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# Barriers to Care for Children with Cerebral Palsy in the Rural State of Maine: A Mixed-Methods Study

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## ORIGINAL RESEARCH

# Barriers to Care for Children with Cerebral Palsy in the Rural State of Maine: A Mixed-Methods Study

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**Introduction:** Guidelines on orthopedic hip surveillance in children with cerebral palsy have been published to minimize the effects of cerebral palsy and maximize quality of life. Researchers aimed to identify barriers to cerebral palsy care and to assess adherence to national hip-surveillance guidelines among a small subset of children with cerebral palsy who live in a rural state.

**Methods:** Parents of children with cerebral palsy were interviewed, and thematic analyses were performed on the recorded transcripts. Patient-specific data about imaging and demographics were manually extracted from the electronic health record to perform a mixed-methods analysis.

**Results:** Twenty-one parents were interviewed, and 4 themes related to barriers to care for cerebral palsy were identified: inadequate local services, communication issues, time burdens, and financial difficulties. Routine surveillance hip x-rays were indicated for 17/21 children; however, 12/17 (71%) did not obtain imaging. In this small group of children with cerebral palsy, inadequate hip surveillance was associated with greater distance to care, lower household education and income, more severe functional limitations, and rurality.

**Discussion:** Many children with cerebral palsy in Maine have not received optimized orthopedic hip surveillance, and issues related to rurality are major barriers identified by parents.

**Conclusions:** Multiple barriers exist that inhibit the ability of families to access recommended orthopedic care for family members with cerebral palsy in the rural state of Maine.

**Keywords:** pediatrics, rural health, cerebral palsy, qualitative research

Cerebral palsy (CP) is a complex neurodevelopmental disorder and is the number one cause of childhood physical disability.<sup>1</sup> People with CP have movement and postural difficulties in addition to sensory, cognitive, or behavioral disabilities that may adversely affect their quality of life. CP is often the result of perinatal brain injury or structural malformation. The condition can affect various parts of the body with wide-ranging symptoms, such as spasticity, dystonia, ataxia, scoliosis, and hip dysplasia/dislocation.

CP management is highly personalized to each child and depends on their Gross Motor Function Classification System (GMFCS),<sup>2-3</sup> Winters Gage Hicks (WGH) gait scores,<sup>4</sup> functional status, and goals of care. Management options include non-pharmacological treatments, such as physical, occupational, speech and bracing therapies,<sup>5-6</sup> as well as pharmacologic medications that target muscle spasticity. As children grow, spasticity can cause profound issues with joints, potentially warranting surgical management.<sup>7-8</sup> The hip joint is particularly vulnerable to orthopedic sequelae of spasticity. Also, although CP itself is not progressive, children may have progressive hip displacement that causes gait difficulties that negatively impact quality of life.<sup>9</sup> To adequately manage and treat such changes, national guidelines have been

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developed by the American Academy of Cerebral Palsy and Developmental Medicine (AACPD). These guidelines recommend routine physical exams and radiographic imaging to identify improper acetabulum formation for early treatment and improved outcomes.<sup>10-12</sup>

Maine is the most rural state in the country, with 61% of its population residing in a rural area, a factor that creates unique challenges in accessing health care.<sup>13-14</sup> Furthermore, only 1 practice in the southern region has specialized, multi-disciplinary CP care. This practice manages more than 200 children with CP living all over the state. Children living in Maine with CP may experience significant barriers to receiving recommended and necessary care. This study aimed to explore barriers to access and use of CP-related care, and to determine adherence to national guidelines for hip surveillance.

## METHODS

### Study design

This mixed-methods study included (1) semi-structured interviews of parents of children with CP and (2) a retrospective chart review of the child's medical record to assess hip-surveillance patterns and demographics. Of note, children did not participate in the interview. The MaineHealth Institutional Review Board approved of this qualitative research under the exempt category of review. Parental HIPAA (Health Insurance Portability and Accountability Act) authorization was obtained before chart review. The Standards for Reporting Qualitative Research checklist was used for reporting this research.

