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Hidden disability: a study of the psychosocial impact of living with pituitary conditions

Norman, Alyson

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Hidden disability: a study of the psychosocial impact of living with pituitary conditions

Alyson Norman, Sue Jackson, Hannah Ferrario and Pat McBride

ABSTRACT

Background: Pituitary patients often experience psychosocial symptoms associated with their condition. Aims: To explore the condition management experiences of pituitary patients and their psychosocial symptoms and to explore the impact of these on quality of life. Methods: A sample of 748 individuals (488 females) aged 18 to more than 65 years) completed a questionnaire relating to quality of life and the psychosocial impact of pituitary conditions. Findings: Analysis of the qualitative sections using content analysis identified four themes: social isolation, emotional and behavioural issues, appearance distress and physical and cognitive effects including fatigue and pain. An overarching theme of hidden disability emerged. Conclusions: The study identified multiple biopsychosocial factors that impact quality of life, with symptoms not visible to others most likely to impact negatively. Nurses are well-placed to provide support and information to patients about the possible psychosocial impact of pituitary conditions to enable positive adjustment.

Key words: Quality of life ■ Pituitary gland conditions ■ Psychosocial effects ■ Long-term conditions

Pituitary gland disorders comprise a range of rare health conditions that affect an estimated 50 000–70 000 patients (approximately 1% of the population) in the UK (Pituitary Foundation, 2014). Pituitary conditions affect hormonal control within the body. Conditions include acromegaly (overproduction of growth hormone), adult growth hormone deficiency (under production of growth hormone), Cushing's disease **AQ2** syndrome? (overproduction of adrenocorticotropic hormone), diabetes insipidus (underproduction of vasopressin) and hypopituitarism (general underproduction of pituitary hormones).

AQ1 Please can we have all authors' Job titles? Are other details correct? Is it OK to include your email address as corresponding author?

Alyson Norman, Job title? University of Plymouth, Plymouth, alyson.norman@plymouth.ac.uk

Sue Jackson, Job title? University of the West of England, Bristol

Hannah Ferrario, Job title? University of Plymouth, Plymouth

Pat McBride, Job title? The Pituitary Foundation, Bristol

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The medical management of pituitary conditions is notoriously difficult, and individuals often experience high levels of distress often not addressed by health professionals despite National Institute for Health and Care Excellence (NICE) guidance stating that distress must be assessed at key points within the patient-care pathway for central nervous system (CNS) tumours (which includes pituitary adenomas) (Levy, 2004; Osbourne et al, 2006; NICE, 2006). The diagnostic process can require multiple tests and scans, ideally undertaken in specialist endocrine centres (Wass and Owen, 2014). For prolactinoma, the commonest of the pituitary conditions (Fernandez et al, 2010), medication is used to shrink the tumour and reduce prolactin levels, while patients with other pituitary conditions are likely to require surgery and radiotherapy in addition to medication (Wass and Owen, 2014). Post-surgery, medication may be required to replace or optimise hormone levels, although getting this right can be frustrating for all concerned, with some patients still feeling unwell despite post-treatment blood results showing hormone levels within the normal range (Rio, 2013). Post-treatment, patients require an annual review in a specialist endocrine centre.

Part of the difficulty in understanding the effect pituitary conditions can have on patients is the dearth of research looking at the needs of patients and how they manage their own care (Jackson et al, 2008). There has been a general focus on the importance of health-related quality of life and the impact that managing long-term conditions may have upon it (Heyworth et al, 2009) and on mental health (Naylor et al, 2012). The quality of life of pituitary patients is likely to be impacted by condition management issues as well as the psychosocial symptoms associated with their conditions (Osbourne et al, 2006; Jackson et al, 2008; Crespo et al, 2015; Lobatto et al, 2018). Quality of life comprises components such as satisfaction with physical and mental health, social goals (including relationships, employment and social activities), and emotional needs (Gregory et al, 2009). These different aspects of quality of life are intrinsically linked. For example, poor physical health is likely to lead to deficits in social satisfaction, and possibly difficulties meeting one's emotional needs (Connell et al, 2012).

