SUMMARY

As introduced in Chapter 1, cerebral palsy (CP) describes a group of permanent disorders of movement and posture caused by non-progressive disturbances that occurred in the fetal or infant brain. These disorders are often accompanied by other impairments, such as intellectual disability or epilepsy. Nowadays, most individuals with CP are adults, but knowledge gaps exist concerning their functioning and health at adult age. To fill these gaps, we conducted a 13-year follow-up at ages 21-34 years of existing cohorts of children and teens with CP. This thesis described health issues in these young adults with CP and their development of activity and participation into and throughout young adulthood.

In Chapter 2 we cross-sectionally studied pain, fatigue, depressive symptoms and sleep disturbance in individuals with CP of average intelligence, i.e. those without intellectual disability, in their twenties. Young adults with CP and Gross Motor Function Classification System (GMFCS) level II-V report higher levels of pain and those with GMFCS level III-V report higher levels of fatigue compared to age-matched individuals from the general population, while those with GMFCS level I report lower levels of pain, fatigue and depressive symptoms. Furthermore, pain and fatigue were more strongly inter-related in individuals with CP compared to reference groups, and also related more strongly to global mental health. We therefore recommend to monitor pain and fatigue in young adults with GMFCS levels II-V. Depressive symptoms and sleep disturbance are no prominent health issues in young adults with CP.

In Chapter 3 we described development curves of performing gross motor, fine motor, self-care, domestic life and community life (finances, employment) activities of individuals with CP from infancy into adulthood per GMFCS level and separately for those with intellectual disability. Development in all domains seemed delayed in individuals with CP compared to reference values of the general population. On average, the maximal gross motor performance level of children with CP was distinctly lower with each lower level of gross motor function. In individuals with CP of average intelligence with walking ability (GMFCS levels I-III) the maximal levels of self-care, domestic life and community life performance did not differ significantly. These individuals approached their limit of gross and fine motor performance at 6-8 years of age, of self-care activities at 11-14 years, of domestic activities at 26-32 years and of community activities at 22-26 years. The ongoing development of daily activities well into adulthood supports the need for taking a life course approach in individuals with CP. Functionally more severely affected individuals (GMFCS IV-V), and those with intellectual disability showed less favourable development of motor performance and daily activities, indicated by much lower maximal levels that they attain at a younger age.

In Chapter 4 we described development curves of communication and social interactions of individuals with CP from infancy into adulthood per GMFCS level and separately for those with intellectual disability. In communication and social interactions, those of average intelligence showed development curves comparable to references, regardless of their GMFCS level. Thus, we concluded that individuals with CP of average intelligence develop typically in the domains of communication and basic social interactions, despite limitations in motor capacity and activity performance. For these individuals of average intelligence, receptive communication stabilizes in childhood, expressive communication and interpersonal relationships in adolescence and written communication, play & leisure and appropriate social behaviour stabilize in early adulthood. For individuals with intellectual disability, communication and social interactions developed to lower
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maximal levels at a younger age, and for individuals with intellectual disability with GMFCS level V maximal levels were even lower. Furthermore, development of communication and social interactions showed large individual variation in individuals with intellectual disability.

In Chapter 5 the course of difficulty in participation of individuals with CP of average intelligence was studied from adolescence into their early thirties. Although on average they had high levels of participation, a large proportion still experienced difficulties in one or more participation domains, particularly in domestic life, employment and leisure. Difficulty in participation was predominantly experienced by those with lower levels of gross motor function. Moreover, we found in the mid- and late twenties of individuals with CP of average intelligence that difficulty in participation in all domains increased with age, regardless of GMFCS level. This increase in difficulty when individuals grow into adult roles suggests that development towards optimal participation of young adults with CP may be improved.

