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# “The healthcare system did fail me repeatedly”: a qualitative study on experiences of healthcare among Canadian women with Cushing’s syndrome

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## Abstract

**Background** As a rare endocrine disorder, Cushing’s Syndrome (Cushing’s) is characterized by numerous symptoms and a non-specific presentation, leading to a delay to diagnosis for patients with this disease. To date, research examining the lived experiences of patients with Cushing’s in healthcare is absent in the literature. This preliminary inquiry into the healthcare experiences of women with Cushing’s aimed to examine the utility of this line of inquiry to support the patient centered care of individuals with Cushing’s.

**Methods** Seven women from across Canada with endogenous Cushing’s participated in the study. Semi-structured interviews were conducted examining participants’ healthcare and body-related experiences with Cushing’s. Results pertaining to healthcare experiences were analyzed for the current study using reflexive thematic analysis.

**Results** Four themes emerged whereby women with Cushing’s experienced (1) a lack of patient centered care, characterized by provider miscommunication and medical gaslighting; (2) a misunderstanding of their symptoms as related to weight gain; (3) weight stigma in healthcare encounters; and (4) a shift in their quality of care following diagnosis.

**Conclusions** The results highlight the importance of patient centered care as well as the negative impact of commonly reported barriers to patient centered care. Cushing’s specific barriers to patient centered care may include weight stigma as well as the rare incidence of Cushing’s. Further research is needed to better understand the healthcare experiences of people with Cushing’s in Canada.

**Keywords** Cushing’s, Patient centered Care, Weight stigma, Medical gaslighting, Qualitative research

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Cushing Syndrome (Cushing's) is a rare disorder caused by an increase in circulating free cortisol [1]. As receptors for glucocorticoids are widespread throughout the body, the effect of this increase in circulating cortisol is prolific [2]. Symptoms include uncontrollable weight gain, dorsocervical fat pad, facial plethora, purple striae, easy bruising, fatigue, proximal myopathy, hypertension, as well as menstrual irregularities and hirsutism among women [1, 3]. While Cushing's is most often caused by corticosteroids (i.e., exogenous Cushing's) with a more easily identifiable cause, this research is focused on endogenous Cushing's, which occurs at an approximate rate of 3.2 cases per million per year globally [4]. Endogenous Cushing's is divided into two types: adrenocorticotrophic hormone (ACTH) dependent and ACTH independent [2]. ACTH dependent Cushing's comprise approximately 80% of endogenous Cushing's cases and is caused by ACTH secreting tumours most often on the pituitary (i.e., Cushing's disease), or an ectopic ACTH secreting tumour found elsewhere in the body [2]. ACTH Independent Cushing's cases account for the remaining 20% and are most often caused by adrenal cortical adenomas or hyperplasia [5].

The rare rate of occurrence, coupled with the broad symptomology contributes to the challenges with diagnosing Cushing's, with a delay to diagnosis of two to six years [6, 7]. Although individuals may experience few symptoms its early stages, disease progression that occurs with delayed diagnosis can lead to significant impairment in daily life as well as hypertension, metabolic diseases, and other complications [8]. Given that the incidence of Cushing's is higher among women compared to men, [9], as well as the gendered nature of weight and appearance expectations for women in society (i.e., thinness), [10] understanding the impact of this disease on women is an important, but unexplored, direction for women's health research.

The non-specific presentation and rare occurrence of endogenous Cushing's is also important to consider in the context of patient centered care, defined as relationship-based care that meets the needs, priorities, and values of patients [11, 12]. Patient centered care focuses on the creation of a positive therapeutic alliance between patient and provider, with shared power and responsibility in decision making [11, 12]. A recent systematic literature review identified that most barriers to patient centered care occur at the provider level, including lack of training, physician burnout, and poor-quality communication [12]. One potential barrier to patient centered care for individuals with Cushing's is weight stigma (i.e., stereotypes and negative attitudes about people with higher weights), which is prevalent in healthcare, [13, 14] and is associated with consequences for healthcare utilization [15, 16].

