



# FUNCTIONAL PRIORITIES OF CAREGIVERS AND THEIR CHILDREN WITH NEUROMUSCULAR DISORDERS: A LITERATURE REVIEW

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## Introduction

Cerebral palsy (CP) is a neurological pathology resulting from damage to the brain in the prenatal, perinatal, or early childhood period<sup>1</sup>. It is characterized by an alteration in the development of movement and posture. CP presents with muscle tone abnormalities, weakness, disturbed coordination, and motor control<sup>2</sup>. Age and functional ability, due to severity and type of CP, will affect treatment outcomes and goals of the children and caregivers<sup>3</sup>.

Patient and family centered care should be one of the major goals of healthcare professionals. The idea behind it is to carry out evaluations with the aim of finding out the patient's and caregiver's goals and designing a treatment plan that includes achieving those goals as best as possible. When developing plans of care for children with neuromuscular disorders, identifying common goals among the patient and caregiver is necessary. The healthcare team must consider the priorities of both groups to ensure effective patient-centered care.

The aim of this literature review was to gain an understanding of the functional priorities of pediatric patients with CP and their caregivers relative to their age and functional level. Further, this review will identify priority similarities and differences between children and caregivers.

## Methods

An initial search for articles was done using the keywords "function\*", "priorit\*", "rehab\*", and "cerebral palsy" in the PUBMED and CINAHL databases. This produced 72 results that were filtered and those that did not discuss child or caregiver priorities for motor function tasks were excluded as well as articles that evaluated priorities for non-neurological pathologies. Additional exclusion criteria were: article not available in English, full text unavailable, and newspaper articles. This left 7 articles for review. Articles were reviewed to identify themes of functional priorities for caregivers and children relative to the age of the patient and gross motor function classification system (GMFCS) levels. The GMFCS describes a child's (aged 2-18 years) current abilities and limitations in self-initiated gross motor movement, taking into account use of assistive devices and developmental milestones<sup>5</sup>.

