

RESEARCH ARTICLE

Empowerment in families raising a child with cerebral palsy during early childhood: Associations with child, family, and service characteristics

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Abstract

Background: Insight into family empowerment is important in order to develop and offer services that support and strengthen parents caring for a child with disability. The aims of this study were to describe empowerment trajectories among parents caring for a young child with cerebral palsy (CP) and to explore associations between parental empowerment and characteristics of the child and family and the services they receive.

Methods: 58 children (median age at first assessment 28 months, range 12–57) and their parents were included in a longitudinal cohort study based on registry data from follow-up programmes for children with CP in Norway. Parental empowerment trajectories were described by averaging scores in the three subscales of the Family Empowerment Scale (FES; family, service situations, and community) at enrollment and at semiannual/annual assessments. A linear mixed model was used to explore associations.

Results: Parental empowerment scores on the FES in family and service situations were high and stable during early childhood, although considerably lower in the community context. In service situations, perceived empowerment was significantly associated with both child, family, and service characteristics, whereas empowerment in family situations was only associated with family characteristics. The service factor *having a multidisciplinary support team* was positively associated with perceived empowerment in both service situations and in the community.

Conclusion: Knowledge about parental empowerment in different contexts and associations with characteristics of the child and family and the services they receive can contribute to further reinforcing family empowerment and identifying parents in need of additional support.

KEYWORDS

cerebral palsy, cohort study, early childhood, parental empowerment trajectories

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1 | INTRODUCTION

Raising a child with a disability like cerebral palsy (CP) requires high levels of knowledge and access to resources, information, and services. Children with CP present with a range of permanent motor impairments, and the disorder often affects other developing functions such as cognition and communication (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). As a consequence, most children with CP and their caregivers will have to prepare for life-long interaction with an extended service system.

A family-centred approach to service delivery is considered best practice in early childhood interventions (King, Teplicky, King, & Rosenbaum, 2004). Facilitating parental empowerment represents a major component of family-centred interventions with the intent to promote child development and wellbeing (Dunst, Trivette, & Hamby, 2007). Empowerment is described both as a multidimensional process (gaining greater control and mastery over life) and an outcome (holding power; Staples, 1990), reflected on different levels: personal (personal power and self-efficacy), interpersonal (influencing others), and political (social action or social change; Gutiérrez & Ortega, 1991). Another dimension reflected in the literature is the way empowerment is expressed; as skills or abilities, self-perception and actions (Staples, 1990). These two dimensions are incorporated and operationalized in the Family Empowerment Scale (Koren, DeChillo & Friesen, 1992), measuring empowerment expressed as attitudes, knowledge, and behavior in the context of family, service situations, and community.

Previous research on associations between caregiver empowerment, measured by the FES, and child and family characteristics has resulted in inconsistent findings across countries and child disorders (Nachshen & Minnes, 2005; Singh et al., 1997; Vuorenmaa, Perälä, Halme, Kaunonen, & Åstedt-Kurki, 2016; Wakimizu, Fujioka, Yoneyama, Iejima, & Miyamoto, 2011; Wakimizu, Yamaguchi, & Fujioka, 2017). Research on the impact of service-provision on parental empowerment is still scant, and even though empowerment has been used as an outcome in some intervention studies involving children with physical disabilities (An et al., 2017; Burton et al., 2018), little is known about the trajectories of parental empowerment across time.

So far, no study has explored empowerment among parents raising a child with CP as a distinct group. The aims of this study were to describe trajectories of parental empowerment in the family, service situations, and community from enrollment in a systematic follow-up programme for children with CP throughout early childhood and to explore longitudinal associations between parental empowerment and characteristics of the child and family and the services they receive.

