

Family-centred practices in the provision of interventions and services in primary health care: A survey of parents of preschool children with cerebral palsy

Abstract

The aims of this study were to explore how parents of preschoolers with cerebral palsy (CP) experienced level of family-centred services using the Measure of Processes of Care (MPOC-20) within primary health care in Norway, and to examine the relationships between these experiences and the provided everyday skills interventions and services.

A survey was sent to 360 parents of preschool children with CP. The response rate was 34%. Of the MPOC scales *Respectful and supportive care* and *Coordinated and comprehensive care* received the highest ratings, and *Providing general information* the lowest. Our findings indicate lower level of family-centredness in primary health care contexts, than reported in specialist health care. Significant positive associations were found between all the five MPOC-20 scales and the parents' satisfaction with the amount of service coordination ($p = 0.000-0.004$). The high scores for *Respectful and supportive care* and the low scores for *General information* indicate that the families experienced relational help-giving practices to a larger extent and participatory practices to a lesser extent. To increase the participatory aspects of family-centred practice,

further research needs to address facilitators and barriers of information sharing and ways of giving this information both in specialist and primary health care.

Keywords

Cerebral palsy, preschool children, provision of interventions and services, primary health care, MPOC-20, survey

Introduction

Cerebral palsy (CP) is a complex condition involving motor impairments, activity limitations, and participation restrictions (Rosenbaum et al., 2007). As a consequence, children with CP receive a variety of interventions to enhance motor function and the learning of everyday skills. In Norway the prevalence of CP is 2.1 per 1000 live births (Andersen et al., 2008), and the primary and specialists health care share responsibility for providing rehabilitation services. The primary health care professionals are responsible for carrying out the interventions in the child's community setting. Such interventions are important for participation in daily activities have provided positive child outcomes (; Novak et al., 2009; Law et al., 2011). The family plays a key role in facilitating the child's opportunities for everyday learning. Therefore support from the primary health care services is of special importance for the families.

Family-centred services (FCS) are a widely acknowledged way to place the child's development and needs within the context of their family and community and at the centre of care. The FCS approach consists of a set of values that recognise each family as unique and constant in the child's life, and it acknowledges family members as the experts on the child's abilities and needs (King et al., 2004). The essential components of FCS include parental involvement in the child's rehabilitation process, partnership building, information sharing, and flexibility in service provision (Dunst and Dempsey,

2007; Bamm and Rosenbaum, 2008). Research has identified two related, but distinctly different aspects of FCS: (1) relational and (2) participatory help-giving practices (Dunst, 2002). Relational practices include professional behaviours, such as active listening, empathy, and respect, whereas participatory practices encompass ways to actively involve parents in decision making, and interventions. Systematic reviews have linked FCS to greater family satisfaction, stronger self-efficacy, greater perceptions of the helpfulness of services (Dunst et al., 2007), and better functional abilities in children with disabilities (Baker et al., 2012).

The Measure of Processes of Care (MPOC-56 and MPOC-20) (King et al., 1995; 2004) is widely used to evaluate FCS in paediatric rehabilitation (Raghavendra et al., 2007; Jeglinsky et al., 2011a,b; Arnadottir and Egilson, 2012). The MPOC targets partnership, information sharing, coordinated, comprehensive, respectful, and supportive care (King et al., 1995; 2004). All previous MPOC-studies have reported that the provision of general information achieved the lowest score, while the provision of respectful and supportive service received the highest (Raghavendra et al., 2007; Jeglinsky et al., 2011a, b; Arnadottir et al., 2012). They have been performed in the context of specialist health care except for the Raghavendra study (2007), which also provided services in the children's home or in the school. However, these studies also included older children than the present study. The results indicate that parents of older children

perceive the services to be less family-centred compared to families with younger children (Granat et al., 2002; Raghavendra et al., 2007; Arnardottir et al., 2012). These results are based on correlations, which inhibit generalisations to other contexts.

Jeglinsky et al., (2011b) found that physiotherapists working in the primary health care rated their own family-centeredness lower, than physiotherapists working in the specialist health care. Still, the parents of preschool children's experiences of family-centred services have not been investigated in primary health care contexts.

It is also of importance to assess how family centeredness of professional behaviour is associated with other aspects of services provision, such as service coordination. This is underlined in a recent review of parents' experiences with physical and occupational therapy services for children with CP (Kruijsen-Terpstra et al., 2013). As for service coordination, Fordham et al. (2011) found a positive relationship between MPOC scores and feelings of empowerment, and for having a professional assigned to coordinate the child's services. This finding is of interest in Norway, since coordination of services is emphasised, but not rigorous investigated (Ministry of health and Care Services, 2010).

