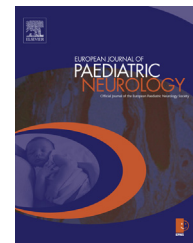




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Original article

Behavioral and emotional problems in children and adults with cerebral palsy

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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 asked 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

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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-of-life 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 Neuro-pediatric 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 Spreeen.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 Chi-square 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 ≥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 ≥40 years of age only

Table 1 – Characteristics of the cohort, which fulfill the inclusion criteria and were asked to take part at the study.

| | Adults (N = 121) | Children (N = 88) |
|---|-----------------------------------|---------------------------------|
| Sex (m) | 74 (61.2%) | 45 (51.1%) |
| Mean age (\pm SD) (range) | 32.8 (\pm 12.3) (18.3–70.9) | 10.7 (\pm 4.0) (2.6–17.9) |
| CP subtypes (%) | | |
| Ataxic | 25 (20.7) | 36 (40.1) |
| Dyskinetic | 14 (11.6) | 4 (4.5) |
| Spastic bilateral | 73 (60.3) | 22 (25.0) |
| Spastic unilateral | 7 (5.8) | 26 (29.5) |
| Etiology of CP | | |
| Preterm | 13 (10.8) | 13 (14.8) |
| Asphyxia | 44 (36.4) | 2 (2.3) |
| Insult/intracerebral hemorrhage | 4 (3.3) | 15 (17.0) |
| Cerebral malformation, congenital infection, syndrome | 47 (38.8) | 35 (39.8) |
| GMFCS level I–III | 70 (57.9) | 69 (78.4) |

social interaction problems are frequently reported using this questionnaire.

In the SDQ, peer problems are the most frequently reported problem in both groups whereas conduct disorders and attention problems are significantly more common in adults, with prosocial behavior more frequent in children (Table 3).

4. Discussion

In children, CP is frequently associated with mental, emotional, social, and behavioral impairments.² Little is

known about what happens in these functional domains during the aging of patients with CP,¹⁵ although psychological problems significantly predict restrictive participation and decreased quality of life,¹⁶ for which treatment is sought by individuals with CP, instead of improving only the physical function alone.¹⁷ Pain intensity, pain anxiety,¹⁸ parental stress and support,⁵ executive function level,¹⁹ better gross motor function, poorer intellect, living in town, and having a disabled/ill sibling⁶ seem to be relevant predicting factors for psychological problems, whereas etiology and CP type seem to influence less the risk of psychological co-morbidities.^{19,20} Two studies investigated the course of behavioral problems in children with CP over a time period of 1–4 years. In these studies, from childhood to adolescents a decreasing rate of behavioral problems⁵ and an increasing rate of social participation²¹ are reported for a subgroup of patients. In this context, absence of intellectual disability, lower severity of CP, and family support with lower family stress are identified as resilient factors. To the best of our knowledge, at first our study compared the frequency of behavioral, emotional and social problems in children/adolescents and adults suffering from CP. The adult cohort was recruited from a specialized outpatient clinic after the patients' transition from the neuropediatric clinic within the last 12 years. The adult group is different from the children's group not only in age, but also with respect to the CP type and severity of the CP. This finding demonstrates the changing spectrum of CP patients after transition, when fewer disabled children are cared for outside a special clinic. However, despite these differences, in both groups an alarmingly high level of psychological problems is documented. Behavioral problems, emotional problems, attention problems, and social contact problems are reported in more than one third and up to half of the patients.

As reported in literature, the type and severity of CP does not seem to strikingly influence the frequency of reported emotional and behavioral problems in comparing adults and children with CP. Therefore, with respect to our data,

Table 2 – Characteristics of the study cohort returning the questionnaires.

