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Determinants of Manual Abilities of Children with Cerebral Palsy: A National Registry-Based Study

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ABSTRACT

Purpose: This cross-sectional study aimed to identify determinants of manual abilities of children with cerebral palsy (CP), as measured by the Manual Ability Classification System (MACS), in terms of intrinsic (child-related) and extrinsic (service-related) variables.

Methods: The participants were 106 children with a confirmed diagnosis of CP (aged 4–16 years). Two ordinal logistic regression models were conducted to identify intrinsic and extrinsic determinants of manual abilities.

Results: Four child-related (intrinsic) variables were found to be significant determinants of manual abilities: bimanual ability, ability to maintain and assume chair sitting, presence of seizures, and gross motor function, and only one service-related (extrinsic) significant variable was identified, which was receiving spasticity medications.

Discussion: The results highlight several determinants that should be considered when assessing and intervening to improve manual abilities of children with CP. The findings are discussed in relation to the intervention approach, contextual modification, and assistive device prescription

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Manual abilities are vital to participation of children in activities of daily living (ADLs), play, and educational activities.[1] It is through their hands that children regularly interact with the environment and manipulate tools needed for participation in ADLs. Children with disabilities that affect hand function, such as cerebral palsy (CP), have decreased opportunities to interact with their environments. CP refers to a group of motor disorders resulting from a non-progressive lesion in a developing brain.[2] In addition to impairment in muscle activity in all or part of the body, disturbances in sensation, perception, cognition, behavior, and communication are often present.[3] Upper limb function in children with CP is usually affected by primary impairments such as impaired proximal control, dynamic stability, disturbances in muscle tone, along with diminished ability to dissociate movements, and secondary impairments such as child's use of the upper limb to stabilize and compensate for trunk weakness.[4]

Manual abilities are complex and determined by several intrinsic and extrinsic factors which have a variable influence on hand functionality. Intrinsic factors include somatosensory functions, visual perception, cognitive factors, and musculoskeletal integrity.[5] Extrinsic factors include social and cultural factors that enhance the exposure and availability of items for hand manipulation, and in the case of children with disabilities, they include rehabilitation services that provide the children with ample opportunities for functional hand use.[5] The Manual Abilities Classification System (MACS) was developed to describe typical hand use by children with CP during everyday routines.[6] Because manual abilities of children with CP are influenced by both intrinsic and extrinsic factors, knowledge about these factors that predict the manual abilities of children with CP is of great importance for service planning.[7]

In limited-resource settings, such as Jordan, there is enormous burden on rehabilitation services, with long waiting lists for rehabilitation services common and children usually receiving fewer rehabilitation services as they grow older.[8] In addition, a high percentage of children with CP do not receive occupational therapy services,[9] highlighting the tendency in Jordan to underestimate the manual ability restrictions in children with CP. Therapists can use the MACS to group children into homogeneous categories based on their manual abilities and to guide plans of care. For example, children who are in levels I and II according to the MACS may benefit from services directed toward advanced functional skills through intensive one-to-one intervention, whereas children who are in levels II, IV, and V according to the MACS may benefit most from assistive technology, adaptive devices, and family education. In addition, knowledge of intrinsic and extrinsic factors that can predict the MACS level of children is necessary to understand and interpret the comprehensive profile of the child that is associated with MACS levels.

In this study, we used the Ecological Model[10] framework to identify the child's characteristics (intrinsic factors) and environmental characteristics (extrinsic factors) that can predict the MACS levels of children with CP. The Ecological

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AbbreviationsMACS: Manual Ability Classification System; GMFCS-E&R: Gross Motor Function Classification System-Expanded and Revised.

Model accentuates the interaction between these adaptable and flexible factors and provides an understanding of how they interplay in the development of motor abilities. Based on the Ecological Model, therapists acknowledge that modifications to tasks and affordances are to be made in order for children to perform successful motor tasks. Thus, we hypothesize that for children with CP, a significant part affecting their hand functioning can be attributed to their body function and activity level as well as to rehabilitation services they usually receive. In the present study, we aimed to examine manual abilities through the two lenses of children and environmental factors in relation to rehabilitation services. The objective of this study was to identify the child's and services' determinants of manual abilities of children with CP as measured by the MACS.