2 | METHOD

2.1 | Participants and procedure

In Norway, all children with CP are offered a systematic follow-up through the Cerebral Palsy Register of Norway and the Cerebral Palsy Follow-up Program, based in the regional paediatric rehabilitation units. An associated research registry, Habilitation Trajectories, Interventions, and Services for Young Children with CP (CPHAB) was established to

Key messages

- Parental empowerment ratings on the FES in family and service situations were high and stable during early childhood, indicating strong family resources.
- Low empowerment ratings in the community context indicate an insufficient utilization of family resources in the quality improvements of services.
- Having a multidisciplinary support team was associated with higher empowerment ratings in service situations and in the community, reinforcing the potential of service providers to enhance parental control over the children's services and strengthen their capability to influence the service systems.
- More research on how services can affect parental empowerment over time is needed to further facilitate family involvement in child rehabilitation.

expand the follow-up by including information about the family and the service provision. Thirteen of the 21 regional paediatric rehabilitation units nationwide took part in the CPHAB. Inclusion criteria were children registered in Cerebral Palsy Register of Norway or Cerebral Palsy Follow-up Program when aged 4 years or younger, between January 2012 and December 2014, with caregivers capable of answering questionnaires in Norwegian or English. During the first 2 years of follow-up, the children and their families were assessed twice a year, thereafter once or twice a year according to the families' own preferences, at least three times. The questionnaires were completed by one of the parents in conjunction with the child's regular consultation at the rehabilitation unit.

The present study has a longitudinal cohort design using data from the CPHAB and the CPOP. The inclusion process is presented in Figure 1. Of the 132 children who fulfilled the age criteria, 11 were not invited in the study due to parental language barriers. 21 families were not invited to participate because of lack of resources in the rehabilitation units but also because service providers considered the strain of some families to be too large to participate. Furthermore, 25 families declined participation, and 17 were excluded due to incomplete questionnaires. A total of 58 families participated in the current study. The study was approved by the regional Committee for Medical and Health Research Ethics of South-Eastern Norway (registration number 2017/782).

2.2 | Measures

Parental empowerment was assessed using the Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992). The FES has three subscales representing different contexts where empowerment can be expressed: (a) Family (12 items), referring to the immediate situation at home; (b) Service situations (12 items), referring to the parents' collaboration with the service system to obtain services addressing the needs of the child and family; and (c) Community (10 items), referring to parents' advocacy for improved services for children with disabilities in general rather than specifically for his or her child. Within each of these contexts, three

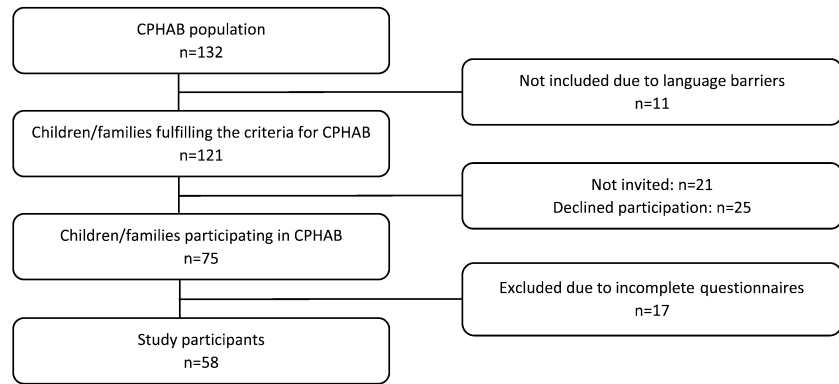


FIGURE 1 The inclusion process. CPHAB, Habilitation Trajectories, Interventions, and Services for Young Children with CP

