Discussing weight with people with Idiopathic Intracranial Hypertension, Results of an online survey: Stigma, support and changing the dialogue.

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Summary

Key messages

- **PwIIH are experiencing weight stigma with 86% believing that IIH is their fault because of their weight**
- **93% of pwIIH were NOT asked permission to discuss their weight with them**
- **78% of people with IIH who were advised to lose weight were NOT offered support in achieving this**
- **84% of the 22% offered support with losing weight did not find the support offered helpful and appropriate**

Background

Weight discussions occur in consultations between health professionals and people with Idiopathic Intracranial Pressure (pwIIH) because of the established links between obesity and outcomes in this condition. IIH UK responded to perceived concerns from IIH UK members about the weight related dialogue they were having with their health care professionals. International guidance shows that the way health professionals engage with people living with obesity impacts on engagement, motivation and relationships.

IIH UK members were also raising concerns about a perceived lack of support for management of their weight.

The aims of this survey were to gather information about weight related discussions between health care professionals and pwIIH and how this dialogue impacted on them. Secondary aims were to gather information on weight management support for pwIIH.

Methods

This study was an anonymous online survey using Survey Monkey™. The questions in the survey were piloted with pwIIH and professionals working with pwIIH. The finalised survey was emailed to members of IIH UK. The survey was also shared on social media groups for people with IIH and IIH UK Facebook and Twitter sites.

Results

IIH UK received a phenomenal response to the survey and in one week over 500 responses were received. The survey remained open for a further two weeks. 625 pwIIH completed the survey after any incomplete submissions were removed. The results are summarized below and the questions from the survey are used for structure and context.

1. **Who is advising people with IIH that they need to lose weight? (n=617)**

A range of professionals are discussing weight with pwIIH and for many people this dialogue is being repeated with more than one:

Neurologist: 88%

Neurosurgeon:17%

Opthalmologist: 50%

GP: 44%

Nurse: 21%

2. **Were you asked permission to discuss your weight? (n=625)**

A staggering 92% of pwIIH were not asked permission to discuss their weight with them.

3. **How did the person who advised you to lose weight raise this with you? (n=615)**

PwIIH free wrote responses to the question and examples below highlight that the way that weight was raised varied considerably. Sadly, the majority of comments were negative but it is important to recognize that there were a minority of people with IIH who had a positive experience.

- The Good

“Weight gain can be a cause for iih, weightloss can help symptoms. Do you need support with this?”

“The ………,matter of factly, told me to lose weight as it would improve my symptoms, I wasn't offended by it, I appreciated that ….. wasn't patronising me”

- The Bad

“Told me lose weight and it would go away…haha”

"To help yourself you need to lose weight, you will not get rid of this until you have"

- The Ugly

“You need to lose weight or go blind. That's your choice”

“I have one thing to say “slimming world”

‘This happens to people who like too much cake’

“If you weren’t fat and had some control you wouldn’t be here”

“There’s no way you eat what you say you do, do the exercise you say you do and are as fat as you are”

4. **How did being advised to lose weight make you feel? (n=623)**

A wordle diagram below uses common words from responses to represent. It is evident that the dialogue was predominantly perceived negatively.

Figure 1. How did being advised to lose weight make you feel: wordle summary (n=623 pwIIH)

Examples of the full responses of the 625 pw IIH who responded to the question are below:

“Awful! Like I had caused the issue myself. Like I was wasting time and hospital resources”

“I knew I had to do it but the amount of times I have been told to do it has had an effect on me and it makes me feel really down about myself”

“The "walk a mile in my shoes" quote sprang to mind”

"It gets tiresome and frustrating and makes me distrust the medical people that should be helping me"

"Fine it was done with sensitivity"

5. **Have you been made to feel that IIH was your fault because of your weight? (n=624)**

86% of respondents reported being made to feel that IIH was their fault because of their weight.

Examples of free written responses to justify the yes/ no response are below:

"At every neuro appointment it's brought up, and I'm weighed"

"If you lose weight it will go away"

"Constantly told its weight related"

"Every doctor who I have seen has told me that my weight has caused my iih without looking into other reasons, even when I have asked"

"It was discussed that because I gained weight it triggered something and now I have IIH, they can't really explain why it happens but losing the weight again can reverse it"

6. **Did you find the person who advised you to lose weight empathetic and supportive? (n=624)**

79% of pwIIH did not find the person discussing weight empathetic or supportive.

Examples of supporting responses to this yes/ no question are given below:

"No support, no sympathy, no understanding of life and living with IIH"

"My calls and emails went unanswered. I tend to depriortize myself as it is but i feel as though my doctors also make me a very low priority. IIH effects my everyday and I feel lost and unsupported most days."