Methods

Participants

This was a cross-sectional study based on data from the CPUP-Jordan registry of children with CP.[11] Data from the first assessment visits between 2015 and 2019 were used. Participants were included in the registry only if they have a confirmed diagnosis of CP by a pediatrician or a neuro pediatrician. In this study, children who were more than 4 years of age were included because the MACS was found to be reliable and valid for children 4–18 years of age.[6]

Measures

Outcome Measure

The Manual Ability Classification System (MACS)[6] classifies children's ability to handle objects and the amount of assistance or adaptation needed to execute everyday manual activities into five categories. Level I reflects minimal limitations and Level V reflects severe limitations in manual abilities. MACS validity and reliability were established for children with CP aged 4–18 years.[6,12] MACS has been found to correlate with the everyday functioning of self-care,[13] as well as mobility, communication, and social functioning.[14,15] Similar to other studies, MACS levels were grouped based on similarities between the manual abilities of children in the levels into three categories: levels I and II, level III, and levels IV and V.

Child-Related Variables

Based on the Ecological Model and available literature[5] about children's manual abilities, the set of child-related and service-related variables was chosen from the available variables in the CPUP-Jordan with researchers' consensus.

Ten child-related variables were included in the study: the ability to assume and maintain floor sitting, ability to assume and maintain chair sitting, Gross Motor Function Classification System-Expanded and Revised (GMFCS-E&R) level, vision impairment, epilepsy, scoliosis, hand dominance, ability to use both hands simultaneously (bimanual ability), ability to cross the midline, and presence of thumb-in-palm. The GMFCS-E&R is a five-level classification system developed to reflect on self-initiated gross motor function of children and youth with CP.[16] As in the MACS, level V indicates the most limitations. The five levels of the GMFCS-E&R were categorized into three groups: levels I & II, levels III, and levels IV & V, similar to MACS grouping. Table 1 provides description of child-related variables.

Service-Related Variables

Five variables related to services were included based on parent-reported questions: Botox injection, spasticity medications, physical therapy services, occupational therapy services, and services focused on activity and participation. Table 1 provides description of service-related variables.

Procedure

All caregivers of children who are registered in a national registry of children with CP in Jordan (named CPUP-Jordan) provided informed written consent to participate in the registry and any related studies afterward. The development of the CPUP-Jordan registry, boards, and ethical approvals, the procedure of research assistant training, recruitment, conducting the assessments, data collection, and data entry are thoroughly detailed in Almasri et al. (2018).[11] Data were collected by trained research assistants who were physical therapists and occupational therapists with an average experience of five years. All research assistants underwent intensive training on obtaining information from the child's caregiver as well as performing assessments. The research assistant determined the MACS and GMFCS-E&R levels based on observing the child's and parents' agreement. Research assistants also determined the presence of scoliosis, hand dominance, bimanual abilities, crossing midline, and thumb in palm based on child examination. The rest of the variables were collected as per the parents' report.

Data Analysis

Data analyses were computed utilizing the Statistical Package for the Social Sciences version 21.[17] Two ordinal logistic regression analyses were conducted to identify significant determinants of MACS levels in children with cerebral palsy. Included in the first model were child variables and in the second model were service variables. A p-value of <0.05 was considered statistically significant a priori.

Results

Participants

A total number of 106 children constituted the sample of this study with a mean age of 6.4 years. Presentation of gender was almost equal. Almost two-thirds of the sample had either spastic diplegia or quadriplegia. Levels I and II of MACS were represented by about two-thirds of the sample as well. Children's characteristics are displayed in Table 2.

Child-Related Variables

In the first model, the goodness-of-fit indices indicated a good fit (Pearson chi-square value (df = 78) = 84.13,

Table 1. Variable description.