It has been suggested that further services need to be developed to support the psychosocial needs of pituitary patients (Jackson et al, 2008). Currently, the most comprehensive package

Box 1. Open-ended survey questions

Patients could opt to answer some or all of the following questions

1. What do you feel are the key issues affecting you as a patient and how could The Pituitary Foundation help address these issues?
2. Can you tell us about the impact that your illness has had on any relationships you have?
3. Have you ever had problems getting people to understand your condition? If yes, please describe how this can be difficult
4. Can you please describe how The Pituitary Foundation has been able to help you?
5. Can you please describe the parts of your illness that you find the most difficult to manage or deal with?
6. What kind of support mechanisms might improve your quality of life?
7. What do you feel are the main issues facing the pituitary community that The Pituitary Foundation could consider focusing on within its campaigns and policy work?

Table 1. Respondent characteristics for free text responses

Respondent characteristics	Number of males (254)	Number of females (488)	Unspecified sex (6)
Age ranges			
12–18 years	3	5	1
18–25 years	12	10	3
26–35 years	76	62	1
36–55 years	46	207	0
56–65 years	117	111	0
Over 65 years	0	88	0
Unspecified	0	5	1
Pituitary condition			
Hypopituitarism	68	97	1
Diabetes insipidus	3	77	0
Non-functioning tumour	38	74	1
Acromegaly	7	61	1
Prolactinoma	11	94	2
Cushing's disease	23	49	1
Craniopharyngioma	8	36	0
Hypogonadism	61	22	0
Sheehan's syndrome	0	11	0

of psychosocial support available to UK pituitary patients seems to be limited to that offered by the Pituitary Foundation (https://www.pituitary.org.uk). **AQ3** OK to add? The organisation provides patient information and support around specific conditions, medical management, and management of psychosocial difficulties. However, further research is required to better understand the psychosocial factors and their impact on quality of life.

The current study explored the impact of condition management and psychosocial symptoms on the quality of life of pituitary patients.

Methods

Ethical considerations

Approval was obtained prior to data collection from the Faculty **AQ4** of? at the University of Plymouth (ref: 10365532). Participants were approached by the Pituitary Foundation; informed consent was obtained from all individuals.

Data collection and analysis

AQ5 Did the authors devise the questionnaire? Each participant was sent either a paper version of the questionnaire or sent a link to an online version using the survey platform Survey Monkey. Participants completed a range of Likert-scale and tick-box questions about their pituitary condition and the care they received as well as a series of open-ended questions that they could respond to in free text (see *Box 1*). The quantitative aspects of the data are reported elsewhere (Norman et al, 2021). This article reports demographic quantitative information using means and standard deviations to clearly represent the population characteristics alongside the qualitative findings from the open–ended survey responses. These latter were analysed using conventional content analysis (CCA), a technique employed to elicit information about a topic with limited pre-existing literature (Hsieh and Shannon, 2005). CCA allows information to be gathered from the participants' responses without placing it in predefined categories (Hsieh and Shannon, 2005). **AQ6** how many? members of the project team began the analysis by reading the data repeatedly to gain a deep understanding (Vaismoradi et al, 2016) and writing exploratory comments. Responses were read again to derive codes within the data that captured key thoughts and concepts (Bradley et al, 2007). These codes were then organised into related categories and then meaningful clusters (Sparkes and Smith, 2014), which coalesced into the master themes. A validation analysis of the codes was conducted by another member of the project team. The final analysis was discussed by the project team, and an agreed interpretation of the data was produced.

Results

Participants

The Pituitary Foundation sent the questionnaire to its 2000 members between June and August 2016. One thousand and sixty-two members responded (683 females, 366 males, 13 unknown); a response rate of 53%. Of these, 748 (254 males, 488 females, 6 unknown; *Table 1*) responded to the free-text section relating to quality of life and the psychosocial impact of pituitary conditions; a response rate of 70% of respondents and 38% of the total sample (a figure in keeping with responses to qualitative questions within questionnaires, McGuirk and O'Neill, 2016; O'Cathain and Thomas, 2004). **AQ7** ref missing?