ways of expressing empowerment are reflected: Attitudes (what a parent feels or believes), knowledge (what a parent knows or potentially can do), and behaviour (what a parent actually does). “I believe that other parents and I can have an influence on services for children” is an example of an item reflecting attitude (on the community level). “I know the steps to take when I am concerned my child is receiving poor services” reflects knowledge (in service situations), while “When faced with a problem involving my child, I decide what to do and then do it”, is an example of an item expressing behaviour (family level). The FES has a five-point Likert scale (1 = *not true at all*, 5 = *very true*), where a higher score indicates a higher level of perceived empowerment. A systematic review of empowerment instruments has reported that FES is a valid and reliable measure of caregiver empowerment (Cyril, Smith, & Renzaho, 2016). It was originally developed for parents whose children had emotional disabilities (Koren et al., 1992), with later studies confirming sufficient content validity for parents of young children in general (Vuorenmaa et al., 2014) and for parents of children with a chronic condition (Segers et al., 2019). The FES was translated into Norwegian as part of the CPHAB, using forward-back translation with harmonization followed by cultural adaptation using interviews, as described by Wild et al. (2005).

Child characteristics included age, subtype of CP, and gross motor abilities. Subtype was classified as spastic (unilateral or bilateral), dyskinetic, or ataxic CP (Surveillance of Cerebral Palsy in Europe, 2000). Gross motor abilities were classified according to the five levels of the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997). The GMFCS has demonstrated good predictive validity and reliability (Palisano et al., 1997; Palisano, Hanna, Rosenbaum, & Russell, 2000; Wood & Rosenbaum, 2000) and is widely used as an indicator of the severity of CP (Level I representing the lowest severity, Level V the highest).

Family characteristics included parents' education, employment, financial concerns, residential problems, and parental quality of life (QOL). The characteristics, except for QOL, were included in the Norwegian version of “Parental Account of Children's Symptoms” (Taylor, Schachar, Thorley, & Wieselberg, 1986). Parental QOL was assessed using the Norwegian version of the Quality of Life Scale (Wahl, Burckhardt, Wiklund, & Hanestad, 1998). The questionnaire consists of 16 items where answers are rated on a 7-point scale and where a higher score indicates a higher level of QOL.

Service characteristics included two means of service coordination (service coordinator and individual service plan; ISP), multidisciplinary support team, parent training, and participation in an intensive rehabilitation programme, and were collected from the HabServ questionnaire. The questionnaire contains information about interventions and services provided to the child and the family during the preceding 6 months and has previously been used in three studies (Klevberg, Østensjø, Elkjaer, Kjekken, & Jahnsen, 2017; Myrhaug, Jahnsen, & Østensjø, 2016; Myrhaug & Østensjø, 2014).

2.3 | Data analyses

Data were analysed using the IBM SPSS Statistics version 25. Participant characteristics were summarized descriptively and compared with characteristics of non-participants by the use of a chi-square test (categorical variables) and two-sample *t*-test (age). Averaging empowerment scores were calculated for each of the three FES subscales at six points of time (enrollment, 6, 12, 18, 24 and 36 months after). A linear mixed-effects model with random intercept was used to explore associations between parental empowerment mean scores and child characteristics (age, CP-subtype, and GMFCS level), family characteristics (maternal and paternal education and employment, parental QOL, and financial and residential concerns), and service characteristics (parent training, ISP and/or coordinator, multidisciplinary team, and intensive rehabilitation programme). This statistical method handles correlated data in the repeated measure design and allow an unequal number of repetitions with disparate time intervals between the assessments. The identification number of the participants was set as a random effect contributing to the covariance structure of the data. The characteristics of the child and family and the services they received were set as fixed effects and explored one by one. Analyses of associations with the child's age were adjusted for the GMFCS level, and vice versa, whereas analyses including family and service characteristics were adjusted for both the child's age and GMFCS level. Due to the small sample size, the categories of some variables were collapsed.

3 | RESULTS

A total of 58 families participated in the study, representing 48% of the cohort (See Figure 1). Child and family characteristics are

presented in Table 1. There was a significant difference between participating and non-participating children with respect to CP subtypes and GMFCS levels, with a greater proportion of children with spastic bilateral CP and children at GMFCS Levels III and IV participating in the study.