Predictors	Methods for measuring the predictor	Scale of measurement
Floor sitting	"Does your child usually perform floor-sitting independently (assume and maintain)?"	Yes/no
Chair sitting	"Does your child usually perform chair-sitting independently (assume and maintain)?"	Yes/no
GMFCS-E&R	"The most suitable level that describes the child abilities on the GMFCS-E&R is"	Group 1 = Levels I and II Group 2 = Level III Group 3 = Levels IV and V
Vision impairment	"Does your child have vision impairment?"	Yes/no
Epilepsy	"Does your child have epilepsy?"	Yes/no
Scoliosis	Instructions: Position the child in standing, sitting on plinth, and prone lying positions, do you observe scoliosis in any of these positions?	Yes, scoliosis was observed NO, scoliosis was not observed
Hand dominance	Place an object related to the child at the midline of the child and instruct the child to pick it up. Repeat three times. If the child is consistent record as the preferred hand. If no consistency is shown, record as mixed	Yes, Dominance is observed No, Dominance is not observed
Bimanual ability	Different bimanual activities organized by difficulty level were listed to be used for the research assistant. Activities were variables to be appropriate for several age groups. Instructions: "To assess bimanual ability use at least two of the provided activities. Record your observations."	Yes, Uses both hands together No, Does not use both hands together
Crossing midline	Instructions: "To examine crossing midline, introduce a favorite item to each side of the child while occupying the hand of that side with another favorite item. Record if child crosses midline to grasp (or attempt to grasp) favorite item"	Yes, Crosses midline No, Does not cross midline
Thumb-in-palm	Instructions: "Do you observe Thumb in palm?"	Yes/no
Botox injection	"Has your child had any Botox injections before now?"	Yes/no
Spasticity medications	"Does your child get medical treatment to reduce spasticity (e.g. Baclofen)?"	Yes/no
Physiotherapy services	"Is your child receiving physiotherapy interventions apart from CPUP assessment nowadays or was he/she receiving physiotherapy during the past month?"	Yes/no
Occupational therapy services	"Is you child receiving occupational therapy interventions apart from CPUP assessment nowadays or was he/she receiving occupational therapy during the past month?"	Yes/no
Services focused on activity and participation	"Is your child receiving interventions to be trained on any activities/ participation towards self-care now or during the past month?"	Yes/no

GMFCS-E&R = Gross Motor Function Classification System- Expanded and Revised.

Table 2. Characteristics of participants (N = 106).

Variable	*n*	%
Age of children, years		
Mean (SD)	6.40 (2.92)	
Range	4.00–16.00	
Gender of the child		
Male	60	56.6
Female	46	43.4
Cerebral palsy type		
Spastic diplegia	36	34.0
Spastic quadriplegia	35	33.0
Spastic hemiplegia	11	10.4
Dyskinetic/athetosis	6	5.7
Ataxic	18	16.9
MACS level		
Level I	44	41.5
Level II	30	28.3
Level III	16	15.1
Level IV	5	4.7
Level V	11	10.4

p = 1.000). The fitted model was significantly different in comparison to the thresholds-only model with a likelihood ratio (chi-square = 85.39, df = 10, p <.0001). Four of the variables were found to contribute to the model: lack of bimanual ability (b = 3.21, SE = 1.63, OR = 24.69, p = .049, 95% CI (1.01, 604.34), suggesting that children who are unable to use both hands together are in higher MACS levels 24.69 times more often than children who can use both hands together; inability to assume and maintain floor sitting (b = 2.86, SE = 1.31, OR = 17.49, p = .028, 95% CI (1.35, 226.16)), indicating that children who cannot assume and maintain floor sitting are in higher MACS levels 17.49 times more often than children who can assume maintain floor sitting; epilepsy (b = 1.93, SE = 0.74, OR = 6.91, p = .009, 95% CI (1.62, 29.46)), suggesting that children who have epilepsy are in higher MACS levels 6.91 times more often than children who do not have epilepsy; and GMFCS-E&R (Levels III, IV, and V, b = 1.58, SE = 0.52, OR = 4.86, p = .003, 95% CI (1.74, 13.55)), suggesting that children who have lower gross motor abilities are in higher MACS levels 4.86 times more often than children who have higher gross motor abilities. Overall, the model accounted for approximately 77.9% of the variance in the outcome, McFadden's pseudo-R^2 = 0.78.