The present study had two aims. The first was to assess, using the MPOC-20, how parents of preschool children with CP viewed the family-centredness of the services provided in a Norwegian primary health care context. The second was to investigate the

associations between the MPOC-20 scores and (1) the parental involvement in everyday skills training, (2) the reported child benefits from these interventions, and (3) the parents' satisfaction with the amount of the provided services.

Methods

Participants

This study was a population-based survey of parents of preschoolers with CP registered in Norway's national CP follow-up programme (CPOP). Participation in the CPOP is based on informed consent and is open to all children with CP 0-18 years. There were 360 eligible children who were six years old or younger. Data on the child's sex, age, CP subtype, and gross motor function (GMFCS level) (Palisano et al., 1997) were collected from the CPOP database. The main characteristics of the participants are reported in Table 1.

Table 1

Questionnaires

The survey consisted of three questionnaires. The first included the sociodemographic questions from the Norwegian version of the Parental Account of Children's Symptoms (Taylor et al., 1986).

The second questionnaire, the Habilitation Services Questionnaire (HabServ), collected information about all of the interventions and services that the child and family received during the preceding six months. It consists of five sections: (1) Training and stimulation, (2) Assistive technology, (3) Individual supervision, (4) Courses and parent training, and (5) Services and benefits (Appendix 1). The parental involvement and parent-reported child benefits of everyday skills training were collected from Section One; from Sections Three and Four, the parent-reported child benefits of supervision and courses targeting everyday skills training were collected ; and from Section Five, the levels of parental satisfaction with the amounts of child-directed services, financial and social services, and service coordination were collected. The HabServ questionnaire was developed for this survey (Myrhaug and Ostensjo, 2013) and for an ongoing longitudinal study (CPHAB) (University of Oslo 2013). It was translated according to established criteria, and is undergoing psychometric testing for reliability.

The third questionnaire, the MPOC-20, consists of 20 items organised into five scales targeting; (1) *Enabling and partnership*; (2) *Providing general information*; (3) *Providing specific information*; (4) *Coordinated and comprehensive care*; and (5) *Respectful and supportive care* (King et al., 1995; 2004). Respondents report the degree to which they feel that service providers display family-centred behaviour, using a 7-point scale that ranges from “not at all” (score = 1) to “to a very great extent” (score =

7). To identify areas for improvement, the authors recommend locating items that receive scores of “sometimes” (score = 4) or lower from at least 30% of respondents (King et al., 1995). The original version and translations have proven to be valid and reliable (King et al., 1995; 2004), including in Norway (Hagen and Bjorbækmo, 2010).

Procedures

Data were collected from April until June 2011 as a postal survey. In total, 121 (34%) of the packages were returned with written informed consent for participation and for the collection of information from the CPOP database. The non-responders received a postal reminder one month later. The study protocol was approved by the Regional Committee for Research Ethics in Norway (Approval Number 2011/194-1).

Statistical analysis

Descriptive analyses were performed for the child and family characteristics, the MPOC scale scores, and the everyday skills training variables. The MPOC scale scores were calculated according to established scoring rules (King et al., 2004). To investigate associations between the MPOC scale scores and characteristics of the interventions and services, both the variables and their categories were collapsed, because of the small number of participants and because most of the original variables were skewed.

The collapsing process involved three steps. First, all the categories of each variable were dichotomised (Appendix 2 and 3). Second, all of the variables presented in Appendix 2 and 3 were collapsed into six variables. The six targets of the parental involvement (Appendix 2) were included in a new variable, “parental involvement in everyday skills training”, and the corresponding reported benefits were included in the variable “child benefits of everyday skills training”. The seven reported benefits of supervision and courses were included in the variable “child benefits of parent-directed interventions”; the amounts of the four types of financial and social support were included in the variable “satisfaction with financial and social support”; the three categories related to the amount of service coordination were included in the variable “satisfaction with service coordination”; and the four categories concerning the amount of child-directed professional services were included in the variable “satisfaction with child-directed services” (Appendix 3). Last, the categories of the six new variables were dichotomised (Table 2), and cut-off criteria were established.

Table 2

The Mann-Whitney U test was used to detect differences between the MPOC scale scores and 1) the parental involvement and child benefits of the interventions and 2) the

parents' satisfaction with the services. Fisher's exact test was used to assess differences between the study participants and non-participants regarding the categorical parameters; sex, CP subtype, and GMFCS level. These data were collected from the CPOP database. Because multiple tests were used, an alpha level of 0.01 was applied.