"I know it's hard but you have to make yourself lose weight" while I was dieting and not losing "you have to exercise" while not taking into account what I've told her about constant pain/other conditions"

"Very black and white. Lose weight. Get out of my office, I can't help you."

"He just said I know its really difficult "

"They are busy and need to get me out quick, the info is delivered matter of fact and as medical information, forgetting that there is feeling attached to the words loose weight, and many of us are fat due to feelings. So just telling us "you need to lose weight" then moving on to the next item of business is not supportive at all"

"They just seem rude and unsympathetic. I have tried to explain that I do exercise as much as I can but I am in pain but they don't seem to care"

7. **Were you happy with how the topic of weight was raised with you? (n=619)**

79% of pwIIH were not happy with how the topic was raised with them.

Examples of the full responses to justify their yes/no answer are given below:

"It was just thrown in! No "have you ever considered...?" Or approaching it in a manner considering the emotional impact"

"Not a single person asked permission to discuss the topic with me. I would've said yes but that's besides the point I could've explained that it's a sensitive subject or that previous medical professionals have left me quite nervous about this topic. It could've helped the way the conversation was had."

"It came out of nowhere. And I was (still am) a healthy bmi"

"I felt like I was being put in a one size fits all basket, rather than my individual health needs and history being taken seriously"

"Just told me to lose weight, no explanation, no help with weightloss"

8. **Are there any words or language that you would prefer medical professionals to use if they need to discuss your weight with you? (n=571)**

A wordle is used below to summarise responses to this question.

Figure 2. Words or language that pwIIH would like professionals to use in weight dialogues: a wordle summary (n=571 pwIIH).

9. How could the experience of being advised to lose weight have been improved? (n=585)

Examples of the responses to this question are given below:

“Is it okay if we can discuss the topic of your weight?” “Are you sure?”

“Let’s explore options to assist you in weight loss and see how this will impact your symptoms and condition”

“Take blame out of it. Approach it as you would any other medical condition. Here is the problem, here are ways to treat it, here are people/resources that can help you”

“Overweight is always nicer than obese but understand that is the true medical term on the scale”

“I wish they’d ditch the “morbidly” or “extremely” as it’s dehumanizing”

“I think that if it's going to be considered such a crucial part of treating the condition, then doctors should take more time to understand potential issues around weight rather than assuming it's a simple case of losing”

“I would rather they listen to me. I am desperately trying to lose weight and maybe I need help to manage it? I must do, I am fat. But provide support not judgement.”

10. Do you feel that you have had less favourable treatment because of the link between IIH and obesity? (n=621)

67% felt that they had less favorable treatment because of their obesity.

Examples of the full answers people gave to justify the yes/no answer to this question are given below.

"Drs see IIH on my notes and then see me a 'fat' person and almost immediately most drs go straight in with loose weight eat healthy (which I do) and there's a disconnect to how they treat me"

"I think obesity is negatively viewed any way and just perceived to be people who are lazy or lack will power and lots of other negative views by everyone. Support medically is lacking and so is the treatment very narrow and treats the symptoms not the cause. So we blame ourselves and doctors blame us which only makes us eat more."

"I kept being told to lose weight for 5 years because it would cure me. I had weight loss surgery and am now underweight and luckily for me my IIH is in remission. I now get praised and got discharged. When my symptoms flared last year I got told I couldn't possibly have it anymore and it was just a migraine. They aren't interested anymore because they can't blame my weight."

"I have lost 7 stone and since losing the weight my treatment has been significantly better. When I was overweight my treatment was not as good. When I was overweight my IIH was "blamed" on my weight. Now the health professionals cannot blame the weight, I definitely receive better treatment and am taken more seriously"

"Because it's all they focus on"

