Introduction
Cerebral palsy (CP) is the most common cause of physical disability in childhood, affecting approximately 2 per 1,000 live-born children in Europe.\textsuperscript{1,2} The prevalence of CP decreased significantly up to the late nineteen sixties, increased significantly to the mid-eighties, then stabilized and decreased slightly in the nineties.\textsuperscript{3,4} The decrease seen in the nineteen nineties has now ceased, due to an apparent rise in CP in children born at term, while CP in children born preterm is still decreasing.\textsuperscript{5,6} Wichers et al. and Haastert et al. found a similar trend for the prevalence of CP in the Netherlands: a prevalence rising from 0.77 in the seventies to 2.44 in the late nineteen eighties.\textsuperscript{6,7}

CP describes ‘a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain’. The motor disorders of CP are often accompanied by impairments of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.\textsuperscript{8} The severity of motor impairment, as well as the cognitive, communicative and behavioral impairments are different for each person,\textsuperscript{9,10} resulting in a wide variability in functioning of children with CP.

**Adolescence and CP**

During growth and development from childhood to adulthood, adolescents are mainly concerned with consolidating identity, achieving independence from parents, establishing relationships, and finding proper education. Indeed, chronic disease inevitably has implications for a child’s development. Adolescents with CP may develop a variety of secondary musculoskeletal problems, such as muscle shortening or joint contractures. These musculoskeletal problems and the physical changes during adolescence may affect the course of motor functioning and may influence their daily activities and social participation. With respect to mobility, the prognosis for walking in children and adolescents with CP has received much attention,\textsuperscript{11,12} and more severely affected children show larger decreases in motor functioning than the mildly affected.\textsuperscript{12} The studies cited defined mobility in terms of capacity (what a child can do). However, it remains unclear whether the development of motor performance (what a child does do) is the same as the development of motor capacity. This is a highly relevant area for investigation, because it provides insight into what children actually do in their natural environment. The growth spurt and increase in body weight that take place during puberty in children is suggested to lead to a (permanent) deterioration in mobility.\textsuperscript{13-15} To the best of our knowledge, the course of growth and possible deterioration in mobility performance during puberty and adolescence in this population has not yet been investigated and might differ from the development of motor capacity.
While mobility is an important domain when considering individuals with CP, it is also important to know how children and adolescents function in daily activities, and to understand which factors are related to the level and course of daily activities. Several studies have demonstrated a strong relationship between the severity of CP and daily activities. Despite this, a considerable amount of variance remains unexplained, suggesting that there are other factors that may be associated with daily activities. Manual ability is thought to be a possible determinant of daily activities such as dressing, personal care, and handling objects, because hand impairments contribute to any difficulties experienced in performing these activities. Describing the level and course of (daily) activities provides interesting information about the functioning of children with CP, and understanding the development of activities would allow (preventive) interventions to be implemented. The physical activities of adolescents with CP are a part of daily activities. According to Fernhall and Unnithan, low levels of physical activity in children with CP indicate that these children are at greater risk of sedentary behavior, and they stress the need to identify the reasons for a lack of physical activity. Little is known, however, about the physical activity level and the determinants of physical activity in adolescents with CP. In healthy children, the physical activity level decreases during adolescence. It is important to know whether this decrease in physical activity also takes place in children with CP. Knowledge about physical activity levels and associated factors could facilitate the development of programs for the prevention of inactivity and secondary complications.

Because of the nature of the disorder, most children with CP require healthcare services provided by physicians, allied healthcare and psychosocial care over their entire lifespan. Recent studies emphasized the need for lifelong care for persons with CP. When providing appropriate healthcare it is important to understand the problems experienced by adolescents and whether healthcare services match these problems. Current knowledge of the specific problems encountered by adolescents with CP is limited, but research indicates that children and adolescents with CP face several barriers to participation in social activities. The association between the medical and psychosocial problems experienced by adolescents and the utilization of healthcare services is not yet understood.

