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ORIGINAL ARTICLE

Probability of independent walking and wheeled mobility in individuals with cerebral palsy

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Abstract

Aim: To estimate the probability of independent walking and wheeled mobility in individuals with cerebral palsy (CP) at home and in the community in relation to age and gross motor function.

Method: This was a longitudinal cohort study using data reported into the combined Swedish CP follow-up programme and national quality registry from October 2000 to October 2022. Walking, walking with aids, wheeled mobility, and assisted mobility defined independent or assisted mobility at home and in the community, based on the Functional Mobility Scale with additional data on wheelchair performance, were assessed.

Results: There were 52 858 examinations reported for 6647 individuals with CP (age range 0–32 years, follow-up period 0–22 years). Most children and adults in Gross Motor Function Classification System (GMFCS) levels I or II walked without assistive devices. The probability of dependence on others for mobility in the community was high for both children and adults in GMFCS levels III to V.

Interpretation: Although independent mobility is vital for participation and social inclusion, many children and adults with CP are dependent on others for mobility. We recommend clinicians, together with families and individuals with CP, explore how to increase access to independent mobility from an early age and continuously throughout the life course.

Cerebral palsy (CP) is characterized by challenges with movement, ranging from independent walking in all settings to being totally dependent on others for mobility. Children with CP often start walking at a later age than children without CP, and the achieved walking ability is not always maintained throughout adolescence and adulthood.[1] Less is known about mobility in adults with CP, but around a third experience a walking decline as early as in their mid-thirties.[1] Almost a third use wheelchairs for mobility,[2] but only a small proportion are independent in their manual wheelchairs, and access to power mobility is still not available to everyone.[3] Children with CP are more dependent on adult assistance for mobility in the community than at home, suggesting that environmental factors are important to consider.[4] Potential adjustments of the environment might improve outcomes, increase self-sufficiency, and reduce dependence on caregivers.[5]

Children learn and develop through play and social interaction. Approximately one-third of their day is spent playing, moving freely in various environments, and engaging in social participation. Independent mobility improves perceptual and social skills, initiation of contact with others, opportunities for parental or peer interaction, and engagement in quality play.[5–7] It allows children to explore their

Abbreviations: CPUP, Swedish cerebral palsy follow-up programme and national quality registry; FMS, Functional Mobility Scale.

environment, whereas adolescents are typically more active with friends outside the home.[8] Being able to move around and be 'where it happens' is one of the most important criteria for participation.[5–7] Young children with less efficient mobility show more passive behaviour, lower motivation, and a lack of curiosity and initiative that persists into later life. Difficulties in movement may lead to 'learned helplessness', where children give up any attempt to take control and become more dependent on others.[9]

Despite the increased focus on 'fixing the environment' rather than 'fixing the child' and advances in technology with more access to assistive technology, there still seems to be a gap between current evidence and clinical practice when it comes to mobility.[10] According to Palisano et al.,[11] only a small proportion of children classified in Gross Motor Function Classification System (GMFCS) levels II to V have access to independent mobility at the age of 4 years. Given this background, the present study aimed to estimate the probability of independent mobility (walking, walking with aids, wheeled mobility) in individuals with CP at home and in the community in relation to their age and level of gross motor function.

What this paper adds

- There is a high probability of independent walking in Gross Motor Function Classification System (GMFCS) levels I to II.
- Mobility options vary most at home and in the community in GMFCS level III.
- Being dependent on others for mobility is likely in GMFCS levels III to V.

METHOD

Study design and setting

This longitudinal cohort study was based on data reported into the combined Swedish CP follow-up programme and national quality registry (CPUP) from October 2000 to October 2022. CPUP includes over 95% of all children with CP in Sweden, and, to date, around 2500 adults.[12,13] Children are followed systematically from early childhood into adulthood with repeated clinical examinations twice a year, once a year, or every other year depending on age and GMFCS level.[13] Adults are followed once every year, every second year, or every third year depending on their GMFCS level.[14] Data on mobility and gross motor function from all repeated clinical examinations were merged with data reported by their neuropaediatricians for verification of CP diagnosis and classification of subtype. This study was approved by the Medical Research Ethics Committee at Lund (443–99).

Participants

All individuals with CP born between 1990 and 2021 reported into the registry were included. The exclusion and inclusion criteria for CP were consistent with those of the Surveillance of Cerebral Palsy in Europe network.[15] CP diagnosis was verified, and neurological subtype was classified from the age of 4 years. Children with suspected CP included in the registry at an early age who turned out not to have CP were excluded ($n = 211$). The subtypes were classified into spastic unilateral, spastic bilateral, ataxic, dyskinetic, or mixed type/unclassifiable CP.

