



A Spectrum for Children with Cerebral Palsy in Order to Improve Quality of Life

Brittany Carbone, Lindsay Corallo, Gianna DeCola

Advisor: Professor Christina Gunther



Objective

Develop a spectrum that will increase the quality of life in children with Cerebral Palsy (CP). A spectrum is beneficial in order to categorize the severity of symptoms and direct families to specific treatment plans tailored to meet the unique needs and symptoms of each child. Current assessment tools will be amalgamated to develop a CP spectrum.



Figure 1: An image of a young girl with Cerebral Palsy using a walker to help her walk. United Cerebral Palsy Foundation of Minnesota <https://ucpmn.org>

Background

- CP is a group of disorders affecting communication, gross motor function, and fine motor movement abilities of an individuals affected.
- Caused by traumatic injury to the developing brain or abnormal brain development during fetal growth.
- No cure; symptom management only.
- Patient symptom variability makes early detection and intervention difficult.
- Three assessment are currently in use: Communication Function Classification System, Gross Motor Function Classification System, and Manual Abilities Classification System.
- Each child with CP is unique, causing treatment plans to vary.
- Similarly, Autism is considered a spectrum disorder due to the wide variation in the type and severity of symptoms, much like CP symptoms.
- An interview with an experienced parent of a CP patient highlighted the need for coordination of information and care among healthcare providers to alleviate disparities in care and caregiver stress. Lack of dissemination of knowledge, stress of multiple doctors' appointments, and a lack of protocol for appropriate and adequate treatment confirm what is found in the literature.
- Quality of life varies for CP patients due to a lack of spectrum diagnosis.
- A spectrum will allow order, direction, efficient communication, and best suited treatments for each unique case of CP.

Methods

Study 1:

- Vindy, Marietta and Anggraini's main focus in the article is to talk about the different levels of classification systems.
- The GMFCS and the CFCS are used.
- These systems place individuals on a designated level depending on their symptoms and abilities.

Study 2:

- Pavão, Silva, Dusing, and Rocha's focus in the article was to list the tools used by rehabilitation professionals.
- Use assessment tools to test motor abilities in children with cerebral palsy (CP)

Study 3:

- Heyrman and Molenaer focused on the psychometric properties (reliability and validity of an instrument) of the Trunk Control Measurement Scale (TCMS) in children with CP was examined.

Study 4:

- Kainz and Graham focused on the Three-dimensional gait analysis (3DGA) clinical tool.
- The focus was to shed light on how this tool is beneficial in directing families/physicians to certain treatment solutions

Study 5:

- Terwiel and Alsem evaluated what parents rated important in reference to care provided when treating their children with CP.

Study 6:

- Chlebowski and Greene investigated the childhood autism rating scale as a tool for Autism Spectrum Disorder diagnoses for 2-year-old and 4-year-old children referred for possible autism.

Participants

Study 1:

- Children from ages of 0-12. Sample size included 36 children..

Study 2:

- Children with CP from birth to 12 years of age

Study 3:

- Twenty-six children with CP (mean age: 11 years 3 months,) with GMFCS levels 1,2,3 were included in this study.
- To determine differences 30 typically developing children (mean age: 10 years and 6 months) were included

Study 4:

- Eleven participants with CP (4 females, 7 males, age: 10.3 ± 4.0 years). Also included were seven typically developed participants (3 female, 4 male, age: 12.5 years)

Study 5:

- 284 parents of children with CP were studied.
- However the participants who completed the questionnaire were 175 parents of children with CP ages 3-9 years old.

Study 6:

- 606 Participants (482 male and 124 female). The 2-Year old sample consisted of 376 children (296 male and 80 female) and the 4-year-old sample consisted of 230 children (186 male and 44 female).

Results

Study 1:

- All participants had speech as well as cognitive disturbances.
- Overall, the study summarized that there are positive correlations between the GMFCS and the CFCS.

Study 2:

- GMGM, PEDI, AND GMPPM have strong evidence regarding validation for use in children with CP

Study 3:

- The total score of the TCMS showed excellent reliability with an ICC of 0.98 for inter rater reliability and 0.97 for test-retest reliability.

Study 4:

- This study proved to be very important and successful in musculoskeletal analysis.
- This model measures muscle-tendon length, flexion/extension, motor function etc., which might improve clinical-decision making in children with CP

Study 5:

- It can be concluded that the education level of the parent/family (PGI $s=0.23$, $P<0.01$) and the age of the child with CP (PGI $s=0.22$, $P<0.01$) can result in variations of what items parents find important and the issues they raise concerns over.
- There was, however, 95% agreement from the parents in relation to the importance of coordinated, comprehensive care for each unique case and a partnership between patients/families and health care providers.

Study 6:

- The use of CARS proved to be a reliable measure of Autism severity and had strong internal consistency with the DSM-IV criteria of autism. In the 2-year-old sample, a cutoff of 26 increased specificity to 0.91. A cutoff score of 25 produces a 0.93 sensitivity and a .085 specificity. In the 4-year-old sample, the cutoff of 30 produced a sensitivity of 0.86 and specificity of 0.80.

