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Comparing parent and provider priorities in discussions of early detection and intervention for infants with and at risk of cerebral palsy

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Abstract

Background: Although literature suggests that parents need support when their child is diagnosed with cerebral palsy (CP), it is unclear to what extent providers implement these supports in practice and what parental perspectives surround provider early diagnosis and management of CP. Therefore, we aimed to characterize and compare experiences of providers and parents of children with CP with regards to early detection and intervention.

Method: Seventeen parents participated in day-long world-café style workshops focused on categories extracted from the International Classification of Function framework and recent systematic reviews of early detection for CP. Thirty regional providers (generalists, specialists, and therapists) caring for infants with CP completed surveys with scaled score and open-ended questions. Quantitative and qualitative data were independently assessed by two reviewers to identify prominent themes.

Results: All parents (100%) stated early diagnosis or high risk for CP classification was beneficial compared with only 50% of providers who often gave early CP diagnoses before 12 months. Top parent priorities were honesty and positively phrased messages. Providers most often addressed cognition, primary care need, motor, and feeding issues (80%, 62%, 54%, 54% frequently/sometimes). Matching priorities for discussion were neuroimaging timing/risk/benefit, cognition, primary care, motor, and feeding/nutrition. Discordance occurred for participation, parent well-being, pain and vision, with parents wanting more education and resources.

Conclusions: Receiving early diagnoses or high-risk for CP classification is a parent priority. Alignment between parents and providers exists for International Classification of Function domains of body functions/structures and activity, but less for those of environment, personal, and participation.

KEYWORDS

cerebral palsy, diagnosis, infant, interventions, parent perceptions, participation

Abbreviations: ASD, autism spectrum disorders; CP, cerebral palsy; GMA, General Movements Assessment; HINE, Hammersmith Infant Neurological Examination; ICF, International Classification of Function; NCH, Nationwide Children's Hospital; SD, standard deviation

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1 | INTRODUCTION

Worldwide, cerebral palsy (CP) is the most common physical disability in childhood and is associated with a wide range of comorbidities (Novak, Hines, Goldsmith, & Barclay, 2012; Rosenbaum et al., 2007). Seventeen million people in the world have CP. Preterm infants and those with encephalopathy at birth are more at risk for CP than their peers, but children without apparent risk factors can also be diagnosed with CP (Facts about Cerebral Palsy, Key Facts). The average age at diagnosis of CP varies by country and setting and is reported to be between 12 and 27 months of age (Byrne, Noritz, Maitre,, & NCH Early Developmental Group, 2017; Granild-Jensen, Rackauskaite, Flachs, & Uldall, 2015; Hubermann, Boychuck, Shevell, & Majnemer, 2016; Novak et al., 2017). A late diagnosis may result in missed intervention opportunities for children and their families: Delays in diagnosis are associated with significant parental dissatisfaction, stress, and depression (Baird, McConachie, & Scrutton, 2000; Novak et al., 2017) and higher rates of mental health problems in children and adolescents (Whitney, Warschausky, & Peterson, 2018). Conversely, early diagnosis, when given in a manner that is respectful, truthful, and responsive to parental need, can result in increased familial engagement and hope, driven by goals individualized to the child and family (McIntyre, Morgan, Walker, & Novak, 2011; Morgan, Novak, & Badawi, 2013; Novak et al., 2012). Families then seek guidance from physicians and other providers about the diagnosis, prognosis, and how to choose interventions (Novak et al., 2013). Though a recent review (Novak et al., 2017) outlines recommendations for parental supports when providing a diagnosis of CP, it is unclear to what extent providers implement these supports in practice and what parental perspectives surround provider diagnosis and management of CP. Therefore, we aimed to address this gap in knowledge to incorporate parent perspectives and improve our clinical practice. Using focus-group and information-harvesting methodologies, parental priorities on diagnosis and management of CP during the first 2 years were established. These were compared with those of surveyed providers in the same community as the parents, using quantitative and qualitative methods. We hypothesized that characterizing differences between parent and provider priorities would provide opportunities for improved communication and care of patients with CP.

Key messages

- Parental feedback can improve medical discussions regarding early diagnosis of CP.
- Discrepancies exist between parents' wishes and what information they obtain regarding early diagnosis and intervention.
- The ICF framework is helpful in assessing concordance between parent and provider priorities.

2 | METHOD

2.1 | Participants

Participants included 17 parents of children receiving care at Nationwide Children's Hospital (NCH), Columbus, OH and 30 medical providers. Providers were eligible if they cared for children under age 3 years with a diagnosis of CP and practiced within the regional catchment area for the NCH CP programs and were included on the electronic mailing list to receive updates from the NCH Early Developmental Clinic Program. Parents were eligible for participation if they had a child with CP seen at the NCH Early Developmental Clinic, Comprehensive CP Program, or in CP Research programs and were fluent in English (English as a second language accepted). Families were recruited during the 2-month period preceding the focus group. Eligible parents were approached via phone by a coordinator. The study was determined to be exempt from review or need for informed consent by the NCH Institutional Review Board given the nonidentifiable nature of the study data.