Services provided to the families during early childhood are presented in Table 2. More than 80% of the families have received support from a multidisciplinary team, a service coordinator or an ISP. About three fourth of the parents have participated in some kind of training, and more than 50% of the children have attended an intensive rehabilitation programme (see Table 2).

3.1 | Parental empowerment trajectories

Figure 2 illustrates the parental empowerment trajectories on the FES in the family, service situations, and community subscales. Empowerment ratings in family and service situations were high and stable during early childhood (mean 4.1, $SD = 0.5$ to mean 4.3, $SD = 0.4$) and considerably lower in the community subscale (mean 2.4, $SD = 0.7$ to mean 2.7, $SD = 0.8$).

3.2 | Associations between parental empowerment and child, family, and service characteristics

In the family context, parental empowerment was significantly associated with three family characteristics: maternal education and employment and parental QOL (see Table 3). Full-time maternal employment was associated with higher empowerment ratings, whereas high level of maternal education was associated with lower ratings. QOL and empowerment were positively associated. No child or service factors were significantly associated with parental empowerment in the family subscale.

In service situations, empowerment ratings were significantly associated with one characteristic of the child, two characteristics of the family, and one characteristic of the services. Caring for a child with moderate gross motor limitations (GMFCS II or III) was associated with lower ratings compared to caring for a child with less severe limitations (GMFCS I). A high level of maternal education was associated with lower empowerment ratings, whereas higher parental QOL and having a multidisciplinary team were associated with higher ratings.

In the community context, parental empowerment was significantly associated with two child and two service characteristics. Ratings were positively associated with the child's age, whereas caring for a child with moderate gross motor limitations (GMFCS II or III) was associated with lower ratings compared to children at GMFCS Level IV or V. Having a multidisciplinary support team and attending an intensive rehabilitation programme were associated with higher empowerment ratings (Table 3).

Four family characteristics, paternal education and employment, financial concerns, and residential problems, were not significantly associated with parental empowerment in any context. This was also the case for the service characteristics *having a service coordinator or an ISP* and *attending parent training*.

4 | DISCUSSION

Parental empowerment ratings on the FES in family and service situations were high and stable during early childhood, whereas considerably lower in the community context. These results indicate that most parents of young children with CP in Norway feel competent and empowered when it comes to issues related to their family and their child's services but less so when dealing with service systems. These findings are consistent with results from other Western countries including young children in a primary health care setting (Vuorenmaa et al., 2016), children receiving early childhood interventions (Fordham, Gibson, & Bowes, 2012), and children with developmental disabilities (Banach, Iudice, Conway, & Couse, 2010; Burton et al., 2018; Minjarez, Mercier, Williams, & Hardan, 2013). The relatively low ratings in the community context may indicate that family capabilities are insufficiently utilized in quality improvements of services for children with disabilities at a system level.

Intervention studies have shown an increase in parental empowerment ratings on the FES from pretests to post-tests (An et al., 2017; Burton et al., 2018), indicating a positive effect of interventions designed to increase family empowerment. In the present study, empowerment scores on the FES were stable from the entering of a systematic follow-up programme and throughout early childhood. The stability of the FES scores might reflect that attending a general follow-up programme focusing on assessments and measures is less efficient in improving parental empowerment than specific goal-directed interventions targeting family empowerment.

By exploring associations between parental empowerment and child, family, and service characteristics, we found different patterns of associations for each of the three FES subscales. Empowerment in the family context was only associated with family characteristics. In the community context, empowerment was associated with both child and service characteristics. Empowerment in the service situations appears to be the most complex context, associated with characteristics within all the three groups: child, family and services.

Previous studies exploring associations between child characteristics and parental empowerment reveal inconsistent results. In a study of families attending an early intervention programme in the United States or Australia, no significant association between perceived empowerment and children's age was found (Dempsey & Dunst, 2004). In the context of primary health care in Finland, children's age was associated with maternal empowerment in service situations, but not in the family and community contexts (Vuorenmaa et al., 2016). In the present study, the children's age was associated with parental empowerment only in the community context. Together, these findings indicate that the child's age alone is not a strong predictor of parental empowerment.

