Team collaboration in Dutch paediatric rehabilitation. Cooperation between parents, rehabilitation professionals and special education professionals in the care for children with cerebral palsy
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SUMMARY
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This thesis describes the collaborative processes in Dutch paediatric teams engaged in the care for children with cerebral palsy (CP). The three main stakeholder groups in these teams are the parents and the professionals in child rehabilitation and special education. Although the need for close collaboration in these specialised teams has been described extensively in the literature and is advocated in the clinical practice, it has proven difficult to define team collaboration adequately and provide a complete overview of related factors and variables. Moreover, despite the commitment of parents, professionals and organisations to a collaborative approach, adoption of prescribed models and their implementation in daily practice proved to be complex. These observations were the rationale for our study.

The aim of the studies reported in this thesis was threefold:
1. To define the concept of team collaboration in paediatric rehabilitation;
2. To describe the organisational characteristics of collaborative efforts in five Dutch paediatric settings and
3. To describe current collaborative practices in the care for children with cerebral palsy (CP).

In Chapter 1 a short description of paediatric rehabilitation in the Netherlands is provided with specific focus on the organisational structures and recent developments regarding teamwork in paediatric rehabilitation.

Chapter 2 comprises a systematic search of the literature. After an initial search to define key features of team collaboration, a systematic search was conducted to identify salient elements of team collaboration. The search was aimed at English language studies covering the period from January 1993 to December 2004 and resulted in 28 studies that were analysed by two independent observers. The evaluation yielded six key features, i.e. communication, decision making, goal setting, organisation, team process and parent involvement, and 29 salient elements defining team collaboration. Together, these identified key features and elements can serve as guidelines and items on a checklist for empirical studies into the efficacy of current collaborative practices. They can, moreover, be utilised to develop new guidelines for the clinical practice that will help enhance the quality of collaboration among the various parties involved in the children's team care.

Chapter 3 discusses the organisational characteristics of team collaboration in Dutch paediatric rehabilitation. Views on how team collaboration should be organised are described and the policies on team collaboration of five paediatric rehabilitation settings and the involvement of team members associated with the care of 44 children with CP analysed. For a comprehensive overview of current ideas and policies on collaboration at the national, the institutional and the child-level written statements from professional associations in Dutch paediatric rehabilitation and the five participating settings were examined. The involvement of the stakeholders was analysed based on team conferences. At the national level, it was concluded that also in the Netherlands collaboration between parents, rehabilitation and educational professionals is endorsed as the key principle in paediatric rehabilitation with at its core the team conference in which the various priorities and goals are formulated and integrated into a personalised treatment plan. The policies on cooperation between the rehabilitation centre and schools for special education rarely differed between the five settings but at child level approaches did vary. As to the involvement of team members, teams proved to be large (averaging 10.5 members) and type of involvement differed per setting. The results merited the conclusions that in Dutch paediatric rehabilitation collaboration among the parents, rehabilitation and education professionals is supported and encouraged and that views on collaboration have been formulated and general guidelines on family-centred and
coordinated care have been made available. Yet, collaborative practices in Dutch paediatric care are still developing and protocols that carefully delineate the commitments to collaborate and that translate the policies into practical, detailed guidelines in which roles and responsibilities are defined, are needed, as they are a prerequisite for successful teamwork.

Chapters 4, 6 and 7 describe the results fulfilling the third aim of this thesis, i.e. the description of current collaborative practices in the care for children with CP in five Dutch paediatric rehabilitation settings.

In Chapter 4 the provision of family-centred care is examined. Although the acknowledgement of the uniqueness of families in the provision of care is a requisite of family-centred services, until now the analysis of family-centredness of care focused only on group means of parental and professional ratings. Such analyses, by definition, do not take the specific needs and wishes of individual families into account. Also, analyses of areas for improvement were based on the occurrence of behaviour only and not linked to the weight the parents attributed to the behaviours. To accommodate for these limitations, we conducted a family-specific analysis of family-centredness of care. In each family-specific team the perceptions and views on the importance of family-centred behaviours of parents, rehabilitation and special education professionals were compared. In addition, it was evaluated whether parents in fact received the family-centred care they deemed important. The parents’ perceptions were assessed by means of the Dutch version of the Measure of Processes of Care (MPOC-NL) and the perceptions of the rehabilitation professionals and special education professionals by means of the family-specific Measure of Processes of Care for Service Providers (MPOC-SP). To allow an accurate assessment of their respective views on the importance of family-centred behaviours, importance scales were added to both measures. The analysis revealed significant differences between the three stakeholders on all MPOC domains. Moreover, in all domains a considerable proportion of the parents (19-38%) indicated not to receive the care they deemed important, which was likely due to the differences in attitudes towards the importance of specific care behaviours of team members. The findings clearly showed that a family-specific evaluation of family-centred care is warranted and that the MPOC and MPOC-SP with the added importance scales allow an effective comparison of perceptions of people in various positions and different roles, in this case of the parents of disabled children and the service providers involved in their care.