Classifications and measurements

Our primary outcome variable was independent mobility, defined as either walking, walking with assistive devices, or independent wheeled mobility. The Functional Mobility Scale (FMS) Version 2[16] was used to describe walking performance over shorter distances at home (5 m), and longer distances outdoors in the community (500 m). The FMS rates what the person does in everyday life, and includes the use of any assistive devices or orthotics the person might use. The FMS is a reliable, valid, and sensitive tool with substantial agreement between direct observation and parental reports.[17] Additional data were obtained on the individual's indoor and outdoor wheelchair mobility. Those who either self-propelled their manual wheelchair or operated their powered wheelchair independently were classified as having independent wheeled mobility.

Four methods of mobility were created to define independent or assisted mobility at home (indoors) and in the community (outdoors) based on the FMS scores and data on wheelchair performance. The mobility methods were walking, walking with aids, wheeled mobility, and assisted mobility. Walking included 'independent on all surfaces' and 'independent on level surfaces' (FMS scores 6 and 5). Walking with aids included 'uses sticks', 'uses crutches', and 'uses a walker' (FMS scores 4, 3, and 2). Wheeled mobility included 'self-propels a manual wheelchair' or 'operates a powered wheelchair independently'. Assisted mobility was defined as those who were 'pushed in a wheelchair' or rated as 'not walking' (FMS scores 1, C, and N). Individuals reported as both walking and using a wheelchair for mobility in the same setting were classified as walking according to their highest FMS score. Gross motor function was classified at all examinations using GMFCS levels I to V.[18]

Statistical analyses

Normally distributed data were presented as mean values with standard deviations, and skewed data as median values and interquartile ranges (IQRs). Probability scores were estimated for independent mobility, either walking, walking with assistive devices or wheeled mobility, or assisted mobility (relying on others for mobility). Multilevel mixed-effects

ordered logistic regression (command 'meologit' in Stata SE v15.1; StataCorp, College Station, TX, USA) with an independent variance/covariance structure and a robust variance estimator was used to estimate the probabilities of each mobility state. The analysis was done for each GMFCS level separately, and the model was adjusted for sex, age, and birth year, where age was modelled as a restricted cubic spline function. For each GMFCS level and each outcome, a set of restricted cubic splines (with number of knots varying from 3 to 7) was fit and the best fit was determined using Bayesian information criterion. For GMFCS level V and mobility in the community, the regression models with splines did not converge for any number of knots. After carefully examining the relation with age and outcome using locally weighted scatterplot smoothing we decided that a linear age relation would describe the data best for most ages (it slightly overestimates the probability of wheeled mobility at the tail ends of age range). We also had to remove birth year from that model to achieve convergence. The probability curves were presented with 95% confidence intervals. SPSS Statistics (version 28.0; IBM Corp., Armonk, NY, USA) and Stata were used for all statistical analyses. Missing data were considered 'missing at random', and observations with missing data were removed from the analysis.

TABLE 1 Characteristics of the 6647 individuals.

Participant characteristics	*n*	%
Sex		
Male	3846	57.9
Female	2801	42.1
CP subtype		
Spastic unilateral	2840	42.7
Spastic bilateral	2348	35.3
Dyskinetic	825	12.4
Ataxic	281	4.2
Unclassified/mixed	304	4.6
Missing	49	0.7
GMFCS level		
I	2780	41.8
II	1153	17.3
III	671	10.1
IV	958	14.4
V	1085	16.3

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

RESULTS

There were 52 858 examinations reported for 6647 individuals with CP during the 22-year study period. Individuals were followed from their first until their last examination or until the end of the study period. The age of the participants ranged from 0 to 32 years, with a median of 8 years (IQR 9). The median age at first examination was 4 years (IQR 6), and the median age at last examination was 13 years (IQR 10). The follow-up period ranged from 0 to 22 years, with a median follow-up period of 6 years 8 months (IQR 10). The characteristics of the sample at baseline are presented in Table 1.

The probability of walking at home was 99% by the age of 4 years and remained stable over time for individuals classified in GMFCS level I. A similar trend was seen for mobility in the community, where the probability of walking was 90% by the age of 4 years and close to 100% through adolescence and adulthood (Figure 1).