Associations between child functioning and parental empowerment have previously been found in the context of mental health services (Resendez, Quist, & Matshazi, 2000; Weiss, Cappadocia, Macmullin, Viecili, & Lunsby, 2012). No previous study has explored associations between parental empowerment and the gross motor limitations (GMFCS levels) of children with CP. In the present study, we

TABLE 1 Child and family characteristics

Characteristics	Participants (n = 58) n (%)	Non-participant (n = 63) n (%)	Sig.
Child's gender			<i>p</i> = .13
Female	22 (38)	30 (48)	
Male	36 (62)	33 (52)	
Age at first assessment (months)			<i>p</i> = .15
Median (min–max)	28 (12–57)	30 (10–48)	
CP subtype			<i>p</i> = .01*
Spastic unilateral	23 (39)	30 (48)	
Spastic bilateral	34 (59)	23 (36)	
Dyskinetic and ataxic	1 (2)	9 (14)	
Not classified	0 (0)	1 (2)	
GMFCS level			<i>p</i> = .00*
I	26 (45)	34 (54)	
II	6 (10)	6 (10)	
III	11 (19)	6 (10)	
IV	11 (19)	4 (6)	
V	4 (7)	10 (16)	
Not classified	0 (0)	3 (4)	
Mother's country of origin			
Norway	51 (88)		
Other	7 (12)		
Father's country of origin			
Norway	50 (86)		
Other	8 (14)		
Primary caregivers			
Mother and father	50 (86)		
Mother	5 (9)		
Father	1 (2)		
Other	2 (3)		
Maternal education			
≤12 years (high-school)	18 (31)		
>12 years (college, university, other)	39 (67)		
Unknown	1 (2)		
Paternal education,			
≤12 years (high-school)	24 (41)		
>12 years (college, university, other)	31 (54)		
Unknown	3 (5)		
Maternal employment			
Full time	28 (48)		
Part-time ≥50%	14 (25)		
Part-time <50%	6 (10)		
Not employed	10 (17)		
Paternal employment			
Full time	50 (86)		
Part-time ≥50%	2 (3)		

(Continues)

TABLE 1 (Continued)

Characteristics	Participants (n = 58) n (%)	Non-participant (n = 63) n (%)	Sig.
Part-time <50%	1 (2)		
Not employed	1 (2)		
Unknown	4 (7)		
Parental quality of life			
QOLS total score, mean (SD)	86.7 (13)		
Siblings			
Yes	51 (88)		
No	7 (12)		
Financial concerns			
No	38 (66)		
Yes	20 (34)		
Residential problems			
No	31 (53)		
Yes	27 (47)		

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; QOLS, Quality of Life Scale; SD, standard deviation; Sig., significance.

*Significant at $p < .05$.

TABLE 2 Services received by the families during early childhood

Services	Participants (n = 58), n (%)
Parent training	
Yes	44 (76)
No	14 (24)
Individual service plan/service coordinator	
Yes	47 (81)
No	11 (19)
Multidisciplinary support team	
Yes	48 (83)
No	10 (17)
Intensive rehabilitation programme	
Yes	32 (55)
No	26 (45)

found no significant association between GMFCS levels and perceived empowerment in the family context. In service situations, empowerment ratings were significantly lower among parents caring for a child with moderate motor limitations (GMFCS II and III) compared to parents of children with less severe limitations (GMFCS I). In the community context, parents caring for a child at GMFCS Level II or III showed significantly lower empowerment ratings than the caregivers of children with the most severe motor limitations (GMFCS IV and V). This non-linear pattern of associations is not easily explained. However, while Level I children are expected to walk with minor difficulties and children at Level IV and V are expected to use a wheelchair, the

expected mobility and gross motor function of children at Level II and III may be more unpredictable. This situation may in turn affect parental feelings of empowerment. Parents of children at GMFCS IV and V will be aware earlier of their need for comprehensive services, which may motivate them to make an effort to improve the service systems. This may explain their high ratings in the community subscale and are in line with findings from a study of children with serious emotional disturbances and attention deficit hyperactivity disorder (Singh et al., 1997).