2.2 | Themes

Categories for themes were predetermined to direct and inform the parent discussions. These were extracted from the World Health Organization International Classification of Function (ICF) framework (Ustün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003), from the most recent and comprehensive systematic review of early detection and intervention for CP (Novak et al., 2017) and from a systematic review of comorbidities in CP (Novak et al., 2012). These included cognition, feeding, medical management of tone, motor interventions, nutrition, orthotics and equipment management, pain, parent well-being, participation, sleep, speech and language interventions, and vision.

2.3 | Focus group methodology

World Café methodology was applied over the course of a single 8-hour-day with three phases: (a) parent stakeholder panel to elicit perspectives around their child's initial diagnosis of CP, (b) brief review of best evidence for early detection/intervention and known comorbidities, and (c) focus group work with priority setting (A Quick Reference Guide for Hosting World Café). All parents attended, whereas three researchers moderated each session, and two trained observers recorded audio (later transcribed), video, and took notes on group dynamics and emergent themes.

2.3.1 | Parent stakeholder panel (90 min)

A panel of six parents of individuals with CP acted as guides to highlight the realities of receiving the diagnosis and the later implications with 11 parent audience members participating, adding their own experiences for contrast or reinforcement. Panel participants were

preselected to represent equal numbers of men and women and asked questions by the moderator to guide the discussion.

2.3.2 | Best evidence review (90 min)

A practicing physician presented early detection and intervention information from systematic reviews and examples of clinical implementation. This session exposed the group to the themes of the focus groups and potential areas for improvements. Parents were encouraged to ask any clarifying questions and the session ended when no questions remained.

2.3.3 | Focus groups (90 min ×2)

Parents were randomly divided into three groups, for a 60-min discussion then brought together again for 30 min of large group discussion. This process was repeated after a 30-min break. The goals of the small group discussions were to solicit parents' interpretation, application, and dissemination of the recommendations and assessments for early recognition (first session) and early intervention (second session) of CP and identify gaps in best practice for high-risk infants. Large group discussions were designed to identify at least one (and ideally three) major, parent-directed priorities in parent-provider discussions.

During each session, a moderator moved the conversation through the predetermined themes and recorded thoughts on a board for participants to correct and approve. Moderators oriented the group to the tasks at hand, maintained focus and integrity of the session goals, facilitated large-group discussions, helped the group adhere to time, provided guidance when needed, and summarized discussions.

After this session, local providers caring for infants with CP diagnosed under the age of 2 years on the hospital academic email list were sent an anonymous survey link. Using a scaled scoring system (0 = *never* to 5 = *always*), they evaluated the priority of each theme discussed by the parents. Free text answers for each theme allowed providers to further describe their priorities.

2.4 | Analyses

For quantitative data, continuous descriptors were summarized using means and standard deviations (SD), whereas scaled and categorical variables were expressed as percentages. For qualitative data, published stepwise procedures were followed (Pope & Mays, 1999). Familiarization included attendance at the event and review of the written materials and audiotapes. The thematic framework was constructed using the a priori topics in the ICF and dictated by parent consensus during the focus group large group sessions. Indexing of parent and provider priorities was drawn by constant comparison, identifying recurrences in the notes, transcribed data, and provider written responses. Charting of the data in corresponding spreadsheets was followed by further tagging of positive and negative word choices. Mapping and interpreting were performed by two reviewers independently, and consensus was achieved through a third reviewer and review of recorded materials when discrepancies existed.

3 | RESULTS

Parent and provider descriptors are presented in Table 1. Of 17 parent/caregiver participants, 24% were male and 70% white. Mean age at diagnosis of CP of children was 13.2 months (*SD* = 6.02). Response rate for the providers was 55% with 30/55 returning the survey (76% physicians, 14% therapists, and 10% nurse practitioners).