Autonomy refers to an individual's freedom of decision and ability to act based on own attitudes and reasoning and can be attained in several participation domains. The development of autonomy of individuals with CP from youth into adulthood was described in Chapter 6. In most life areas, 90% of individuals with CP reached autonomy in adult roles in their late twenties, with the exception of intimate relationships. Compared to the general population, in intimate relationships individuals with CP were less often autonomous from their teens until their early thirties, and in finances and housing in their (early) twenties. Regardless of age, individuals with GMFCS levels III-V were less often autonomous in transportation and intimate relationships compared to those with GMFCS levels I-II. In the late twenties those with GMFCS levels III-V also became less autonomous in employment and domestic life compared to those with GMFCS levels I-II. The present study was the first to describe the course of autonomy for subgroups of GMFCS levels, and suggested that development of autonomy lagged behind in individuals with CP in intimate relationships, employment and independent living, especially for individuals with lower gross motor function.

Childhood predictors of young adult (21-27 years of age) participation in domestic life and interpersonal relationships were identified in Chapter 7. The results showed that childhood factors are highly predictive of participation in young adulthood. Children with CP with limited manual ability, epilepsy, intellectual disability or limited motor capacity were found to be at risk for restricted participation in domestic life and interpersonal relationships in young adulthood. Addressing gross and fine motor skills, communication skills and interpersonal relationships in childhood rehabilitation, especially in individuals at increased risk, might contribute to improved participation in domestic life and interpersonal relationships later in life.

In Chapter 8 we identified teenage predictors of adult (29-34 years of age) participation in domestic life and interpersonal relationships of individuals with CP of average intelligence. Gross motor capacity, environmental factors (parenting style, education type) and personal factors (gender, personality, coping style) were predictors for future participation. Higher levels of gross motor capacity specifically predicted better participation in domestic life. Attending special education, having little daily social support and receiving protective or rejective parenting predicted poorer participation in domestic life and interpersonal relationships. Additionally, being male, a rigid or avoidant personality and avoidant coping style predicted lower future participation in these domains. Finally, the level of communication and self-care skills in teenage life predicted the adult participation outcome. Therefore, adult participation in domestic life
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and interpersonal relationships may be improved by supporting a positive parenting style and proactive coping ability. Additionally, optimizing gross motor capacity and performance of activities as a teenager may contribute to better participation in domestic life and interpersonal relationships as an adult.

In Chapter 9 the results of this thesis were discussed in the context of other literature and clinical implications were given. The results of this thesis provided information for subgroups of young individuals with CP based on their GMFCS level and intellectual disability that may guide their expectations for future functioning and health as young adults.

The main messages of this thesis are:
- Young adults with CP of average intelligence with GMFCS levels II-V report much higher levels of pain and slightly higher levels of fatigue than the general population of the same age. Pain and fatigue are highly interrelated and specifically relate to mental health in young adults with CP.
- Individuals with CP of average intelligence continue to develop performance of activities and participation well into adulthood. The development of mobility, self-care, domestic life and community life seems to be delayed for these individuals, while the development of communication and social interaction is comparable to reference values.
- In emerging adults with CP of average intelligence, difficulty in participation in several domains increases and development of autonomy seems to lag behind compared to typically developing youth.
- Individuals with lower levels of gross motor function have lower maximal levels of activity and participation performance, experience more difficulty in participation and are less often autonomous than those with GMFCS level I, especially in domestic life, employment and intimate relationships.
- Individuals with CP with intellectual disability develop to much lower levels of activity and participation performance and reach these levels at younger age.
- Boys, individuals with epilepsy, low mobility capacity, low manual ability, a rigid or avoidant personality, protective or rejective parents and those with low levels of activity and participation in childhood are at increased risk of future participation restrictions.

From the main results of this thesis the following clinical recommendations for subgroups of individuals with CP can be made:
- For young adults with CP of average intelligence with GMFCS level II-V in their twenties regular monitoring of health issues and functioning is suggested, so they can timely receive adequate support.
- For young adults with CP of average intelligence with GMFCS level I in their twenties, on average the outlook regarding future perceived health and performance of activity and participation is rather positive. In addition to informing them well about possible future restrictions and available treatment programs, it may be suitable for the majority of this subgroup of individuals with CP in their twenties to invite them to contact rehabilitation when they experience health problems.
- Males and those with epilepsy, an avoidant personality or coping style may need support especially, regardless of their level of GMFCS.
- For individuals with CP with intellectual disability, support of activity and participation should focus on promoting optimal participation by creating opportunities while offering adequate support and resources.