

British Journal of Community Nursing

Pituitary conditions: Importance of geography and the Pituitary Foundation in patient support --Manuscript Draft--

Manuscript Number:	bjcn.2019.0035R1
Full Title:	Pituitary conditions: Importance of geography and the Pituitary Foundation in patient support
Short Title:	Living with a pituitary condition
Article Type:	Original research
Keywords:	Pituitary; Patient support; Psychosocial
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Abstract:	<p>Background</p> <p>Quality of life is significantly impacted for those with pituitary conditions; patients need support to meet ongoing physical and psychological needs.</p> <p>Aims</p> <p>To explore the support needs and experiences of patients with pituitary conditions in the community.</p> <p>Methods</p> <p>Ten self-selected members of the Pituitary Foundation were interviewed about their conditions, needs and experiences. Data were analysed using thematic analysis. Secondary thematic analysis was conducted on data from a sample of 748 members of the Pituitary Foundation.</p> <p>Findings</p> <p>Four themes were revealed, coming under one overarching theme of geography; 1) Life-changing diagnosis, 2) The Foundation as a source of support, 3) Access to the Foundation, and 4) Attendance at support groups. A pituitary diagnosis is life-changing, and requires significant physical and psychological support.</p> <p>Conclusions</p> <p>Better training is required for health professionals about pituitary conditions, their long-term consequences, and the need to signpost patients to wider services offering</p>

	essential support.
Suggested Reviewers:	
Response to Reviewers:	<p>Reviewers' comments:</p> <p>Reviewer #1: If you have specific feedback for the author about how to go about improving the article or bringing it up to a publishable standard, please enter it here.</p> <p>Some of the research used in this is old -for example Anderson (1992). There is a wide range of more contemporary literature available to support the key points and this would strengthen this research article. Old references have been removed and replaced or added to throughout.</p> <p>1.An outline of the pathophysiology of this condition would enhance readers understanding of the condition and provide the necessary professional focus for the readership of this piece.</p> <p>The following has been added to the introduction: By far the most common type of tumour (about half of all cases) is the 'non-functioning' tumour. Despite not producing any hormones itself it can cause headaches and visual problems or it can press on the pituitary gland, causing it to stop producing the required amount of one or more of the pituitary hormones. This effect can also happen as a response to treatment for pituitary tumours such as surgery or radiotherapy. Other common pituitary conditions are Acromegaly (an adenoma causing too much growth hormone), Adult Growth Hormone Deficiency (resulting from damage to the pituitary gland or its blood supply), Craniopharyngioma (a very slow-growing cyst-like tumour most commonly found in children), Cushing's Disease (over-production of cortisol), Diabetes Insipidus (problems with the production, or action, of the hormone vasopressin), Hypopituitarism (under-production of hormones by the pituitary gland), and Prolactinoma (prolactin-producing tumour). In the early stages, each of these conditions presents with an array of symptoms including mood swings, problems with memory and concentration, fatigue, headaches, weight changes, to name but a few. The combination of vague symptoms and rarity tends to mean that diagnosis for a lot of patients is a very long process (Pituitary Foundation 2016).</p> <p>2.The role and work of The Pituitary Foundation could be more explored. There is some explanation of the support available but it seems this is locality specific and variable so it would be good to know what core services are available nationally for the reader.</p> <p>The following has been added to the introduction: To this end the Foundation has a website which provides information on each pituitary condition. In addition, the Foundation has a number of publications ranging from simple leaflets describing each condition through to longer booklets and a regular magazine that identify key issues in living with various aspects of the conditions which can be ordered by both patients and their healthcare professionals.</p> <p>The Foundation also offers support through patient conferences and local support groups run by volunteers. In addition, there are a number of patient helplines including one provided by a specialist endocrine nurse, and a series of webinars also provide information and a chance for patients to talk to experts.</p> <p>3.It seems that the research is heavily biased towards the work of the Pituitary Foundation -an explanation of the background of the foundation is required and a summary of why this specific research was considered necessary would provide some underpinning for the reader.</p> <p>The following has been added to the introduction: While there have been a number of charities set up to support patients with specific pituitary conditions, the Pituitary Foundation is the one with the largest membership and most educational materials offering support to patients with any pituitary condition.</p> <p>The methodology selected requires further explanation -it is unclear why in-depth semi structured interviews were not considered sufficient to explore the lived experience of the participants in this research. It is unclear why in-depth interviews were not carried out until saturation was achieved. It is also unclear why the researchers decided that a large open ended survey was required. There is no description of the survey methods or tools used to support data collection. The following was added at the end of the description of stage 1 of data collection: The authors had intended to continue data collection until data saturation was complete but were unable to recruit further. Therefore, it was decided to utilise a survey conducted for the Pituitary Foundation to include qualitative questions to identify if similar experiences had occurred in the wider</p>