### Inclusion criteria and recruitment

Parents/guardians were included in the interviews if they were English-speaking and living in Maine, and if their child with CP was between 0 and 17 years of age. No incentives were provided for participation. Parents were recruited during their child's scheduled pediatric neurology office visit or botulinum toxin-injection procedure between June 1, 2021, and July 13, 2021, by researchers 1 and 3.

### Qualitative interview development

A semi-structured interview guide was developed and iteratively reviewed by a multidisciplinary team of CP clinic personnel, including a pediatric

neurologist and orthopedic surgeon (who specialize in CP care), a registered nurse and medical assistant (who organize the CP clinic), an orthotist (who makes orthotics for children in the CP clinic), and a medical student on a summer internship. All these people, except for the medical student, provide direct patient care. Questions were open-ended to avoid influencing the character or content of participant responses. Probing questions were developed to delve deeper into certain targeted areas (see Supplemental Information for the full interview guide).

### Qualitative interview procedure

All interviews were conducted by the same member of the research team (researcher 1), who had no prior relationship with participants or the CP clinic. Interviews were conducted virtually via Tufts HIPAA-compliant Zoom software or in person after scheduled appointments in a private room per the family's preference to maximize participant comfort. Interviews lasted 30 to 60 minutes each. Interviews were audio recorded with Zoom or Otter.ai and transcribed by Otter.ai with names and personal health information manually redacted. All interview recordings and transcribed interviews were stored only on the encrypted Tufts Box online platform. A REDCap key linked the interview number with both qualitative and quantitative data.

### Qualitative interview analysis

Participants were enrolled until thematic saturation, the point at which collecting additional data resulted in no new information, was achieved.<sup>15-16</sup> Thematic saturation occurred after 19 interviews, and 2 additional interviews were performed to ensure no new themes would emerge. Twenty-one children were represented by 21 parent interviews. Thematic analysis of transcribed interviews was performed using MaxQDA Analytics Pro qualitative content analysis software version 20.4.1 (VERBI Software, Berlin, Germany). The first and last authors of this publication reviewed Transcript #1 together and developed a coding framework based on interview responses. Then both researchers independently coded 2 to 3 transcripts at a time and created new codes based on additional unique participant responses. Differences in codes were resolved between each group of 2 to 3 transcripts for ongoing intercoder reliability checks and to discuss emerging themes and subthemes. All transcripts were then recoded using the final framework.

## Quantitative chart review

Researcher 1 manually extracted the child's CP history and x-ray frequency from the electronic health record (EHR). The extracted characteristics included: date of birth, sex assigned at birth, zip codes at home and locations of CP care, CP diagnosis and documentation of the GMFCS and WGH scores, cause of CP, verbal vs non-verbal communication, previous CP treatments (including Baclofen, bracing, botulinum toxin, surgical correction), CP clinicians seen [including neurology, physical therapy (PT), occupational therapy (OT), speech therapists, orthotists, and orthopedics], and number of prior hip x-rays. To ensure confidentiality, REDCap was used as a secure platform with a separate REDCap key linking deidentified EHR data to the interview of the parent.

## Quantitative variables defined

Distance to care was calculated using zip codes and the Google Maps Directions function. The shortest distance was recorded out of all Google Maps routing options to underestimate, rather than overestimate, distance. Rural zip codes were delineated based on rural definitions outlined in the Rural Maine Census Report.<sup>13</sup> Poverty level and free/reduced-lunch qualification was determined using household size and reported 2020 income based on 2021 poverty guidelines.<sup>17-18</sup> Adherence to hip surveillance recommendations was calculated based on the AACPD 2017 Hip Surveillance Care Pathway<sup>10</sup> using patient age, functional scores, and results of previous x-rays. Researchers 1 and 3 jointly assigned a GMFCS level and WGH score for patients without documentation using established guidelines and observed functional mobility during the scheduled appointment.<sup>3-4</sup> The physical exam part of the hip-surveillance algorithm was excluded to avoid bias due to COVID-19 disrupting care during the timeline of this assessment.