Although researchers have documented the clinical presentation of Cushing's, [7] approaches to working with patients with a possible diagnosis, [1] as well as treatment approaches and outcomes, [17, 18] there is an absence of research on the lived experience of patients with Cushing's in healthcare. Given the established delay to diagnosis of Cushing's [6, 7] and the possible impact of weight stigma on patient centered care, we sought to conduct a preliminary inquiry into the patient experience in primary care. Thus, the aim of this study was to examine the healthcare experiences of women with Cushing's in Canada, as women experience greater incidence of Cushing's [9] as well as greater appearance-based socio-cultural pressures [10].

## Methods

### Research team background and epistemological underpinnings

We recognize that our identities and positionalities as researchers have a significant impact on the research we conduct [19]. All authors identify as White cisgender women with lived experiences with weight-related issues, and SCJ has lived experience of Cushing's Disease. SCJ led this research project as part of her degree requirements in a double-major biology and psychology undergraduate program. SN is a weight stigma researcher with a background in qualitative research. JFS conducts research on body image and eating disorder recovery, with a background in qualitative methods. Further, this research was undertaken from a social constructionist epistemological position, recognizing the power of sociocultural discourses related to appearance, weight, and health on the experiences of higher-weight people in society broadly as well as healthcare specifically [20–22]. These sociocultural discourses position weight as an accurate indicator of health that is within individual control, with lower body weights considered healthiest (i.e., "normal" weight body mass index) [20–22].

### Participants

Participants were seven women from across Canada (see Table 1 for demographics). The mean age of the sample was 44.14 ( $SD=13.32$ ) and mean self-reported time to Cushing's diagnosis after first seeking medical care was 2.14 years ( $SD=0.58$ ). Six participants experienced Adrenocorticotrophic hormone (ACTH) dependent Cushing's, while one patient experienced ACTH independent adrenal adenoma. Of the six participants with ACTH dependent Cushing's, five had an ACTH secreting pituitary adenoma and one participant had an ectopic ACTH producing lung carcinoma. All participants self-declared that they exhibited clinically significant 24-hour urine free cortisol levels, which contributed to their diagnosis.

**Table 1** Participant demographics and pseudonyms

Participant Pseudonym	Age	Ethnicity	Household income	Sex & Gender	Time to diagnosis
Abby	68	White	\$20,000–\$49,999	Female/ Woman	2 years
Bethany	40	White/ Metis	\$80,000–99,999	Female/ Woman	3 years
Christy	23	White	\$20,000–\$49,999	Female/ Woman	1.5 years
Darby	52	White	Over \$100,000	Female/ Woman	3 years
Emily	40	White	\$80,000–99,000	Female/ Woman	2 years
Franny	35	White	\$20,000–\$49,999	Female/ Woman	1.5 years
Honey	51	White	\$80,000–99,999	Female/ Woman	2 years

Note. Participants demographics are presented. Given that Cushing's is a rare disease and participant geographic location may allow participants to be identified, we have omitted this information from the table

### Procedure

This study received research ethics approval from the first and second authors' institution (#21–0507). Convenience sampling occurred in February 2022 via a shareable recruitment post on five Facebook support groups for Cushing's Syndrome. Potential participants were directed to reach out to the first author to indicate their interest in the study. Participation was limited to cisgender women over the age of 18 who had been diagnosed with endogenous Cushing's and received care in the Canadian healthcare system. Nine individuals from one Facebook support group contacted the researcher, two of whom did not receive treatment in Canada. The remaining seven participants were provided with a consent form and demographics survey, which they completed prior to scheduling a semi-structured interview.