3.1 | Early diagnosis of and assessments of CP

Of 30 providers, 50% gave early diagnoses of CP sometimes/often, whereas only 40% gave a "high risk for CP" diagnosis (Figure 1). Provider perspectives and priorities surrounding the diagnosis and treatment of CP differed from those of parents (Table 2). Themes include communication style, neuromotor diagnostic tools, neuroimaging, and communication content/predicting outcomes. For communication styles, all parents valued honesty, hopefulness, directness, and simplicity, with a mandate not to be "too general" compared with 37% of providers who indicated they used a negative tone focusing on deficits and lack of progression. Parents wanted an explanation of diagnostic tools whereas 77% of providers rarely or never mentioned neither Hammersmith Infant Neurological Examination nor General Movements Assessment by name even though frequently using them (Burger & Louw, 2009; Dubowitz, Dubowitz, & Mercuri, 1999; Ferrari, Einspieler, Prechtl, Bos, & Cioni, 2004; Haataja et al., 1999; Pizzardi, Romeo, Cioni, Romeo, & Guzzetta, 2008). Parents wanted the need for neuroimaging assessments discussed factually and as soon as possible. In contrast, 70% of providers rarely or never prioritized obtaining magnetic resonance imaging (MRIs) immediately during their discussions with parents. Prognosis was not discussed by 59% of providers during the initial conversations surrounding the diagnosis. Instead, providers focused discussion on the uncertainty of predictions at young ages, the importance of surveillance, and the ability of early interventions to change trajectories.

3.2 | Early interventions and comorbidities in CP

Table 3 highlights provider discussion priorities. The most frequent areas of intervention and comorbidities discussed by providers included importance of the general paediatric provider in the continued care of patients with CP, feeding, communication, and sleep. Least discussed themes were pain, vision, and participation. Parents and providers exhibited high concordance on information and education themes, particularly around topics of cognition, the role of the paediatrician, motor, pain, sleep, parent well-being, speech, and vision. Concordance was poor in themes of access and coordination of services, specifically regarding orthotics, tone management, participation, nutrition, and feeding practices. Most often, providers did not state

TABLE 1 Parent and provider demographics

Age of parent	Sex of parent	Race of parent	Highest education of parent	Age at CP dx for child in months	Sex of child
53	F	Caucasian	Master's degree	8	F
36	F	African American	Some college	24	M
27	F	Caucasian	Some college	13	F
29	M	Caucasian	High school graduate	13	F
43	F	Caucasian	Bachelor's degree	9	M
32	F	Caucasian	Doctorate	5	M
33	M	Caucasian	Bachelor's degree	7	F
33	F	Caucasian	Bachelor's degree	7	F
60	M	Caucasian	Doctorate	12	F
41	F	Caucasian	Master's degree	12	F
28	F	African American-Somalian	7th grade	9	F
43	F	African American	Some college	18	M
35	F	Caucasian	High school equivalency and technical school	24	F
19	F	African American	High school graduate	24	M
34	F	African American	Unknown	15	F
34	M	Caucasian	Bachelor's degree	12	M
33	F	Caucasian	Bachelor's degree	12	M
Provider setting			*N* (%)		
Community paediatrics			16 (53)		
Developmental paediatrics			2 (6)		
Outpatient clinical therapies			4 (14)		
Paediatric neurologist			4 (14)		
NICU follow up			4 (14)		
Provider type			*N* (%)		
Physician			23 (76)		
Therapist			4 (14)		
Nurse practitioner			3 (10)		

Abbreviation: CP, cerebral palsy.

these as priorities in their discussions, deferring to potential social services providers.

4 | DISCUSSION

This is the first study to contrast parent and provider priorities in conversations surrounding early diagnosis, intervention, and comorbidities in infants with CP. Although no value judgments can be made about the correct approach, understanding the priorities of each party can help bridge communication gaps in critical early conversations. Many parent and provider priorities centred around the themes of information, education, and access to treatment. In these early conversations, parents and providers agreed that early access to interventions was important for the child; discussions about how to best maximize neuroplasticity occurred early and were of mutual interest. Barriers to access, need for education, and coordination were however under-recognized by providers.

4.1 | Early diagnosis and assessments of CP

Overall, parents and providers demonstrated variable concordance regarding information and education about early diagnosis and assessments, including neuromotor diagnostic tools and neuroimaging. Parents and providers agreed that early diagnosis was critical, consistent with a large survey of neonatal intensive care unit (NICU) graduates, in which the majority of parents believed in the benefit of receiving a CP diagnosis (Guttmann, Flibotte, & DeMauro, 2018). Because early diagnosis and interventions offer the best potential for long-term outcomes, this open communication is a strength of current practice (McIntyre et al., 2011). In this study, over 75% of

