Negative impact of COVID-19 lockdown on papilloedema and idiopathic intracranial hypertension

INTRODUCTION
The neurological complications of SARS-CoV-2 infection are increasingly being recognised, as is the impact of enforced lockdown on both acute admissions and those with pre-existing neurological conditions. Papilloedema is a medical emergency requiring correct identification, timely investigations and a multidisciplinary approach. During the first National lockdown, access to optometric and hospital services, in the UK, was limited to absolute emergencies. The aim of this study was to evaluate the impact of lockdown on those presenting with new onset papilloedema and those with existing idiopathic intracranial hypertension (IIH) at a neurosciences centre in the UK.

METHODS
A 10-week prospective evaluation (15 May 2020 to 30 July 2020) of emergency papilloedema and IIH clinics. Patients seen were referred urgently with new papilloedema or potential exacerbation of existing IIH. IIH follow-up appointments, cancelled due to enforced national lockdown and deployment of staff to frontline services, were also seen. Data collected included demographics, final diagnosis, weight, visual acuity (logarithm of the minimum angle of resolution (logMAR)), perimetric mean deviation (MD) (Humphrey 24–2 (Swedish Interactive Testing Algorithm (SITA)) central threshold) and papilloedema (optical coherence tomography (OCT), average global peripapillary retinal nerve fibre layer (RNFL)). Headache frequency (days per month) and the headache impact test-6 questionnaire (HIT-6) were noted. Depression and anxiety were evaluated (Hospital Anxiety and Depression Scale (HADS) scores: 0–7 normal, 8–10 mild, 11–14 moderate, 15–21 severe). Cerebrospinal fluid (CSF) shunt data for IIH from 2019 were recorded retrospectively. Mean and SD have been reported. Worst eye data were reported. Changes were evaluated using the \( \chi^2 \) test with the significance set at \( p<0.05 \). Missing data were excluded (constituting <16%).

RESULTS
Hundred and thirty adult patients were assessed in 10 weeks. 92% were women with mean age of 32.5 and SD of 9.3 years, 123 had IIH, of these, 43 were new onset patients (new onset group) and 80 had a pre-existing diagnosis of IIH (follow-up group); 7 had secondary causes of raised intracranial pressure (including 3 cerebral venous sinus thromboses with 2 secondary to COVID-19 and 1 other case also had COVID-19).

In the IIH cohort (new onset and follow-up groups), the mean weight was 104.7 kg and SD of 25.9 (mean body mass index of 38.4 kg/m\(^2\) and SD of 9.1). Visual function was recorded: mean logMAR visual acuity was 0.13 log units and SD of 0.22; perimetric MD was \(-5.69\) dB and SD of 8.77 and mean OCT RNFL thickness was 128 \(\mu\)m and SD of 75. The headache burden as demonstrated by the HIT-6 mean score was 58.7 and SD of 11.9 and mean monthly headache days were 17.1 and SD of 12.9, while 17% reported no headache.

Among the IIH cohort, 58% gained weight over lockdown (increase of 6.2 kg and SD of 4.6) and this was associated with a significant (p=0.013, \( X^2 = 6.06 \)) increase in papilloedema (OCT RNFL increased by 15.5 \( \mu\)m and SD of 57.3). In those patients with IIH who lost weight (mean reduction of 6.0 kg and SD of 5.6), there was an improvement in papilloedema (OCT RNFL fell by 8.8 \( \mu\)m and SD of 23.4).

In the IIH follow-up group, 44% (35/80) were in remission (no papilloedema) at the last clinic visit (prior to the lockdown). Of these, 11% became active (recurrence of papilloedema with increased OCT RNFL), which was associated with 4.3% increase in weight (mean+4.7 kg and SD of 10) (table 1). Sixty-seven per cent of the patients with IIH with papilloedema prior to the pandemic had ongoing active papilloedema after the first lockdown.

Emergency CSF diversion surgery was required in 13% (17/130). All were for sight-threatening disease (increasing severe papilloedema with declining visual fields that would result in permanent visual loss). Of 14/17 had IIH (weight gain consistently self-reported) and 3/17 had secondary pseudotumour cerebri. Twenty-one per cent of the new onset and 6.3% of the follow-up groups underwent shunting. The CSF diversion rate between 01 May 2019 and 31 July 2019 was 3 patients compared with 14 patients over the same time period in 2020. This represented a 367% (or 4.7-fold) increase.

Anxiety and Depression scores were raised (HADS >7) in 64% and 51%, respectively. With patients with pre-existing severe anxiety did not change following the COVID-19 lockdown, those with no or mild anxiety levels pre-lockdown deteriorated (12% increased HADA score post-lockdown).

DISCUSSION
Unprecedented strategies have been instigated globally to deal with the SARS-COV-2 pandemic that have resulted in much of the world’s population being subjected to lockdown for variable durations. In this report, we present the negative impact, this required quarantine has had for UK patients presenting with new onset papilloedema and those with pre-existing papilloedema due to IIH.

CSF diversion surgery is typically performed in 7.6% of those with IIH; here 11.4% required emergency surgery to save vision. The 367% increase in CSF diversion surgery in our centre, following lockdown, is a major concern. This was reflected in patients’ feedback describing the impaired access to emergency care, delayed routine waiting times, reservations to seek help and lifestyle changes imposed by quarantine leading to weight gain.