An overarching theme of hidden disability was identified,

Table 2. Themes

Overarching theme	Theme	Sub-theme
Hidden disability	1. Physical and cognitive effects (161)*	a) Fatigue (528) b) Pain (352) c) Sleep disturbance (330) d) Feeling unwell (208)
	2. Emotional and behavioural Issues (610)	a) Mood swings (417) b) Anxiety and depression (510) c) Poor self-esteem (140)
	3. Appearance distress (510)	a) Weight gain (413)
	4. Social isolation (628)	a) Employment (63) b) Personal relationships (444)

*Numbers in brackets represent number of times the theme was identified in the survey data

Table 3. Quotes supporting overarching theme: hidden disability

Theme	Supporting quotation
Hidden disability (overarching theme)	‘It is incredibly difficult and really frustrating—if you had an arm missing people would have so much more sympathy for your condition, with this it is a totally hidden illness that nobody can relate to’ P170 ‘Living with a hidden disability. I fear being judged’ P158 ‘Lack of understanding of this hidden illness from lots of medical staff’ P338

P=AQ8 what does P stand for? Patient? Participant?

Table 4. Quotes supporting theme 1: physical and cognitive effects

Theme	Supporting quotation
Theme 1: physical and cognitive effects	‘I don’t have a functioning pituitary gland. I struggle with anxiety, fatigue, memory issues, weight problems’ P198 ‘I have had to stop work because … I have lapses in concentration and energy crashes. I can’t work regularly’ P97 ‘…general reduction in ability to concentrate has made me lose confidence at work and has limited my opportunities as it is a “hidden” disability’ P144
Sub-theme: fatigue	‘Fatigue. I do feel no one takes it seriously enough. It affects my whole life. Feel too tired to travel, to work full time, to go out in the evening’ P24 ‘Managing energy, fatigue etc, naming what is often invisible but very real’ P204. ‘Chronic fatigue—impacts personal and social life’ P363
Sub-theme: pain	‘I have so many debilitating symptoms … head pain, spine pain through the roof …’ P44 ‘Pain in head “chronic and intractable” has had the biggest impact on my life. Had to give up career. Best experts haven’t cured it’ P273
Sub-theme: sleep	‘Tiredness and sleep problems …’ P399 ‘My lack of sleep! Everytime I ask my GP or endocrinologist about it they just raise their eyebrows and say [they] don’t know.’ P418 ‘Days my body just shut down on me, tired, falling asleep’ P487
Sub-theme: feeling unwell	‘I constantly still feel unwell, quality of life has been poor’ P28 ‘Pituitary tumours are rare and therefore people who may feel very unwell are put into the too difficult category and dismissed by their GPs. I felt I went through something close to hell for nearly two years’ P178

P=?

which was associated with four other themes of social isolation, emotional and behavioural issues, appearance distress, and physical and cognitive effects, all of which had sub-themes (See *Table 2*).

Overarching theme: hidden disability

The concept of pituitary conditions being a ‘hidden disability’ (where the cause of most of the illness symptoms cannot be observed by others and/or are not easily explained) was linked to all other themes. The fluctuating nature of some pituitary conditions, for example, participants reported being able to function well on some days but not on others, made things worse and was often cited as the cause of a lack of understanding from others. Many of the symptoms and quality-of-life issues reported by participants were linked to the invisible aspects of pituitary conditions (*Table 3*).

Theme 1: physical effects and cognitive effects

The most reported issue was fatigue followed by pain, sleep disturbance and feeling generally unwell, all of which are subjective states and none of which are amenable to objective measures such as blood tests, which can make it difficult for patients to be believed by health professionals. Prior to diagnosis such symptoms are often dismissed or attributed to mood disorders or conditions such as chronic fatigue syndrome or fibromyalgia. Post-treatment patients often complained that health professionals focused on biological function measured by medical tests. As long as these are within normal ranges, subjective patient reports of problems are largely ignored. This lack of acknowledgement from health professionals can add to the patients’ difficulties when trying to explain what they are experiencing to others.

Respondents also reported cognitive difficulties, with memory and concentration problems featuring most prominently. These cognitive changes can be so significant that people can no longer undertake skilled and valued activities or may have to change or cease employment (*Table 4*). Cognitive changes can carry the fear of dementia or the potential stigma of incipient ‘madness’ for patients. Although cognitive difficulties can be assessed it was rare for patients to report undergoing such assessment. Again, the lack of acknowledgement or support from health professionals makes life difficult for patients.