Results

The respondents were mostly mothers (74%) with higher educational levels (71%) (Table 1). No significant differences between the participating and non-participating children were identified regarding sex, CP type and GMFCS level.

Parents' perceptions of the family-centredness of service provision

The parents' perceptions of the level of family-centredness according to the five MPOC-20 scales are reported in Table 3. *Respectful and supportive care* and *Coordinated and comprehensive care* received the highest scores (median 5.1 and 5.0, respectively). The lowest score was assigned to *Providing general information* (median 3.1). Both *Enabling and partnership* and *Providing specific information* received a median score of 4.3, which indicates that service provision was perceived as family-centred to some extent. As much as 72-84% of the parents identified all five items from *Providing general information* as areas needing improvement. These items concern information

about the child's type of disability, the types of services offered, to whom and how such information was provided, and information about how to contact other families in similar situations. Many of the parents (> 60%) indicated that improvement was needed in two items related to whether treatment choices were fully explained and whether the family received written information about the child's therapy.

Table 3

Associations between MPOC scores and interventions and services

Associations between the MPOC scores and the parental involvement and child benefits of the interventions aimed to improve everyday skills, as well as the satisfaction with the amount of services, are reported in Table 4. Only 8 of the 30 possible associations showed a significant relationship ($p \leq 0.01$). Of these, the level of parental satisfaction with the amount of service coordination was associated with higher scores on all five MPOC scales ($p = 0.000-0.004$). Parents who were very satisfied with the amount of child-directed services and financial and social support tended to rate *Coordinated and comprehensive care* higher than did parents who were only somewhat satisfied ($p = 0.01$ and 0.001 , respectively). The final significant relationship was between satisfaction with child-directed services and *Respectful and supportive care* ($p = 0.007$).

Table 4

Discussion

The aims of this study were to explore how parents of preschoolers with CP experienced level of family-centred services within primary health care in Norway, and to examine the relationships between these experiences and the provided interventions and services.

The parents perceived that professional behaviour was family-centred to some extent in terms of *Enabling and partnership* and *Providing specific information* and to a fairly great extent in terms of *Coordinated and comprehensive care* and *Respectful and supportive care*. *Providing general information* received the lowest rating. These findings are similar to those of other MPOC studies (Granat et al., 2002; Raghavendra et al., 2007; Fordham et al., 2011; Jeglinsky et al., 2011a; Arnadottir et al., 2012). All of the scores in this study were among the lowest published scores, and they were particularly lower than the scores reported by other studies of preschool children (Granat et al., 2002; Raghavendra et al., 2007; Arnadottir et al., 2012). One possible explanation for these results might be that our study was conducted in primary health care settings in Norway, where the therapists often work alone in small communities and may follow only one child with CP. They may gain less knowledge and experience of preschool children with CP than therapists working in hospitals. Jeglinsky et al., (2011b) indicated that it might be easier for multidisciplinary team members in hospitals

to develop experience and a common understanding of FCS, than therapists in the primary health care.

The greatest need for improvement was found in the area of *Provision of general information*, which received low ratings from 72-80% of the parents. This finding indicates that families of young children with CP need more information than they currently receive about the CP diagnosis, interventions and services, and how to contact other families in similar situations. All of this information is critical for enabling parents to make informed decisions for their child. Many parents reported that their treatment options had not been fully explained. The need for more information about available treatments is common among families caring for a child with disabilities. Thus, therapists should be aware of their own preferences and biases about treatments (McHugh et al., 2013).

Effective participation in decision making is dependent on access to reliable information about diagnosis, treatment and prognosis, and the necessary skills to obtain, evaluate and act upon such information (McHugh et al., 2013). Based on the findings from our and previous MPOC-studies, there is a need for different ways to facilitate families' access to reliable information and their ability to use this information, through websites, leaflets, and parental education.

Information sharing between parents and professionals is essential for participatory practices that facilitate active parental involvement in decision making (Dunst et al., 2007; Fordham et al., 2011). Shared decision making and active involvement are emphasised by the Norwegian health authorities' (Ministry of Health and Care Services, 2012). Our findings showed low level of information sharing and high scores assigned to *Respectful and supportive care*. This might indicate that many service providers are competent at relational help-giving practices and have less experience with participatory help-giving. Participatory help-giving is not only characterised by information sharing behaviour, but also by active parental involvement in planning and implementation of the interventions (Dunst et al., 2007).

