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Physical Functioning in Adolescents and Adults Suffering from Cerebral Palsy

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ABSTRACT

The level of physical activity in adults with cerebral palsy (CP) and to analyse its relationship with physical activity as adolescents, pain, and gross motor function. A prospective cohort study was performed using data from the Swedish National CP Registry (CPUP) for all 129 individuals born in 1991–1993 living in Skåne and Blekinge who reported to CPUP at 14–16 years of age. Physical activity as adult was analysed relative to physical activity as adolescents, pain, and the Gross Motor Function Classification System (GMFCS). Seventy-one individuals at GMFCS I–V were followed up as adults and included in the analyses. Of these, 65% were physically active, but only 56% performed physical activity at least once a week. Their physical activity as adults differed relative to their physical activity as adolescents (p=0.011) but not to pain or GMFCS. Being physically active as an adolescent doubled the probability of being active as an adult (OR 2.1;p=0.054), indicating that physical activity in adults with CP is related to their physical activity as adolescents. Therefore, interventions to increase physical activity among adolescents with CP are likely also to improve physical activity in adulthood.

1. Introduction

The brain lesions causing cerebral palsy (CP) are non-progressive, the symptoms change over time as a child grows and ages [1]. Many adults with CP experience a decrease in gross motor function, and 10% stop walking before 35 years of age [2–4]. The decrease in locomotion skills is associated with fatigue, pain, impaired balance, and limitations on the ability to participate in personally adjusted physical activity [3, 4]. About 40% of adults with CP report pain regularly. The pain is often located to joints with limited range of motion and the most common pain location is back and hip [5]. Both adolescents and adults with CP are less physically active than their typically developed peers and often do not achieve the recommended guidelines for physical activity [6, 7]. Adults with bilateral CP have a reduced level of everyday physical activity and reduced aerobic fitness compared with nondisabled adults [8]. A reduced level of gross motor function is associated with lower participation in physical activities [9, 10].

Physical activity, defined as “any bodily movement produced by skeletal muscles that requires energy expenditure” [11, 12], leads to a reduced risk of cardiovascular disease and overweight [13], has a positive effect on self-image and mental health [14, 15], and results in a higher bone mass density in children and adults [16].

The recommendations regarding physical activity for adults are moderate-to-high-intensity physical activity every week. Moderate physical activity for an hour a day is recommended to further enhance the health benefits of physical activity, and moderate aerobic exercise should be combined with strength and flexibility exercises at least twice a week [17]. Children and adolescents are recommended to be physically active for at least an hour a day with diversified activities, including fitness, strength, coordination, and flexibility exercises.

Because of the positive effects of physical activity, it is of interest to study the level of physical activity in young adults with CP after their transition from paediatric rehabilitation units to adult health care and the extent to which their physical activity in adulthood can be predicted by their level of physical activity as an adolescent, their pain, and their level of gross motor function. In this study, the term “physical activity” refers to all physical activities that lead to increased energy consumption, including moderate to vigorous physical efforts such as walking, swimming, soccer, dancing, weightlifting, cycling, and horseback riding.

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2. Review of literature

Adolescence is a period of development that involves preparation for social roles associated with young adulthood, including postsecondary education, employment, and independent living. The transition to adulthood is thought to be particularly challenging for adolescents with cerebral palsy.1,2 Adolescents with disabilities demonstrate low rates of high school graduation and are less likely to pursue college education.3Adults with cerebral palsy have low employment rates, have restricted participation in leisure and social activities, and are often dependent on family members for living arrangements. Many parents of adult children with severe disabilities are faced with lifelong responsibilities for care that can become more difficult as the child and parent get older.

The transition to adulthood is a future oriented process in which adolescents express their desires and goals and begin planning for adult activities.10 In the United States, the

importance of transition planning is recognized by the Individuals With Disabilities Education Improvement Act of 2004 (PL 108–446).11 Preparation of students with disabilities for postsecondary education, employment (including supported employment), independent living, and community participation must begin no later than 16 years of age. The American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Society of Internal Medicine have published a consensus statement recommending that adolescents with disabilities have a written health care transition plan by age 14 years to identify appropriate health care professionals and provide guidelines for primary as well as preventive care.12

An inverse relationship between functional limitations and social participation has been demonstrated for adolescents and adults with cerebral palsy; however, the mediating factors are not well understood.13–15 Research on mobility and self-care of adolescents with cerebral palsy consists mainly of results from small clinical samples, and often the data are retrospective. Adolescents and young adults with cerebral palsy have reported that they walk less compared with when they were children.4,16–19 These findings are consistent with the results of a retrospective study in which 46% of adults with cerebral palsy stated that their current gross motor function was one or more levels lower on the Gross Motor Function Classification System (GMFCS) compared with their function during childhood.20 Andersson and Mattsson4 surveyed adults with cerebral palsy who did not have cognitive impairments. Fifty-four percent of the respondents indicated that they were not limited in their ability to transport themselves in the community regardless of whether they walked, suggesting that the inability to walk does not in itself necessarily restrict participation.