	<p>population. Therefore, in stage 2...</p> <p>The following has also been added to stage 2 information in the method: The survey consisted of seven section, most of which consisted of quantitative questionnaires about the experiences of the members when managing their conditions and the access to services they had received through the Pituitary Foundation (these data are reported elsewhere). The final section of the survey consisted of open-ended questions asking about experiences of living with a pituitary condition, quality of life, and access to support. Surveys were sent out to members either as a pen and paper questionnaire or via a link to a survey monkey version.</p> <p>In your discussion you highlight the role of health professionals in signposting individuals towards The Pituitary Foundation-there is a need to consider the importance of factors such as patient activation and any other potential barriers that individuals may face in accessing services outside of 'traditional' NHS provision. The following has been added into this section: While it is important to note that there are other barriers to patients accessing such third sector services, such as denial about their need for such services (Kogan et al, 2013), and issues with patient activation (patients lacking the knowledge, skills or confidence to manage their own healthcare needs; Greene & Hibbard, 2012), the participants in this study did often report a lack of referral to the Foundation. This may be due to a lack of awareness on behalf of HCPs</p> <p>The reference list is not in alphabetical order. All references now in alphabetical order – thank you</p> <p>Please can you explain why an application was not made to Health Research Authority (HRA) in England was not made for ethical approval when patients were being interviewed. As recruitment was conducted through the Pituitary Foundation, HRA ethics approval was not required.</p> <p>Please can you add a full stop after et. al eg et. al. Changed throughout – thank you pg5 - ' with a living with a patient' please rephrase as this does not read well. Apologies but this phrase could not be found in the document</p> <p>Please also rephrase that last paragraph. Changed as follows: Conclusions: The study identified the value of the Pituitary Foundation as a vital source of support and information for patients when trying to make sense of their condition. That the organisation provides long-term support, not just immediately after diagnosis, but through the patient journey, matters to patients. However, there are difficulties with signposting to the Foundation and the services available through the organisation. This may, in part, explain why so many people with pituitary conditions throughout the UK are still not members of the Foundation. Greater publicity of the Pituitary Foundation, and improved referral from HCPs is required.</p>
Additional Information:	
Question	Response
Please enter the word count of your manuscript, excluding references and tables	2607

Pituitary conditions: Importance of geography and the Pituitary Foundation in patient support

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Abstract

Background: Quality of life is significantly impacted for those with pituitary conditions; patients need support to meet ongoing physical and psychological needs.

Aims: To explore the support needs and experiences of patients with pituitary conditions in the community.

Methods: Ten self-selected members of the Pituitary Foundation were interviewed about their conditions, needs and experiences. Data were analysed using thematic analysis. Secondary thematic analysis was conducted on data from a sample of 748 members of the Pituitary Foundation.

Findings: Four themes were revealed, coming under one overarching theme of geography; 1) Life-changing diagnosis, 2) The Foundation as a source of support, 3)

Access to the Foundation, and 4) Attendance at support groups. A pituitary diagnosis is life-changing, and requires significant physical and psychological support.

Conclusions: Better training is required for health professionals about pituitary conditions, their long-term consequences, and the need to signpost patients to wider services offering essential support.

Competing Interests: None of the authors have any competing interests to declare

Acknowledgements: The authors would like to thank the participants involved in the study and the Pituitary Foundation for providing support with recruitment.