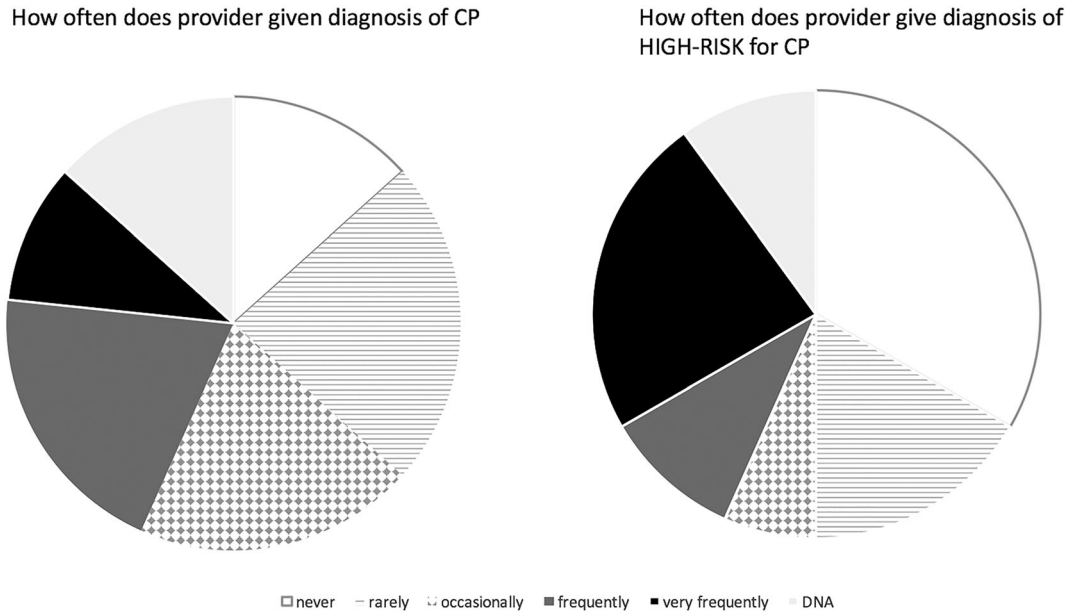

FIGURE 1 Provider survey responses regarding frequency of cerebral palsy (CP) diagnoses versus high risk for CP diagnoses

providers on the survey had current knowledge with the recommendations for early diagnosis of CP. This emphasis by parents and providers on the benefit of early diagnosis is also described in other populations of children with developmental disabilities, including autism spectrum disorders, where early diagnoses appear to promote best outcomes (Sperry & Symons, 2003).

Previous studies suggested that parents occasionally find providers overly pessimistic (Guttmann et al., 2018; Lemes & Barbosa, 2007). This study supports previous work indicating parental dissatisfaction with information and education surrounding diagnosis of CP (Baird et al., 2000; Novak et al., 2012). As in other reports, the majority of providers in our study (63%) appeared to meet parental expectations with regards to the structure and positive tone of discussions rather than with regards to the actual information provided (Baird et al., 2000). However, there was still a portion of providers who focused on deficits and lack of progression apparent in children with CP (Guttmann et al., 2018; Lemes & Barbosa, 2007). Parents consistently requested written information on CP, specific to their child and regarding local services and support groups (Baird et al., 2000; Novak et al., 2012). This observation holds for parents of children with other types of developmental disorders including autism, where parents also emphasize the need for written care plans and information, as well as parent support groups (Carbone et al., 2013; Pain, 1999).

Parents experience frustration when providers are too general. They want a discussion of CP specifically pertaining to their child, not to all children with CP. Parents desire a discussion of prognosis, with prediction of their child's development—including what their child will do—and a clarification of neuroplasticity. In this study as in others (Novak et al., 2012), providers tended to offer a general range of prognosis and spectrum of function. Providers varied with their approach and used phrases such as describing a "wide range of prognosis and spectrum" and "huge amount of unpredictability" when communicating a diagnosis. Providers may want to offer high quality data on prognosis for each specific child, understanding that most functional limitations are proportional to the child's degree of motor impairment (Novak et al., 2012). Novak et al. (2012, 2017) advocate for an optimistic, honest, and evidence-based explanation such as "It is not possible to be certain of severity under 2 years, as the baby's brain is still developing. There are 5 levels of gross motor severity …" These personalized discussions for children with developmental disorders are part of an evolving model of family-centred care, in which health care moves from a "one-size-fits-all" approach to a dynamic care plan that takes the individual child and family into account (MacKean, Thurston, & Scott, 2005; Sperry & Symons, 2003).