A high percentage of adults with cerebral palsy have reported needing physical assistance in self-care and activities of daily living.17,21,22Turk et al17 reported that between 27% and 43% of women with cerebral palsy required “some” or “much” assistance for self-care. In a study of adolescents and young adults with cerebral palsy, 45% of the subjects were categorized as being independent in activities of daily living, 18% were considered to need assistance with some daily living tasks, and 37% required assistance for all daily living tasks.21 Senft et al22 surveyed 19 adults with cerebral palsy and reported that the need for caregiver assistance varied depending on the task and that the need was highest in adults with quadriplegia. Availability of people to provide physical assistance is a particular concern for adolescents with cerebral palsy, who frequently rely on others for physical assistance in mobility, self-care, and transportation.

Secondary impairments in body functions and structures that develop over time are thought to contribute to changes in motor function of adolescents and adults with cerebral palsy.Factors hypothesized to contribute to secondary musculoskeletal impairments and pain include: physical growth, inability of muscle to lengthen in proportion to bone growth, excessive biomechanical forces through joints during weight-bearing activities, overuse syndromes, immobility, fatigue, obesity, stress and depression, and early joint degeneration.Proposed relationships among secondary impairments, health status, and changes in function are based primarily on retrospective cross-sectional clinical data.

Self-efficacy (a person’s belief that he or she can successfully perform certain behaviors) is a personal factor that is associated with independence and persistence in adolescents with physical disabilities.A positive self-image is associated with greater autonomy and mastery motivation.Adolescents with cerebral palsy have identified being believed in, believing in yourself, and being accepted by others as important for success in life.29 Choosing from among a list of tasks, parents of adolescents and young adults with physical disabilities identified the following as most important to support the transition to adulthood: “Do not do for them what they can do for themselves,” “Assign appropriate household chores,” and “Help children interact with others in varied settings.”

A supportive environment may improve performance of physical activities and increase social participation. Whiteneck et al proposed that accessibility, accommodation, resource availability, social support, and equality are characteristics of the environment that facilitate social participation among people with disabilities. Instruction in independent living skills, accessible and reliable transportation, and independence in mobility outside the home has been identified as important factors for successful employment of young adults with disabilities. Accessibility and accommodations for physical restrictions, physical and emotional support of family and friends, availability of health and rehabilitation services, and opportunity for exercise are environmental factors that may be particularly relevant for mobility and self-care of adolescents with cerebral palsy.

The purpose of this study was to characterize performance of physical activities by adolescents with cerebral palsy from the perspective of the adolescents themselves. Performance refers to what a person “does do” in daily life and, therefore, involves person-environment interaction. Performance should be distinguished from capability, what a person “can do” when environmental conditions are controlled (eg, standardized measure administered in a clinical setting). We examined: (1) overall performance of physical activities by adolescents with cerebral palsy grouped by GMFCS level, (2) change in overall performance over a 1-year period, and (3) performance of individual activities. We were particularly interested in activities related to tasks that parents of adolescents and young adults with physical disabilities identified as most important to support the transition to adulthood.30We hypothesized that adolescents’ overall performance would differ based on their GMFCS level but would not change over a 1-year period.

3. Physical functioning in adolescents and adults with cerebral palsy

In order to separate PF from social aspects of participation, McChonaki et al created a profile of participation by organizing main themes revolving around life situations. The themes identified are –

Those essential to survival

Those that support individual development, discretionary and educational situations

They opined that PF is vastly dictated by underlying ICF constructs of body structure, body function, activity and participation. Although impairments may play a higher role in restricting PF, contextual factors and personal factors and their qualifiers may further enhance or reduce PF. Physical function can be defined as one's ability to carry out various activities requiring physical capability; ranging from self-care (activities of daily living) to more vigorous activities that require increasing degrees of mobility, strength, or endurance.