## Quantitative data analysis

To examine statistical differences in patient characteristics between patients who had adequate versus inadequate surveillance, Fisher's exact tests were used for categorical variables. Wilcoxon rank-sum tests were used for continuous variables, and Cochran-Armitage trend tests were used for ordinal variables. All statistical analyses were conducted in R version 3.6.2.

## RESULTS

Twenty-four parents/guardians were consented for the study, of which 21 participated in the interview, representing 21 children with CP. Eighteen (86%) mothers, 1 father (5%), and 2 couples (9%) were interviewed. Four families had children with other complex health care needs, and 5 families had twins (other characteristics are outlined in Table 1).

### Qualitative interviews

Thematic analysis of parent interviews identified the following themes: inadequate services, communication issues, time burdens, and financial difficulties.

#### Inadequate services.

The "inadequate services" theme refers to the parents' reported need for more local, experienced, and accessible providers to address their children's specialized needs, especially in the wake of the COVID-19 pandemic (Figure 1). Although some parents requested more neurology and orthopedic personnel, they also called for more specialized PT, OT, orthotists, in-school aids, and home nurses. One parent shared, "Living up here [northern Maine], there's not a lot of people that...work with CP... we have no pediatric physical therapists." Another stated, "Her primary care physician is amazing, but they don't have any [CP] experience." The paucity of local, experienced medical professionals led to delays in certain aspects of care, such as receiving orthotics, which require regular reevaluation and resizing as children grow. Although one mother noted, "... she's constantly growing and constantly complaining about the brace", another parent shared, "We're needing a new [ankle foot orthosis] right now. He's outgrown it. And we know that takes time to get sent out and made. And he hasn't had a new one since January [7 months prior]." Parents also reported added strains on the medical system during the COVID-19 pandemic: "During the pandemic especially, everything was either canceled or hasn't been caught up yet. We haven't been seen, offices have closed, we no longer have a bracing specialist anymore." Another mother explained, "When COVID hit, I kind of just kept her home and we didn't do as many [PT] as we should have."

**Table 1.** Demographic Characteristics and Health Care Utilization Among Pediatric Study Participants with Cerebral Palsy Cared for in Maine, [June 2021-July 2021], N= 21

Characteristic	Value*
Age, y, median (IQR)	7 (4, 11)
Female sex, No. (%)	7 (33)
Type of cerebral palsy, No. (%)	
Quadriplegic	5 (24)
Triplegic	3 (14)
Diplegic	4 (19)
Hemiplegic	9 (43)
Cause of cerebral palsy, No. (%)	
Periventricular leukomalacia	6 (29)
Intraventricular hemorrhage	1 (5)
Stroke	7 (33)
Hypoxic ischemic encephalopathy	1 (5)
Congenital brain malformations	4 (19)
Other/Unknown	2 (9)
Therapies for cerebral palsy	
Physical therapy appointment within the past year, No. (%)	20 (95)
Physical therapy appointments per week, median (IQR)	2 (1, 2)
Occupational therapy appointment within the past year, No. (%)	19 (9)
Occupational therapy appointments per week, median (IQR)	2 (1, 2)
Speech therapy appointment within the past year, No. (%)	11 (52)
Speech therapy appointments per week, median (IQR)	2 (1, 2)
Medical care for cerebral palsy	
Medical appointments in the past year, median (IQR)	8.5 (5, 16)
Orthotics/bracing, No. (%)	18 (86)
Spasticity medication, No. (%)	8 (38)
Botulinum toxin injections, No. (%)	18 (86)
Serial casting, No. (%)	3 (14)
Has seen an orthopedic surgeon, No. (%)	16 (76)
Had orthopedic surgery, No. (%)	5 (24)
Household demographics	
Reside in a rural zip code, No. (%)	16 (76)
Household size, median (IQR)	4 (3.75, 5.25)
Income below federal poverty level, No. (%)	3 (14)
Highest parental educational level obtained, No. (%)	
High school diploma	4 (20)
Associate's degree	3 (15)
Bachelor's degree	8 (40)
Graduate degree	5 (25)
Distance traveled to obtain cerebral palsy care	
Distance to neurology clinic, miles, median (IQR)	72 (37, 89.5)
Distance to orthopedic clinic, miles, median (IQR)	72 (39, 118)
Distance to x-rays obtained, miles, median (IQR)	12 (0, 23.5)
Sought medical care outside Maine, No. (%)	10 (48)

Abbreviation: IQR, interquartile range.