Approximately half of the parents in our study were significantly involved in everyday skills training. One might expect that this would be associated with a higher level of FCS; however, such an association was not found. A limitation of our data is that we collected no information about parental involvement in setting goals and planning interventions, or the family's opportunity to choose its level of involvement in the rehabilitation process. Maybe to be the performer of the training was experienced as less important and even stress full. Previous studies show that parents are often taught to carry out the therapists' prescriptions at home (Novak and Cuick, 2006). Such practice is not in accordance with family-centred philosophy that emphasises to strengthen the

families' ability to provide young children with everyday natural learning opportunities (Swanson et al., 2011).

Forty-six and 71% of the parents reported large or very large benefits of everyday skills training and parent-directed interventions, respectively. One could expect to find positive associations between MPOC-20 scores and the reported benefits of interventions, and particularly for parent-directed interventions. We found no such associations. One possible explanation is that supervision and courses to a little extent have taken the everyday routines of the unique family into consideration. This is supported by a meta-analysis showing that family-centred practices were not directly associated with child development outcomes; instead, child development outcomes were indirectly mediated by the parents' perceptions of self-efficacy (Dunst et al., 2007). Fordham et al., (2011) found that family empowerment was strongly correlated with MPOC scores. Another review showed that active involvement of parents in decision making and training led to better functional outcomes for the children (Baker et al., 2012).

Fifty-two percent of the parents that had an individual service plan (ISP), a coordinator, and/or a multidisciplinary team were well satisfied with the amount of services. These services aimed to enhance provision of coordinated and comprehensive care for the

family and the child. We found significant associations between all the five MPOC-20 scales and the parents' satisfaction with the amount of service coordination. This confirms previous findings by Fordham (2011) and Sloper (2006), who found significant associations between having a service coordinator and parents' satisfaction with the services. In Norway, all children who are in need of long-term and coordinated services have the legal right to an ISP (Ministry of Health and Care Services, 2012). Because primary and specialists health care share responsibility for providing rehabilitation services in Norway, coordination of services is important for the parents' experience of comprehensiveness of care.

Forty-three percent of the families that received financial and social support and child-directed services were well satisfied with the amount of services. Parents that were most satisfied with the amount of these services experienced higher level of respectful and supportive care. This indicates that the parents experienced the child's need of treatment and the family's need of support as met.

The main limitation of the current study that might have influenced its results is the low response rate, which is in accordance with other self-administered postal surveys (Sloper et al., 2006; Fordham et al., 2011). Another factor is the high educational level among the responding mothers. Because of respondent limitations, the results may not

be representative of Norwegian parents of preschool children with CP. Moreover, the current absence of psychometric testing of the HabServ Questionnaire should be considered when interpreting the results.

In conclusion, the parents of preschool children with CP in Norway rated the provision of primary health care services as family-centred to some or a fairly great extent on all MPOC-scales, with the exception of *Providing general information*. Our findings indicate lower level of family-centeredness in primary health care than in specialist health care. Significant associations were found between all the five MPOC-20 scales and the parents' satisfaction with the amount of service coordination. These and other associations between different aspects of family-centred care need further investigation. The high scores for the *Respectful and supportive care* and the low scores for *General information* indicate that the families experienced relational help-giving practices to a larger extent and participatory practices to a lesser extent. Recommendations for clinic and research are to increase the participatory aspects of family-centred practice, to address facilitators and barriers of information sharing, and to work intensively on coordination of services between the specialist and primary health care.

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Declaration of Conflicting Interests

The authors have no conflicts of interest to declare.

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Table 1. Characteristics of the children and the respondents

	Participants (n = 121)	Non-participants (n = 233)	p-value
Children			
Sex, n (%)			0.84
Female	54 (44.6)	101 (43.5)	
Male	67 (55.4)	131 (56.5)	
Age (y), mean (SD)	4.4 (1.2)	4.4 (1.2)	
CP distribution, n (%)			0.21
Unilateral	63 (52.1)	102 (43.8)	
Bilateral	58 (49.9)	131 (56.2)	
CP type, n (%)			0.44
Spastic	106 (87.6)	199 (85.4)	
Dyskinetic	10 (8.3)	20 (8.6)	
Ataxic	3 (2.5)	4 (1.7)	
Not classified	2 (1.7)	10 (4.3)	
GMFCS level, n (%)			0.63
I (mildest limitations)	53 (43.8)	92 (40.5)	
II	14 (11.6)	34 (15.0)	
III	11 (9.1)	25 (11.0)	
IV	17 (14.0)	20 (8.0)	
V (most severe limitations)	21 (17.4)	45 (19.8)	
Not classified	5 (4.1)	11 (5.0)	
Respondents, n (%)			
Mother	89 (72.4)		
Father	29 (24.6)		
Other caregivers	3 (3.0)		
Mother's education (n = 119), n (%)			
≤ 12 years (high school or less)	35 (29.4)		
> 12 years (college or university)	84 (70.6)		
Father's education (n = 114), n (%)			
≤ 12 years (high school or less)	52 (45.6)		
> 12 years (college or university)	62 (54.4)		