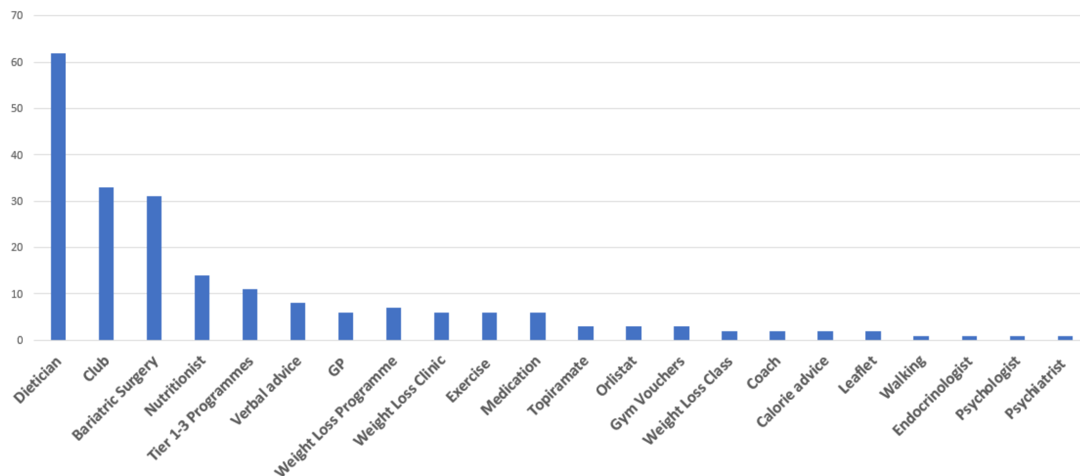
11. When you were advised to lose weight, were you offered support to do this? (n=624)

78% of pwIIH were not offered support to lose weight.

12. If you were offered support to lose weight; please detail the support that you were offered? (n=478)

The graph below shows the breadth of support that the 22% of pwIIH who were offered support with weight loss were offered.

Figure 3: Support offered to pwIIH to help them manage their weight (n=478)



Examples of the supporting information to this question are detailed below:

“I was put on a tier 3 program and am yet to have them engage with me on it, I still call them every month 19 months after the acceptance on to tier 3 support”

“I have had to fight to get support. I am under a mental health team and have had to have them email my GP digging that they refer me to a complex weight management team for them to even consider it.”

“Consultant told me to exercise more eat less”

“referral to medical dieticians. More paper information such as leaflets etc at our appointments.”

“I was sent to a dietitian but when I attended the appointment she had a quick chat about food swaps, gave me a food wheel leaflet and that was it. No further appointments, no support, no targets, nothing to work to. No follow up”.

“Slimming world/weight watchers. I was diagnosed during COVID-19 so it was harder to access these groups” I wasn’t. I was told to eat less and move more and “ignore the cravings”

“The neurologist said she would get in touch with a dietician I never heard from one though”.

“Tier 3 weight management which I agreed too, and was never sent anything about it. No idea what I’m meant to do”

13. Was the support offered helpful and appropriate?

84% of people with IIH did not find the support offered helpful or appropriate.

Examples of responses to this question are detailed below:

“Referral to a nutritionist by my neurologist. My GP offered 12 weeks of Weight Watchers/Slimming World yet again - I detest those groups, they're like cults”

"A nutrionalist with the hospital. They took 2-3 months to write out to me with a leaflet on healthy choices. There was no follow up from them once this was received."

"I was offered 5 appointments with a Dietician, she suggested weight loss surgery, I then had to do all the research, my GP isn't very knowledgeable with IIH and struggles helping me with things, so anything i do i have to research myself."

"I did go a weight loss weekly thing but they kept talking about me having gastric surgery which scared and upset me"

"The reasons for this related to not being referred or not able to access due to covid – such as clubs"

"Expense, affordability issues"

"I was told I would be given help to lose weight: for example weight management classes, appointments with a nutritionists and I am still waiting for this after 1 year. I felt like I just got the blame and shunned"

"Waiting lists….."

14. If you were not offered support to help lose weight did you ask for support?

38% of the 78% of pwIIH not offered support asked the professional for support to lose weight.

15. What support would you like the professionals who look after you to offer to help with weight management? (n=562)

A wordle is used to provide information on the response to this question.

Figure 4. Support that pwIIH would like to help them manage their weight (n=562).

Examples of responses to this question are detailed below:

“Ongoing access to a dietician to help with the right diet choices. Ongoing access to a physio therapist to help with an appropriate exercise programme.   Ongoing access to a psychologist to help me change my thoughts about food and the way I eat.”

“Psychological therapy, nutritionist consultant, real options for the future (for example bariatric surgery…). If they consider weight loss a solution they should aid it, not leave it on to the patient to resolve it.”

“If it is just weight management then... Nutrition advice and guidance, support for exercise and guidance on how to do it without ending up in bed for days with high pressure pain.”

“I think it’s good to be at a overweight clinic there you can see a number of different specialist like dietitian, a doctor and a physiotherapist and a therapist. So you can get an individual plan that suits my individual needs.”

“An actual conversation explaining the facts on losing weight and how it will help with the condition, just to feel listened to, that they actually interested in what we have to say! “

“Achievable advice based on how you are with IIH not just the same advice given to a 'normal' overweight person.”