Following the completion of informed consent, interviews took place over zoom, in a private location of the participant's choosing. To obtain a rich understanding of experiences with Cushing's, we asked a series of questions about participants': (1) journey to diagnosis, (2) healthcare experience pre- and post-diagnosis, and (3) perception of body and weight pre- and post-diagnosis. Interview questions were open-ended and provided opportunity for participants to describe positive and/or negative experiences. Please see the Appendix for full interview protocol. Interviews lasted approximately one hour with \$30 compensation, were recorded, and were transcribed verbatim by the first author. Following transcription, participants had the opportunity to review their transcript and remove any data they were uncomfortable including in the analysis (i.e., member checking). One participant removed a small portion of her transcript, which did not impact the analysis.

### Analysis

Following transcription, anonymization, and member checking, the first and second author used a qualitative descriptive approach [23] in the preliminary data analysis stages to become familiar with the data and the experiences of the seven women interviewed. Two main content areas predominated: (1) negative experiences in healthcare and (2) women's body image as connected to Cushing's-related changes. Given these divergent content areas, the research team engaged in a two-pronged approach to qualitative data analysis, one for the negative healthcare experiences (reported here) and one for women's body image.

The data pertaining to negative experiences in healthcare were analysed using reflexive thematic analysis [24, 25]. This method allowed for a rich and flexible understanding of similarities in individual experiences. To generate themes, the first and second authors read the transcripts line-by-line and assigned descriptive codes, which were then reviewed and re-coded at a more interpretive level to create themes in the data, both latent (i.e., underlying) and semantic (i.e., explicitly stated) [24, 25]. Themes were reviewed and approved by all authors. Throughout data collection and analysis, effort was made to discuss reactions to the data and potential biases.

### Results

The results of the inductive thematic analysis indicated four overarching themes in the data: (1) lack of patient centered care prior to diagnosis; (2) patient misunderstanding of symptoms; (3) experienced weight stigma; and (4) diagnosis as a golden ticket to treatment and stigma-reduced care. Each of these themes is reviewed below.

### Lack of patient-centered care

Lack of patient-centered care prior to diagnosis often took two forms: (1) provider miscommunication, and (2) medical gaslighting. These sub-themes are described below.

**Provider miscommunication.** In the beginning stages of their investigations, participants reported difficulties in communication with their primary care providers. Honey stated that she was “going back and forth continually, feeling like I wasn’t being heard, feeling like I had to fight for every... For every feeling. I had to try to justify everything I was saying” Similarly, Abby noted: “I started to wake up in the morning with little bruises on my body like almost like a fingerprint. And I thought that was weird and I brought it up to her ... And she was like oh that, there’s nothing wrong with that, it’s fine.” Participants described confusion and worry when they perceived that something was wrong but did not perceive they were being taken seriously by their primary care provider.

Sometimes, miscommunication made the diagnostic process even more challenging, as was the case when Bethany was asked about stretch marks by her family doctor:

*I remember my family doctor asking me at one point, do you have stretch marks? And I said, ‘no, I don’t have stretch marks. Last time I had them was when I was pregnant. And that was many years ago.’ But he didn’t describe the stretch marks. I was thinking of the pregnancy stretch marks with the fine white lines. And he must have thought about Cushing’s with the striae that are wide and purple. But there was no description of them. If I had [a description], I would have shown them immediately!*

Christy noted how phone appointments may have negatively impacted her diagnostic process:

*All of this went down in the [COVID-19] pandemic, so I actually never met a doctor in person about this ever. ... I explain the weight gain I’m like kay I was 110. Now I’m 230 and these are the bursts. These are when it happened. Um, but they actually never saw me, not once, not even over zoom it was all over the phone ... When I explained how much I gained they were just like, no.*

In general, participants felt like they were not receiving the care they hoped for from their primary care provider. For example, Abby said that “Cushing’s patients have a lot of things going on and most regular doctors when they see you...they think you’re a hypochondriac because there’s always something wrong with [you].” Participants perceived their primary care providers as missing the

big picture. Darby recognized that “I think each time I went into the doctor for the different things, ... I would go in for specific things, but we never sort of put them all together as to what it was.” In describing her frustration with this process, Emily said: “And I’m just like how many other people are struggling with stuff like this, and they just get [dismissed].” Together, this miscommunication contributed, in part, to the delayed diagnosis, as it took time for providers to recognize the possible diagnosis of Cushing’s.