GMFCS* CFCS**	I	II	III	IV	V
I					
II		1			
III	2				
IV			1		
V					1

Note: *GMFCS: Gross Motor Function Classification System, **CFCS: Communication Function Classification System
Figure 2 Distribution of Gross Motor Function Classification System and Communication Function Classification System Levels among Spastic Hemiplegic Cerebral Palsy Samples

Figure 2. The distribution of GMFCS and CFCS and their levels with patients with Spastic Hemiplegic Cerebral Palsy. (Vindy, Marietta, & Anggraini, 2017)

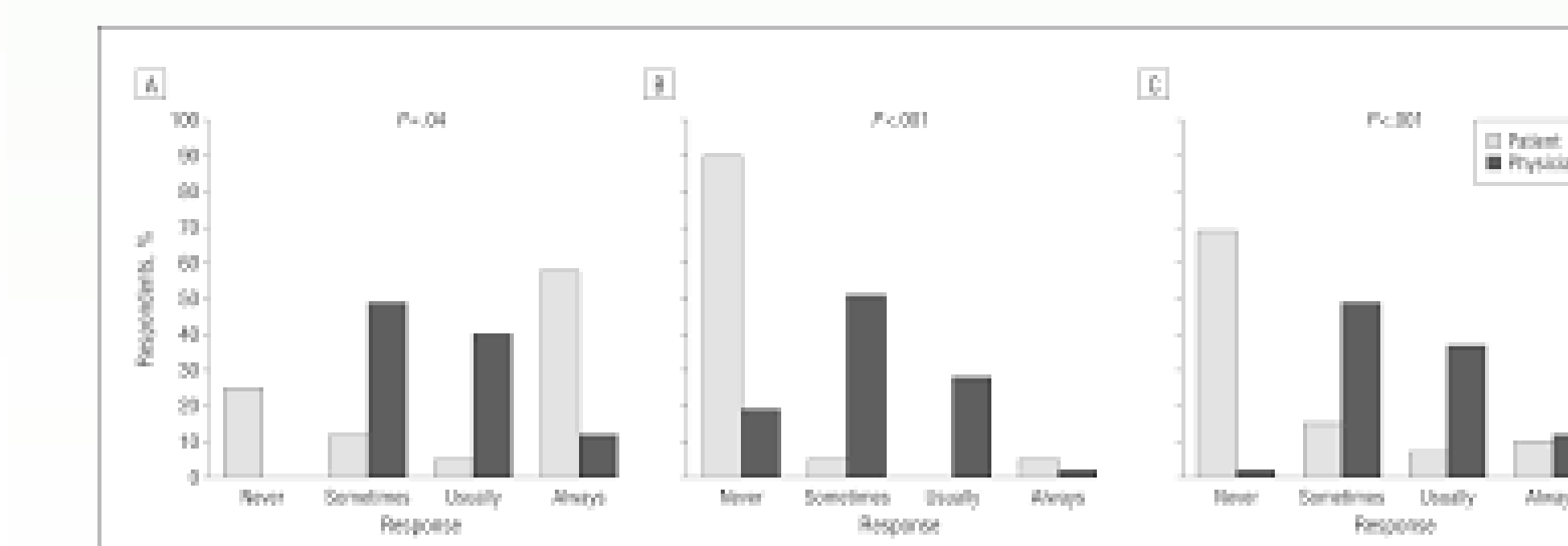


Figure 3. Communication Discrepancies between Physicians and Hospitalized Patients <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/775589>

Conclusion

- Importance in using assessment tools to measure several aspects of CP .
- Tools are necessary for assessing, diagnosing and treating patients.
- Literature confirms that there is a lack of direction upon receiving data from assessment tools and delivering treatment. This affects quality of life.
- After data is extracted, there is a dead end on where measurements go.
- A spectrum, allows measurements to be placed accordingly ranging from symptoms mild to severe, leading to a plan of treatment/therapy that can be properly applied to every unique case of CP.
- A spectrum will allow order, direction, efficient communication, and best suited treatments for each unique case of CP.
- A spectrum will direct individuals to best fit therapies such as SLP, OT, PT, or BT. These therapies have proven to be effective in enhancing the quality of life in children with CP.