Discussion of early referral for brain MRIs was often complicated by characteristics of the current U.S. health care system. Parents wanted to discuss how MRI results supported the diagnosis of CP and have the risks and benefits explained. Some parents were concerned about high nonreimbursable costs and the potential risks of general anaesthesia in children between the ages of 3 and 24 months ("International Federation of Health Plans. 2015 Comparative Price Report: Variation in Medical and Hospital Prices by Country, 2015; Yu, Yuen, Wong, & Irwin, 2013). Providers also weighed the urgency of the medical situation versus risks of general anaesthesia at an age past comfort/swaddling measures especially when light sedation without intubation was not considered and the possibility of false negative results (Benini, Dagenais, & Shevell, 2013; Bosanquet, Copeland, Ware, & Boyd, 2013). When other hospital neuroimaging (e.g., cranial ultrasound) had already confirmed a lesion consistent with the observed pathology or when the disorder was stable, providers often did not think the immediate MRI was worth the benefits. A likely compromise would be an honest and clear discussion of risks/benefits with parents and providers enabling joint decision making. When considering the goals of early diagnosis, earlier screening prior to hospital discharge may allow more general nonsedated

TABLE 2 Provider and parent perspectives and priorities surrounding the diagnosis and treatment

Themes	Parent priorities	Provider priorities and % of providers reporting these priorities
How the diagnosis is communicated	Tone positive: "Be honest, realistic, hopeful." Language: Adapted to parent "Start with simple words and offer numbers if a parent wants more details"—"we shouldn't need a translator, just an interpreter if it is a different language." Specific to disorder and child: "Don't be too general or use platitudes." High-risk for CP: Acceptable diagnosis "We understand that the conversation will continue, and diagnosis may be revisited."	Tone positive: "We focus on continued development" "We emphasize the importance of early interventions and surveillance to improve function." Tone: Negative. "We state that deficits and lack of progression will be apparent in children with CP." Language: Specific to disorder and child: "We discuss the wide range of prognosis and spectrum of function." High-risk for CP: Uncertainty is not always acceptable. "We are concerned about making a correct diagnosis or uncertainty in diagnosis." "We think that there is a huge amount of unpredictability of outcomes."
Neuromotor diagnostic tools	Name and purpose of test: "Explain the purpose of this test to us." "Explain what you're doing, whether it is videotaping or looking at the baby." Communication style: "We prefer a brief description as you are doing an exam and a summary at the end."	Name and purpose of test: Majority of providers never or rarely mention GMA or HINE by name or explain its purpose. Communication style: A minority of providers use tools to communicate. "We try to demonstrate findings on assessments for parents." "We discuss the relation between findings and future function."
Neuroimaging	Discussing the risks and benefits of MRI Timing: "We want these tests done as soon as possible." Risks: "We can weigh the risks of general anaesthesia and intubation vs. need if you give us the information." "We would prefer sedation if possible" Cost: "MRIs are very expensive. Can you help find ways to make this completely reimbursed by insurance?" Interpretation: "It needs to leave room for hope, growth and possible recovery in the future."	Discussing the risks and benefits of MRI: Timing: Most providers rarely or never prioritize MRI in discussions. Risks: "We discuss what the risks (sedation, costs) and benefits (eliminating other disorders) can be in infants." Lack of benefit: "We do not always need an MRI, especially to diagnose CP when a condition is stable and other imaging modalities have already confirmed an underlying lesion." Costs: "There is no guarantee that insurance will fully reimburse an MRI and parents should call to ask if concerned." Interpretation: "We discuss the fact that in most cases MRI will not change our management of CP."
Predicting outcomes	Tone positive/hope: "Don't compare our child's outcomes to others." "Give predictions but leave room for hope that work and therapy can change this." "Make sure you talk about plasticity, and potential development; what our child will do, not just what they won't do." Specificity vs uncertainty: "Predict the typically expected development along with the trajectory of impairments (puberty, toddlerhood)." Evidence for prediction: "Make sure you explain the assessment and evidence upon which you base your prediction."	Tone positive/hope: Most providers do not discuss prognosis during initial conversations. "Rehabilitative interventions can change trajectories and therefore change predictions." Specificity vs uncertainty: "We discuss the uncertainty of predictions at very young ages." Evidence for prediction: "We state that prognosis can be re-evaluated after each standardized assessment of function."

Abbreviation: CP, cerebral palsy.

MRIs near term-equivalent age. Discussions between parents and providers could then be refocused on MRI findings rather than on obtaining the MRI.

An easier discrepancy to remedy is that of neuromotor diagnostic tools. All parents wanted information about specific tools, and providers often did not mention the names of the tools used (Hammersmith Infant Neurological Examination and General Movements Assessment; Dubowitz et al., 1999; Ferrari et al., 2004; Haataja et al., 1999). On the basis of this study, providers should describe the neuromotor assessment tools to parents when making a diagnosis of CP, in words that they can understand, but stating the names of the assessments. This finding is consistent with a study of parent preferences in children with autism spectrum disorders in which parents also appreciated providers explaining to them the reasons for their child's diagnosis (Moh & Magiati, 2012).