Physical functioning is considered as a mark of independent living and good PF increases the individual's opportunity to undertake social roles. World Health Organisation has recognized this accomplishment of goal of societal functioning as quality of life (QOL). World Health Organisation defines QOL as 'the individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'.24 Optimum levels of PF has been reported to improve body image, self-efficacy, provide opportunities and employment, reduce caregiver's supervision and help in maintaining healthy life style and leisure activities.25 Physical functioning has an important role to play in maintaining QOL therefore, it is likely to be affected by the underlying constructs of PF and individual's state of health that maintains PF. Conversely, a decrease in PF and QOL can be a major factor in the disablement process. The interaction between physical function and disablement. Quality of life is sometimes used synonymously with health related quality of life (HRQOL) but to a greater degree it forms a part26 or a close independent construct of QOL of a person with a health condition.27 Moreover, in individuals with chronic disabling conditions of childhood origin, in low resource settings, QOL is dictated by health and its maintenance. Therefore, for the purpose of this study we have used HRQOL instead of global QOL.

4. Functioning - core-sets and documentation of physical functioning

The introduction in the previous chapter focused on the concept of PF in AAWCP within the ICF framework. ICF using evidence based approach classified health domains into categories for different health conditions, and developed standardized sets for each health function or domain. These core-sets help in understanding a health condition in a meaningful way; such that all the health related concerns are documented similarly across the world. Schiariti and colleagues pioneered development of core-sets for children and youth with CP. The core sets represent international standards and guides for ''what to measure'' in relation to functioning and disability; but how the functioning will be measured is not addressed by those categories. Though the age group specific coresets, provide maximum information about functioning for a given group of individuals with CP, the core-sets developed for age above six years are used in this study, as deterioration of PF in CP is observed to start from the second decade of life. Moreover, core-sets for AAWCP are not yet available. The domains dealing with environmental and personal factors, and policy and systems are country and culture specific constructs. the core-sets for children with CP above six years of age, related to PF directly. With this focus, the following section reviews literature on deterioration of PF in AAWCP and factors hypothesized as being causative.

5. Physical Functioning Status In India

Physical functioning status and its impact on participation and HRQOL in AAWCP has not been reported in India. India is divided into five main socio-political regions.9 The culture varies from state to state and geographical characteristics both of which may potentially have an impact on the physical functioning status of individuals. Hence, documenting PF from one region may not be generalized to other states. In order to get a nationwide profile, it becomes necessary to adopt a sampling strategy that encapsulates the whole country. There is no central or local register following up cerebral palsy in any part of India. The follow-up depends on the clinics catering to this population in tertiary centres, or Non-Governmental Organisations (NGO's) liaising with hospitals. These NGOs may have broad aims in terms of disability prevention and advocacy. The Community Based Rehabilitation (CBR) workers associated with the NGOs or local health care systems have a list of people with disability in their work area. Therefore, in order to get a big picture of community dwelling AAWCP in India, it is necessary to contact NGOs, private clinics, hospitals and voluntary health associations spanning the five cultural zones of the country. However, this could be only possible through, longitudinal studies which consist of structured assessment framework, co-operation of participants and feasibility of the study. Thus this information could be used to generate models of cause and effect to answer the deterioration in activity & participation levels and quality of life in AAWCP. One of the most remarkable use of longitudinal data has been used in hip surveillance programmes to prevent dysplasia and destruction of hip joint in early years of CP. This has led to the programmes of early intervention which facilitates early weight bearing and has been fruitful in containment of hip.5 This exercise could possibly help development of early intervention strategies and proactively recognise the signs of decline. Physical functioning status would be best understood by studying the interactions between the building blocks of physical functioning. The data on BS, BF activity and participation, can be modelled so that a causal link could be established to answer which domains are involved in physical functioning in AAWCP and which factors could be manipulated by intervention to improve participation and quality of life.

6. Conclusion

The adults with CP perform a physical activity at least once a week. Being physically active as an adolescent with CP seems to increase the likelihood of being physically active as an adult. Therefore, interventions to increase physical activity among adolescents with CP are recommended. Modifiable and non-modifiable factors that influence participation and health related quality of life in this population were identified through structural equation modeling. Strength and spasticity were identified as the two modifiable factors which could aid in participation. These factors influence health related quality of life of adolescents and adults with cerebral palsy

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