Maternal educational and employment were two family characteristics that were significantly associated with perceived empowerment. Working full time was associated with higher ratings in the family context, whereas higher education was associated with lower ratings both in family and service situations. The same relationship between maternal education and empowerment is observed in two other studies including caregivers of children with emotional and behavioral problems (Curtis & Singh, 1996; Singh et al., 1997). No significant association was found between empowerment and paternal employment or education level.

Family empowerment and parental QOL are two areas of concern in paediatric rehabilitation services. In previous studies of children with disabilities, a significant association between parental health-related QOL and caregiver empowerment has been revealed (Wakimizu et al., 2016; Wakimizu et al., 2017). In the present study, parental global QOL was significantly associated with empowerment in both family and service situations. This positive association substantiates the importance of strategies to reinforce parental empowerment.

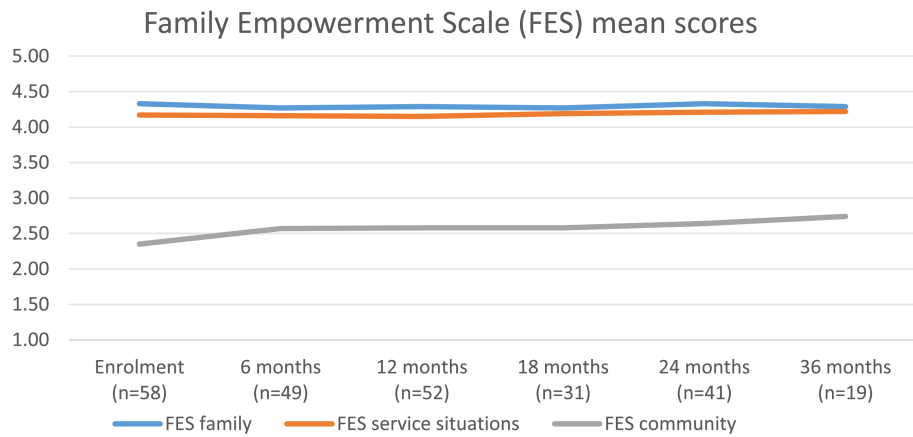


FIGURE 2 Mean FES scores in the subscales family, service situations, and community from enrollment in CPHAB and throughout early childhood. CPHAB, Habilitation Trajectories, Interventions, and Services for Young Children with CP [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 3 Associations between longitudinal FES mean scores and child, family, and service characteristics in the context of the family, service situations and community during early childhood

Subscale	FES family			FES service situations			FES community		
	Estimate	95% CI	p-value	Estimate	95% CI	p-value	Estimate	95% CI	p-value
Child characteristics									
Age ^a (month)	-5×10^{-4}	$-4 \times 10^{-3}, 0.33$.708	1×10^{-3}	$-3 \times 10^{-3}, 5 \times 10^{-3}$.574	0.01	$2 \times 10^{-3}, 0.01$.003*
GMFCS level ^b									
I	0.16	-0.09, 0.42	.197	0.28	0.02, 0.55	.037*	0.26	-0.11, 0.62	.162
II-III (reference)									
IV-V	0.04	-0.24, 0.33	.771	0.19	-0.11, 0.49	.216	0.48	0.06, 0.89	.025*
Family characteristics									
Maternal education ^c									
≤12 years (reference)									
>12 years	-0.16	-0.31, -0.01	.041*	-0.30	-0.47, -0.13	.001*	-0.13	-0.37, 0.12	.311
Maternal employment ^c									
Full time (reference)									
Part-time/no work	-0.16	-0.27, -0.4	.007*	-0.05	-0.18, 0.07	.423	-0.03	-0.22, 0.15	.739
QOLS ^c	0.01	0.01, 0.02	.000*	0.01	0.01, 0.02	.000*	0.01	$-2 \times 10^{-3}, 0.01$.188
Service characteristics									
Multidisciplinary support team ^c									
No (reference)									
Yes	0.01	-0.10, 0.12	.872	0.14	0.02, 0.27	.025*	0.23	0.05, 0.40	.011*
Intensive rehabilitation programs ^c									
No (reference)									
Yes	0.02	-0.08, 0.12	.640	0.05	-0.07, 0.17	.394	0.18	0.01, 0.35	.038*

