Idiopathic intracranial hypertension: evaluation of births and fertility through the hospital episode statistic dataset

What was the aim of the study?

This is a summary of a research study in England that followed a population of patients. The study looked at the effect of a condition called idiopathic intracranial hypertension (IIH) on becoming pregnant and pregnancy. This group was compared to the general female population and those with a diagnosis of polycystic ovary syndrome (PCOS). The full paper is available from https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.17241

What was the study about?

IIH is a condition where there is high pressure of the cerebrospinal fluid (CSF) which surrounds, protects, and provides nutrients to our brain. It typically affects young females and has been linked with increased body weight. Recently people with IIH have been shown to have problems with their body's control of energy, blood sugar control and hormones called androgens compared to the general "normal" population of the same sex.

PCOS is a condition where multiple cysts develop on the ovaries and can making getting pregnant difficult and in some cause pregnancy loss. IIH shares some similar features with PCOS such as increased body weight, abnormal blood sugar control and high androgen levels. As IIH and PCOS have similar features, this study looked at whether IIH shared the problems that PCOS has with fertility and pregnancy.

Many patients with increased body weight and blood sugar control problems have trouble becoming pregnant but they can also develop complications in pregnancy called gestational diabetes and pre-eclampsia. These complications need to be detected early to prevent them from becoming harmful. This paper aimed to see if having a diagnosis of IIH makes you more likely to develop these complications in pregnancy.

Both medical professionals and patients are often concerned about the pushing part of labour and its effect on the brain pressure. As a result, this paper investigated whether IIH patients were more likely to have a surgical delivery of their babies (caesarean section).

How was the study performed?

This research gathered data from all hospital admissions in England from April 2002 to March 2019 by the NHS Health Episode Statistics (HES) dataset. All the patients were women aged between 18 and 45 years old.

This was a large study of four populations called cohorts. The first included 17,587 people with IIH, the second 1,942 with a diagnosis of IIH and PCOS, the third 199,633 with a diagnosis of PCOS alone and the fourth 10,947,012 without a diagnosis of PCOS or IIH; this last population was used to resemble the general population.

Data was gathered to include which patients became pregnant, when they became pregnant, and if they had any difficulties during their pregnancy and giving birth. In the IIH cohorts, this data was split to see whether they happened before or after the person was diagnosed with IIH. Pregnancy complications such as pre-eclampsia and gestational diabetes were recorded. Information on whether patients needed help to deliver their baby (assisted delivery) during labour was collected.

All of the data was then processed using statistic software so the different cohorts could be compared to each other.

What did the study find and what does it mean for patients?

This study found multiple key links between IIH and fertility rates, pregnancy complications and assisted delivery.

Patients with IIH were found to have around half the fertility rate of the general population. The researchers thought that this may be due to several factors linked to IIH including high body weight, high androgen levels and reduced energy control. In PCOS the chances of becoming pregnant are better when these factors are treated with family planning, weight management and medications. This provides evidence of this issue in people with IIH and in the future we might be able to improve the chances of people with IIH becoming pregnant by using similar options as seen in PCOS.

Both pre-eclampsia and gestational diabetes were found to be more common in people with IIH than the general population. This was thought to be linked to the energy control problems that people with IIH have. As the risk of these complications happening are higher the researchers think that patients may need closer monitoring during their pregnancies to allow for these conditions to be picked up and treated earlier.

Fortunately, this study did not find a link between IIH and still births or miscarriages when compared to the general population. This is very encouraging and people with IIH should be reassured that there is no direct risk to their baby due to their condition.

This study found that people with IIH were twice as likely to have planned and emergency caesarean sections when compared to the general population. They were also much more likely to have a planned caesarean section when they were known to have IIH. The cause of this is unclear, but the researchers thought it could be because of the medical team or person's preference. The researchers pointed out that planned caesarean sections should not be preferred to normal deliveries just because a person has a diagnosis of IIH alone. This is because there is not much proof that one method is better than the other in IIH and even though pushing causes brain pressure to increase, there is enough time in between pushes for the brain pressure to recover before the next push.

Are there any problems with this study?

This study had data taken from a very large population which was spread over the country and compared two non-IIH populations to allow comparisons.

All research studies have their strengths and weaknesses, and most research groups try to have as little flaws as possible. Unfortunately, despite their best efforts, some flaws remain.

Different hospitals require different information to diagnose people with IIH. This means that some hospitals will document some pieces information and not others. Some data from HES was missing making it unclear if some patients fitted all the criteria to be diagnosed with IIH.

Body mass index (BMI) values were not included the HES data. This meant that weight and height data was not available to be used in the study. The researchers used techniques to take this into account, but weight and height data would be useful to include in future studies.

The HES data was only gathered from hospitals. This means that there may be appointments managed in the community which were not included in the study. Certain events like early miscarriages or problems with fertility were not collected and may be more common in real life than they seem from the data.

The researchers have described full details of the studies limitations in the published article, available from https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.17241.

What are the next steps?

This study has helped us to improve our understanding of IIH and planning a family. It is the first of its kind to show a link between IIH and reduced fertility. The research has also shown that people with IIH are more likely to have problems during pregnancy and need surgery to help delivery than others. The study suggests that more research needs to be done so that we may improve fertility and pregnancy outcomes in patients with IIH in the future.