To be able to accurately evaluate the degree of family-centeredness of the care provided to a specific family and to acknowledge the uniqueness of families and their preferences and needs in this evaluation, the validity and utility of the family-specific use of the Dutch MPOC-SP was examined in Chapter 5. Based on 240 family-specific MPOC-SPs completed by 116 service providers involved in the rehabilitation and education of 41 children with CP, the study tests the tool’s construct validity. To test the ability of service providers to discriminate between general and family-specific ratings, a subgroup of 81 service providers filled in a general MPOC-SP and at least one family-specific MPOC-SP, resulting in 151 general–family-specific MPOC-SP pairs. The results confirmed the scale structure of the family-specific MPOC-SP and the analysis of the differences between the general and the family-specific MPOC-SPs indicated that service providers were able to discriminate between the two types of ratings. The family-specific MPOC-SP was accordingly concluded to be a valid measure suitable for use in individual evaluations of family-centred services. In our view this measure could serve as an impetus for the further enhancement of the quality of family-centred care in Dutch paediatric rehabilitation.
Chapters 6 and 7 relate to the collaborative goal-setting processes as they evolved in five Dutch paediatric rehabilitation venues. Here, the quality and content of the needs, principal problems and shared principal goals of 41 children with CP as formulated in the Children’s RAP, i.e. the Rehabilitation Activities Profile for Children, were the subjects of analysis. In the Netherlands the Children’s RAP is the benchmark for the formulation of interdisciplinary paediatric treatment plans. These individualised, integrated treatment plans are crucial for the communication among the various professionals and the parents. In both chapters the data analyses were child-specific. Raw text data describing the needs, problems and goals were extracted from each Children’s RAP and then organised, after which two raters independently weighed the entries’ quality against the protocol criteria and linked the extracted content to the categories of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). In Chapter 6 the data analysis mainly focused on the quality and content of the conceptualised needs, problems and goals and in Chapter 7 the main point of interest was the extent to which these need and problem concepts were integrated into the children’s rehabilitation goals. The study reported in Chapter 6 revealed that the children’s treatment plans did not completely satisfy the basic requisites and quality criteria of the Children’s RAP, restricting an effective use of this communication instrument. In 12% of the reports no needs and in 24% no principal goals were formulated. Furthermore, the treatment plans did not provide information on whether parents and team members had set priorities and reached unity on the most important needs, problems and goals. The results of the study described in Chapter 7 showed that only 23% of the needs and 46% of the problems were incorporated into the goals. Furthermore, 52% of the formulated goals proved not to be related to either a need or a problem. Because of the often suboptimal documentation in the reports (Chapter 6) and because the prioritisation of needs and problems was lacking, it was difficult to objectify the integration of the principal needs and problems into treatment goals and thus prevented a proper interpretation of the quality of integration. In summary, the data presented in Chapters 6 and 7 clearly demonstrated that the goal-setting procedures in Dutch paediatric rehabilitation warrant improvement. Evidently, the Children’s RAP can only be effective in clinical practice if its basic requisites and recommendations are fulfilled. Adequate instruction of team members in how to implement the Children’s RAP paradigm and assistance in how to adhere to its stipulations is expected to help augment goal-setting practices.

In Chapter 8 the main findings of this thesis are summarised and discussed and placed into perspective. The results of the various studies have contributed threefold to the charting and hence hopefully to the enhancement of the collaboration among parents, rehabilitation professionals and special education professionals in paediatric rehabilitation venues in the Netherlands. First, the present analysis of the operant team collaboration procedures has made the process quantifiable, allowing a transparent representation of current practices. Furthermore, the data collection methods and analytic strategies used in this thesis have provided the field of child rehabilitation with new tools to assess (parts of) team collaboration practices, allowing targeted fine-tuning of the process. And finally, the new insights into the current collaboration practices has helped identify areas for improvement.

To conclude the thesis, various methodological reflections are offered and three main targets for improvements in the clinical practice and recommendations on how to achieve these targets are provided.