| | Adults (N = 43) | Children (N = 39) | p-level |
|---|-------------------------------|-----------------------------|----------|
| Sex (m) | 29 (67.4%) | 15 (38.5%) | |
| Mean age (\pm SD) (range) | 29.7 (\pm 9.0) (18.1–58.0) | 9.6 (\pm 3.9) (5.0–16.6) | <0.001 |
| CP subtypes (%) | | | |
| Ataxic | 3 (7.0) | 14 (35.9) | } <0.001 |
| Dyskinetic | 4 (9.3) | 2 (5.1) | |
| Spastic bilateral | 32 (74.7) | 11 (28.2) | |
| Spastic unilateral | 4 (9.3) | 12 (30.8) | |
| Etiology of CP | | | |
| Preterm | 4 (9.3) | 6 (15.4) | 0.401 |
| Asphyxia | 14 (32.6) | 0 (0.0) | <0.001 |
| Insult/intracerebral hemorrhage | 2 (4.7) | 6 (15.4) | 0.102 |
| Cerebral malformation, congenital infection, syndrome | 18 (41.9) | 16 (41.0) | 0.939 |
| GMFCS level I–III | 18 (41.9) | 30 (83.3) | 0.001 |

Table 3 – Percentage of abnormal results in emotional and behavioral problems in children and adults with cerebral palsy and number of abnormal results in the subgroup of adults ≥ 40 years of age ($N = 7$).

| CBCL | Children ($N = 36$) % abnormal | Adults ($N = 43$) % abnormal | Adults ≥ 40 years of age ($N = 7$) number of abnormal results | p-Values (children/adults) |
|-----------------------------|-------------------------------------|-----------------------------------|--|-------------------------------|
| Social withdrawal | 19.4 | 9.6 | 0/7 | 0.263 |
| Somatic complaints | 11.1 | 19.3 | 0/7 | 0.345 |
| Anxiety/depression | 5.6 | 19.4 | 0/7 | 0.082 |
| Social interaction problems | 33.3 | 32.3 | 3/7 | 0.926 |
| Thought problems | 25.0 | 19.3 | 0/7 | 0.580 |
| Attention deficits | 36.1 | 32.4 | 0/7 | 0.826 |
| Dissocial behavior | 2.8 | 3.2 | 0/7 | 0.914 |
| Aggressive behavior | 8.3 | 3.2 | 0/7 | 0.379 |
| SDQ | Children ($N = 37$) % abnormal | Adults ($N = 31$) % abnormal | Adults ≥ 40 years of age ($N = 7$) number of abnormal results | p-Values (children/adults) |
| Emotional symptoms | 27.0 | 16.7 | 0/7 | 0.285 |
| Conduct problems | 0.0 | 11.2 | 1/7 | 0.037 |
| Hyperactivity/inattention | 5.4 | 25.0 | 4/7 | 0.019 |
| Peer problems | 75.7 | 38.9 | 2/7 | 0.115 |
| Total difficulties | 59.5 | 30.6 | 2/7 | 0.013 |
| Prosocial behaviors | 16.2 | 41.7 | 2/7 | 0.016 |
| VABS | Children ($N = 37$) % abnormal | Adults ($N = 33$) % abnormal | Adults ≥ 40 years of age ($N = 7$) number of abnormal results | p-Values (children/adults) |
| Communication | 61.5 | 88.2 | 5/7 | 0.010 |
| Daily living skills | 71.8 | 90.9 | 5/7 | 0.041 |
| Socialization | 63.2 | 78.8 | 5/7 | 0.150 |

comprehensive care involving the psychological dimensions of cerebral palsy is demanded in the process of transition²² and also should be considered in the discussion about quality of life of patients with CP. However in future a construction of more simple screening instruments, which measure reliable and valid the psychological dimensions also in repeated sessions during the time of transition are recommended.

Further to find out which factors are predictive for psychological problems during adulthood (i.e. insufficient treated psychological problems during childhood) require prospective longitudinal observation studies.

4.1. Study limitations

Although our results underline the high frequency of behavioral problems in children as well as in adults with cerebral palsy, the data based on non-self-reporting questionnaires. Some other studies reported, that self-reported quality-of-life is different from reports by caregivers in patients suffering from cerebral palsy – this phenomenon is not ruled out in our study, too.

Additionally in our study cohort we have an unusual high number of children with non-spastic cerebral palsy, which is critical for the generalization of our results. Further a significant limitation of the results is caused by the hospital-based sampling instead of a population-based recruitment of the cohort. Finally our small sample size is mentioned as a limitation, especially in respect of questions which would recommend subgroup analysis such as the relevance of the cause or the subtype of CP or of resilient factors.

5. Conclusion

Psychological, behavioral, emotional, and communicating problems are frequent in children as well as in adults with cerebral palsy and have to be taken into account in the counseling situation.

Conflicts of interest

The authors declare no potential conflict of interest.

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