**Medical gaslighting.** Medical gaslighting is the process by which medical professionals will downplay, dismiss, or silence a patients’ view of their illness [26]. Abby described her experience with the first primary care provider she consulted: “he basically told me that I had mental baggage, and it was that I was a head case and that was my problem.” After moving to a different city, she described the next provider she met with as having a similarly dismissing response: “I also explained to her what was going on. I said I think there’s something wrong, I exercise and the harder the exercise more I gain weight. She basically said you’re not trying hard enough and suggested the South Beach diet to me.” Besides their weight, other symptoms were also dismissed. Emily said:

*It was always passed off as oh, your high-stress job, high-stress family life, you’re depressed; those were always the comments to me. You’re just depressed, you’re just anxious because of this stuff and blah blah, blah. ... As time went on the symptoms started multiplying. So, I’m like it’s not just not sleeping and depressed and anxious I’m like... my resting heart rate is in the 160’s without moving um, my vision’s starting to get impaired, I feel like I’m crazy, um and then the weight gain started. And once again they just said oh you know take up, take up cycling. That’s what the doctor told me.*

In describing her experiences with feeling downplayed or dismissed, Honey stated:

*I had swollen hands and feet, too, so he said, Well, you’re gonna have to get your diet under control, and I said well my diet is really good actually and I’ve been going to weight watchers for a year, haven’t dropped a pound, so there’s an issue there. And again, he would just chalk it up to PMS.*

Honey also experienced skin sensitivities and was told she simply needed to use sunscreen more frequently. During the diagnostic process, Christy experienced medical gaslighting when completing her 24-hour urine free cortisol test:

*I did the test and waited months again for my results. And then it came back super high. And so, he accused me of doing the test wrong. He said there's no way um this makes sense. You need to do the test again. So, then I did the test again. And it was high again. And he accused me of doing it wrong again. And I was like, I'm telling you like I don't know what you, I've got the instructions in front of me. ... And so I did it again, and it came back like again in the thousands. ... I did feel like I was going nuts, the same way when he kept telling me I was doing the test wrong.*

### Patient misunderstanding of symptoms

Participants also described misunderstanding their symptoms, which highlights a further breakdown in patient-provider communication about their disease, as these misperceptions were not clarified for them upon diagnosis and treatment. Participants appeared to hyperfixate on, and misunderstand, their weight gain. They also misunderstood other symptoms as related to weight. Emily noted this fixation on weight directly when she said: “In the very beginning I noticed the weight gain first to be honest.” Abby shared that she decided to approach a health professional because of her weight gain:

*I was a happy, healthy active athletic person, and all of a sudden something in my life happened where I just kept gaining weight and gaining weight. No matter how much like exercising or eating properly that I had done... The catalyst for me going to the doctor was, um, I noticed a bunch of stretch marks on my stomach and to me that was a sign of like rapid weight gain in such a small amount of time.*

Like Abby, other participants misunderstood their weight gain and attempted to engage in behavioural changes to reverse this process. Bethany said:

*Thankfully I did not have a doctor that told me to go and exercise and eat less. But when you did that, you still gained weight. The more I exercised, the more walking I did, the less I ate, the more I gained and the rounder the face got. And the more hair I lost.*

Similarly, Christy described her weight gain as the catalyst behind her decision to hire a personal trainer:

*I kind of decided based on super significant weight gain that I was going to invest in a personal trainer... So, I was with the personal trainer for about three months, and was only gaining weight, like I was*

*cutting calories and working out I think it was like 12 times a week. ... But everything was just getting worse. Like I was weaker, I couldn't do things the same way that I used to, like the stretch marks were nuts I kept gaining weight I didn't know why, despite still I was still walking every day and doing what I could.*

