Participation of Children and Youth with and without Cerebral Palsy across Settings: An Exploratory Study

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BACKGROUND

Meaningful participation and involvement in everyday activities and routines have a positive influence on child well-being, development, and optimal health and is a key component of health equity.[1,2]

Environment has been identified as a key factor influencing participation.[3] Children and youth with disabilities often participate less in home, school, and community activities.[4]

One of the most common pediatric health conditions resulting in childhood disability is cerebral palsy (CP).[5] Individuals with CP have varying degrees of movement limitations, which affects participation,[6] in addition to social characteristics such as age and sex.[7]

Research exploring participation in children and youth across various activity settings is limited.

PURPOSE

The purpose of this study was to:

1) Explore differences in participation of children/youth with and without CP across home, school, and community settings
2) Examine participation of children with CP across age groups and sex, and between ambulatory and non-ambulatory children with CP in those settings.

METHOD

- Cross-sectional Design
- Parent-reported Survey Study
- Anonymous Responses collected using PEM-CY = Participation and Environment Measure for Children and Youth©
- Electronic Data Collection via REDCap®

Inclusion:
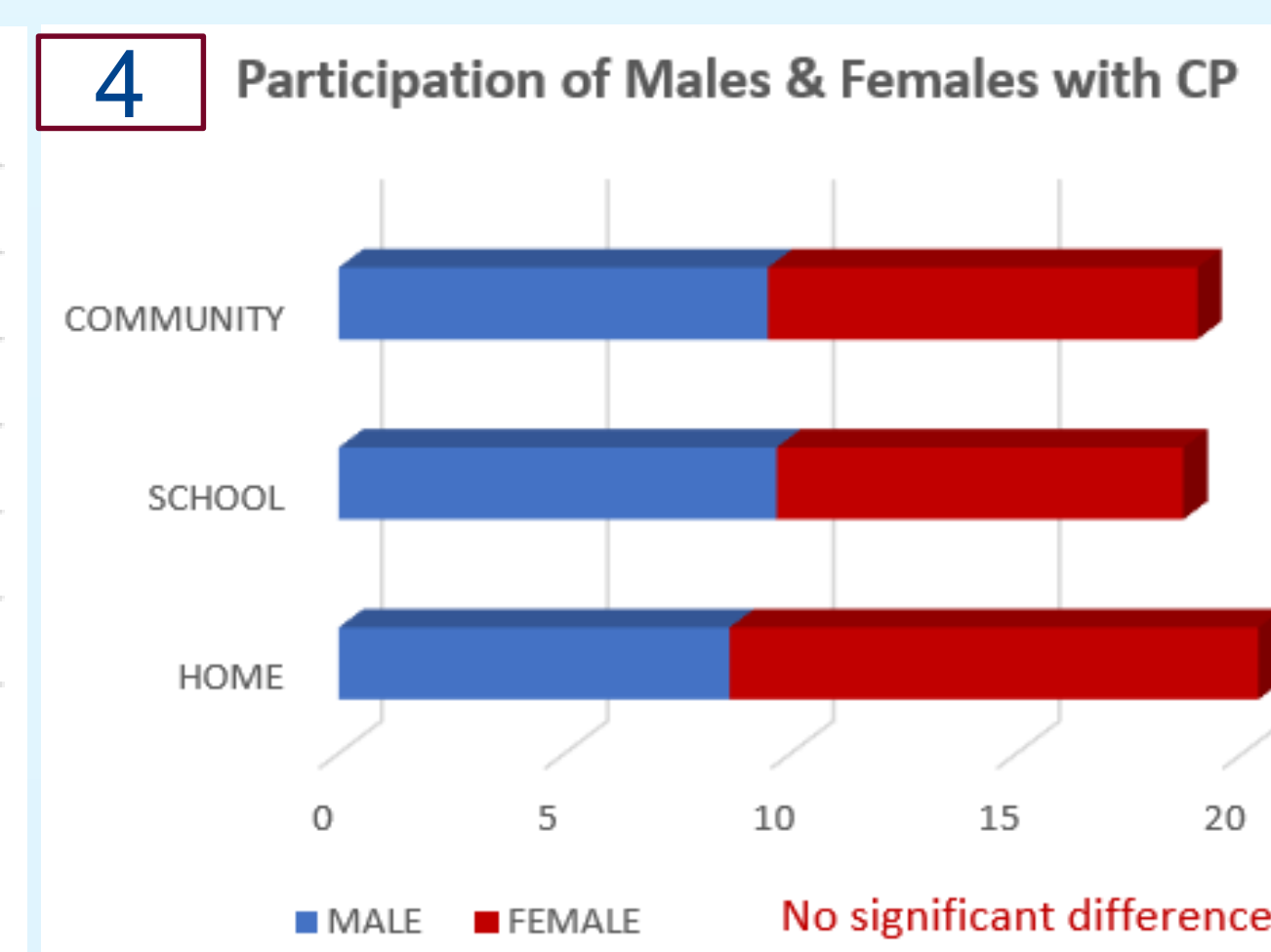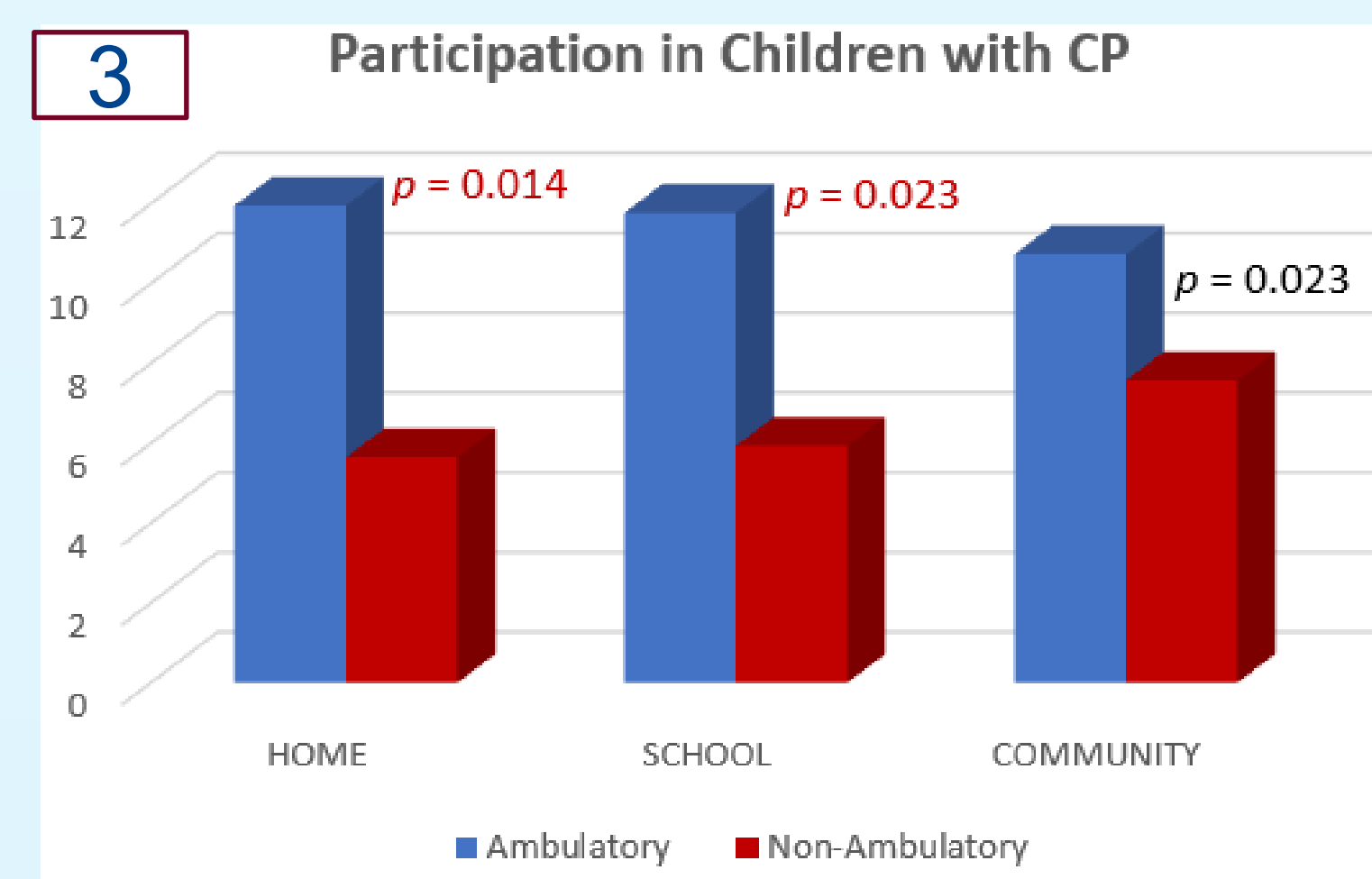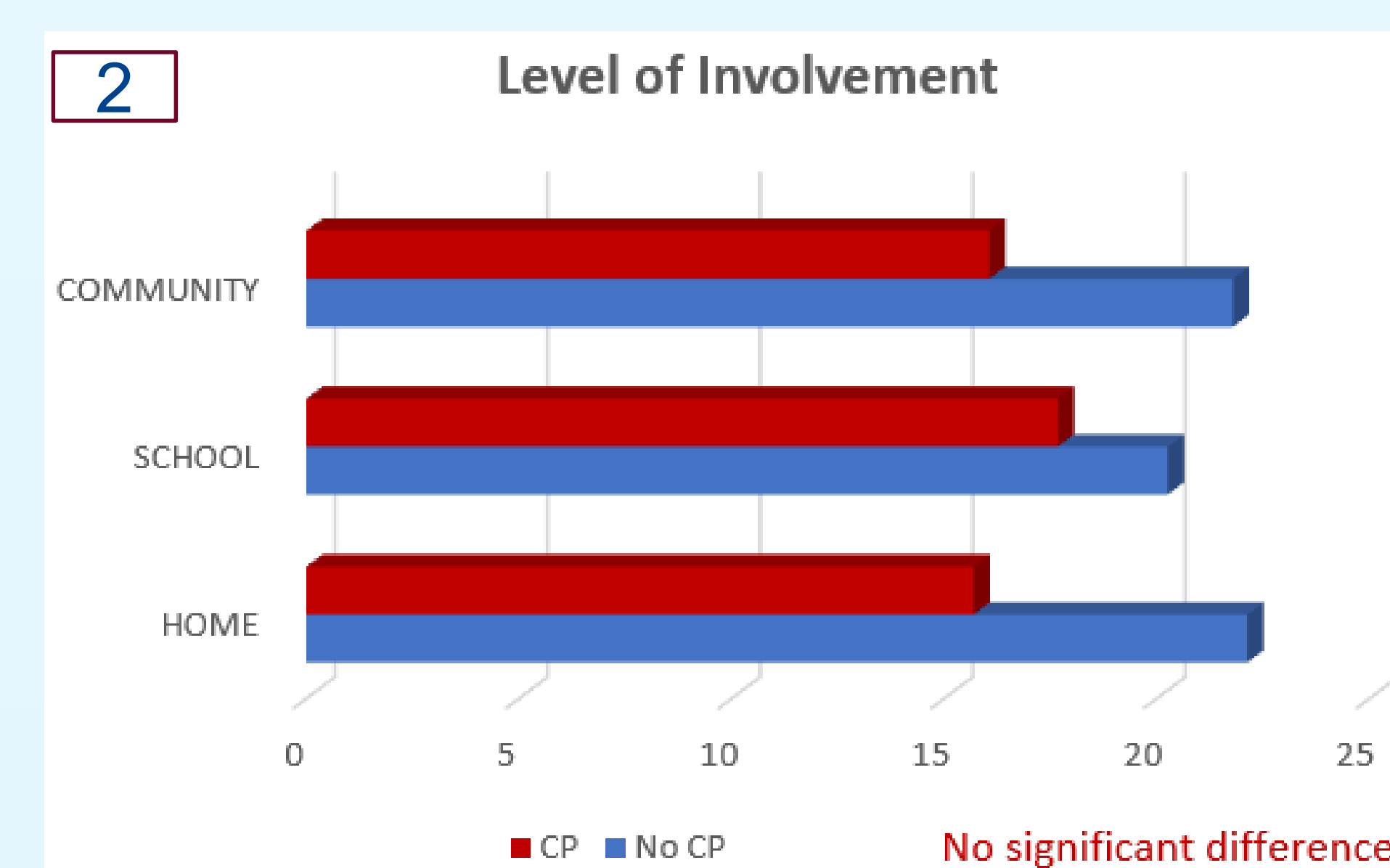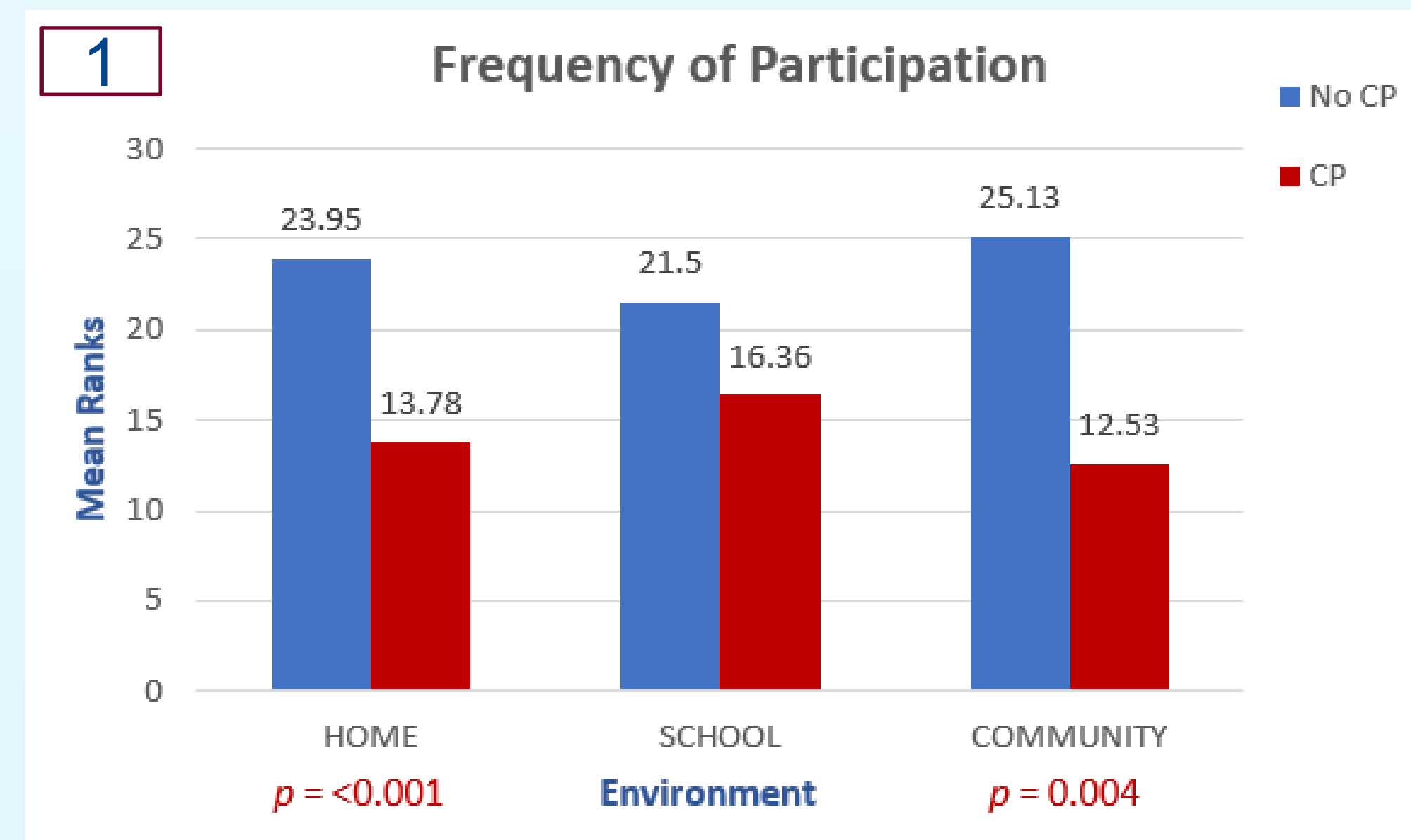   Parents of Children/Youth 5 to 17 years old with and without CP
Exclusion:
   Parents of children hospitalized in the past 4 months