Service-Related Variables

The model goodness-of-fit indices for the second model of service variables indicated a good fit (Pearson chi-square value (df = 32) =27.81, p = .87). The fitted model was significantly different in comparison to the thresholds-only model with likelihood ratio chi-square = 26.04, df = 6, p <.0001. Only one of the variables was found to contribute to the model, which was receiving spasticity medication (b =1.91, SE = 0.48, OR =6.78, p = .000, 95% CI (2.64, 17.45), suggesting that children who receive spasticity medications are in higher MACS levels 6.78 times more often than children who do not receive spasticity medications. Overall, the model accounted

for approximately 13% of the variance in the outcome, McFadden's pseudo-R^2 = 0.13.

Discussion

The results of this study supported our hypothesis in that several child intrinsic factors and one service extrinsic factor were found to determine manual abilities in children with CP. Relating these findings to the Ecological Model, manual ability could be seen as the interplay between intrinsic child-related factors and extrinsic service variables. Child factors explained 77.9% of the variance in MACS levels of children with CP, whereas the service factors explained only 13% of the variance in the MACS levels. This suggests that the influence of the child's characteristics overcomes the influence of service provision in determining manual ability of children with CP. Although rehabilitation/medical services are expected to be related to MACS levels of children with CP, our results did not support this expectation, suggesting that rehabilitation services in Jordan are not consistent with the child's manual ability as determined by MACS. However, in this study, service characteristics were based on parent report, and no independent assessment of the quality of rehabilitation services was carried out, which limits inference about the reason for this finding.

Several child-related determinants of manual abilities were identified with the strongest being the ability to use both hands together (bimanual ability). Developmentally, the ability to use both hands simultaneously in role-differentiated strategies (i.e., one hand for manipulation and the other hand for stabilization) allows the child to perform several ADLs as well as interact with different objects, bearing in mind that bimanual activities are more complex compared to unimanual actions. This is in congruence with a previous population-based study of children with CP that has found poor children's bimanual ability being correlated with higher MACS level.[18] Based on our clinical experience, therapists usually pay more attention to the affected hand in children with hemiplegia or more affected side of children with quadriplegia, undermining the importance of encouraging the use of both hands in functional activities during sessions. A previous systematic review has found that for children with hemiplegic CP, bimanual therapy may be more effective in improving functional tasks compared to constrained-induced movement therapy, which tends to focus more on the affected upper extremity.[19] In addition, Novak et al. (2013), in their systematic review of interventions for children with CP, accentuated that bimanual training should be included as standard care for children with CP.[20] Thus, our finding has a significant impact on clinical practice in that therapists are encouraged to pair manual ability interventions for children with CP with functional bimanual tasks for increasing functionality and generalizability to improve children outcomes of rehabilitation services.[21]

Children's ability to assume and maintain a sitting position was also found to be a strong determinant of manual ability. This finding was very predictable with previous studies attesting to the relationship between postural stability and hand function.[22] Postural stability in children with CP has been linked to manual functionality.[23] Many children with CP tend to use their upper extremities to aid in stabilization and compensation of trunk weakness which affects active use of the hand in functional activities. Thus, the ability to assume and maintain a sitting position would free their hands and provide opportunities for hand use with previous research emphasizing the importance of proper and stable positioning to optimal upper extremity function.[24] Not uncommonly, occupational therapists in Jordan (and perhaps in other low-resourced settings) problematically focus on manual abilities while disregarding the importance of postural control during manual tasks. Thus, for clinical purposes, occupational therapists are encouraged to work on postural control, whether through providing direct intervention to maximize a child's control ability or via providing adaptive and assistive devices to provide such control, necessary to provide children with CP with the opportunity to explore and work with their hands. Such interventions should, indeed, consider the variability of postural control during different functional activities.

In the current study, the presence of epilepsy has also been found to be a determinant of manual ability. This finding is consistent with previous research that has found decreased manual abilities in the presence of epileptic seizures.[25] Epilepsy is common in children with CP with reports estimating its presence in about one-third of children with CP and being associated with severe intellectual disabilities.[26] As epilepsy and cognitive impairment have high co-occurrence,[26] it is unclear whether the deterioration of manual abilities is due to the presence of epilepsy itself or the co-occurrence of decreased intellectual functioning. A recent study has found a positive relationship between motor abilities as measured by the GMFCS-E&R and MACS and non-verbal cognitive abilities.[27] However, investigating the relationship between cognitive abilities and manual abilities is important to establish causality in future research.