For individuals in GMFCS level II, the probability of walking with or without aids at home was almost equal in 2-year-olds and walking without aids increased rapidly thereafter. By the age of 4 years, the probability of walking without aids was 80%, and then varied between 92% and 95% up to 20 years. In early adulthood, the probability of walking without aids at home decreased slightly, and the use of walking aids increased. Up to the age of 3 years, most children in GMFCS level II relied on assisted mobility outdoors, but from the age of 4 years, a slightly higher proportion were walking independently outdoors in the community. From the age of 8 years, the probability of walking without aids in the community remained around 70% (Figure 1).

Most variation in mobility options, both at home and in the community, was found for those in GMFCS level III. Walking with aids was most likely indoors, whereas the probability for assisted mobility was highest in the community. By the age of 4 years, the probability of walking with aids at home was 33%. This probability increased to 47% by the age of 8 years and remained stable until the age of 16 years, where both walking with and without aids decreased slightly and the need for assisted mobility increased. The probability for independent wheeled mobility in the community was approximately 30% from the age of 6 years throughout adolescence and adulthood, while walking with aids did not exceed 20%, and assisted mobility remained around 50%.

For individuals in GMFCS level IV, the probability was highest for assisted mobility both at home and in the community, followed by independent wheeled mobility. The probability of independent wheeled mobility at home increased from 20% by the age of 4 years to 38% by the age of 10 years, whereas the probability for assisted mobility at home decreased from 77% by the age of 4 years to around 55% by 10 years. A similar pattern was seen for outdoor mobility in the community, where the probability was highest for assisted mobility with 70% from the age of 10 years up through adulthood. The probability of independent wheeled mobility in the community increased from 7% by the age of 4 years to 28% by the age of 10 years.

Individuals in GMFCS level V were most likely to rely on assisted mobility both at home and in the community throughout their lives. However, the probability of independent wheeled mobility in the community seemed to increase