Note. The estimates represent the differences in mean FES scores when the continuous variables increase with 1 month (age) or point (QOLS) and when scores are compared with the reference values (categorical variables). GMFCS level II-III was set as a reference value because the lowest empowerment mean scores were revealed in this category.

Abbreviations: CI, confidence interval; FES, Family Empowerment Scale; GMFCS, Gross Motor Function Classification System; QOLS, Quality of Life Scale.

^aAdjusted for the child's GMFCS level. ^bAdjusted for the child's age. ^cAdjusted for the child's age and GMFCS level.

*Significant at $p < .05$.

Previous research on caregiver empowerment has revealed a positive correlation between empowerment ratings on the FES and how parents perceive the coordination and comprehensiveness of care (Fordham et al., 2012). In the present study, we explored associations between empowerment and different types of rehabilitation services provided to the families. Families having a multidisciplinary support team perceived themselves as more empowered than parents without such a team, both in interaction with service providers and in their advocacy for services for children with disabilities. Interestingly, having a service coordinator and/or ISP was not significantly associated with perceived empowerment in any context. A child's ISP should be based on family-identified needs and goals, and the role of the service coordinator includes facilitation of family involvement (Norwegian Directory of Health, 2018). With that in mind, the lack of positive associations between coordinated services and parental empowerment is somewhat disappointing—but not surprising, because previous studies have identified multiple challenges when coordinated services are to be implemented in practice (Bjerkan, Richter, Grimsmo, Hellesø, & Brender, 2011; Holum, 2012; Høyem, Gammon, Berntsen, & Steinsbekk, 2018).

Parent training is another service provided to families aiming to strengthen competence and confidence. Providing families with information is found to be strongly correlated with parental empowerment in the family, service situations, and community contexts (Fordham et al., 2012). In the present study, however, no significant associations were found between perceived empowerment and participation in courses and training. As opposed to parent training, attending an intensive rehabilitation programme was associated with higher empowerment ratings in the community context. Such rehabilitation programmes provide a setting where parents of children with CP meet and spend time together, which may positively affect their confidence and motivation for involvement in quality improvements of services. This is in line with previous findings of positive outcomes of peer support for parents of children with a chronic disabling condition (Shilling et al., 2013).

4.1 | Limitations

This exploratory registry-based study described longitudinal associations between parental empowerment (FES scores) and child, family, and service characteristics. Because of the limited number of participants, it was not possible to conduct multivariable analyses besides adjustments for the child's age and GMFCS level. Due to the study design, no causal relationships could be revealed, only associations. In the CPHAB registry, no information was available on which caregiver filled out the forms. By that, we missed the opportunity to differentiate between mothers and fathers.

5 | CONCLUSION

Most parents perceived themselves as empowered in family and service situations, but less so when it comes to influencing the service

systems. The associations between parental empowerment and characteristics of the child and family and the services they received varied across contexts. Knowledge of factors associated with parental empowerment can contribute to further facilitating empowerment in families and identifying parents in need of additional support. The positive association between empowerment and having a multidisciplinary support team indicates that some services have a potential to reinforce parental control over service situations and strengthen their capacity to influence the service systems.

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