Sub-theme: fatigue

Many of the participants (769 respondents **AQ9** Table 2 states 528?) reported issues with fatigue. It is important to note that fatigue is not simply feeling tired; it is characterised by a sense of exhaustion that has physical, emotional and cognitive components (McCabe, 2009; Carriker, 2017). Fatigue forced individuals to make choices—deciding how to spend the little available energy, with responsibilities such as work and household chores tending to take priority. Fatigue is a subjective state that is largely invisible to others, but the strain of it can cause significant problems in relationships, employment, and social activities (*Table 4*).

Sub-theme: pain

Participants reported feeling pain, usually headaches but also more general chronic or intermittent pain. Like fatigue, pain is a subjective state largely invisible to others. Chronic pain is exhausting and often impacts on sleep, which creates a vicious cycle where a lack of rest results in increased stress and tension and possibly more pain. Like fatigue, it can result in individuals being unable to meet their employment, social or household obligations (*Table 4*).

Sub-theme: sleep

Sleep disturbance was also reported, including episodes of insomnia, poor quality sleep and bouts of unplanned sleep during the day. Lack of sleep has serious effects and impacts on concentration, attention and mood. Continued lack of sufficient sleep leads to problems with language (getting words out), memory, planning, and decision-making.

Sub-theme: feeling unwell

The final physical symptom reported by respondents was a feeling of being generally unwell. Although pituitary conditions may make patients feel unwell at particular times, participants highlighted more chronic ill health such as having poor immunity and experiencing longer recovery times from illness. Many of the symptoms can be vague and fluctuating and may be interpreted by health professionals and others as indications that the patient is poor at managing the stress of their lives, with a tendency to somatise it.

Theme 2. Emotional and behavioural issues

Participants in the study detailed the impact that their pituitary condition had on their mental wellbeing and behaviour, with some reporting mental health difficulties. Respondents identified a need for more support such as counselling and psychoeducation to improve their mental health. Specifically, respondents reported lowered self-esteem, mood fluctuations, and increases in depression, anxiety and stress since the onset of their condition (*Table 5*).

Sub-theme: mood fluctuations

Participants provided detailed information about the difficulties they experienced managing mood fluctuations. Commonly reported were short-lived and fluctuating episodes of feeling angry and out of control, tearful or hyperactive. Such mood swings were identified as a key factor in the breakdown of personal relationships (*Table 5*).

Table 5. Quotes supporting theme 2: emotional and behavioural effects

Theme	Supporting quotation
Theme 2. Emotional and behavioural effects	'Emotional/mental impact of diagnosis and the subsequent lack of information, care and support with symptom management from doctors and specialists, which seems to be very common' P10 'Mental issues are the main area I need help with …' P154
Sub-theme: fluctuations in mood	'The overarching daily effects of having a pituitary condition, not just having a tumour … mood swings' P9 'Acute tiredness, mood swings …' P282 'Tiredness; low mood; body image; infertility' P509
Sub-theme: depression and anxiety	'…anxiety. Originally had a consultant for 3.5/4 years that never answered any questions. Had to be diagnosed with depression (stemming from lack of awareness about my condition) before I was directed to other sources of information …' P138 'Loss of livelihood and membership of professional body as a result. Depression linked to condition' P324
Sub-theme: self-esteem	'Not enough is said about anxiety, loss of confidence, nervousness that affect so many of us.' P116 'The effect the condition has on emotional well-being, mental health and confidence' P142

P=?

Sub-theme: depression and anxiety

In some instances, participants reported that they were experiencing ongoing periods of anxiety and depression because of their conditions. Respondents were keen to note the lack of support that they had received and the 'need [for] help with anxiety and depression' (*Table 5*).

Sub-theme: self-esteem

Participants also commented on the impact their condition had on their self-confidence and self-esteem. Having conditions that impact on mental health and are potentially difficult to manage medically left patients feeling nervous and lacking confidence. Mental health issues are still stigmatised and sometimes misunderstood, leaving patients in a difficult position, needing help and support but having significant concerns about what impact such a diagnosis might have for their employment prospects, which might already be under threat because of their health status (*Table 5*).