4.2 | Early intervention and comorbidities in CP

Parents and providers agreed that environmental stimulation and early assessment/intervention are critical to optimize cognitive, vision, language, and motor outcomes, and as with previous work, called for more studies of pain and sleep in children with CP (Novak et al., 2012; Novak et al., 2013). All parties demonstrated a sophisticated understanding of

TABLE 3 Percentage of provider priorities in conversations with parents of infants with cerebral palsy under the age of 2 years

Priority area	Always or frequently	Sometimes	Rarely or never	Does not apply
Pain	10.0	13.3	66.7	10.0
Participation	13.3	23.3	56.7	6.7
Vision	23.3	13.3	56.7	6.7
Communication	43.3	0.0	53.3	3.3
Sleep	30.0	10.0	53.3	6.7
Tone	20.0	23.3	50.0	6.7
Parent well-being	20.0	26.7	50.0	3.3
Motor	33.3	20.0	40.0	6.7
Equipment and orthotics	23.3	23.3	40.0	13.3
Nutrition	36.7	16.7	36.7	10.0
Feeding	30.0	23.3	36.7	10.0
PCP importance	48.3	13.8	31.0	6.9

Abbreviation: PCP, primary care provider.

the interconnectedness of different developmental domains (Maitre et al., 2017). Parents and providers both emphasized the role of evidence-based motor interventions in order to support functional abilities (Morgan, Novak, Dale, & Badawi, 2015; Novak et al., 2013) and the importance of augmentative communication devices if needed. As with other parents of children with developmental disabilities, parents wanted guidance from providers as to which services and interventions would be best suited for their child (MacKean et al., 2005). This study suggests that parents and providers can engage in meaningful and mutually satisfying discussions about early interventions that might be of most benefit to each particular patient with CP.

Another strong area of concordance, as found in studies of other disorders, was the emphasis on parent support and self-care, with an understanding that each parent and family's process is unique (Auger, Kenyon, Feudtner, & Davis, 2014;MacKean et al., 2005 ; Sperry & Symons, 2003). Perhaps because of acknowledgement of needed support for parents, parents and providers also highlighted the importance of the paediatrician's involvement. As with all children with special health care needs, children with CP benefit from a medical home to coordinate and help the family access care (Carbone et al., 2013). The medical home concept refers to a U.S. approach for providing comprehensive primary care. It facilitates partnerships between patients, clinicians, medical staff, and families and emphasizes personal patient–physician relationships and collective team responsibility for a patient's ongoing and coordinated care across settings and disciplines. Implementation of this medical home model is still a work in progress, but one that may be a worthwhile investment, particularly for patients with special health care needs, like those with CP (Carbone et al., 2013).

The need for emphasis on access to and coordination of care was discordant between parents and health care providers. Parents of children with developmental disorders often experience providers as skilled diagnosticians but then feel overwhelmed trying to coordinate care or access early interventions for their child after diagnosis (MacKean et al., 2005; Sperry & Symons, 2003). Parents want providers to help them access the best care for their child, whereas providers want parents to navigate these systems themselves (MacKean et al., 2005). In the early years, orthotics appeared particularly difficult to access, given the rarity of orthotists familiar with infants, time, expense, and rapid rates of child growth. This study suggests that more support in navigating systems of care and accessing resources may be of benefit to parents of and children with CP.

The most consistent area of discordance between parents and providers, in our study and seen elsewhere in the literature, involved nutrition and feeding practices in children with CP (Morrow, Quine, Loughlin, & Craig, 2008; Novak et al., 2012). Providers focused on weight gain and logistics of feeding (for example, if child has dysphagia or eats by mouth or via tube), whereas parents prioritized feeding quality of life and socialization surrounding feeding practices (Morrow et al., 2008). It may be that feeding practices are a surrogate for another central parental concern: quantity and quality of participation of their child in community activities and social engagement (Ustün et al., 2003); for children with CP and other developmental disabilities, it appears under-recognized and undersupported by providers (Novak et al., 2013; Sperry & Symons, 2003). The supports and barriers for child participation in both school and extracurricular recreation and leisure activities are complex and multifactorial (King et al., 2003). However, participation is critical for well-being and quality of life for all people—with and without disabilities (Felce & Perry, 1996; King et al., 2003). Parents appear to intuit this more than providers, and participation should rise among the top concerns for anyone caring for children with CP.

4.3 | Limitations

In this study, we did not address hearing comorbidities, because of efficient state and national initiatives for continued screening, surveillance, and intervention for children with hearing loss, regardless of CP. We also did not study behavioural challenges, as behaviour is one of the few comorbidities not related to degree of physical disability and thus, behavioural disturbances are often a later finding in children with CP (Novak et al., 2012). Still, given higher rates of behavioural problems in children with CP, efforts in screening and communication should start as early as possible (Novak et al., 2012). Lastly, this study only qualifies the experience in one U.S. centre. Although our parent sample represented a variety of parent ages, races, sexes, and educational achievement, this study consists of 17 parents at a single institution and may not be generalizable to all parents of children with CP. Additionally, our providers had benefited from a higher level of awareness of early detection for CP than many others across the nation as this site has encouraged hospital-based implementation efforts since 2016 (Byrne et al., 2017). Regardless, discrepancies and opportunities for improvement still abounded, and we hope that this study will encourage future inquiries in this area.