\* Percentages may not total 100% due to rounding.

### Communication issues.

The “communication issues” theme refers to parents’ reported needs for improved communication with providers, including improved transparency about their child’s diagnosis, providing CP resources, and streamlining scheduling and office experiences (Figure 1). Most participants requested more guidance on CP education, mental health resources, home services, affordable equipment, and spaces to speak with other people experiencing life with CP. One mother called for “more resources, just getting more resources, just guidance... You know, where can we find help? Where can we find people to talk to?” Another mother plainly asked, “Where’s the guidance for families like us? Who do we ask, who do we go to, who can help us?” Many parents also urged providers to improve their anticipatory guidance for families first diagnosed with CP and to set expectations for their child’s possible needs and interventions. One parent noted, “I’m glad that people said that [CP isn’t linear]... it was less devastating when he had a setback...it can be hard to hear that, but I find it useful that you’re not blindsided later.” Parents also admitted to being nervous about missing information and not asking the right questions during specialty visits. One parent shared, “A lot of times I get nervous that I’m missing information... and then I’m relaying the information, and I hope I’m doing it right.”

### Time burdens.

The theme of “time burdens” refers to parental reports of long travel times to obtain care, frequent medical visits, and resulting strains on their respective careers (Figure 1). When asked what would make the biggest difference in their child’s CP care, one parent said, “Just having them [medical providers] closer... I wouldn’t have to travel, you know, from the top of Maine to the bottom of Maine [a 6-hour drive one-way].” In addition to long travel times, many parents reported the high frequency of appointments as an additional barrier to care. One parent admitted, “I think she needs therapy more, but it’s literally impossible. I can’t work and do it. So we’ve had to make hard decisions and... one of those is [cutting] PT or OT.” Some families had a stay-at-home parent to help with medical visits and others had accepted part-time jobs to accommodate such frequent absences. One parent said, “I’m a teacher. So if it’s not during a vacation week, then I have to either use the only time I have, or not get paid.”

### Financial difficulties.

The “financial difficulties” theme refers to parent reports of difficulties with the cost of care, travel, and making their home accessible to their child with unique CP needs (Figure 1). Our participants reported spending large sums of money on insurance (often using multiple) while still having to pay for therapy appointments and adaptive equipment out of pocket. One father shared, “There’s been times where MaineCare [Medicaid] said no. And I was concerned about how I was going to come up with \$7,000 to \$8,000 [for equipment].” Apart from the cost of medical appointments and treatments, these families noted the cost of travel (such as gas and vehicle upkeep) as a large barrier to obtaining care: “It’s only 45 minutes, but if it’s 3 times in 1 week, it’s exhausting. It’s a financial burden no matter how you look at it.” Several parents also reported having to find expensive accommodations for the night before or after their appointments. For multiple participants, having a reliable car and an accessible home that fit their child’s needs was a particular struggle. Some even noted dangerous consequences of having unreliable vehicles or inadequate home equipment, such as car accidents and injuries while transporting their child. One couple shared, “We’re not very high up there, socioeconomically. The house isn’t necessarily the most accessible for him. At any point, it’s a little overwhelming, because we still carry him up the stairs [17-year-old].”