Theme 3. Appearance distress

Raised frequently by respondents, pituitary conditions can alter appearance significantly, although keeping individuals within usual population norms. A range of physical changes were identified as distressing; weight gain, excessive/heavy perspiration; hair loss or growth, acne and other skin complaints. Other distress related to the lack of understanding from others. Participants reported friends and family telling them that they should simply be grateful to be alive. In these instances, respondents referred to some pituitary conditions as being

Table 6. Quotes supporting theme 3: appearance distress

Theme	Supporting quotation
Theme 3: appearance distress	'I was diagnosed in my late teens at a point in my life when I was still coming to terms with who I was physically and emotionally and career wise … dealing with my 'more manly appearance!' P63 'The fact that outwardly your physical appearance is fairly normal whilst you mentally and physically are struggling, pituitary conditions are long term' P371
Sub-theme: weight gain	'Weight gain, more information and how to deal with weight gain whilst on steroids' P147 'I feel things like weight gain and fatigue are part of my condition and yet healthcare professionals do not acknowledge this' P111

P=?

Table 7. Quotes supporting theme 4: social Isolation

Theme	Supporting quotation
Theme 4: social Isolation	'Mainly it's all the issues that are not deemed as important by the doctors eg mental health, physical appearance, emotional effects …' P431 'Isolation, survival of relationships is by pretending the problems I experience with my two rare conditions do not exist' P12 'Isolation socially as I do not have the energy that I used to' P75
Sub-theme: employment	'During this time lost work colleagues and friends as they didn't understand' P108 Financial difficulties—having to take time off of work following surgery but no advice on financial help for working people just advice on benefits, which workers are not entitled to. Maybe some advice on whether or not critical illness insurance might help' P104 'As I am not working, the costs of attending hospital and other clinical appointments is an issue. Managing finances are also impacted' P387
Sub-theme: personal relationships	'My partner left, family don't understand' P135 'Family relationships were put under strain due to breakdown in communication' P405 'My partner felt my personality changed' P293 'I am single and would love to meet someone but feel as though I am living under a cloud' P88 'I have gone from being independent to living with my children' P87

P=?

'hidden conditions' because the change in appearance that was significant to them as indicative of their illness was not interpreted as meaningful in the same way by others (*Table 6*).

Sub-theme: weight gain

Many participants complained of experiencing weight gain since the onset of their condition. Many also reported feeling stigmatised and hearing prejudicial remarks from others about the reasons for their weight gain (*Table 6*).

Theme 4. Social isolation

Respondents commented on the social difficulties brought about by having a pituitary condition. This was particularly apparent in employment and personal relationships, both of which had been impacted greatly.

Sub-theme: employment

Respondents reported having problems staying in, or returning to, employment after the onset of their condition, or after treatment. Many had to reduce their working hours or change employment because they were unable to maintain their previous role. Others reported having to cease employment due to ongoing symptoms associated with their condition (described in themes 1 and 2). Whereas a loss of employment had a large financial and economic burden on individuals, it also had an impact on quality of life; a lack of employment reduces social contact and can lead to increased social isolation, and symptoms of pituitary conditions can lead to reduced social support from colleagues (*Table 7*).

Sub-theme: personal relationships

The issue of emotional support from friends and relatives was raised by respondents. Participants highlighted a lack of understanding because 'people haven't heard of it' or what the pituitary gland does in the body. Tied into this was a lack of understanding of the nature of pituitary conditions; participants reported how others fail to understand the variable nature of symptoms, that they had been told that they did not have cancer so would be fine, and that they could be 'cured'. In some cases, pituitary conditions can be life-threatening, but participants reported difficulties in getting others to understand this. With no obvious physical markers of serious or chronic ill health to show to others, participants struggled to find credibility for their suffering in the eyes of others (*Table 7*).

These problems with understanding often put huge pressures on the relationships between individuals with pituitary conditions and their wider family and friends. Many reported that the condition had put a strain on their relationship with their partner/spouse, or wider family, or that their relationship had broken down because of their condition. The lack of understanding many experienced was linked to being a 'different person' since their condition developed. Others highlighted that wider symptoms (noted above) had led to them losing contact with friends or having strained relationships with family and partners (*Table 7*).