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Introduction

The pituitary gland is extremely important for regulating the functioning of the hormones within the body and is particularly vulnerable to the development of benign non-cancerous tumours called adenomas - the largest cause of problems associated with the pituitary gland. These growths can lead to an over or under production of various hormones throughout the body. Research has estimated that there are between 50,000 – 70,000 pituitary patients in the UK which equates to 0.08% -

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0.11% of the population (Pituitary Foundation 2016). By far the most common type of tumour (about half of all cases) is the 'non-functioning' tumour. Despite not producing any hormones itself it can cause headaches and visual problems or it can press on the pituitary gland, causing it to stop producing the required amount of one or more of the pituitary hormones. This effect can also happen as a response to treatment for pituitary tumours such as surgery or radiotherapy. Other common pituitary conditions are Acromegaly (an adenoma causing too much growth hormone), Adult Growth Hormone Deficiency (resulting from damage to the pituitary gland or its blood supply), Craniopharyngioma (a very slow-growing cyst-like tumour most commonly found in children), Cushing's Disease (over-production of cortisol), Diabetes Insipidus (problems with the production, or action, of the hormone vasopressin), Hypopituitarism (under-production of hormones by the pituitary gland), and Prolactinoma (prolactin-producing tumour). In the early stages, each of these conditions presents with an array of symptoms including mood swings, problems with memory and concentration, fatigue, headaches, weight changes, to name but a few. The combination of vague symptoms and rarity tends to mean that diagnosis for a lot of patients is a very long process (Pituitary Foundation 2016).

Many pituitary conditions impact on day-to-day functioning, not least due to the required drug treatments (e.g. hydrocortisone) to regulate hormones (Pituitary Foundation 2016). Conditions require life-long monitoring and management, which is notoriously difficult and patients often experience high levels of distress which are often not recognised or addressed by health care professionals (HCPs; Osbourne et al. 2006). As a result, pituitary conditions have been found to have a large negative impact on quality of life (Osbourne et al. 2006).

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Part of the difficulty in understanding the effect of pituitary conditions is the lack of research on the needs of patients and how they manage their care (Jackson et. al. 2008). In particular, further research is needed to understand the psychosocial needs of patients, including the role of support groups like the UK Pituitary Foundation.

Set up in 1994, the Pituitary Foundation's main objective is to provide information and support to help individuals with pituitary conditions to manage the day-to-day issues they may face. The Foundation offers many resources to its members, including access to emotional and psychological support for their diagnosis. To this end the Foundation has a website which provides information on each pituitary condition. In addition, the Foundation has a number of publications ranging from simple leaflets describing each condition through to longer booklets and a regular magazine that identify key issues in living with various aspects of the conditions which can be ordered by both patients and their healthcare professionals. The Foundation's resources are evidence-based and designed by experienced researchers and HCPs in the field. The Foundation also offers support through patient conferences and local support groups run by volunteers. In addition, there are a number of patient helplines including one provided by a specialist endocrine nurse, and a series of webinars also provide information and a chance for patients to talk to experts.

While there have been a number of charities set up to support patients with specific pituitary conditions, the Pituitary Foundation is the one with the largest membership and most educational materials offering support to patients with any pituitary condition. It has been proposed that education is the best resource to prevent medical decline in patients with pituitary conditions (Chapman et. al. 2016,

(Arlt & Allolio 2003). This suggests the importance of the role of both HCPs and the Foundation in establishing what pituitary patients know in reference to their condition, as well as helping to identify what they need to learn, to enable them to be better equipped to cope with their condition on a daily basis. Taylor (2012) has suggested that if an individual has little information regarding their illness, they will find it harder to adjust to their diagnosis and to create adequate and effective coping mechanisms. Thus, if the Foundation is a good source of information, actively promoted to patients with pituitary conditions, then the expectation would be for individuals being better able to cope with their diagnosis and condition.

