

Long-term outcomes of primary idiopathic intracranial hypertension in Hong Kong Chinese patients

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Abstract

Objectives: To review the patient characteristics, presenting symptoms, management plans, and long-term visual outcomes of Hong Kong Chinese patients with primary idiopathic intracranial hypertension (IIH).

Methods: Case notes of Chinese patients diagnosed with primary IIH who attended one of three public ophthalmic centers in Hong Kong (Hong Kong Eye Hospital, Prince of Wales Hospital, and Alice Ho Miu Ling Nethersole Hospital) between January 2003 and December 2022 were retrospectively reviewed. The modified Dandy criteria were used to diagnose IIH. Data collected included patient characteristics, presenting symptoms, weight, body mass index (BMI), visual acuity (VA), automatic visual field (VF) indices, lumbar puncture opening pressure, treatment plans, and peripapillary retinal nerve fiber layer thickness.

Results: In total, 32 eyes in 14 women and six men (mean age, 34.6 years) were included in the analysis. The mean BMI was 27.7 kg/m². Overall, 18 patients were symptomatic at presentation; 25 eyes had normal or near-normal VA (Snellen $\geq 20/30$). All overweight patients received weight loss advice, whereas 18 patients were treated with oral acetazolamide, and eight of them required additional interventions, including medical therapy (n=3), cerebrospinal fluid shunting (n=3), repeated lumbar puncture (n=1), and venous sinus stenting (n=1). The mean follow-up duration was 9.0 years. At final follow-up, 26 eyes retained normal or near-normal VA, whereas eight eyes had mild VF loss, and one eye had peripapillary retinal nerve fiber layer thickness <90 microns.

Conclusion: Primary IIH is uncommon in Hong Kong; most patients presented with mild visual impairment and achieved favorable long-term outcomes. Weight management and medical therapy remain the primary treatment. Lower BMI thresholds should be applied for Chinese patients. Referral for structured dietetic support may be beneficial.

Key words: Chinese people; Idiopathic intracranial hypertension with papilledema; Pseudotumor cerebri

Introduction

Idiopathic intracranial hypertension (IIH), previously known as pseudotumor cerebri or benign intracranial hypertension, is a neuro-ophthalmic disorder characterized by raised intracranial pressure (ICP) without a structural lesion. IIH can be classified as primary, when no underlying cause (eg, certain medications or systemic diseases) is identified, or secondary, when caused by other factors. Primary IIH typically affects overweight women of childbearing age and is a relatively common neuro-ophthalmic disease in the United States and Europe, potentially causing severe vision loss if not treated promptly. Studies of IIH in Asian populations remain scarce. This study aimed to review the patient characteristics, presenting symptoms, management plans, and long-term visual outcomes of Hong Kong Chinese patients with primary IIH.

Methods

Case notes of Chinese patients diagnosed with primary IHH who attended one of three public ophthalmic centers in Hong Kong (Hong Kong Eye Hospital, Prince of Wales Hospital, and Alice Ho Miu Ling Nethersole Hospital) between January 2003 and December 2022 were retrospectively reviewed through the territory-wide electronic database. The modified Dandy criteria were used to diagnose IHH (Table 1).^{1,2} Patients with uncertain diagnoses, secondary IHH, other causes of increased ICP, incomplete medical records, or of an ethnicity other than Chinese were excluded.

Data collected included patient characteristics, presenting symptoms, weight, body mass index (BMI), visual acuity (VA), automatic visual field (VF) indices, lumbar puncture opening pressure, and treatment plans. Peripapillary retinal nerve fiber layer (pRNFL) thickness was measured using spectral-domain high-definition optical coherence tomography (OCT) [Cirrus; Carl Zeiss Meditec, Dublin [CA], USA]. Aided VA or best-corrected VA was measured using a Snellen chart and converted to logMAR units for analysis; pinhole VA was used in cases when best-corrected VA was not available.

