begin tot de turbulente ont-knoping een vijfkoppig creatief productieteam aan het werk.



Bas Het mooiste huis ooit

Promotor Prof. Dr. A. Vermeer, beste Adri, zelfs vanaf een kameel in de woestijn en een tropisch eiland mailde je binnen het uur terug. Je gaf me alle ruimte mijn "ideetjes" uit te werken en dit project naar eigen inzicht in te kleuren. Je kunt weer rustig slapen nu je laatste Utrechtse telg de eindstreep ook gehaald heeft.

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Co-promotor Dr. M. Ketelaar, beste Marjolijn, ik was in mijn nopjes toen je "ja" zei in het verre Bled. Je drive werkt aanstekelijk en motiverend en je mailtjes en telefoontjes op precies het goede moment waren sterker dan Red Bull. Je bracht me de kunst van het reduceren bij en je heldere stapsgewijze aanpak legde mijn hink-stap-sprong-techniek aan banden.

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Prof. Dr. M.J. Jongmans, beste Marian, je bent een geweldige professor (zolang je maar niet gaat hoofdrekenen...) en ik bewonder je veelzijdigheid. Bedankt voor het meedenken en je luisterende oor.



Jop Ballende kinderen

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Rogier Rogier bij de appelboom

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Myrthe Mama

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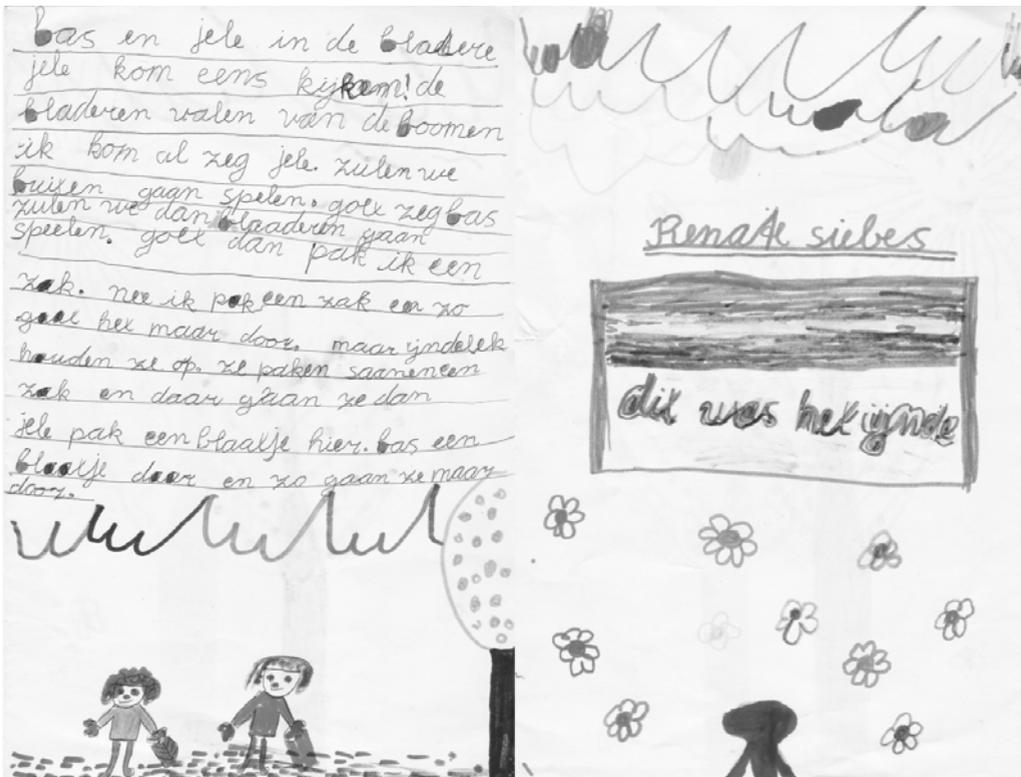
Lieve **Twan**, ik heb het beste voor het laatst bewaard. Je stelde je vrijwillig bloot aan grote doses alpha- en gammastraling en bluste alle technische brandjes. Je was mijn vertaalcomputer totdat Word deze functie overnam, previewde alle artikelen, ving de dames op "als er iets af moest" en was mijn $\text{\LaTeX} 2_{\epsilon}$ -vraagbaak. Ik heb nu weer (even) tijd om je overhemden te strijken. 😊

About the author



Renate Siebes was born in Dordrecht, the Netherlands, on October 8, 1973. The author received her Atheneum diploma in 1993 from the Titus-Brandsmacollege in Dordrecht. In the meantime, in 1992, she was admitted to the Brabants Conservatorium in Tilburg, where she studied oboe for three years. In 1993, she moved to Utrecht and started her educational sciences study majoring in psychosocial problems in childhood and adolescence at the Faculty of Social Sciences at Utrecht University.

In her fourth study year, she weekly faced the Antwerp ringway during the evening rush, commuting between home and her "international" practical training at the Department of Child Psychiatry at University Hospital Gasthuisberg, Leuven, Belgium. In 1998 she concluded her studies with a thesis on the effects of the KOPP program for children with parents with psychiatric problems.



Excerpt from an early publication

During and after her master study, she changed loads of diapers and practiced a lot with babies and toddlers at a daycare centre. She particularly enjoyed taking care of

special children at an organization for children with complex disabilities, both in home care and at the institution.

Before entering the PhD program in the Langeveld Institute for the Study of Education and Development in Childhood and Adolescence of Utrecht University in 2000, she worked as a research assistant at the Department of Educational Sciences of Utrecht University (OpStap Opnieuw project) and the Julius Center for General Practice and Patient Oriented Research at the University Medical Center Utrecht (AEOLUS project). From 2000 to 2006 she worked on her dissertation, studying processes of care in paediatric rehabilitation. This thesis summarizes the results of this study.

During her PhD study the author visited conferences in some beautiful parts of Europe, with a fabulous stay in Monaco during HRH Prince Albert's inauguration weekend in 2005 as the grand climax. A more scientific culmination was reached at the EACD 2002 conference in Gothenburg, where the author won the poster award for "the most original and scientific work". One year later, this same work was awarded the ISED paper prize.

Somewhere between the second and the third chapter of this thesis Myrthe was born (2002), and Merah was born about three chapters later (2004). In her spare time, the author is a fanatic oboe and cor anglais player in the Groot Film- en Musicalorkest Timbres Divers. She likes to co-organize queer orchestra projects and is the orchestra's webmaster.