As well as a negative impact on relationships, respondents commented on the burden that having a pituitary condition puts on the wider family unit. Participants identified that in some cases their partners and families had been incredibly supportive, but there had been a change in the relationship with them as their condition made them increasingly reliant for help, putting an unfair strain on their family (*Table 7*).

Discussion

The findings from this study identified that pituitary conditions can have a detrimental impact on the quality of life of patients. Key symptoms were those that affected emotional, behavioural, physical and cognitive functioning. These had a negative effect on the ability of respondents to return to work either after disease onset or after treatment, also impacting on personal relationships. Heald et al (2004) previously identified the impact on personal relationships, but limited research exists on the impact of **AQ10** of or on? returning to work post-treatment (Prince, 2017; Lobatto et al, 2018).

Respondents reported that many of the symptoms of pituitary conditions were not physically noticeable to others, so their day-to-day disabilities were 'hidden', leading to a lack of understanding and support from health professionals, friends and family. This concept of a hidden disability has been identified by other patients with cognitive and emotional difficulties, such as those with acquired brain injuries (Moore et al, 2019; Odumuyiwa et al, 2019), and those with chronic fatigue (Hughes et al, 2016). Although physical impairments are difficult to manage, their visibility affords a degree of support in terms of understanding and access to appropriate help. For those with hidden disabilities, support and understanding is often lacking, even among health professionals (Osbourne et al, 2006; Prince, 2017; Odumuyiwa et al, 2019; Moore et al, 2019).

Specific emotional and behavioural issues reported included mood swings, depression and anxiety. Previous literature has already identified the link between pituitary conditions and mood swings (Spencer et al, 2015) and with depression and anxiety (Brown and Kroenke, 2009). Despite these established links it seems there remains very little support and information for patients about these aspects of their condition, demonstrating a need for access to counselling, psychoeducation, and health psychology within endocrine teams (Osbourne et al, 2006; Andela et al, 2018).

Respondents also reported cognitive issues, such as memory impairments and poor concentration. These findings are supported by previous literature (Andela et al, 2016). Respondents also reported physical symptoms invisible to others, such as sleep disturbance, pain and fatigue, which have been noted in previous studies of patients with pituitary conditions (McCabe, 2009; Crespo et al, 2015; Hirotsu et al, 2015; Akopian et al, 2018 **AQ11** reference missing), and yet patients still reported a lack of support in managing these aspects of their condition.

Finally, the impact that these quality of life aspects have had on patients was identified through the theme of social isolation. Patients consistently reported difficulties with returning to work or continuing in employment. Reduced social contact and a lack of support from colleagues and employers are detrimental to quality of life and financial stress is a likely additional burden, as outlined in the sub-theme 'employment'.

Limitations

Although it is likely that the symptoms reported in this study reflect the wider population, with the sample coming from the membership of the UK's Pituitary Foundation it is possible that these individuals represent those **AQ12** who have sought support from the charity? and therefore may have experienced less support from health professionals. Additionally, the survey answers were relatively limited, lacking the richness and depth of information arising from interviews. This is an important aspect for future research as a detailed and more nuanced account of the impact of these elements on quality of life would better inform improvements in interventions.

Implications for practice

Many respondents reported a marked lack of support and information regarding their quality-of-life issues. Although other studies have identified that the 42 endocrine specialist centres across the UK provide good continuity of care to patients in terms of medical management (Forrest et al, 2018), this is not the case for the psychosocial effects of the conditions (Osbourne et al, 2006). A key recommendation would be regular referral to counselling and/or routine inclusion of a health or clinical psychologist within endocrine services. This kind of routine psychological support is in the guidelines for patients with other long-term conditions such as those with cleft lip and palate (Norman et al, 2015) and those with cancer (Price et al, 2006), although service provision is not always available. To help plug the gap, the use of psychoeducational information for patients about the potential quality-of-life impact of pituitary conditions is recommended.

Webb et al (2002) suggested that there are 12 areas that impact on health-related quality of life for pituitary patients where support is needed: physical, psychological, social, symptom management, undertaking daily activities of living, cognition, general health perception, sleep, sexual function, pain, low energy/fatigue, and body image. It would be beneficial if each specialist service had information sheets documenting how these issues impact patients, suggesting self-management strategies and advice on how to access specialist support from a variety of sources. This would also make effective use of clinician time. Over the past decade the Pituitary Foundation has published a series of articles addressing these issues in its patient magazine, *Pituitary Life*. Taking these and formatting them into information sheets available for health professionals to download from its website would go a long way to improving the provision of useful information.