The local support groups and buddying system offered by the Foundation may be especially beneficial as they allow the exchange of life experiences and expertise between individuals with pituitary conditions. Previous research suggests that social interaction for individuals with health conditions is beneficial as it can facilitate social adjustment (Feeney & Collins 2015), reduce depressive symptoms (Pfeiffer et. al. 2011), and even extend the individual's life (Holt-Lunstad et. al. 2015). The current study aimed to explore patients' experiences of interacting with the Pituitary Foundation, in particular, the forms of support that have helped them to manage their condition.

Method

Participants

Recruitment to the study took part in two stages. In stage 1 the study was advertised at the Pituitary Foundation Annual Conference and through local support groups in the South West of the UK. Ten individuals (four men and six women aged between 37 and 72) with a pituitary condition took part in interviews about their experiences of

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having pituitary conditions and being involved with the Pituitary Foundation. The authors had intended to continue data collection until data saturation was complete but were unable to recruit further. Therefore, it was decided to utilise a survey conducted for the Pituitary Foundation to include qualitative questions to identify if similar experiences had occurred in the wider population. Therefore, in stage 2, 2000 members of the Pituitary Foundation were asked to complete a survey about having a pituitary condition and their experiences with the Foundation. Of these 1062 participants responded (254 males, 488 females, 6 did not state their gender), with 748 responding to qualitative questions similar to those posed to the interviewees in stage 1. Respondents in stage 2 ranged in age from under 18 to over 65 years. The survey consisted of seven sections, most of which consisted of quantitative questionnaires about the experiences of the members when managing their conditions and the access to services they had received through the Pituitary Foundation (these data are reported elsewhere). The final section of the survey consisted of open-ended questions asking about experiences of living with a pituitary condition, quality of life, and access to support. Surveys were sent out to members either as a pen and paper questionnaire or via a link to a survey monkey version. Ethical approval was gained from the University Faculty Committee. As recruitment was conducted through the Pituitary Foundation, HRA ethics approval was not required.

Data collection & Analysis

Stage 1: Each participant was interviewed over the phone by the first author using an interview schedule to ensure consistency, and was audio recorded with permission. Interviews ranged from ten minutes to one hour in duration.

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Stage 2: Each participant was asked to complete a series of open-ended questions about their experiences of having a pituitary condition and the role the Foundation played in supporting them either as a pen and paper exercise or using an online version of the survey.

The interview recordings from stage 1 were transcribed and analysed using inductive thematic analysis based on the method described by Braun and Clarke (2006).

Transcripts were scrutinised to identify the themes associated with having a pituitary condition and having contact with the Pituitary Foundation. The open-ended survey responses from stage 2 were analysed using qualitative content analysis (Hsieh & Shannon 2005) to identify key themes.

In order to ensure the rigour of the data analysis, independent validity checks were carried out at different points in the research process. Annotated transcripts and surveys showing the coding and emerging themes generated by the first author were checked by the second author in order that the analytic process could be verified and to enable the clarification of ambiguities. The final thematic structure was discussed by all three authors, and an agreed interpretation of the data was produced.

Results

The analysis revealed four main themes with associated sub-themes, plus one overarching theme outlined below (Table 1). The themes and sub-themes will be described in the order outlined in Table 1 while the relationship to the overarching theme will be described at the end of each theme section.

Table 1: Table of Themes

Theme One: Life-changing diagnosis

The biggest issue that participants felt they needed support with was the life-changing aspects of being diagnosed with a pituitary condition. Diagnosis had been overwhelming and transformative, in particular changing participants' perception of normality, and had a significant impact on their daily lifestyle, well-being, and how they felt others perceived them (Table 2).

Table 2: Theme 1 indicative quotes

Such a major life-changing diagnosis had two specific features that could be identified; a) difficulties with condition management, and b) mental health impact.

Sub-theme a) Difficulties with condition management:

Participants talked about how diagnosis can be a lengthy process, as HCPs often have insufficient knowledge about pituitary conditions owing to their rarity, and there is limited access to HCPs specialised in pituitary conditions in certain locales across the UK. Participants talked about long processes with medication trial and error until they found the balance of treatment, and HCPs often having poor understanding of the need for precise treatment regimens (Table 2).