16. If you were advised to lose weight were you given a weight loss goal? (n=610)

70% of people with IIH were not given a weight loss goal when advised to lose weight.

Examples of responses to this question are detailed below:

“At first it was 5% body fat but this changed to 10% once I achieved the goal so I feel he wouldn't have stopped with new targets and no improvement to symptoms”

“It was realistic goal each week to achieve”

“I got told to lose half my body weight”

“I was told even losing 10% of my body weight would be a massive help”

“It sounded like a big number. 13% of your body weight sounds huge.”

“I was told to lose 75 pounds”

17. If you were given a weight loss goal did this feel achievable for you? (n=412)

Of the 30% of people given a weight loss goal 76% did not feel that the goal was achievable for them.

Examples of the supporting information for this question are given below:

“Got told to lose 15 stone I am no good with massive goals like that”

“Having pressure to hit a weight target quite often has the opposite effect. Doctors should be breaking it down into achievable goals.”

“Only they kept moving it 5%, 6% 10% 12%, then i didn't lose it fast enough.”

“I was told to lose between 8 and 10 stone within 6 months. I was never given a goal, just to lose weight so my pressure would go down. I felt overly pressured to reach this "ideal" goal and no matter what I did, it didn't work, so it felt very unachievable.”

“5% and it made no difference. Then he said 100lbs. I've gone from 98kg to 58kg”

“10st is just so huge, it feels like a mountain I can’t climb. I have issues with my relationship with food. I can’t exercise as this instantly gives me a headache. So how am I supposed to loose weight?”

“It was the lowest end of healthy bmi and it just seemed impossible that my body would ever be that small”

“It sounded like a big number. 13% of your body weight sounds huge”

Discussion

Stigma can be defined as ’ a strong feeling of disapproval from most people in a society about something, especially when this disapproval is unfair’ Albury et al 2020**.** It is evident from the responses by pwIIH to this survey that obesity (weight based) stigma is being experienced during their consultations with health care professionals.

Why is how you are advised to lose weight important? Research evidence shows that, adults who experience weight-based stigma are more likely to avoid exercise and physical activity, and to engage in unhealthy diets and sedentary behaviors that increase the risk of worsening obesity *International Consensus Statement on Obesity Stigma 2020.* Therefore, the consultation could be having the opposite effect to that intended and actually exacerbating the condition.

National guidance from Albury et al 2020 propose that weight stigma can trigger physiological and behavioural changes that themselves contribute to poor metabolic health and further weight gain. These changes include increased eating, reduced self-control, a 2-5 times increased likelihood of mood and anxiety disorders, stimulation of cortisol, itself an obesogenic hormone and avoidance of exercise. The

potential mechanisms are summarized in figure 5 below.