Results

Of 49 patients with a diagnosis of IHH, benign intracranial hypertension, or pseudotumor cerebri, 29 were excluded owing to disc swelling from causes other than IHH (n=1), non-Chinese ethnicity (n=2), lumbar puncture opening pressure not fulfilling the modified Dandy criteria (n=8), use of medications associated with increased ICP (n=4) [including tetracyclines (n=2), corticosteroid withdrawal (n=1), and oral contraceptives (n=1)], venous sinus thrombosis (n=2), obstructive sleep apnea (n=8), or systemic diseases (n=4) [including Addison's disease (n=1), systemic lupus erythematosus (n=1), anemia (n=1), and other central nervous system comorbidities (n=1)]. In total, 32 eyes in the remaining 14 women and six men aged 16.8 to 55.5 (mean, 34.6) years were included in the analysis. Eight eyes with incomplete records were excluded from the analysis.

Table 1. Modified Dandy criteria for the diagnosis of idiopathic intracranial hypertension.^{1,2}

Criteria
Symptoms and signs of increased intracranial pressure
Normal neurological examination (except papilloedema or abducens nerve palsy)
Elevated intracranial pressure (>25 cm H ₂ O) with normal cerebrospinal fluid composition
Neuroimaging showing no identifiable cause for increased intracranial pressure
No other cause of increased intracranial pressure

Diagnoses were usually made during the first ophthalmic visit. The mean duration between the onset of symptoms to the date of the first ophthalmic visit was 100.3 days. One patient was diagnosed at age <18 years and two at age >50 years. At presentation, the mean BMI was 27.7 kg/m². Overall, 25 eyes had normal or near-normal VA (Snellen $\geq$ 20/30); the mean logMAR VA was 0.064 (range, -0.18 to 0.54), equivalent to Snellen 20/23. Two patients were asymptomatic and diagnosed incidentally on routine eye examinations. In the 18 symptomatic patients; the most common symptoms were headache (n=8), blurring of vision or VF loss (n=8), transient visual obscuration (n=7), diplopia (n=4), and pulsatile tinnitus (n=2). Fifteen patients were detected to have bilateral (n=14) or unilateral (n=1) disc swelling by ophthalmologists on clinical examination; five patients did not have disc swelling. pRNFL thickness was measured in 15 of the eyes with disc swelling. Among eight patients with VF defect, four had inferonasal loss or nasal step, two had an enlarged blind spot, and two had paracentral loss. The mean lumbar puncture opening pressure was 37.6 $\pm$ 9.9 (range, 22-55) cm H₂O.

Overweight patients were advised to lose weight. Two were managed without medication, and 18 patients were initially treated with oral acetazolamide; three required additional medications such as topiramate, furosemide, or spironolactone. Three patients underwent cerebrospinal fluid shunting procedures such as ventriculoperitoneal or lumboperitoneal shunting, whereas one patient underwent repeated lumbar punctures, and one underwent venous sinus stenting. None required bariatric surgery, optic nerve sheath fenestration, or glucagon-like peptide 1 agonist. The mean follow-up duration was 9.0 $\pm$ 7.4 years. At the final follow-up, 14 patients had resolution of symptoms and disc swelling, and the remaining six patients still required long-term acetazolamide but had good visual function and controlled symptoms, without surgical treatment.

The mean final logMAR was 0.07 (range, -0.19 to 0.48), equivalent to Snellen 20/23; 26 eyes retained normal or near-normal VA (Snellen $\geq$ 20/30); only four eyes had Snellen $\leq$ 20/40. In eight eyes with documented VF, the VF loss was mild, with a mean deviation of -1.3 $\pm$ 0.9 dB. The mean BMI slightly increased to 28.5 $\pm$ 5.9 kg/m². It was 27.2 $\pm$ 6.2 kg/m² among those who required no further treatment and 31.4 $\pm$ 4.6 kg/m² among those who required long-term acetazolamide. Three eyes in two patients had minimal residual disc swelling, and one eye developed mild optic atrophy with a mean pRNFL thickness of 80 microns.