Sub-theme b) Mental health impact of diagnosis:

Participants often spoke about how their diagnosis has made life a battle. Many described facing a lot of uncertainty when first diagnosed, and profound fear about

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their health and wellbeing. There were significant psychological impacts associated with diagnosis and subsequent life with the condition, such as depression and reduced self-esteem, with treatment having drastic effects on physical and emotional wellbeing (Table 2).

Overarching theme of Geography and relationship to theme one

Participants described a life-changing journey through diagnosis and onwards. In some cases this is literal geographic changes associated with work and home life due to; being unable to meet employment obligations, changes to the way individuals engage with their environment, or having to move closer to family members where support is more readily accessible. These changes can result in a changed life trajectory and expectations often associated with emotional distress exacerbated by the lack of acknowledgement, support and advice from HCPs. There are also practical geographic issues associated with healthcare. We associate hospitals and other medical environments with a sense of reassurance induced by access to medical knowledge and expertise perceived to be available at those locations. To discover this is not the case heightens the emotional distress associated with the condition – especially when it is ignored or the patients' lived experience is undermined by HCPs (Table 2).

Theme two: The Foundation as a source of support

Participants found the Foundation to be very beneficial for them. Where theme one described how participants felt they needed support in helping them to live with their condition, theme two describes how participants mainly accessed the support

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available from the Foundation. There were two distinct aspects to the support received: a) support with condition management, and b) reducing isolation (reducing the sense of being the only person with the condition).

Sub-theme a) Condition management:

All participants described the invaluable role of the Foundation in the provision of information, support and access to professionals who understand pituitary conditions. The Foundation was praised for providing information about diagnosis, conditions, adapting to life with a pituitary condition, and condition and lifestyle management. Individuals accessed these resources through other members of the Foundation, the local support groups, and the Foundation's website (Table 3).

Table 3: Indicative quotes for Theme 2.

Sub-theme b) Reducing isolation:

Participants felt that support groups not only helped them gain reassurance, they created a space which helped them achieve a shared understanding as individuals disclosed their mutual experiences of living with a pituitary condition. Other specific aspects of the Foundation that helped to reduce isolation included attendance at the annual conference and services provided for patient's families.

Overarching theme of Geography and relationship to theme two

The Foundation can help participants to move on in their care in a number of ways, not least in providing the understanding and reassurance that enables people to manage their condition. This is a useful service for patients who are

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feeling let down by their local hospital; it can help people to navigate the NHS and to locate the HCPs best placed to assist them.

Theme three: Attendance at support groups

Local groups are one way in which the Foundation provides support to patients with pituitary conditions. Regular membership at meetings and strong leadership were identified as key to the success of local groups. Leadership was important both in terms of attracting members and managing group cohesion, part of which was sharing similar values and interests (Table 4).

Table 4: Supporting quotations for theme 3 and overarching theme

Overarching theme of Geography and relationship to theme three

The Foundation does not have local support groups in every area of the UK. It was clear that local groups are highly valued, with some travelling long distances to attend. Yet many participants were unable to travel and others were in locations too remote to enable travelling (e.g. Channel Islands). Not being able to attend a local group can be ameliorated by members using other aspects of support provided by the Foundation, such as the information provided on the website. This highlights how the online resources of the Foundation also help to keep members connected.

Theme four: Finding the Foundation

Participants discussed how they had come into contact with the Foundation. Many participants described how they initially found finding information about the Foundation quite challenging, with some coming across it by accident, or through their own research. Only one participant out of the ten in stage one of the study was

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given information about the Foundation quickly after diagnosis. A similar situation was observed in the stage two analysis (Table 5). This lack of awareness was associated with the need for publicity.

Table 5: Indicative quotations for theme 4

Sub-theme: Publicity

Individuals need information regarding the Foundation as soon as possible after their diagnosis, but the general experiences of our participants tend to suggest that this is not happening. It seems so straightforward; HCPs just need to signpost newly diagnosed individuals to the Foundation, as happens in some areas. The participants were aware that the Foundation has been working hard to ensure a better referral pathway from hospitals, but there was recognition that it is an uphill struggle to get HCPs on board.