5 | CONCLUSION

In the current study, multiple areas of concordance and discrepancy in discussions surrounding early CP diagnoses were identified. Parents and providers agreed that future studies surrounding pain, sleep, and behavioural difficulties, personalized care plans, coordination of care, and role of the primary paediatric provider are paramount. Therefore, furthering a medical home model that supports early diagnosis and intervention for CP will also allow patients, families, and physicians to optimize care in all domains of the ICF for the present and the future, from body structures and function, to environmental, participation, and personal considerations.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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REFERENCES

A Quick Reference Guide for Hosting World Café. (2015). Retrieved from http://www.theworldcafe.com/wp-content/uploads/2015/07/Cafe-To-Go-Revised.pdf

Auger, K. A., Kenyon, C. C., Feudtner, C., & Davis, M. M. (2014). Pediatric hospital discharge interventions to reduce subsequent utilization: A systematic review. *Journal of Hospital Medicine*, *9*(4), 251–260. https://doi.org/10.1002/jhm.2134

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, *83*(6), 475–480. https://doi.org/10.1136/adc.83.6.475

Benini, R., Dagenais, L., & Shevell, M. I. (2013). Normal imaging in patients with cerebral palsy: What does it tell us? *The Journal of Pediatrics*, *162*(2), 369–374.e361. https://doi.org/10.1016/j.jpeds.2012.07.044

Bosanquet, M., Copeland, L., Ware, R., & Boyd, R. (2013). A systematic review of tests to predict cerebral palsy in young children. *Developmental Medicine and Child Neurology*, *55*(5), 418–426. https://doi.org/10.1111/dmcn.12140

Burger, M., & Louw, Q. A. (2009). The predictive validity of general movements—A systematic review. *European Journal of Paediatric Neurology*, *13*(5), 408–420. https://doi.org/10.1016/j.ejpn.2008.09.004

Byrne, R., Noritz, G., Maitre, N. L., & Group, N. E. D (2017). Implementation of early diagnosis and intervention guidelines for cerebral palsy in a high-risk infant follow-up clinic. *Pediatric Neurology*, *76*, 66–71. https://doi.org/10.1016/j.pediatrneurol.2017.08.002

Carbone, P. S., Murphy, N. A., Norlin, C., Azor, V., Sheng, X., & Young, P. C. (2013). Parent and pediatrician perspectives regarding the primary care of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(4), 964–972. https://doi.org/10.1007/s10803-012-1640-7

Dubowitz, L. M., Dubowitz, V., & Mercuri, E. (1999). *The neurological assessment of the preterm and full-term newborn infant*: Cambridge University Press. Facts about Cerebral Palsy. (2018). Retrieved from https://cparf.org/what-is-cerebral-palsy/facts-about-cerebral palsy/?gclid = Cj0KCQjw2v7mBRC1ARIsAAiw34_94fcwukwf4EJSXJRTasBLjk_Lh-YSnaWU4jl88J3bfc_-44E-F-oaAsqCEALw_wcB

Felce, D., & Perry, J. (1996). Exploring current conceptions of quality of life: A model for people with and without disabilities.

Ferrari, F., Einspieler, C., Prechtl, H., Bos, A., & Cioni, G. (2004). *Prechtl's method on the qualitative assessment of general movements in preterm, term and young infants*. London, UK: Mac Keith Press.

Granild-Jensen, J. B., Rackauskaite, G., Flachs, E. M., & Uldall, P. (2015). Predictors for early diagnosis of cerebral palsy from national registry data. *Developmental Medicine and Child Neurology*, *57*(10), 931–935. https://doi.org/10.1111/dmcn.12760

Guttmann, K., Flibotte, J., & DeMauro, S. B. (2018). Parental perspectives on diagnosis and prognosis of neonatal intensive care unit graduates with cerebral palsy. *The Journal of Pediatrics*, *203*, 156–162. https://doi.org/10.1016/j.jpeds.2018.07.089

Haataja, L., Mercuri, E., Regev, R., Cowan, F., Rutherford, M., Dubowitz, V., & Dubowitz, L. (1999). Optimality score for the neurologic examination of the infant at 12 and 18 months of age. *The Journal of Pediatrics*, *135*(2), 153–161. https://doi.org/10.1016/S0022-3476(99)70016-8

Hubermann, L., Boychuck, Z., Shevell, M., & Majnemer, A. (2016). Age at referral of children for initial diagnosis of cerebral palsy and rehabilitation: Current practices. *Journal of Child Neurology*, *31*(3), 364–369. https://doi.org/10.1177/0883073815596610

International Federation of Health Plans. 2015 Comparative price report: Variation in medical and hospital prices by country. 2015 [cited 2019 Jan 20]. Available from: http://static1.squarespace.com/static/518a3cfee4b0a77d03a62c98/t/57d3ca9529687f1a257e9e26/1473497751062/2015+Comparative+Price+Report+09.09.16.pdf.