### Quantitative hip-surveillance data

The chart review revealed that 9 (43%) children did not have a documented GMFCS level in the EHR. Also, only 2 of 7 children with spastic hemiplegia had a documented WGH score. Adherence to national AACPDM x-ray recommendations was assessed after assigning appropriate GMFCS and WGH scores. For 17 of 21 children, at least 1 hip x-ray was recommended, and 12 (71%) children had not received the recommended hip imaging. Between patients who had obtained the recommended hip imaging versus those who did not, children who had received appropriate imaging tended to be younger and had less severe CP. Several nonsignificant characteristics were found in children without appropriate surveillance, including greater distance traveled to clinics and living in a rural area as designated by zip code (Table 2).

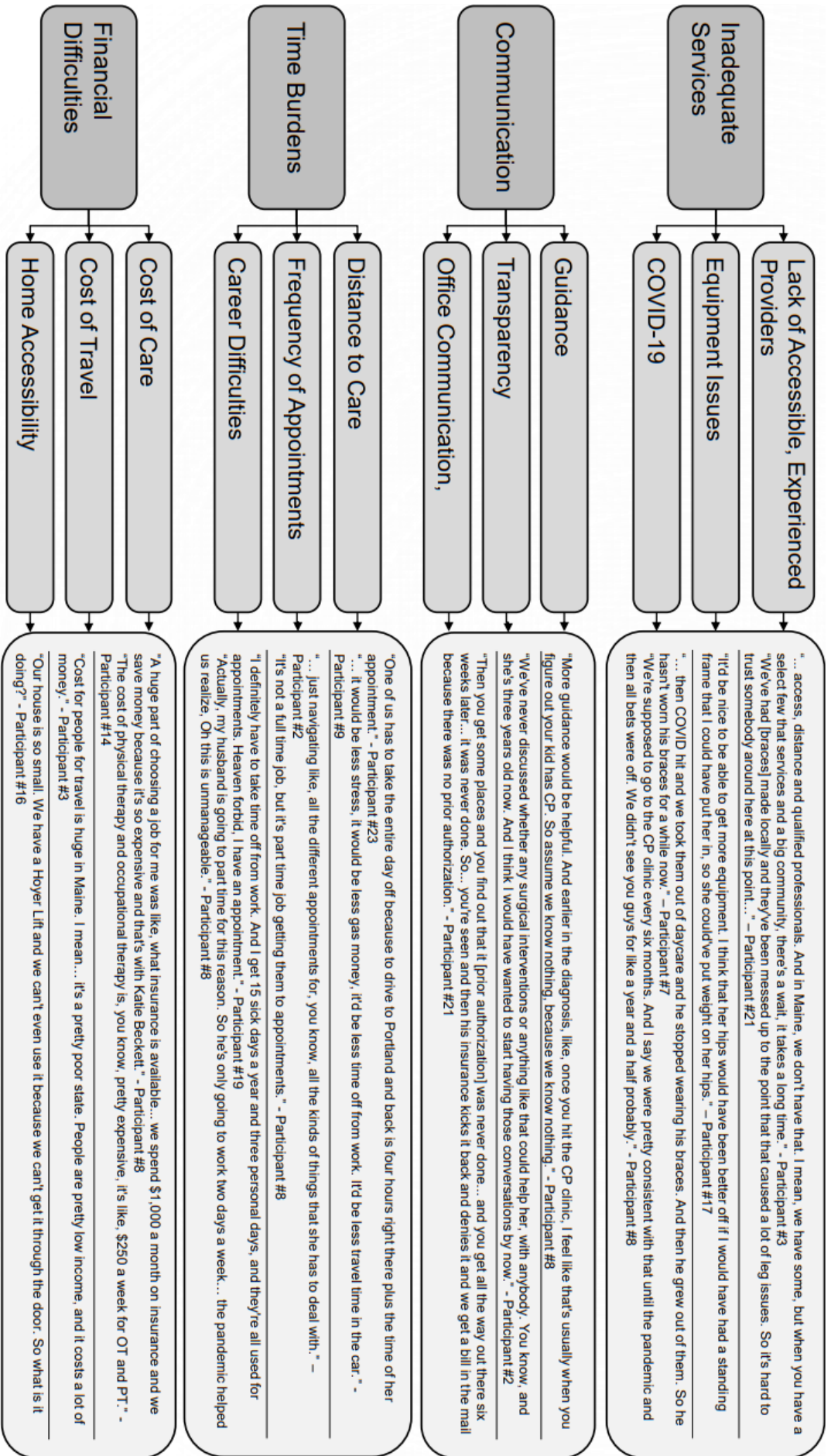


Figure 1 Parental Perceptions of Barriers to Cerebral Palsy Orthopedic Surveillance and Care. [June 2021-July 2021]. CP, cerebral palsy.