Overarching theme of Geography and relationship to theme four: Finding the Foundation

It would appear that the Foundation is often not signposted by HCPs but located by individuals on the internet. This is the kind of searching for resources that can be done from a safe and familiar environment (home) making it something that is doable in a situation where individuals may feel let down by the medical services, and thus isolated and vulnerable. Signposting has a literal geography associated with it – if the necessary psychosocial understanding and help cannot be provided by the hospital or GP then those places need to have information about how to locate the Foundation for their patients. HCPs have a great deal of social power which they

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could use to great effect in helping patients with pituitary conditions find their way to the Foundation.

Discussion

Summary

Pituitary conditions affect patients physically, mentally and emotionally, all of which have an impact on their interactions with their environment. There are multiple challenges to be faced and dealt with. It is clear that the participants find the work of the Foundation both highly valuable and important.

Limitations

A limitation of stage one was the small sample size. Whilst this is less important in qualitative analysis, it was felt that saturation had not been reached, leading to the incorporation of the data from stage two. Throughout the qualitative content analysis the themes highlighted in the original interview study were supported and data saturation was reached (no new themes were emerging). Therefore, the authors are confident that the analysis presented here can be generalised more widely to the population of pituitary patients who are members of the Pituitary Foundation.

Comparison with existing literature

This study has found that patients with pituitary conditions view their diagnosis as “life-changing”, particularly in relation to the need for careful condition management and the impact on mental health. This echoes previous research which has identified the difficulties patients experience with condition management (Osbourne **et. al.** 2006).

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One of the identified strengths of the Foundation was the variety of ways it provides information and support, with local support groups being especially important. Other researchers have found that support groups can provide a vital boost to well-being to individuals with long-term health conditions, as well as providing much needed sources of information (Dennis 2003).

Implications for Research and Practice

A long term condition can have a lasting impact on an individual's general health, well-being, quality of life and mental health resulting in significant costs for the NHS (Naylor [et. al.](#) 2012). In an over-burdened NHS, the third sector will be increasingly important in assisting and empowering patients to manage their condition. The Foundation are well placed to provide the specialist medical knowledge and emotional support needed by patients. Despite the importance of the work of the Foundation, there is clearly a lack of referral to the Foundation by HCPs, with patients often happening upon the Foundation during information-based internet searches when newly diagnosed. **While it is important to note that there are other barriers to patients accessing such third sector services, such as denial about their need for such services (Kogan et al, 2013), and issues with patient activation (patients lacking the knowledge, skills or confidence to manage their own healthcare needs; Greene et. al. 2015), the participants in this study did often report a lack of referral to the Foundation. This may be due to a lack of awareness on behalf of HCPs** which needs to be addressed.

Conclusions: **The study identified the value of the Pituitary Foundation as a vital source of support and information for patients when trying to make sense of their**

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condition. That the organisation provides long-term support, not just immediately after diagnosis, but through the patient journey, matters to patients. However, there are difficulties with signposting to the Foundation and the services available through the organisation. This may, in part, explain why so many people with pituitary conditions throughout the UK are still not members of the Foundation. Greater publicity of the Pituitary Foundation, and improved referral from HCPs is required.

Key Words

Pituitary, Patient support, Psychosocial.

Key Points

- Previous research on pituitary conditions have focused on the physiological impact of the condition.
- Limited research exists on the psychosocial impact of pituitary conditions and the subsequent effect of quality of life.
- This study highlights that pituitary conditions, and their management has a significant impact on the quality of life of patients and their families.
- The study also highlights the need for wider signposting by healthcare professionals to the Pituitary Foundation

Reflective questions

- How many patients have you seen in the last year with a pituitary condition, or who might have had a pituitary condition that was undiagnosed?

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- If you were to see a patient with a pituitary condition would you know how to manage their condition?
- What knowledge do you or your colleagues have about pituitary conditions and the Pituitary Foundation?