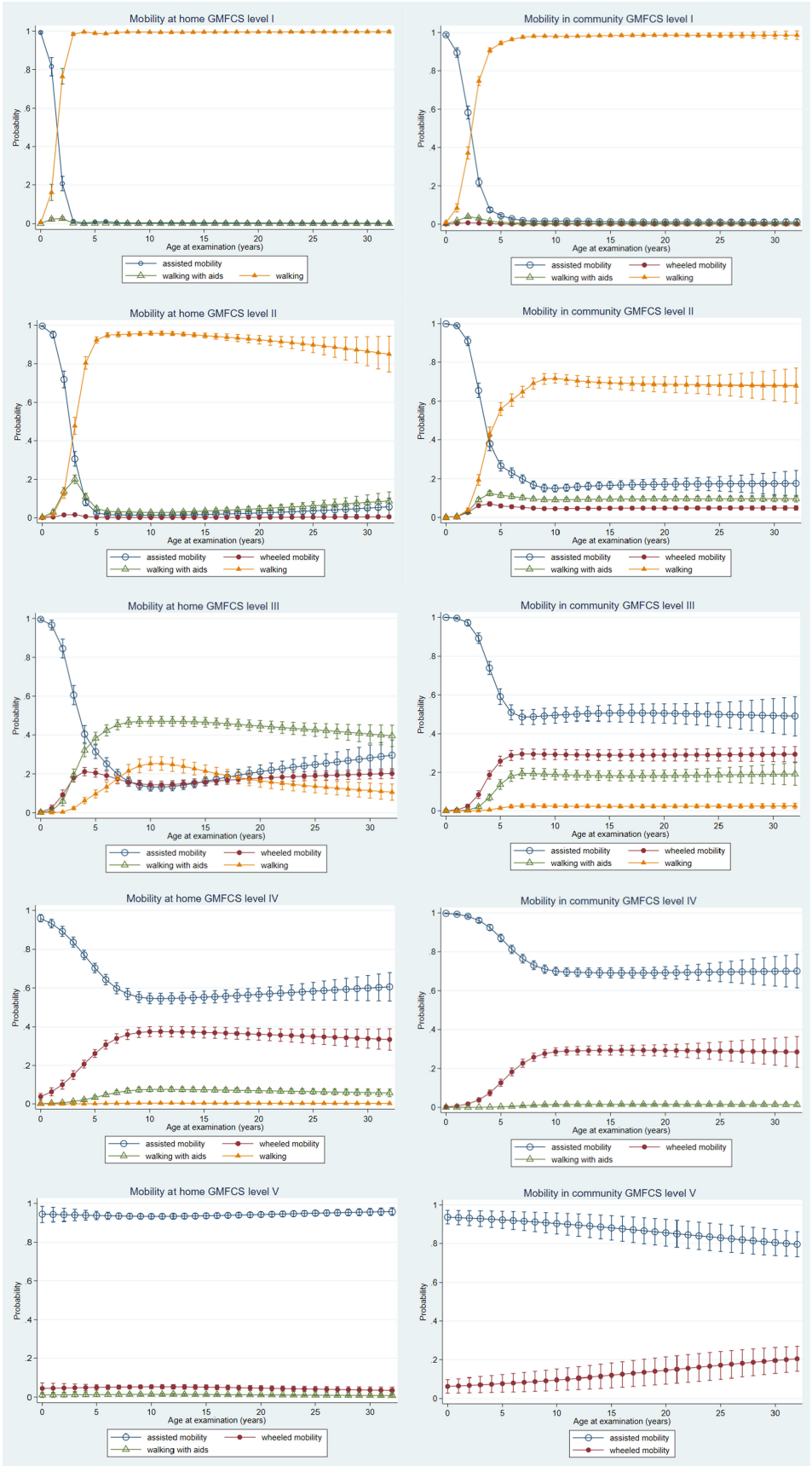

FIGURE 1 Estimated probabilities of each mobility method as a function of age among individuals classified in Gross Motor Function Classification System (GMFCS) levels I–V[a] at home (left) and in the community (right).[a] For each GMFCS level and each outcome a set of restricted cubic splines (with number of knots varying from 3 to 7) was fit. For GMFCS level I it was 7 knots both indoors and outdoors; GMFCS level II, 6 knots indoors, 7 outdoors; GMFCS level III, 7 indoors, 5 outdoors; GMFCS level IV, 4 knots both indoors and outdoors; GMFCS level V, 3 knots indoors, linear model outdoors.

slightly with age from 7% by the age of 4 years to 20% by the age of 32 years (Figure 1).

DISCUSSION

This longitudinal cohort study estimated the probabilities of independent mobility at home and in the community among individuals with CP in Sweden in relation to their age and level of gross motor function. The results showed high probabilities of independent walking for children and adults in GMFCS levels I and II, variation in mobility methods for those in GMFCS level III, and low probabilities of independent mobility for individuals in GMFCS levels IV and V.

Our results reflect those of Palisano et al.,[11] who performed a longitudinal study on the probabilities of walking, wheeled, and assisted mobility in children and young adults with CP aged 3 to 21 years in Canada. There are some differences between our studies such as sample size (642 vs 6647), age (1–21 years vs 0–32 years), and grouping of walking and walking with aids into one category in their study. The probability of independent mobility at home and in the community was higher in our study and was achieved at an earlier age for individuals in GMFCS levels I, II, and III, which is a positive development. Compared to previous findings, the probability of assisted mobility by the age of 4 years decreased substantially from 50% to 10% at home, and from 58% to 37% in the community for children in GMFCS level II. A similar trend with 15% to 20% lower probability for assisted mobility was also seen for children in GMFCS level III. For younger children in GMFCS levels IV and V, independent mobility was relatively unchanged compared to the previous findings. However, for older children and adults in GMFCS level IV, the probability of assisted mobility both at home and in the community was higher in our study, which means that they are dependent on others for mobility and participation even more than 10 years ago, which is worrisome. The results of our study are also comparable with a recent study by Rethlefsen et al.[19] of 788 children with CP. Similar to our findings, they reported most variability in mobility at home for children in GMFCS level III. In contrast, they reported most variability outdoors for children in GMFCS level II.[19]

Most individuals in GMFCS levels I and II walked independently at home and in the community both as children and adults, which is encouraging. There are many factors that influence walking performance. For children without CP, their walking capacity increases at up to 5 to 6 years of age and thereafter their chosen mobility method is more influenced by environmental factors and personal choices.[20] However, in children with CP, walking capacity continues to influence the choice of mobility at an older age.[21] Several factors influence walking performance in adulthood, including a lack of balance, pain, fear of falling, and weakness.[22,23] Even though walking capacity affects mobility, much of the variation in FMS is not explained by walking capacity, indicating that other environmental factors play an important role.[21] In our study, walking performance was fairly stable throughout the years. There seemed to be a slight decline in walking ability at home for those in GMFCS level II, whereas the probability of walking in the community remained stable up to 32 years. This is promising because in previous research, adults with CP were found to experience a continuous deterioration in walking function.[1,24]