**Table 2.** Demographic Characteristics Among Participating Children with and without Recommended AACPDH Hip Surveillance, [June 2021-July 2021] N=21\*

Characteristic	Inadequate surveillance, n=12	Adequate surveillance, n=9	P value
Age, y, median (IQR)	10.0 (5.8, 12.0)	4.0 (4.0, 7.0)	.032 <sup>§</sup>
GMFCS, No. (%)			
Level 1	0 (0)	4 (44)	.014 <sup>†</sup>
Level 2	4 (33)	4 (44)	
Level 3	2 (17)	0 (0)	
Level 4	3 (25)	0 (0)	
Level 5	3 (25)	1 (11)	
GMFCS documented in medical record, No. (%)	7 (58)	5 (56)	>.9 <sup>‡</sup>
Orthopedic care obtained, No. (%)	7 (58)	6 (67)	>.9 <sup>‡</sup>
Reside in rural zip code, No. (%)	10 (83)	5 (56)	.3 <sup>‡</sup>
Distance to neurology clinic, miles, median (IQR)	79 (64, 90)	44 (36, 84)	.4 <sup>§</sup>
Income below federal poverty level, No. (%)	3 (14)	0 (0)	.2 <sup>‡</sup>
Highest parental education, No. (%)			
High school diploma	3 (25)	1 (12)	.14 <sup>†</sup>
Associate's degree	2 (17)	1 (12)	
Bachelor's degree	6 (50)	2 (25)	
Graduate degree	1 (8)	4 (50)	
Unknown	0 (0)	1 (12)	

Abbreviations: AACPDH, American Academy of Cerebral Palsy and Developmental Medicine; GMFCS, Gross Motor Function Classification System; IQR, interquartile range.

\* Percentages may not total 100% due to rounding.

† Cochran-Armitage test for trend.

‡ Fisher's exact test.

§ Wilcoxon rank-sum test.

## DISCUSSION

In this mixed-methods study of parents of children with CP, semi-structured parent interviews revealed 4 overarching barriers to obtaining care: inadequate experienced local services, poor communication with clinicians, time burdens due to distance and frequency of care, and high financial burdens. Overall, less than one-third of the children who required hip imaging had received it, illustrating a very low adherence to national AACPDH guidelines. Though quantitative conclusions are limited based on the number of participants, those living in rural locations and those with more severe CP had the lowest rates of appropriate surveillance. Interpreting the interview data with the x-ray adherence data suggests that rurality contributes to barriers to care for children with CP in Maine.

Qualitative studies have become a mainstay of primary research into health care barriers due to their ability to provide intimate, first-person context to health and health care processes.<sup>19</sup> Two urban-based qualitative studies in the United States and Canada explored parental views of barriers to obtaining and keeping CP-specific appointments. Similar to our findings, these studies identified limited finances, transportation and travel, competing priorities, provider availability, and inconvenient scheduling as the leading barriers.<sup>20-21</sup> Another study of barriers to participation in activities for children with CP found transportation, finances, and lower parental literacy as factors that impeded participation.<sup>22</sup> A research team in urban Australia asked clinicians who specialize in CP and parents of children with CP to separately describe what they perceived to be barriers to achieving adequate

hip imaging. Parents and clinicians agreed that poor communication, unclear provider roles, and inconsistent clinician teams were major obstacles to achieving adequate surveillance.<sup>23-24</sup> Clinicians reported inconsistent practices and standards in radiology, low parent engagement, and forgetfulness as major barriers.