When describing their experience of symptom onset prior to receiving their diagnosis, participants understood many of their physical changes as connected to their weight gain. This was especially true for those experiences that surrounded muscle weakening and movement, despite these being Cushing's symptoms that are independent from weight. Bethany recalls how, when called for her appointment in her primary care provider's waiting room, she “*staggered to stand up and was almost immobile to a point, I was so big,*” an experience she attributed to her weight gain. As symptoms worsened, participants felt disconnected from their bodies. Emily said: “*I can't trust [my] own body,*” and Christy felt “*so exhausted*” because “*of course that's exhausting. Like, carrying all that [weight] around is tiring. Like, if you're not exhausted, that would be weird.*”

Participants also noted a misunderstanding of other Cushing's symptoms, both alongside and independent of their weight gain. In recognizing the impact of stress on her symptoms, Honey said:

*I opened a business, and the stress came back because of that, and then everything came to a head. Then I got the bruising, then I got the buffalo shoulders, then I got the big moon face. ... People were starting to say, like is your whole life okay? It was kind of insulting. And then I got the big belly, and it just got bigger and bigger, and within 3 weeks I had gained 25lbs.*

Darby noted that, in the fullness of her busy life, it was easy to explain away her symptoms:

*I didn't acknowledge what was going on it, I just didn't push to find out why. I was always able to find a reason in my own brain or my own thinking as to all, you know. You know, I'm just I'm working too much and this will pass, and then it'll get better. Or, you know, when I was falling down for no reason, it was like oh man you just got to pay more attention. All right, you know, I need to eat better because I'm not, you know, exercising. When I was gaining the weight and went to weight watchers and some reason the weight wasn't coming off. ... And I'm thinking, I'm doing all the right stuff.*

Similarly, Franny described how she perceived her symptoms to be related to anxiety:

*Oh, it's just anxiety you're always... It's like the palpitations Oh, it's just you're nervous about something. ... I guess I just... in my case, like I haven't... maybe they caught it so soon enough that, like I haven't really got to the point where like I'm I'm feeling a lot of symptoms?*

### Experienced weight stigma

Participants described numerous experiences of weight stigma in healthcare while seeking a diagnosis. Invalida-tion occurred when patients' personal accounts of their illness were dismissed or not taken seriously, as described in the Lack of Patient Centered Care sub-themes. While many participant experiences of medical gaslighting can also be regarded as experiences of weight stigma, these themes were differentiated by whether or not participants reported they were dismissed or silenced, consistent with the definition of gaslighting [21].

Participants contributed their negative experiences, at least in part, to their weight. Participant's felt like there was a significant difference in how they were treated by practitioners before the onset of their Cushing's symptoms. Christy contrasted her experiences in healthcare pre- and post- Cushing's: "When I went to the doctor and I was concerned about something as a kid, nobody ever doubted me like. And yeah, since then ... people in general just don't get [taken] seriously looking the way that I do. And don't respect me as much it seems." Although Christy spoke of "people in general," this sentiment included her primary healthcare provider. Similarly, Honey described a perceived change in her relationship with her primary care provider pre- and post- Cushing's onset and felt that her weight contributed to this change. She described her once positive relationship as one that is now associated with hurt:

*Prior to Cushing's my doctor was very forthcoming. I would tell him what I needed if I needed, felt I needed blood work, or felt I needed anything, or suggested that I... maybe he's not the one to help me that I need to see a specialist he would send me on to that specialist. So, yes, I always felt hurt by him.*

Abby summarized participants' experiences when she said: "Judging books by covers that's, that's what the healthcare system seems to do and I do feel that, like some of my treatment was definitely due to my body [size] and what, what they preconceived that I was a fat person, so it was my fault." Franny described having requested her entire medical file and that seeing herself repeatedly

referred to as a "morbidly obese female" in emails and other communication had a negative impact on her body image and self-esteem.