Another child-related determinant of manual ability in this study was the gross motor function level of children as measured by the GMFCS-E&R. Several previous studies have found a relationship between the MACS and the GMFCS-E&R.[11,28] This finding has a significant implication to practice for both assessment and intervention; in that manual ability should not be considered in isolation from gross motor function, and thus the MACS and the GMFCS-E&R should both be used when evaluating children with CP.[14] For intervention planning, therapists should consider working in parallel on gross motor function and manual ability as advancement in one should contribute to the advancement of the other.

Interestingly, only one service variable was found to be a significant determinant of the manual ability which was the child being treated with generalized spasticity medication. In general, children with spasticity or hypertonicity experience several secondary impairments such as contractures and joint deformities leading to decreased range of motion, poor control, and compensatory movements, all of which have a direct effect on simple hand and arm functions such as reaching, grasping, releasing, and more complex in-hand manipulation and bimanual hand use. Thus, these children experience functional limitations related to hand use. Also, general spasticity medication might have a negative impact on the activity level of the

children due to its effect on the central nervous system, leaving the child drowsy and sedentary most of the time.[29] An implication for clinicians is to consider the type of medication as well as the adverse effects of general spasticity medications of children with CP when formulating plans of care. Interdisciplinary consultation among the team of professionals who work with the child is critical to set realistic goals and capitalize on the child's abilities to maximize outcomes.

A thought-provoking, yet not expected finding, of this study, was that provision of physical and occupational therapy services for children with CP was not a significant determinant of manual ability classification level of children. A reason for this finding could be related to the nature of the rehabilitation services itself in Jordan. In general, it was found that children with CP receive more physical therapy than occupational therapy services,[9] with a greater focus on gross motor functions with prioritization of developing independent walking. Treatment plans in public settings in Jordan tend to be non-individualized, with mostly all children offered the same treatment protocol.[9] Family-based interventions are very limited with needed improvements in family–professional collaboration. Also, the rehabilitation-educational system in Jordan is highly focused on neurodevelopmental treatment and less on function and participation.[30] Based on this, we recommend that occupational therapists classify children according to the MACS while taking into consideration the presence of epilepsy, the manual abilities, the sitting and postural control, and the gross motor abilities of the child to provide a comprehensive view of the child's manual abilities that can be used to guide an individualized plan of care.

Strengths and Limitations

A unique implication of this study is the identification of child and services' determinants of classifying children with CP at different MACS levels. In addition, since the data were derived from the CPUP-Jordan registry, the results are generalizable to Jordanian children with CP and to low-resource settings. However, several limitations are present and should be considered for future studies. First, variables included in this study were not comprehensive; other variables whether child related (such as cognitive, visual perceptual, and fine motor abilities or motivational variables) or environmentally related (such as social, cultural, socioeconomic, and role expectation and exposure) factors should be considered and assessed against its relationship to manual ability. In addition, the data were collected mainly from one governmental setting in the capital city, Amman. Other cities as well as other settings should be considered to increase the generalizability of the results. Furthermore, the age of children should expand to younger children, using reliable outcome measures for younger children such as the MINI-MACS[31] and also having more children in the older age groups as our sample included more children younger than 8 years of age. Finally, although parent and therapist consensus on gross and fine motor functioning of children with CP was established,[32] we used parent-report measures for other child-related factors which might contribute a source of bias. Future studies can use both therapist-report and parent-report measures for determining children's abilities.

Clinical Implication and Conclusion

In the current study, several child-related and one service-related variables were found to be significant determinants of manual abilities in children with CP. Enhancement of manual ability and prevention of further decrease in abilities require early intervention as well as longitudinal screening for optimized function. According to the results of our study, bimanual ability, sitting and postural control, presence of seizures, and gross motor function should be considered along with the MACS level to guide any plan of care that targets manual ability. An interdisciplinary approach and monitoring of medical issues that could affect manual abilities, such as epilepsy and undertaking spasticity medications, should be considered as early as possible. As a functional classification of manual abilities, the MACS levels were found to be stable over time[33]; thus, our results would aid in the prognoses and choice of intervention approach as well as prescription of assistive devices or environmental modification.

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Disclosure Of Interest

The authors report no conflict of interest.

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Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

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