AQ13 Could you add a couple of sentences on helpline operators here so that it is not just in the conclusion?

There have been promising initial results from an 8-week cognitive behavioural therapy self-management intervention for partners and patients with pituitary conditions developed in the Netherlands (Andela et al, 2017). If possible, a trial in the UK facilitated and/or supported by the Pituitary Foundation could be instructive on how best to support patients and their families. The foundation could also facilitate more research on the psychosocial issues faced by this patient population to enable the production of more nuanced psychoeducation materials. The foundation's wellbeing leaflets particularly would benefit from this—as they stand, they detail common problems faced by patients with pituitary conditions along with suggested self-help strategies and ideas. However, they tend to give the impression that all the issues documented are equally likely to be experienced by all patients with every pituitary condition, but this may not be true. The series could also be usefully expanded to address some currently notable omissions on topics such as memory problems ('brain fog'), pain and sleep, thus providing an

KEY POINTS

- Psychosocial and physical symptoms are commonplace among patients with pituitary conditions
- It is important for health professionals to address these issues directly with patients
- Patients expressed experiencing social isolation, emotional and behavioural issues and appearance distress associated with their condition
- Common physical and cognitive effects included fatigue and pain
- Patients reported having a ‘hidden’ disability which negatively impacted on their quality of life

additional resource to support patients with these issues, along with more helpline sessions for patients with their specialist endocrine nurse. The Pituitary Foundation could also do more to promote the services and materials they have available to both GPs and other health professionals, including nurses and social workers.

It would be of benefit if specialist endocrinology nurses offered education and training to primary care colleagues in their locality (advanced nurse practitioners, GPs, community nurses, and practice nurses) to raise awareness of the unseen burdens that patients with pituitary conditions have to deal with. This would hopefully have the additional benefit of improving integrated care for patients. Since it is not realistic to expect the specialist centres to offer all the necessary care, signposting to other support in the locality would be an important element of such training and if the strategy of using information sheets to support the key areas of quality of life were adopted, as suggested above, this training could also include sharing such resources with primary care colleagues. Nurses, particularly advanced nurse practitioners, are well-placed to provide information to individuals with pituitary conditions, and their families, about the kinds of difficulties they may experience and offer support in navigating these. For example Llahana et al (2019) under the auspices of the European Society for Endocrinology, have developed materials to enable this. Written by an international team of eminent health professionals and supplemented by contributions from patient advocacy groups, their two-volume book, *Advanced Practice in Endocrinology Nursing* not only provides comprehensive information on all areas of endocrinology but also has a final section of three chapters describing how the materials in the book relate to the fulfilment of the key competencies of advanced practice nursing.

Social workers also play a key role in supporting patients through an increased understanding of hidden disabilities and the impact such symptoms, particularly cognitive difficulties, can have on day-to-day living (Findley, 2014). Increased awareness and training are required to enable these professionals to identify and support people with hidden disabilities.

Conclusions

As found in previous literature, the psychosocial symptoms associated with pituitary conditions include appearance distress, emotional and behavioural issues, and physical and cognitive difficulties. Of particular interest is that the symptoms most likely to impact negatively on quality of life were those that were least visible to others. Arguably, pituitary conditions are a form of hidden disability accompanied by a lack of understanding and support from others within healthcare settings, at work and within personal relationships. Further psychological support is needed to improve quality of life for pituitary patients. Not all patients can always be seen or treated in endocrine specialist centres so it behoves other health professionals such as nurses to be aware of some of the hidden problems that patients might be dealing with. The Pituitary Foundation could also provide more and better psychoeducational materials for health professionals and patients to use as well as more specific psychosocial training for their helpline operators. **BJN**

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CPD reflective questions

- What resources could be provided to pituitary patients in your area to support them with their psychosocial and physical symptoms?
- How can health professionals offer support to those with hidden disabilities?
- How might nursing staff facilitate a conversation with patients about psychosocial and physical symptoms?