

Headache Long Term Follow-up in Patients Who Suffered From PTCS
During Their Childhood

1.7.24

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1. Introduction

Pseudotumor Cerebri (PTC) is an uncommon syndrome characterized by increased intracranial pressure due to an unclear (idiopathic) cause, leading to pressure on the optic nerve and headaches. The diagnostic criteria include signs of increased pressure: headaches and vomiting, optic disc swelling (papilledema) observed in eye examinations, normal brain imaging, and elevated opening pressure in lumbar puncture with normal CSF fluid content.

The prevalence of the syndrome in the general population is approximately 1 in 100,000. The syndrome can occur at any age, including in children, where the incidence varies across different studies from 26% to 85%. In women of childbearing age, the prevalence increases to approximately 3.5 per 100,000. Among women whose weight exceeds the ideal body weight, the prevalence reaches 19 per 100,000, which is 19 times higher in obese women of childbearing age.

In prepubescent children, most patients are young, thin boys. The most common symptom of PTC in adults (occurring in 90% of cases) is headache. Another symptom is transient vision loss, ranging from mild blurring to complete loss of vision, which may accompany headaches or occur independently. Among the pediatric population, symptoms vary by age: older children and adolescents typically complain of headaches accompanied by vomiting, similar to adults, while younger children may present with irritability, diplopia, strabismus, and stiff neck, and may even be asymptomatic. In infants, the only symptom might be sleepiness or apathy. In all patients, there is some evidence of optic nerve disease, such as slightly reduced visual acuity, color deficiency, or visual field defects.

The prognosis concerning optic nerve damage is good. Studies have shown that only 3-4% suffered from mild vision impairment, and severe impairment was extremely rare. But what about headaches? Short-term studies (3 months) have shown that about 70% will stop complaining of headaches, with an apparent link between the initial presentation and the final outcome.

The goal of this study is to examine how many will continue to suffer from headaches 10 years after the initial diagnosis, what factors predict these complaints, and whether and how it is possible to intervene to improve this outcome.

2. Research Hypothesis

A significant portion of patients diagnosed with PTC during childhood will continue to suffer from headaches despite the resolution of elevated intracranial pressure.

3. Research Methods

The study will be conducted prospectively, utilizing existing medical records of patients previously diagnosed with PTC. Patients diagnosed with PTC who were under follow-up in the pediatric neurology clinics at the following centers: Bnai Zion, Ruth-Rappaport Rambam, Hadassah Jerusalem, Schneider Petah Tikva, Dana Tel Aviv, and Hillel Yaffe Hadera, will be contacted by phone. After obtaining informed consent, a telephone interview will be

conducted, gathering information about headaches and quality of life. Information regarding PTC will be extracted from the medical records. We will use a demographic questionnaire to assess the type of headaches, the HIT-6 questionnaire to evaluate headache severity, and a validated quality of life questionnaire.

Inclusion Criteria: Patients who were diagnosed with PTC in childhood according to accepted criteria, have diagnostic information available in their records, are willing to participate in the study, and complete the questionnaires over the phone.

Exclusion Criteria: Patients who refuse to answer the questionnaire, or those without details of their initial diagnosis or follow-up in the medical records.

4. Variables

The variables in the study will include the current status and nature of the headaches and quality of life, compared to the demographic, clinical, and laboratory measures at the time of their original diagnosis.

The initial diagnosis of PTC will be extracted from the records, including:

- Age, gender, height, and weight (BMI)
- Initial presentation, with emphasis on the duration of headaches before diagnosis
- Eye examination findings, including fundus examination

5. Statistics

Data analysis will be conducted using statistical tools in SPSS. The analysis will allow for the characterization of the patient population and the examination of the relationships between the various demographic, clinical, and laboratory parameters studied, as well as their mutual influence. Statistical significance will be determined with a p-value of less than 0.05.

6. Ethical Considerations

We will contact parents via text message to request their permission to reach out to their young/adult children to obtain information about their current headache status and quality of life. After receiving their consent, a link to a full informed consent form (according to the patient's age) will be sent, and a phone call will be made. The study was approved by the local IRB BNZ 72-21.

7. Reference

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