### Diagnosis as a golden ticket

Post-diagnosis, participants experienced a profound sense of relief and validation, perceived themselves to be lucky to have received a diagnosis, and were thankful for the subsequent treatment they received. Bethany said: "once you get a diagnosis, it doesn't matter what the diagnosis is, you've got a diagnosis and now we work towards that. Let's correct it". Christy felt like "Having that diagnosis under my belt was like a golden ticket ... everything was easier." Abby declared that the doctor who officially diagnosed her saved her life: "She had taken the time to like, say I believe you. Instead of just seeing a fat person and blaming it on me, which is really what the healthcare system does. Really it ruins people." After waiting three years for a diagnosis, Darby stated that she felt "very lucky" and said:

*From when my doctor said to me 'I think it's Cushing's' to when the actual diagnosis was, it was fast. It was weeks. It was, it was very, very quick. ...Once we actually knew what it was to actually being able to have the surgery to have the tumor removed and start reversing the process of what was going on with my body. So. I was very lucky.*

In hindsight, participants noticed there was a difference in how they were treated by healthcare professionals pre- and post-diagnosis. Abby said: "I firmly believe that there is a correlation there between how I was treated before, and then how I was treated after." She elaborated to say that: "people have to believe me now, because a specialist has said, 'This is what I have, and you may not understand it, but I do.'" Emily noted that "after I got the diagnosis my family doctor was very, very open, and caring with moving forward. And he commended me for pushing and knowing that things were wrong, and he was really good about it, and he apologised that it took long to get figured out." Honey also noted "I'd have to say like during the diagnosis, not great, but since I've had my pituitary tumor removed great, the aftercare has been fantastic."

### Discussion

Across seven semi-structured interviews with women with endogenous Cushing's, the results of our preliminary inquiry into the lived experience of patients suggest that both patients and providers struggle to understand the progressive and individualized presentation of Cushing's. This struggle can come, unintentionally, at the expense of patient centered care in the form of provider miscommunication, medical gaslighting, and weight

stigma. Our results also suggest that diagnosis is viewed by patients as an important turning point for both effective treatment as well as reduced stigma.

Overall, the results of our study highlight the importance of patient centered care. Participants reported miscommunication, invalidation, weight stigma, and gaslighting in their healthcare encounters, all of which are contrary to the goals of patient centered communication [11, 12]. These findings are consistent with previous research identifying structural, educational, and resourcing barriers to patient centered communication [11, 27]. These barriers include understaffing, specific healthcare settings (i.e., acute care), limited time, insufficient communication, lack of training in patient centered communication, and inadequate patient education [11, 27]. Given that patient engagement is associated with improved outcomes, a better understanding of their condition, and more awareness of resources, [27] identifying strategies to enhance patient centered communication are of critical importance. Researchers have identified staffing longevity as associated with greater engagement and less burnout [27] and have identified provider training and professional development as significant in the implementation of patient centered communication [12]. Thus, in addition to patient centered communication skills, providers require knowledge of weight stigma and Cushing's as well as appropriately resourced work environments to enact patient-centered care. However, an important responsibility falls to broader healthcare systems to empower providers by providing comprehensive training, addressing provider burnout, and changing healthcare culture and systems to allow for increased engagement in patient centered communication [12].

The rare occurrence [6, 7] and non-specific presentation [8] of endogenous Cushing's is a unique barrier to patient centered communication. Participants in this study recognized the impact that the rare occurrence of their disease had on their provider's misunderstanding of their symptoms. Bethany noted one interaction whereby her primary care provider mentioned being told in medical school that they would never see a case of Cushing's in their careers. However, knowledge of Cushing's is a pre-requisite for early detection [6]. Such knowledge is important, as overlooking endogenous Cushing's is associated with increased mortality rates due to hypertension, metabolic diseases, and bone-related complications, with continued cardiovascular risk persisting after treatment [8].

