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Behavioral and emotional problems in children and adults with cerebral palsy



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Peter Weber ^{a,*}, Philipp Bolli ^a, Nadine Heimgartner ^a, Pierina Merlo ^a, Tonia Zehnder ^a, Christian Kätterer ^b

^a University of Basel, University Children's Hospital Basel, Division of Neuropediatrics and Developmental Medicine, Basel, Switzerland

^b Rehab Basel, Center of Rehabilitation, Basel, Switzerland

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ABSTRACT

Objective: In patients with cerebral palsy (CP), psychological problems influence their participation in society. Little is known about the persistence of behavioral and social problems into adulthood.

Materials and methods: In a two-center cross-sectional study, caregivers of 121 adults and 88 children were ask to assess behavior of the patients through the parent/caregiver forms of the Child Behavior Checklist (CBCL), the Strengths and Difficulties Questionnaire (SDQ), and the Vineland Adaptive Behavior Scale II (VABS). Questionnaires were returned from 43 adults and 39 children.

Results: In both groups we found the same frequency of abnormalities in attention problems (32.4 vs. 36.1%, p = 0.826) and social interaction problems (32.3 vs. 33.3%; p = 0.926) in the CBCL, and peer problems (38.9 vs. 75.7%; p = 0.115) in the SDQ. Children show a lower percentage of abnormal prosocial behavior (41.7 vs. 16.2%, p = 0.016) and lower abnormal rates of communication (88.2 vs. 61.5; p = 0.01) and daily living skills (90.0 vs. 71.8; p = 0.041), whereas the level of abnormalities in both groups in these dimensions of VABS notably high.

Conclusion: The persistence of psychological and social problems from childhood into adulthood underlines the importance of focusing on early intervention.

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1. Introduction

Cerebral palsy (CP) is the most common cause of motor impairment in children, frequently resulting in a life-long

disability. A recent definition of CP by Rosenbaum et al.¹ mentions not only the aspects of the etiology and movement disorder, but also the issue that CP is often accompanied by disturbances of sensation, perception, cognition, communication, or behavior. Only a few studies have investigated the

E-mail address: Peter.Weber@ukbb.ch (P. Weber).

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^{*} Corresponding author. University Children's Hospital Basel, Spitalstr. 33, CH-4052 Basel, Switzerland. Tel.: +41 61 7041906; fax: +41 61 704 1277.

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behavioral and emotional problems of children with CP. These studies report that children with CP suffered more often from emotional problems, peer problems, social withdrawal, attentional problems or dissocial behavior.² These psychological problems can result in a reduced well-being for the children as well as a reduced quality of life for their family members.^{3,4} These psychological problems seem to be associated with parental stress, well-functioning in daily activities as well as the patient's level of pain.^{5–7}

The increased life-expectancy of children with CP, especially those with severe disabilities, requires organizing their transition from a pediatric to an adult health-care system, which creates numerous medical and psychosocial challenges. A successful transition seems to involve professional monitoring and age-appropriate treatment of gastrointestinal and neuroorthopedic problems, seizures, chronic pain and fatigue,⁸ but it also needs to focus on mental health and daily functioning aspects such as self-estimation, self-care, and mobility.

Interestingly, although behavioral problems are a major issue which impact the social functioning and the quality-oflife of patients with chronic diseases,⁹ studies about social and emotional behavioral problems in adult patients with CP are rare.

The aim of this cross-sectional prospective study was: first, to describe and characterize emotional and social behavioral problems in adults and children with CP; and second, to compare these problems between the two different age groups. We hypothesized that the frequency of behavioral problems is the same in both groups.

2. Patients and methods

Children with CP, who were treated at the outpatient clinic of the University Children's Hospital Basel, Division of Neuropediatric and Developmental Medicine, were identified from the local patient registry. Adults were identified from the patient registry of the special outpatient clinic for adults with severe disabilities at the Rehab Basel, a national center for medical rehabilitation. These are the primary care centers for persons with CP in the North-West region of Switzerland with a catchment area of 650,000 inhabitants.

Data about age, sex, CP-type, etiology of the CP and Gross Motor Function Classification Systems (GMFCS) level¹⁰ were collected from the patients record.

The diagnosis of CP was used as inclusion criteria; exclusion criteria were: first, unconfirmed diagnosis of CP; and, second, parents'/caregivers' lack of German-language proficiency.

2.1. Behavioral measurements

All parents or caregivers of the identified patients were sent an informational letter about the study, a consent form, and three questionnaires: Vineland Adaptive Behavior Scales II – parent/caregivers rating form (VABS); the German-language version of the age-adapted Child Behavior Checklist (CBCL); and the German-language version of the Strengths and Difficulties Questionnaire (SDQ). A stamped reply envelope was included. Four weeks later a reminder letter was sent to the parents/caregivers.

The VABS and SDQ are standardized for both age groups; the CBCL is standardized for the age group 1½ to 18 years, but not for adults. However, none of the adult patients had a developmental level older than 18 years as defined by the adaptive behavior level scales by Spreen.¹¹ To increase the comparability of the data we decided to use these instruments for both groups.

The VABS¹² is a standardized questionnaire measuring age-related functional levels in the areas of communication, daily living skills, and socialization. Pathological levels are defined by a standard score <70.

The SDQ¹³ is a standardized behavioral screening questionnaire designed to measure psychological attributes in the fields of conduct problems, hyperactivity-inattention, emotional symptoms, and peer relationship problems as well as a level of prosocial behavior. SDQ values were classified as normal/borderline pathological and pathological according to the published age-related data.

The CBCL¹⁴ allows the estimation of behavioral problems, including social withdrawal, somatic complaints, anxiety and depression, social interaction problems, thought problems, attention deficits, dissocial behavior, and aggressive behavior. A pathological value was defined by a *T*-value > 70.

2.2. Statistical analysis

The descriptive statistics were done using IBM statistics SPSS version 22.0.

The statistical comparisons of the frequencies of pathological results between the groups were done by the Chisquare test using IBM statistics SPSS version 22.0.

The study was approved by the local Ethics Committee of Basel and performed in accordance with the ethical standards laid down in the Declaration of Helsinki.

3. Results

At the Children's Hospital, 88 patients with a CP diagnosis were identified and fulfilled the inclusion criteria; at the Rehab Basel, 121 patients fulfilling inclusion criteria were identified.

The characteristics of these cohorts are documented in Table 1. After the above described procedure, completed questionnaires were returned from parents of 39 children (response rate: 44.3%) and from parents/caregivers of 43 adults (response rate: 35.5%) including 7 adults \geq 40 years of age. The characteristics of the sample of patients, for whom data are available, are documented in Table 2. The total cohort and the samples are not statistically different with respect to sex, age, CP type, etiology of CP and GMFCS levels.

In the VABS in both groups, a majority of patients showed a pathologically dysfunctional level of communication, daily living skills, and socialization (Table 3).

In the CBCL, the main problems for both groups are reported in the areas of attention problems, social interaction problems, and thought problems. In none of the eight scales does a significant difference exist between adults and children (Table 3). Interestingly in the age group \geq 40 years of age only

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