Table 2. Collapsed variables related to parental involvement in everyday skills training, child benefits of interventions, and parental satisfaction with amounts of services

Collapsed variables (criteria for cut-off)	n (%)
Parental involvement in everyday skills training (n = 111)	
No or some involvement (parent performed ≤ 2 reported activities)	55 (49.5)
Significant involvement (parent performed 3-6 reported activities)	56 (50.5)
Parent-reported benefits of everyday skills training (n = 109)	
No or some benefits (maximum two reported targets with large and very large benefits)	59 (54.1)
Large or very large benefits reported for all targets	50 (45.9)
Parent-reported benefits of parent-directed interventions (n = 74)	
No or some benefits (maximum two reported targets with large and very large benefits)	21 (28.4)
Large or very large benefits reported for all targets	53 (71.6)
Parental satisfaction with the amount of child-directed services (n = 111)	
Not or quite satisfied (maximum two received services rated as well to very well satisfied)	63 (56.8)
Well or very well satisfied reported for all services	48 (43.2)
Parental satisfaction with the amount of financial and social support (n = 93)	
Not or quite satisfied (maximum two received services rated as well to very well satisfied)	53 (57.0)
Well or very well satisfied reported for all services	40 (43.0)
Parental satisfaction with the amount of service coordination (n = 93)	
Not or quite satisfied (maximum two received services rated as well to very well satisfied)	45 (48.4)
Well or very well satisfied reported for all services	48 (51.6)

Table 3. Descriptive data for the five MPOC-20 scales

MPOC scales*	Mean (SD)	Median (range)
Scale 1: Enabling and partnership	4.08 (0.33)	4.3 (1-6)
Scale 2: Providing general information	3.18 (0.31)	3.1 (0-6)
Scale 3: Providing specific information about the child	4.27 (0.45)	4.3 (1-7)
Scale 4: Coordinated and comprehensive care	4.63 (0.17)	5.0 (0-7)
Scale 5: Respectful and supportive care	4.99 (0.23)	5.1 (1-7)

*Score 0 = not applicable; 1 = does not happen at all; 2 = happens to a very small extent; 3 = happens to a small extent; 4 = happens to some extent; 5 = happens to a fairly great extent; 6 = happens to a great extent; 7 = happens to a very great extent.

Table 4. Associations between MPOC-20 scale scores, parental involvement, child benefits of interventions, and parents' satisfaction with amounts of services

Characteristics of interventions and services	Scale 1		Scale 2		Scale 3		Scale 4		Scale 5	
	Enabling and partnership		Providing general information		Providing specific information		Coordinated and comprehensive care		Respectful and supportive care	
	n	p-value	n	p-value	n	p-value	n	p-value	n	p-value
Parental involvement in everyday skills training ^a	110	0.13	110	0.08	110	0.40	110	0.18	110	0.30
Parent-reported child benefits of everyday skills training ^b	108	0.30	108	0.70	108	0.28	108	0.26	108	0.78
Parent-reported child benefits of parent-directed interventions ^c	74	0.40	74	0.75	74	0.54	74	0.31	74	0.09
Parental satisfaction with amount of child-directed services ^d	110	0.05	110	0.40	110	0.03	110	0.001*	110	0.007*
Parental satisfaction with amount of financial and social support ^e	92	0.05	92	0.31	92	0.19	92	0.01*	92	0.03
Parental satisfaction with the amount of service coordination ^f	92	0.003*	92	0.003*	92	0.004*	92	0.000*	92	0.003*

* $p \leq 0.01$, analysed with the Mann-Whitney test

a = no or some parental involvement/significant parental involvement; b = no or some benefits/large or very large benefits; c = no or some benefits/large or very large benefits; d = not or quite satisfied/well or very satisfied; e = not or quite satisfied/well or very satisfied; f = not or quite satisfied/well or very satisfied.