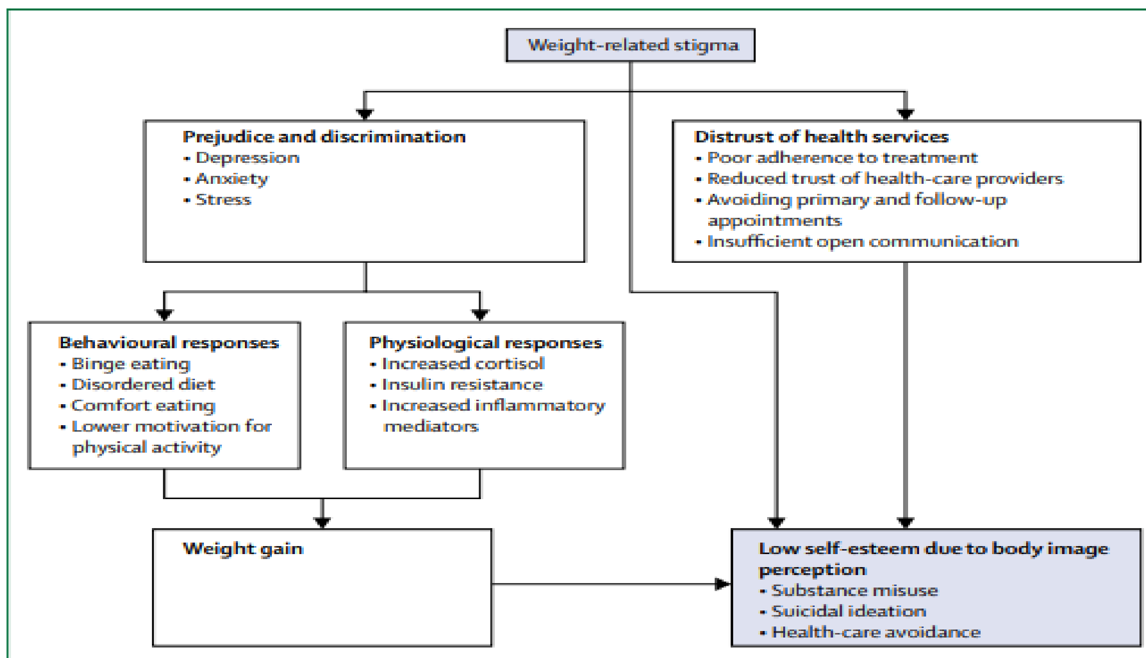


Figure: **Potential mechanisms by which weight-related stigma might perpetuate obesity and contribute to the adverse health outcomes associated with obesity**

Brown and Flint 2020 propose that the way health care professionals communicate with people living with obesity impacts engagement motivation and the patient-practitioner relationship. They further discuss that terminology is important such as the term obese have negative emotional effects on the person. This is supported by the results of this survey and pwIIH would prefer that this terminology is not used in their consultations. It is clear from the responses to this survey that improvements are needed in consultations regarding weight with pwIIH.

The results of this survey suggest that education is needed with health care professionals to promote improvements in language and dialogue in their consultations with pwIIH about weight. Albury et al 2020 propose the following principles should be used in communication about weight.

Figure 5 Albury et al 2020

Panel: **General principles* for communication between a health-care practitioner and a person living with obesity to reduce stigma and improve the individual's wellbeing**

Be positive
- Focus on the gains that might be accomplished by weight management, rather than the potential negative effects of failing to address obesity

Be helpful and supportive
- Offer specific help and advice where appropriate
- Signpost and guide people towards more information and local services
- Acknowledge that there are many routes to lose weight and that what works for one might not work for all

Be aware of non-verbal communication
- Talking about obesity is difficult; ensure that body language recognises this difficulty by engaging in a way that would be deemed appropriate for any other medical condition

Be collaborative
- Whenever possible, build meaningful and specific goals together
- Percentage change in weight or even weight neutrality should not be used as a goal, but rather a step towards reaching a meaningful person-centred outcome

Be understanding
- Up to 80% of obesity might be genetically determined
- Ensure not to attribute blame, but to acknowledge the difficulties faced by the person

Be environmentally aware
- Chairs with arms and weight limits can be restrictive
- Tight spaces with back-to-back chairs can be hard to navigate
- Appropriate medical equipment should be available, including scales that weigh up to 150 kg in a private space and a range of different sized cuffs to measure blood pressure

*Adapted from the NHS England guide by Partha Kar.[42]

What needs to happen in response to this survey?

In response to this survey there are key area that pwIIH would like to be addressed and key actions that IIH UK plans to take.

What would people with IIH like to change in response to this survey?

- PwIIH request that health care professionals ask first if it is ok to discuss weight with them
- PwIIH acknowledge that weight MAY be one of the factors but they do not want this to be the sole focus of their interactions with health care professionals
- PwIIH would like support with weight loss that is evidence based from a multidisciplinary team who are specialized in weight loss and have knowledge of the specific needs of people with IIH.

- PwIIH want weight management options that are affordable, supported and manageable within the context of living with one or more long term conditions.
- PwIIH asked if weight loss is a goal then they need regular reviews of their weight with realistic short term goals

Actions from IIH UK to address weight stigma in pwIIH?

- Information on weight stigma experienced by people with IIH will be included in information packs sent to health care professionals.
- IIH UK will circulate a Top 10 tips for having a conversation about weight with people with IIH developed in collaboration with people with IIH to include in information packs sent to health care professionals.
- IIH UK will develop infographics focused on addressing weight stigma experienced by people with IIH to share with professional bodies and on social media.
- A new self-management programme: HOPE for people with IIH will be co-designed, developed and delivered to people with IIH supported by National Lottery Funding (starting march 2022)
- IIH UK will join the All Parliamentary Group on Obesity and will represent the views of pwIIH at national policy level.
- IIH UK will register as stakeholders for the proposed NICE guidance on obesity management
- IIH UK will engage with organisations addressing weight stigma such as Obesity UK.
- IIH UK will disseminate the results of this survey at relevant conferences for health care professionals working with pwIIH.
- IIH UK will publish this survey summary on their webpages to share with pwIIH.

Conclusions

PwIIH are experiencing obesity stigma during consultations with health professionals. Education about conducting a weight related dialogue is needed for professionals engaging with pwIIH. This survey also showed a lack of accessible and appropriate support to achieve weight loss despite the known links to improvement in outcomes for people with IIH.

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