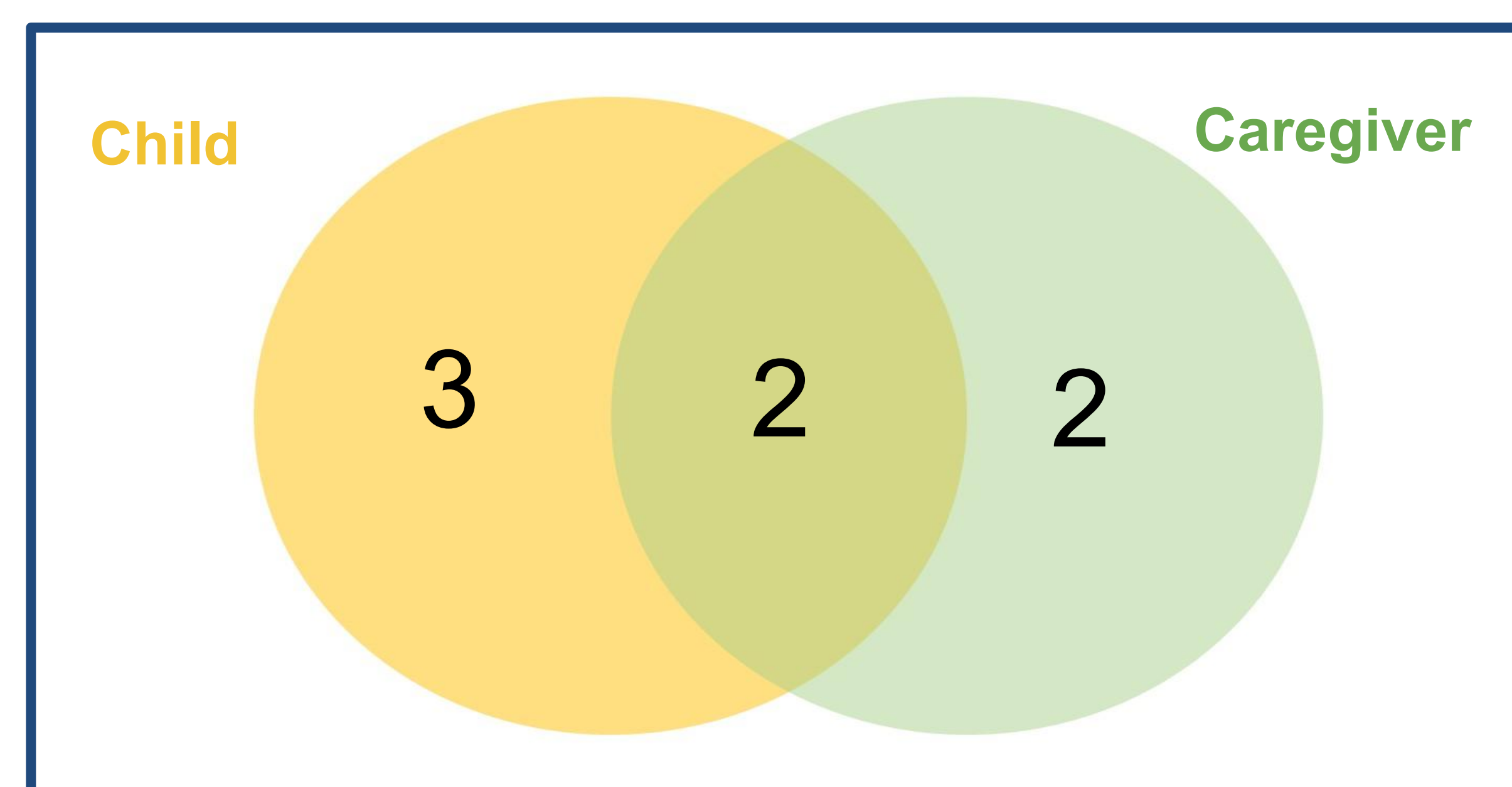


Figure 1: The number of articles reviewed that evaluated functional priorities from the perspective of the child, the caregiver, or both.

## Results

All articles used the COPM to evaluate functional priorities. The COPM is a semi-structured interview used to identify issues in areas of self-care, productivity, and leisure. Participants rate each issue from 1 to 10, and the top 5 are chosen as goals for treatment<sup>4</sup>. Four articles specifically considered the GMFCS level.

Priorities were aggregated into six categories (Figure 2). Self care included tasks such as bathing, dressing and eating. Adult tasks included tasks of independence, such as having a job, driving, living alone. Mobility included tasks such as standing up alone and transfers. School tasks included pencil use and attending as well as participating in school activities. Play included playing with toys or outside with others. Physical activity included sports and other exercises.

Caregivers of children aged 3-21 reported the highest priorities in self-care. Children aged 12-21 indicated the highest priorities were self-care and adult tasks. No studies evaluated the priorities from the child's perspective when under the age of 12. Regardless of GMFCS level, the highest priorities for both caregivers and children fell into the self-care category. After self-care, caregivers' top priorities were in the themes of mobility and school, while children's priorities were play and school. Across all age groups, physical activity was in the top five priorities for children.

	Patient		Caregiver	
	Adolescent (age 12-21)	Youth (age 3-11)	Adolescent (age 12-21)	
Self-care	↑	↑	↑	
Adult Tasks	↑	↑	↑	
Mobility		↑	↑	
Play	↑			
School	↑	↑	↑	
Physical Activity	↑			

Figure 2: Top priorities identified by kids and caregivers for each age group evaluated.

## Discussion

Overall, children and their caregivers have similar priorities when it comes to their rehabilitation and daily life. The top categories identified by both groups were self-care, adult tasks, and mobility. This indicates that both children and caregivers are concerned with achieving independence with hygiene tasks.

Of the articles included in this review, school was a priority for both children and caregivers. Caregivers want their children to have the ability to take part in classes and be able to simply use a pen or pencil to do their own homework.

## Discussion

Physical activity and play were categories that were brought up primarily by the children. The occupation of children is play, and this is represented by young children prioritizing play over mobility in lower GMFCS levels. Self-care was consistently the top priority for both kids and caregivers in both age groups. Improving the ability to do small tasks within the home such as bathing, eating, and dressing give rise to considering the future and being independent as they get older<sup>6</sup>. This idea of striving for independence through improving self-care, school, and social tasks goes along with children prioritising adult tasks to achieve an even bigger goal of not needing to rely fully on their caregiver as they get older.

Health care providers recognizing the overlapping priorities of both the patients and the caregivers can lead to an open line of communication to demonstrate where priorities align. Collaboration among all three parties to develop treatment goals based on the priorities allows the clinician to create a patient-centered care plan. Involving the child and caregiver allows them to have agency and autonomy in their healthcare.

One limitation of this review is that the research on patient and caregiver priorities specific to CP is limited. Many of the studies only focused on either patient or caregiver but not often from the same family. One other limitation of this review is the small sample sizes of the studies reviewed. Having larger sample sizes can help the quantitative research and outcomes, which would provide more clear results to review and compare to others.

## Conclusion

Based on the results, it was concluded the top concern of caregivers and patients was ensuring independence for self-care needs. As well as a large focus on any type of mobility including physical activity and play. Though the caregivers and patients may have worded their wants and needs differently, ultimately they were focused on the same objectives. Patients and their caregivers are more likely to listen to what their healthcare provider is focused on rather than expressing their own concerns to be included in the goals for the treatment plan. Therefore, healthcare providers should strive to integrate these priorities with their treatment plan to provide successful patient-centered care with open communication to ensure the patient and caregiver feel reassured for the future.

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