The evolution of the Orthoptists role in supporting patients with Idiopathic Intracranial Hypertension

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Description

The natural habitat of the Orthoptist is within the Ophthalmology service. As the communication, knowledge and skill set of the Orthoptist are transferable to other areas, increasingly the Orthoptist can be an asset in a variety of departments. The aim of this work in the short-term was to improve health and in the long-term, protect health in the population of patients with Idiopathic Intracranial Hypertension (IIH) within the Neurology Service. The IIH service is situated in The Institute of Neuroscience on the Queen Elizabeth Hospital campus in Glasgow. IIH is a rare condition which can be associated with weight gain/obesity mainly in women 18-45. The condition is associated with raised CSF (Cerebrospinal fluid). It can cause disabling daily headaches and visual loss, which can be permanent. The raised CSF can cause papilloedema (swollen optic discs) and this can affect vision. The role of the Orthoptist in a new patient with IIH is to assess vision, visual fields and take a detailed history from the patient regarding the onset of symptoms. At this early-stage conversations with the patient are had around weight and lifestyle. The Orthoptist's role in ongoing management is to enable patients to understand their long-term condition and help them aim to maintain a healthy lifestyle.

Context

IIH is considered a rare disease. It has been found 1-3 in 100,000 people in the UK (and 2.6 in Scotland) in the normal population have this condition. The rates are increased in people with obesity up to 20 per 100,000. (IIH.org.uk 2022)

In the UK the increase in obesity of the population was already widely known and currently there are almost two-thirds of the adult population defined as overweight Body Mass Index (BMI) 26 Kg/m^2 or obese over 30Kg/m^2. (Obesityactionscotland.org Nov 2019)

It has been documented that the rates of IIH are increasing in the UK. (Subramaniam 2017)

Within the Neuro-Ophthalmology service it was recognised that there was an increasing number of patients with IIH in the clinic and not enough time to assess the patient and to manage the causes of IIH effectively or empathetically. The aims were to try to support health improvement and behaviour change in this long-term condition and reduce the need for multiple visits and admissions to hospital. Although this service is based in NHS Greater Glasgow and Clyde the service provides care to patients from NHS Lanarkshire, NHS Dumfries and Galloway and NHS Ayrshire and Arran.

Method

A joint approach was designed and rolled out to increase capacity to have a dedicated service for these patients. Training was secured for the Orthoptist with the Glasgow weight management team which centered on education in nutrition, exercise and motivational interview techniques. The Orthoptist underwent training in further Ophthalmic skills such as Optical Coherence Topography (OCT) training, slit lamp skills and medical exemption certificate (masters module certificate). A joint approach was designed and rolled out to increase capacity to have a dedicated service for these patients. A need was identified for managing patients as they become stable to help the patients move on and be happily discharged with an understanding of how to keep the IIH in remission by continuing with healthy lifestyle changes. This culminated in a dedicated Orthoptic-led service for static and stable patients without a need to be seen by the Neurologist. To enable the patients in this clinic to manage their lifestyle the Orthoptist gathered as many leaflets and access to digital help as they could to support the patient long-term. A leaflet was designed and printed by the Orthoptist and Neurologist to give clear information, including answers to frequently asked questions and explain how to access help for this condition.

Outcomes

Now the service is running well and one of the measurements of impact is the rate of DNAs (did not attend). Nationally across a wide range of specialties in Ophthalmology the DNA rate is between 8% and 14%. Within this IIH service the DNA rate is 6% which is based also on figures collated before the Covid lockdown. Also, on the impact of Covid on the service it has been necessary to use telephone consultations at times. This has been of benefit to the patients with anxiety regarding hospital attendance and at times an inability to access GP and Optician services over lockdown.

Many of the patients have a preference to discuss weight and other health factors with an AHP than a consultant. This can be beneficial as a rapport can be built with the patient which means an honest and sometimes difficult dialogue can be made easier with a familiar practitioner.

Using the “What matters to you?” day the patients were asked about this specific clinic and any changes they would like to see. The feedback was almost entirely positive. Only one patient requested that the physical layout of the clinic was altered, and that suggestion was acted on. Even in the waiting area the patients find support with one another as they are aware that the clinic is wholly for IIH patients.

It is more cost effective to reduce the number of appointments that the patient requires with:

- The consultant
- Being equipped to manage their own condition
- Understanding how to access help without presentation to A&E
- Supporting health improvement for possible future conditions ie type II diabetes

Key learning points

The role of the Orthoptist in public health is very important and they are well equipped to promote health improvements in several areas. The learning from Orthoptists in having difficult conversations was important in benefitting themselves and the patients and it has been reassuring to get support

with this aspect. It has also been satisfying that if there is any training required or support it is easy to find resources.

There are significant areas that require improvement regarding patient support and self-management. As this service is accessed by four NHS areas further input and collaboration are suggested to reduce waiting times. Recent staff shortages have now highlighted this issue to the other NHS areas. There are very motivated Orthoptists that would be able to support these patients closer to home and the training is available to do this following this model. The ideal model of Public Health for AHPs is ultimately where the service should be aiming to be across all Health Boards. There is a great interest in enhanced Orthoptic roles which should be more in keeping with holistic approaches to the patient and with the patient than individual specialties.

References

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