Key Facts. Retrieved from https://www.yourcpf.org/statistics/

King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, *23*(1), 63–90. https://doi.org/10.1080/J006v23n01_05

Lemes, L., & Barbosa, M. (2007). Telling the mother that her newborn has a disability. *Acta Paulista de Enfermagem*, *20*, 441–445. https://doi.org/10.1590/S0103-21002007000400009

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations*, *8*(1), 74–85. https://doi.org/10.1111/j.1369-7625.2005.00319.x

Maitre, N. L., Key, A. P., Chorna, O. D., Slaughter, J. C., Matusz, P. J., Wallace, M. T., & Murray, M. M. (2017). The dual nature of early-life experience on somatosensory processing in the human infant brain. *Current Biology*, *27*(7), 1048–1054. https://doi.org/10.1016/j.cub.2017.02.036

McIntyre, S., Morgan, C., Walker, K., & Novak, I. (2011). Cerebral palsy—Don't delay. *Developmental Disabilities Research Reviews*, *17*(2), 114–129. https://doi.org/10.1002/ddrr.1106

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(1), 293–303. https://doi.org/10.1016/j.rasd.2011.05.011

Morgan, C., Novak, I., & Badawi, N. (2013). Enriched environments and motor outcomes in cerebral palsy: Systematic review and meta-

analysis. *Pediatrics*, *132*(3), e735–e746. https://doi.org/10.1542/peds.2012-3985

Morgan, C., Novak, I., Dale, R. C., & Badawi, N. (2015). Optimising motor learning in infants at high risk of cerebral palsy: A pilot study. *BMC Pediatrics*, *15*, 30. https://doi.org/10.1186/s12887-015-0347-2

Morrow, A. M., Quine, S., Loughlin, E. V., & Craig, J. C. (2008). Different priorities: A comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. *Archives of Disease in Childhood*, *93*(2), 119–125. https://doi.org/10.1136/adc.2006.115055

Novak, I., Hines, M., Goldsmith, S., & Barclay, R. (2012). Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics*, *130*(5), e1285–e1312. https://doi.org/10.1542/peds.2012-0924

Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., & Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: State of the evidence. *Developmental Medicine and Child Neurology*, *55*(10), 885–910. https://doi.org/10.1111/dmcn.12246

Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J., & Badawi, N. (2017). Early, accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment. *JAMA Pediatrics*, *171*, 897. https://doi.org/10.1001/jamapediatrics.2017.1689

Pain, H. (1999). Coping with a child with disabilities from the parents perspective: The function of information. *CCH Child: Care, Health and Development*, *25*(4), 299–313.

Pizzardi, A., Romeo, D., Cioni, M., Romeo, M., & Guzzetta, A. (2008). Infant neurological examination from 3 to 12 months: Predictive value of the single items. *Neuropediatrics*, *39*(06), 344–346. https://doi.org/10.1055/s-0029-1214423

Pope, C., & Mays, N. (1999). Qualitative research in health care, 2nd edn. *London: BMJ. Retrieved November*, *16*, 2009.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., & Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology. Supplement*, *109*, 8–14.

Sperry, L. A., & Symons, F. J. (2003). Maternal judgments of intentionality in young children with autism: the effects of diagnostic information and stereotyped behavior. *Journal of Autism and Developmental Disorders*, *33*(3), 281–287. https://doi.org/10.1023/A:1024454517263

Ustün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health: A new tool for understanding disability and health. *Disability and Rehabilitation*, *25*(11-12), 565–571. https://doi.org/10.1080/0963828031000137063

Whitney, D. G., Warschausky, S. A., & Peterson, M. D. (2018). Mental health disorders and physical risk factors in children with cerebral palsy: A cross-sectional study. *Developmental Medicine and Child Neurology*, *61*, 579–585. https://doi.org/10.1111/dmcn.14083

Yu, C. K., Yuen, V. M., Wong, G. T., & Irwin, M. G. (2013). The effects of anaesthesia on the developing brain: A summary of the clinical evidence. F1000Res, 2, 166. https://doi.org/10.12688/f1000research.2-166.v2

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