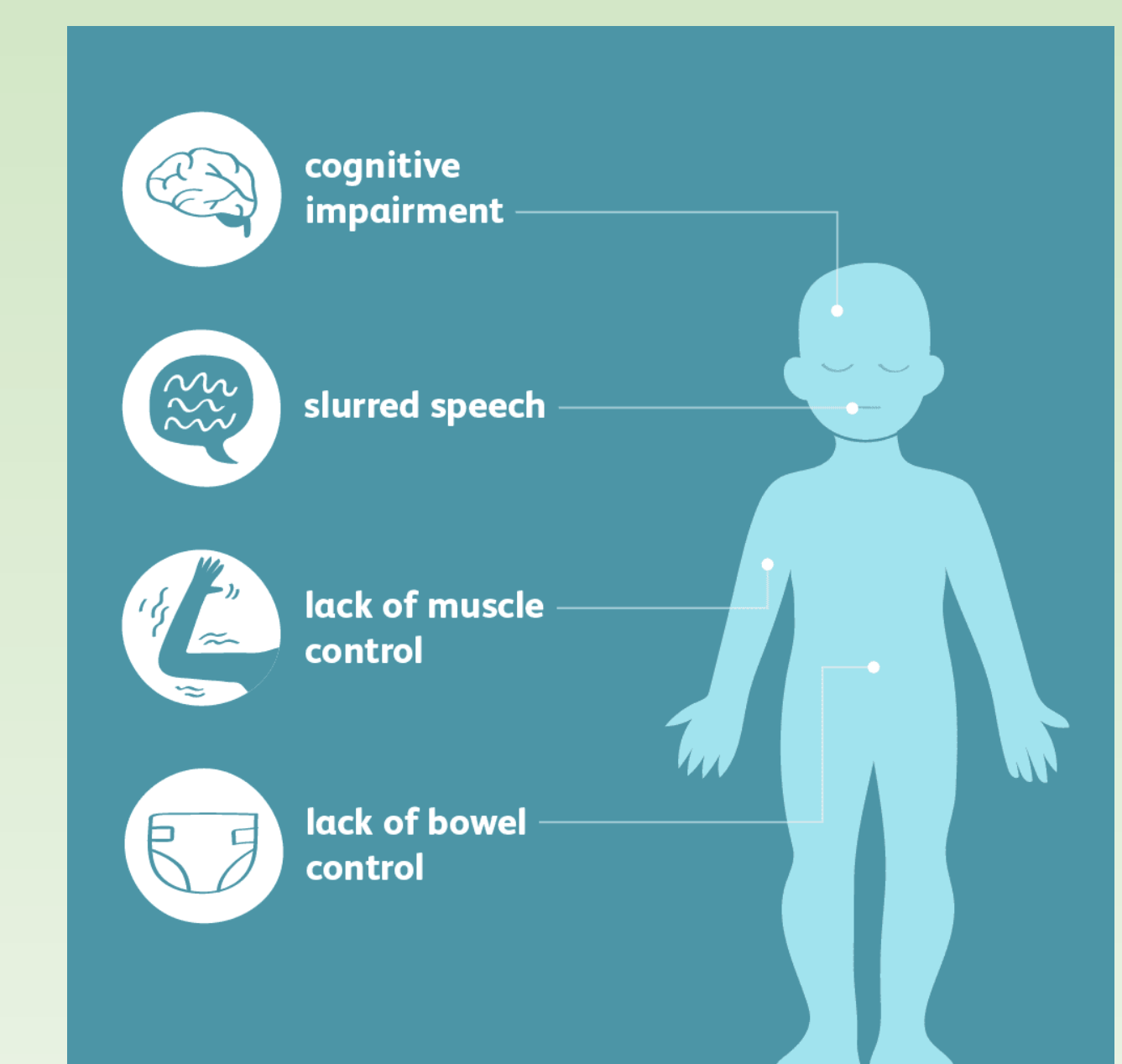


Figure 4. Symptoms of Cerebral Palsy <https://www.verywellhealth.com/cerebral-palsy-signs-symptoms-and-complications-4160369>

References

- Chlebowski, C., Green, J. A., Barton, M.L., & Fein, D. (2010). Using the childhood autism rating scale to diagnose autism spectrum disorders. *Journal of autism and developmental disorders*, 40(7), 787-799. doi:10.1007/s10803-009-0926-x
- Heyrman, L., Molenaers, G., Desloovere, K., Verheyden, G., De Cat, J., Monbaliu, E., & Feys, H. (2011). A Clinical Tool to Measure Trunk Control in Children with Cerebral Palsy: The Trunk Control Measurement Scale. *Research in Developmental Disabilities: A Multidisciplinary Journal*, 32(6), 2624-2635.
- Kainz, H., Graham, D., Edwards, J., Walsh, H. P. J., Maine, S., Boyd, R. N., ... Carty, C. P. (2017). Reliability of four models for clinical gait analysis. *Gait & Posture*, 54, 325-331
- National Institute of Mental Health. (2018). Autism Spectrum Disorder. Retrieved from <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>
- Pavão, S. L., Silva, F. P. S., Dusing, S. C., & Rocha, N. A. C. F. (2017). Clinical tools designed to assess motor abilities in children with cerebral palsy. *Developmental Neurorehabilitation*, 20(3), 149-159.
- Terwiel, M., Alsem, M. W., Siebs, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: Differences in what parents of children with cerebral palsy rate important. *Child Care Health Development*. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/28326571>.
- Vindy M., Marietta S., & Anggraini A. (2017). *Correlation between Gross Motor Function Classification System and Communication Function Classification System in Children with Cerebral Palsy*. *Althea Medical Journal*, Vol 4, Iss 2, Pp 221-227 (2017), (2), 221.

Acknowledgement

We would like to thank Niamh Coleman for her time and information about her own experiences with healthcare providers and her journey with her son's CP. Her story will help bring awareness to the gap in diagnosis and treatment of CP and will assist in providing a path to better treatment, care, and healthcare interactions in the future.