RESULTS

Forty surveys completed; however, $n = 37$ due to missing responses on three of the surveys.
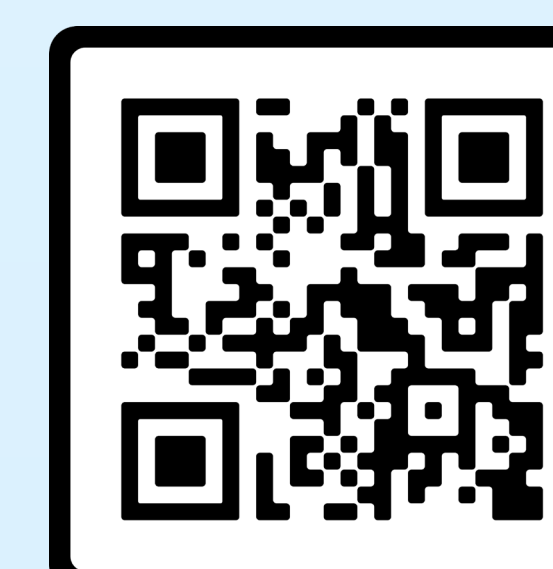
Participants

Parents of children without CP: $n = 19$
Children without CP
11 males, 8 females
Age: M = 8.6 (4.1)

Parents of children with CP: $n = 18$
Children with CP
13 males, 5 females   Ambulatory, $n = 11$
Age: M = 8.84 (3.5)   Non-ambulatory, $n = 7$
   < 6 years, $n = 5$
   6 to 11 years, $n = 8$
   12 to 17 years, $n = 5$

1 — Frequency of Participation (No CP / CP)
HOME: 23.95 / 13.78 $p = <0.001$
SCHOOL: 21.5 / 16.36
COMMUNITY: 25.13 / 12.53 $p = 0.004$
Mean Ranks — Environment

2 — Level of Involvement (CP / No CP)
COMMUNITY, SCHOOL, HOME
No significant differences

3 — Participation in Children with CP (Ambulatory / Non-Ambulatory)
HOME $p = 0.014$
SCHOOL $p = 0.023$
COMMUNITY $p = 0.023$

4 — Participation of Males & Females with CP (MALE / FEMALE)
COMMUNITY, SCHOOL, HOME
No significant differences

5 — Participation in Children with CP Among Age Groups (< 6 / 6 to 11 / 12 to 17)
HOME $p = 0.115$
SCHOOL $p = 0.005$
COMMUNITY $p = 0.167$

DISCUSSION

This survey study used the PEM-CY, a new out-come measure, to explore differences in participation across settings in children with and without CP. Significant differences in frequency of participation were found in home and community environments, similar to previous studies. However, no significant differences were noted in the school setting, which is a positive finding, possibly indicating that education systems are removing barriers and schools are moving toward equal access.

Motor ability of children with CP impacted participation in home and school, but not in community settings, perhaps a reflection of greater accessibility and increased community involvement.

CONCLUSION

Findings from this exploratory study highlight the need for future research investigating participation of children with CP in home, school, and community environments. Optimizing a child's ability to participate across settings is an important outcome of pediatric rehabilitation programs. Participation data could help clinicians identify patterns and develop intervention plans that focus on maximizing child participation in all settings.

SUMMARY OF FINDINGS

1. Significant differences were found between children with and without CP in frequency of participation at home and in community activities. No significant differences were identified participation frequency in school.

2. No significant differences were noted in level of involvement; therefore, we can assume that children are equally involved when they do participate.

3. In children with CP, those able to ambulate reported significantly more participation in home and school settings than non-ambulatory children.

4. There were no significant differences in frequency of participation between males and females with CP.

5. In children with CP, frequency of participation in school was significantly different between age groups—specifically, between younger and older groups, and between younger and middle groups.

Scan code for ABSTRACT, **References** for BACKGROUD, & Researcher's Contact Info

SCAN ME

Photo release on file