Discussion

The modified Dandy criteria are widely used to diagnose IHH, and most patients with IHH are young or obese women of childbearing age.³ Taking a thorough medication history is essential to identify any causative agents, including vitamin A analogues, tetracyclines, corticosteroid withdrawal, and oral contraceptives, as well as any history of obstructive sleep apnea, autoimmune diseases, blood dyscrasias, or

Table 2. Causes of secondary intracranial hypertension.⁵

Cause
Intracranial compressive lesions (tumor, abscess, hematoma)
Obstructive hydrocephalus (Dandy-Walker malformation, aqueductal stenosis)
Venous outflow obstruction (venous sinus thrombosis, jugular vein compression)
Decreased cerebrospinal fluid absorption (subarachnoid hemorrhage, previous intracranial infection)
Increased cerebrospinal fluid production (choroid plexus papilloma)
Systemic diseases (systemic lupus erythematosus, Addison's disease, sleep apnea)
Drugs (tetracyclines, vitamin A analogues, oral contraceptives, steroid withdrawal)

Table 3. Two World Health Organization (WHO) classifications for body mass index (BMI) and the numbers of patients with primary idiopathic intracranial hypertension (IIH).

Classification	BMI, kg/m ² (No. of patients with primary IIH)			
	Underweight	Normal	Overweight	Obese
WHO	<18.5 (n=0)	18.5-24.9 (n=6)	25.0-29.9 (n=5)	≥30 (n=9)
WHO Western Pacific Regional Office	<18.5 (n=0)	18.5-22.9 (n=4)	23-24.9 (n=2)	≥25 (n=14)

endocrinologic abnormalities.⁴ Neuroimaging, preferably magnetic resonance imaging and magnetic resonance venography of the cerebrovascular system, are required to rule out secondary causes⁵ of raised ICP such as venous sinus thrombosis and a space-occupying lesion (**Table 2**), and to identify radiological features such as the empty sella sign. Diagnosis of primary IIH is confirmed by a lumbar puncture opening pressure of >25 cm H₂O with normal cerebrospinal fluid composition.

Treatment comprises lifestyle modification, elimination of causative factors, medication, and surgical management. Overweight or obese patients are advised to lose weight.⁶ Glucagon-like peptide 1 agonists, a class of medication to manage type 2 diabetes and promote weight loss, may lower ICP in patients with IIH.⁷ Any medications that may raise ICP should be discontinued. Medical therapy includes the use of carbonic anhydrase inhibitors (eg, acetazolamide, topiramate) and loop diuretics (eg, furosemide). For patients with sight-threatening or refractory IIH, surgical options include cerebrospinal fluid shunting, venous sinus stenting, and optic nerve sheath fenestration.⁸

The World Health Organization (WHO) classification for BMI may not be applicable to the Asian Pacific population, in which a large proportion with normal BMIs are at elevated risk of cardiovascular disease and type 2

Table 4. Comparisons of Caucasian and Chinese patients with primary idiopathic intracranial hypertension (IIH).²³⁻²⁶

Variable	Caucasian*	Taiwanese*	Our cohort*
Male:female ratio	1:9	1:7	3:7
Age, y	37±10	33.4±12.2	34.6±9.9
Body mass index, kg/m ²	37.7±0.41	29.3±6.4	27.7±4.3
Symptom			
Headache	65.0	90.2	44.4
Blurring of vision	35.0-40.0	12.7	44.4
Pulsatile tinnitus	17.2-43.2	23.5	11.1
Transient visual obscuration	21.1-28.1	25.5	38.9
Diplopia	11.0-14.6	22.5	22.2

* Data are presented as mean±standard deviation or % of patients.

diabetes.^{9,10} Therefore, the WHO Western Pacific Regional Office classification recommends lower BMI thresholds for this population (**Table 3**).¹¹ Based on the latter classification, 14 patients were considered obese, compared with none using the standard WHO classification. As weight control is the first-line treatment for IIH, clinicians should be aware of the lower BMI thresholds in Chinese patients.

The catchment population of the three ophthalmic centers was approximately 2 million.¹² In Hong Kong, the annual incidence of IIH among children aged 0 to 18 years was estimated to be 0.78 per 100 000 admissions between 2007 and 2012.¹³ In England, the annual incidence of primary IIH increased from 2.26 in 2002 to 4.69 in 2016 per 100 000 population.¹⁴ In the United States, the annual incidence of IIH also increased from 0.9 to 1.15 per 100 000 population between 1997 and 2016.^{15,16} In Parma, Italy, the annual age-adjusted incidence of IIH was 0.28 per 100 000 population between 1990 and 1999.¹⁷ In an ophthalmology department in Spain, the annual incidence of pseudotumor cerebri (also known as IIH) was 3.2 per 100 000 population between 1994 and 2004.¹⁸ In Hokkaido, Japan, the incidence of IIH was 0.03 per 100 000 population in 1993.¹⁹ In the United States and England, >42.4% and >25.9% of adults, respectively, are obese,^{20,21} compared with 8.1% in China.²² IIH in Chinese is relatively uncommon, even after adjustment for obesity, suggesting different racial susceptibility to IIH.