An additional barrier to patient centered care highlighted in our results is weight stigma. Our findings are consistent with previous qualitative research on experienced weight stigma in healthcare contexts [28–31]. In previous research, patients have consistently reported the attribution of presenting concerns by healthcare

providers to weight without a full exploration of the issue as well as poor verbal and non-verbal communication [28–31]. Such experiences with poor quality communication and stigmatization from healthcare providers are associated with subsequent patient healthcare delay and avoidance, [15, 17] and may contribute to increased internalization of weight stigma [32]. Our results highlight that, for patients with endogenous Cushing's, weight stigma may be a contributing factor in the consistently reported delays to diagnosis, [6, 7] due to stereotyped assumptions about weight gain coupled with a lack of knowledge about Cushing's, among providers as well as patients. Although participants in this study reported symptoms beyond weight gain, they perceived their weight as having an impact on their healthcare encounters.

Our findings related to weight stigma highlight the potential harm of weight- and appearance-focused socio-cultural discourses [21, 22] on Cushing's-related healthcare. For patients, internalization of these discourses may have contributed to the extent to which they understood symptoms such as fatigue and muscle weakening as caused by their weight gain. For providers, this may have contributed to their clinical impressions and decision-making. Researchers have previously identified weight and appearance discourses as contributing to a weight-centric practice paradigm, whereby higher weights are regarded as within individual control as well as the cause of poor health [33]. Within a weight-centric paradigm, recommending weight loss is regarded as an effective health-promoting solution and failure to achieve or sustain weight loss is regarded as the fault of the patient. Criticisms of the unintended consequences of a weight-centric paradigm have prompted researchers to call for a weight-neutral approach to healthcare that recognizes and addresses weight stigma, assesses cardiometabolic and lifestyle health risks in patients across the weight spectrum, and seeks to promote the health of patients independent of changes in weight status [33].

This research was conducted as a preliminary inquiry into the lived experience of patients with Cushing's, given the lack of such research in the literature. Our findings suggest that patient experiences are an important, but unexplored, line of inquiry and that more research is needed in this area. Given that lived experiences may differ across contexts and may vary by an individual's culture, race, relationship status, and/or geographical location, further research is needed with larger samples to elucidate the potential impact of provider miscommunication, medical gaslighting, and weight stigma on the experiences of patients with Cushing's throughout the diagnostic and treatment process. Future research examining Cushing's-related healthcare experiences access gender and racial identities is also needed to fully

understand the broad experiences of patients with this disease.

### Limitations

To our knowledge, this is the second study to examine the lived experiences of people with Cushing's, with only one other qualitative study examining the impact of Cushing's on quality of life, published in Italian [34]. However, this is the first study to examine patients' lived experiences in healthcare, as this previously published Italian study examined patients' perceived quality of life. Despite this novelty and strength, this research is not without its limitations. First, as only seven women with Cushing's were recruited, this preliminary inquiry is limited by sample size. Thus, the results are not generalizable to all women with Cushing's, their healthcare providers, or their experiences in healthcare. Second, given that our participants were recruited from an online support group, their reported experiences may be different from those who have not sought such support from the online patient community. Third, our sample was limited in demographics. All participants identified as white women but did represent a broad range in age and socioeconomic status. Finally, as our participants reported a delay to diagnosis of 1.5 to 3 years, their experiences may not represent those of individuals who experienced a longer delay to diagnosis.

### Conclusion

The findings of this research indicate that a lack of patient centered care may have an impact on the recognition and referral/diagnosis of Cushing's in primary healthcare settings. Our results highlight an important area of inquiry that warrants further attention. Given the small sample size, further research is needed to clarify and to expand on these findings. However, these results highlight the importance of patient centered care and curious investigation into the causes of unexpected and uncontrollable weight gain in patient encounters.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12875-024-02580-5>.

Supplementary Material 1

### Acknowledgements

Not applicable.

### Author contributions

SCJ and SN conceptualized the study. All authors contributed to the study design and SCJ conducted all interviews and transcriptions. Data analysis was conducted by SCJ and SN with support from JFS. All authors contributed to manuscript preparation.

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### Data availability

Data for this study is available on reasonable request to the corresponding author.

### Declarations

#### Ethics approval and consent to participate

This study received ethics approval from the Human Research Ethics Board at the University of Victoria (#21–0507). Informed consent was received from all participants.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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