**PERRIN CP 9–16 year study**

In 2001, the Pediatric Rehabilitation Research in the Netherlands (PERRIN) research program was initiated with three aims: 1) to develop an instrument to measure daily activities in children with CP (i.e. a study on cross-cultural validation of the PEDI), 2) to describe the
form, content, and coordination of rehabilitation programs in Dutch pediatric rehabilitation of children with CP (i.e. a study called PERRIN pro-CP), and 3) to describe the course and determinants of daily activities, participation, and quality of life of children and adolescents with CP in different age groups (i.e., studies referred to as PERRIN CP 0–5, PERRIN CP 9–16, and PERRIN CP 16–24).

PERRIN CP 9–16 is a longitudinal study on the course and determinants of daily activities of adolescents with CP. Rehabilitation centers, special schools for physically and mentally disabled children (in the Netherlands called Mytyl and Tyltyl schools) and outpatient clinics of departments of rehabilitation medicine in the northwest region of the Netherlands identified 244 children with CP, aged 9, 11 and 13 years of age. Of these 244, 110 children and their parents participated in the study.

Three annual follow-up assessments were planned, with the children and their parents visiting the Department of Rehabilitation Medicine of the VU University Medical Center each year for a period of three years (four measurements). Two weeks before the visit, the child’s parents received a questionnaire concerning sports activities and the utilization of healthcare services. During the visit, a researcher asked standardized questions about diagnosis, epilepsy, and type of school, and then classified the children according to the Gross Motor Function Classification System (GMFCS). During the second part of the visit a qualified physician or physical therapist carried out a physical examination and assessed mobility capacity with the Gross Motor Function Measure (GMFM). At the same time, a trained researcher investigated the level of mobility performance, daily and social activities by scoring the Pediatric Evaluation of Disability Inventory (PEDI) and Vineland Adaptive Behavior Scales (VABS).

Prior to this PhD thesis, Jeanine Voorman carried out research on the same study population, which she later described in her thesis in 2009. The aims of that study were: 1) to describe the level and course of activities and participation, and the relationship to disease characteristics, personal factors and environmental factors in children and adolescents with CP aged 9 to 16 years, and 2) to investigate self-esteem in children with CP and provide insight into their health-related quality of life. She concluded that despite the heterogeneity of CP, only a small number of factors explained to a large extent functioning on distinct domains of activities and participation. In addition, certain impairment characteristics, especially poor selective motor control, might be useful in identifying children at risk for deterioration in gross motor function and might thus serve as a guide for interventions. Her study on social functioning and communication showed that apart from disease characteristics, personal
factors and environmental factors were associated with more restrictions in social functioning and communication. In general, children with CP had a positive perceived competence and self-worth comparable to that of children without disabilities and were confident that they could meet the demands and expectations appropriate to their age and development. Health-related quality of life (HRQOL) was found to be lower in children with CP than age mates, and was influenced not only by the motor functioning of the children, but to an even greater extent by their behavioral problems.

The aims of this PERRIN CP 9–16 year thesis are to describe the course of (daily) activities and to determine its relationship with disease characteristics, personal factors and environmental factors in children and adolescents 9 to 16 years. The second aim is to investigate their physical activity level and get insight in the experienced activity and participation problems of the children and adolescents with CP, and to examine whether the utilization of healthcare services matches the problems experienced.

**Outline of this thesis**

Chapters 2 and 3 describe longitudinal analyses of the course of (daily) activities of 9–16 year old children with CP. Chapter 2 describes the skeletal growth of 100 children aged 9–16 years with CP and its relation to motor functioning. First, skeletal maturation in relation to chronological age is described. Second, the influence of changes in skeletal age on changes in gross motor function is analyzed. In Chapter 3, the course of motor performance (does do), measured with the VABS, and its relationship with motor capacity (can do), measured with the GMFM, is analyzed in 104 children with CP over the follow-up period of 3 years.

Chapter 4 is based on a cross-sectional study on 94 adolescents with CP aged 12 to 16 years and describes the manual ability, assessed with the Manual Ability Classification System (MACS) and the ABILHAND-Kids, and their relationship with daily activities, measured by VABS.

In Chapter 5, the physical activity level of 72 adolescents with CP and associated factors are investigated. Chapter 6 describes the activity and participation problems experienced by 94 adolescents with CP and examines whether the utilization of healthcare services matches these problems.

The thesis concludes with a general discussion (Chapter 7) describing the main findings and clinical implications, followed by proposals for future research.
REFERENCES