Caucasian and Chinese patients with IIH differ in male-to-female ratio, age, BMI, and symptoms (**Table 4**).²³⁻²⁶ In Caucasian patients, female predominance is more marked; age at presentation is higher; and BMI is substantially higher. Headache is the most common presenting symptom in both Caucasian and Chinese patients; however, other symptoms vary between ethnic groups.

A small proportion of patients with IIH can develop severe symptoms or rapidly progressive vision loss (ie, fulminant IIH).^{27,28} Prompt surgical intervention is required to reduce

the likelihood of permanent vision loss. A study in the United States reported a fulminant IIH prevalence of 4.2% among all IIH patients.²⁹ Repeated lumbar puncture, in conjunction with medical therapy, is a temporary measure before cerebrospinal fluid shunting or venous sinus stenting. In our cohort, no fulminant IIH was observed across the 20-year study period; most patients maintained normal or near-normal VA and VF without significant optic atrophy. These findings suggest a relatively milder spectrum of IIH in Chinese patients.

In our cohort, no patient was referred for structured dietetic or weight-management care. Their BMIs at presentation and final follow-up were similar, suggesting that counselling alone may be insufficient to achieve meaningful weight loss. Therefore, referral to dietetic and multidisciplinary services, potentially involving endocrinology and bariatric surgery, may be considered.

Ganglion cell-inner plexiform layer (GCIPL) or ganglion cell complex assessment using spectral-domain OCT can serve as a biomarker for IIH. The pRNFL determines the degree of disc swelling and its resolution, whereas the GCIPL determines the degree of retinal ganglion-cell loss, serving as a prognosticator of permanent visual damage.³⁰ Baseline GCIPL thinning correlates with greater VF loss and poorer visual prognosis.³¹ Although GCIPL was not assessed in our cohort, we advocate assessment of both pRNFL and GCIPL as well as VF at baseline in every IIH patient to help predict visual outcomes and guide treatments.

The present study had several limitations. The study design was retrospective; data were extracted manually; the sample size was small; and examinations performed were heterogeneous. The estimated incidence may not be accurate, because not all at-risk patients were included. Patients managed by neurologists or neurosurgeons or at other public ophthalmic centers or private practitioners were not included. The availability of key clinical findings—including VF indices and OCT parameters—varied among patients, resulting in incomplete records. Selection bias towards referral or more severe cases may limit the generalizability of findings to other patients. Prospective studies incorporating standardized VA assessment, automated

VF testing, and assessment of both pRNFL and GCIPL are warranted to further our understanding of IIH in this population.

Conclusion

Primary IIH is uncommon in Hong Kong; most patients presented with mild visual impairment and achieved favorable long-term outcomes. Weight management and medical therapy remain the primary treatment. Lower BMI thresholds should be applied in Chinese patients. Referral for structured dietetic support may be beneficial.

Contributors

All authors designed the study, acquired the data, analyzed the data, drafted the manuscript, and critically revised the manuscript for important intellectual content. All authors had full access to the data, contributed to the study, approved the final version for publication, and take responsibility for its accuracy and integrity.

Conflicts of interest

All authors have disclosed no conflicts of interest.

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Data availability

All data analyzed in this study are available from the corresponding author upon reasonable request.

Ethics approval

This study was approved by Kowloon Central / Kowloon East Cluster Research Ethics Committee (reference: KC/KE-17-0221/ER-4) and Joint Chinese University of Hong Kong – New Territories East Clinical Research Ethics Committee (reference: 2026.156). The requirement for written informed patient consent was waived due to the retrospective nature of the research. The study was conducted in accordance with the tenets of the Declaration of Helsinki.

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