Rural families may experience the aforementioned barriers in addition to significant obstacles that often coincide with rural living. A New Zealand study identified barriers contributing to delayed presentation of pediatric appendicitis and found that families living in rural areas with reduced financial and social resources had even greater delays.<sup>25</sup> Our study offers insight into overlapping barriers for families experiencing both CP and the health disparities of rural living. Our study also identified new CP-specific issues, such as those related to medical equipment, lack of anticipatory guidance from providers, and difficulties with attending frequent appointments.

Distance to care was a major theme expressed in parental interviews and was supported by quantitative data that revealed large travel distances based on zip codes. Although this study sought to identify barriers to CP care for rural children, it is important to note that living in a nonrural area of Maine does not ensure you have adequate local providers. Some nonrural participants lived more than 60 miles away from Maine's only CP clinic. In addition to greater distances to care and rural zip codes, all participants living below the federal poverty line also had inadequate CP surveillance. Of particular importance, all families (regardless of income) reported difficulty paying for the various costs of CP care.

Notably, the CP clinic where these children received their care was established before the COVID-19 pandemic and all but ceased function during the pandemic. Likely due to many factors, this clinic's CP team did not adequately document GMFCS, which may be a particular disservice to patients with higher GMFCS levels who, by definition, need more involved care. It is also important to recognize the bidirectional nature of adherence to medical recommendations because recommendations must be clearly communicated, ordered, and followed up by providers and attended/pursued by families. Australian research cited unclear provider roles, poor provider-provider and provider-family

communication, knowledge gaps, and inconsistent clinician teams as significant barriers to proper CP hip surveillance.<sup>23-24</sup> In our study, the large number of participants who did not have GMFCS documentation or WGH scores suggests that much more work on the part of the clinical team is needed to overcome these disparities and provide optimal CP care.

One strength of our study is the mixed-methods approach. This approach revealed insight on barriers to hip surveillance in the voices of Maine families directly affected by CP while also quantifying actual hip surveillance. Another strength of our study design was the flexible scheduling for virtual interviews, which maximized the chances that families from more rural locations could participate.<sup>26</sup> Lastly, interviews were conducted using scripted questions to provide a standardized experience and minimize variation and bias.

Due to the qualitative nature of this study and the associated sample size, our results may overestimate Maine's actual hip-surveillance rates. This overestimate could be because participants were established at the pediatric neurology clinic and, thus, had already exhibited means of seeking out and obtaining care for their children. Additionally, nearly half of participants obtained care outside Maine, and because these records were not available for review, additional imaging may have been obtained. Though the number of participants was reasonable for a qualitative study, it may not be sufficient for drawing statistical conclusions. The true nonadherence to hip-surveillance guidelines across all children with CP in the state, including those who do not attend a specialty clinic, is potentially higher than reflected in this sample. Participants were aware of being observed and may have altered their responses, resulting in observation bias. Also, researchers may have experienced confirmation bias in thematic analysis, though the coder inter-reliability check worked to minimize this bias. Due to the nature of limited, unique qualitative cohorts, the identified themes may not be generalizable to the entire Maine population affected by CP.

## CONCLUSIONS

This study aimed to identify barriers to CP hip surveillance and care in children in the rural state of Maine. Qualitative parental interviews identified 4 overarching thematic barriers, including inadequate local services, poor communication,

time burdens, and financial difficulties. Quantitative analysis revealed that children with inadequate hip surveillance tended to have greater distance to care, lower household education and income, more severe functional limitations per the GMFCS score, and rural zip codes. However, these findings were largely nonsignificant. Perhaps related to these barriers, less than one-third of children with CP who required imaging received appropriate hip surveillance per AACPDM guidelines. The poor adherence to CP hip-surveillance guidelines illustrates the need for improving communication between clinicians and families, and for further education and health system redesign to make optimal CP care accessible to patients residing in rural areas.

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**Conflict of interest:** The authors have no conflicts of interest to disclose.

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