Clinical practice also changed with reduced fundoscopy examinations due to potential risk of COVID-19 transmission (Association of British Neurologists Advisory Notice on Fundoscopy 25 March 2020). COVID-19 drove transition to telemedicine, further impairing access to fundoscopy.

Weight gain is a risk factor for the development and the recurrence of IIH. The UK COVID-19 Symptom Study of 1.6 million people reported an average weight gain since March 2020 of 0.78 kg, double that which was documented over the Christmas period. In comparison, the average weight gain in our cohort was 1.13 kg. The reduction in physical activity, caused by the COVID-19 lockdown, could have contributed to weight gain.

There were increasing numbers of patients reporting anxiety and depression in this cohort. A progressive detrimental psychological impact of lockdown has been documented, particularly affecting those between 18 and 30 years, and attention to treating mental health in this disease is important.

Due to the study design, the interpretation of findings could be limited by the single-centre design and by the redistribution of emergency access in the region, potentially leading to reporting bias;
however, this is the largest IIH service in the UK. The retrospective 2019 shunt data also have potential for reporting bias. We purposefully altered our clinical protocol to reduce patient contact to minimise COVID-19 transmission risk, hence visual field examination was omitted in patients with improving papilloedema based on OCT imaging. Documentation of weight change post-lockdown was limited to those with both pre and post lockdown measurements. Subjective descriptions of weight gain were described by the majority.

This study demonstrates that national lockdown, caused by the COVID-19 pandemic, increased the risk of disease deterioration and CSF shunting in those with both existing and new IIH. To help mitigate this risk, we would advise funduscopy, with appropriate personal protective equipment, should still be performed. Patients should be encouraged to seek medical care when unwell despite restrictions. Prioritisation of patients who have gained weight may identify those with increasing papilloedema. In the future, provision should be made to support these patients by limiting disruption to neurological and ophthalmological services that investigate and manage papilloedema.

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Table 1 The impact of UK COVID-19 lockdown on IIH disease activity

| Change in IIH disease status (prelockdown to postlockdown) | Prelockdown mean (SD) | Postlockdown mean (SD) | Change mean (SD) % |
|-----------------------------------------------------------|-----------------------|------------------------|--------------------|
| Remission to active (n=4)                                  |                       |                        |                    |
| Weight                                                     | 109.2 (12.0)          | 113.8 (15.2)           | +4.7 (10.0)        | +4.3%              |
| BMI                                                        | 42.1 (8.0)            | 42.9 (10)              | +0.8 (7.5)         | +2.4%              |
| Papilloedema                                               | 102 (6)               | 128 (16)               | +26 (22)           | +37%               |
| Active to Active (n=29)                                    |                       |                        |                    |
| Weight                                                     | 99.6 (31.3)           | 103.5 (30.9)           | +1.96 (6.3)        | +2.1%              |
| BMI                                                        | 37.1 (9.6)            | 38.0 (9.5)             | +0.21 (3.4)        | +1%                |
| Papilloedema                                               | 130 (39)              | 137 (70)               | +5 (72)            | +3%                |
| Remission to Remission (n=30)                              |                       |                        |                    |
| Weight                                                     | 103.7 (21.1)          | 106.5 (21.3)           | +2.22 (22.2)       | −0.5%              |
| BMI                                                        | 39.3 (6.6)            | 39.1 (8.3)             | −0.21 (7.4)        | −0.3%              |
| Papilloedema                                               | 89 (23)               | 88 (21)                | −1 (12)            | 0%                 |
| Active to Remission (n=15)                                 |                       |                        |                    |
| Weight                                                     | 110.8 (24.9)          | 110.6 (26.3)           | −0.2 (6.2)         | +0.5%              |
| BMI                                                        | 41.5 (10.4)           | 40.7 (9.4)             | −1.0 (5.9)         | −0.6%              |
| Papilloedema                                               | 107 (44)              | 87 (18)                | −20 (33)           | −11%               |

BMI (kg/m²) indicates body mass index. Papilloedema measured by RNFL thickness (µm). Weight is measured in kg. Remission indicates the absence of papilloedema. Active indicates the presence of papilloedema.

IIH, intracranial hypertension; RNFL, retinal nerve fibre layer.

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Ethics approval This study was approved by NHS National Research Ethics Committee (14/LO/1208), IIH:LIFE study.

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mean (SD) mean (SD) %
REFERENCES

1. Mollan SP, Davies B, Silver NC, et al. Idiopathic intracranial hypertension: consensus guidelines on management. *J Neurol Neurosurg Psychiatry* 2018;89:1088–100.

2. Mollan SP, Aguilar M, Evison F, et al. The expanding burden of idiopathic intracranial hypertension. *Eye* 2019;33:478–85.

3. Ko MW, Chang SC, Ridha MA, et al. Weight gain and recurrence in idiopathic intracranial hypertension: a case-control study. *Neurology* 2011;76:1564–7.

4. COVID Symptom Study. The silent pandemic: how lockdown is affecting future health, 2020. Available: https://covid.joinzoe.com/post/lockdown-weight-gain [Accessed 29 Oct 2020].

5. Pandey D, Bansal S, Goyal S, et al. Psychological impact of mass quarantine on population during pandemics—The COVID-19 Lock-Down (cold) study. *PLOS One* 2020;15:e0240501.