For those in GMFCS level III, variability in the method of mobility was seen; the probability of using walking aids was around 47% at home and 19% in the community. A higher proportion might have the capacity to walk with assistive devices but prefer not to do so in daily life.[4] The use of assistive devices can be influenced by support from families, motivation, and preferred level of participation. The willingness to use devices can vary between environments.[9] Parents report uneven surfaces, dependence on supervision, interference with balance, and time pressure as some of the barriers for their child's participation in daily life situations.[25] Some young people express a clear desire to walk more often, but a majority focus on the fastest and most efficient mobility method in the particular situation to keep up with their peers.[5] Adults report that seasonal changes and energy cost affect their choice of mobility.[22]

As shown in our study, the probability of independent walking is unlikely in many children and adults classified in GMFCS levels III to V. To increase the probability of independent mobility, they would most likely need access to powered mobility and adapted seating solutions for stability. A qualitative study by Gibson et al.[26] revealed that parents described walking as a long-term goal that was being pursued and did everything possible for their children to achieve successful outcomes. Also, walking is generally seen as 'normal' from a societal perspective, and people not meeting this standard might feel like a failure, which could affect the self-confidence of children with CP. By contrast, children experienced walking as exercise and walked to fulfil their parents' wishes, but rarely preferred walking as their choice of mobility. They preferred wheelchair use to move around and catch up with friends.[26] In addition, adults struggle to maintain walking ability. Pain, fatigue, balance problems, arthritis, and overexertion are some reasons for a walking decline.[24] Wheelchairs can paradoxically be looked upon as the 'ultimate enemy', until they are actually introduced and then some ask themselves why they waited so long.[24] Wheelchairs can facilitate efficient, autonomous mobility, and engagement in activity and participation in everyday life. Ultimately, the child or adult living with CP

should always be the most important person in the decision making.

Several studies emphasize the impact of powered wheelchairs on development, independence, participation, and self-initiated behaviour,[10,27] and support the introduction of power mobility by the age of 2 years.[10] However, in practice, they are provided to a limited extent.[3,10,27]

A study of factors influencing wheeled mobility in children with CP showed that only a few achieve independent mobility in their manual wheelchairs even if they have good hand function and upper extremity range of movement.[27] In contrast, studies of power mobility report high performance even for children and adolescents in GMFCS levels IV to V with restricted hand function (Manual Ability Classification System levels IV–V).[27,28] With increasing evidence of the benefits of independent mobility and with sufficient mobility options available nowadays, it is time to close the gap between research and clinical practice. To encourage independent mobility from an early age and throughout life, therapists should provide available information to parents and those living with CP and make sure different mobility options are available in different settings. The mobility curves created in this study can be used to give children and adults living with CP and their families' perspective over the long term and support them in making decisions regarding realistic mobility goals and interventions with a focus on participation.

This study had several limitations. When interpreting the results, it should be kept in mind that the FMS only permits selection of the most frequently used mobility methods. It is known that some individuals use more than one method within a setting. The wide confidence intervals seen in mobility outdoors for individuals in GMFCS level V are a result of a higher between-patient variance (the random effect of individual). Even though the linear age relation, used to model mobility in the community for children in GMFCS level V, described the data best for most ages, it may slightly overestimate the probability of wheeled mobility at the tail ends of the age range. Although all individuals included in the CPUP were included in this study and represented all GMFCS levels and ages, there is a relatively low number of individuals in GMFCS level III in this Swedish population. In addition, there may be reporting errors in the data set. While we validated the data for unlikely combinations such as FMS 6 and GMFCS level V, we found very few errors (approximately 0.1%) and corrected the data after validating it against other available parameters. Although assistive devices are prescribed free of charge for families and financed through taxes in Sweden, their use may also be a matter of funding in other countries. Also, weather conditions in Sweden vary throughout the year and might influence mobility options, especially outdoors.

Although independent mobility is vital for participation and social inclusion, the probability of being dependent on others for mobility in the community is still high for children and adults in GMFCS levels III to V. There are several options available to facilitate independent mobility, so our recommendation is that clinicians, together with families and individuals with CP, should actively explore how to increase access to independent mobility from an early age and continuously throughout the life course. Stimulating children with CP at an early age affords them the opportunity to be more integrated into society, which is important for both engagement in activities and participation in everyday life. However, access to independent mobility is of utmost importance also in adolescence and adulthood.

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DATA AVAILABILITY STATEMENT

The data sets analysed for this study are available in the CPUP registry. Permission to access data is granted by KVB Region Skåne (https://vardgivare.skane.se/kompetens-utveckling/forskning-inom-region-skane/utlamnande-av-patientdata-samradkvb/) after ethical approval

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