Funding: No funding was given to this research study

Ethical Approval: Ethical approval was received from the University of Plymouth, Faculty of Health and Human Sciences committee reference

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Table 1: Table of Themes

Theme	Sub-theme	Overarching theme
1. Life-changing diagnosis	a) Difficulties with condition management b) Mental health impact of diagnosis	Geography
2. The Foundation as a source of support	a) Condition management b) Reducing isolation	
3. Attendance at support groups		
4. Finding the Foundation	Publicity	

Table 2: Theme 1 indicative quotes

Theme	Indicative Quotations
Theme 1: life-changing diagnosis	<p>“There are long term implications and effects of pituitary problems on all aspects of life”. S77.</p> <p>“...you put it to the back of your mind...being truthful you can't really remember what it is like to be normal” P3.</p> <p>“I am an unreliable person socially and work wise...I have to cancel an appointment, a social engagement whatever...” P1</p> <p>“I constantly still feel unwell, quality of life has been poor”. S28.</p>
Sub-Theme: Difficulties with condition management	<p>“I spent three nights in hospital from being admitted into A&E with people going “We don't think he has had a stroke, we don't think he has had a heart attack”. I was then discharged... The next morning I was called back in to see a neurologist in the stroke team who suddenly started talking about pituitary apoplexy and that instigated the start of testing...which decided that I was adrenal insufficient”.P10.</p> <p>“I feel GPs, junior doctors and nurses need to have more knowledge of pituitary illness. I am grateful that the Pituitary Foundation and my consultants have given me the knowledge to point others in the direction of knowledge of pituitary illness” S154</p> <p>“Some doctors don't seem to take this very seriously or don't know what to do or think that the condition can't cause such problems” S319</p> <p>“Taking hormones artificially, they don't work the same way they would do normally. You're getting the medication wrong and quite often have to put it right again...” P10</p>
Sub-theme: mental health impact of diagnosis	<p><i>“I snap at times and normally at the people that I am closest to. I am single and would love to meet someone but feel as though I am living under a cloud”.</i> S88.</p> <p><i>“There were <u>dark days</u> when I first was diagnosed with Cushing's really <u>dark days</u>; in fact I didn't think I was going to make it”.</i> P7.</p> <p><i>“It knocks your self-esteem, because you do think back to things you might have achieved had the mere pituitary not decided to kick off...”</i> P1.</p>

	<p><i>“Not enough is said about anxiety, loss of confidence, nervousness that affect so many of us”. S116</i></p> <p><i>“...hit by an impact at high speed once a month, every time I got the injection...now I am on a different medication which is milder effects I am still trying to work out what it does” P3.</i></p> <p><i>“They do not realise damaged pituitary and medication = mood swings and tiredness and apathy” S603.</i></p>
<p>Overarching theme of Geography and relationship to theme one: Life-changing diagnosis</p>	<p><i>“I had to give up work. I had a professional job in the city...I haven’t been able to have a family...for a long time it was very difficult not having a family and not having a profession at that age [thirties]” P8.</i></p> <p><i>“I always have to plan going out...emergency bracelet... tablets...water...an alarm on my ipad for taking hydrocortisone...food”. P6.</i></p> <p><i>“When I was diagnosed I had to give up my job and move near my family, it has taken me a long time to get work and get established again”. S14.</i></p> <p><i>“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”. S63.</i></p> <p><i>“Trained medical staff I have encountered (ambulance, hospital A and E, surgical ward nurses, surgeons) do not understand the implications of being hydrocortisone dependent. I had my medication taken away from me...” S228.</i></p>

Table 3: Indicative quotes for Theme 2.

Theme	Supporting Quotation
Sub-theme: Condition management	<p>“I certainly came away feeling very impressed with the organisation... the leaflets about my condition and the endocrine support nurse and the support groups, those are probably the three things that have helped me” P8.</p> <p>“The endocrine nurse has helped me a number of times to deal with my diagnosis and understand the suggested treatment from my doctors” S6.</p> <p>“Initially a great source for information on condition and treatment. Also a great emotional information help from local group” S618.</p> <p>“I did not join/read anything about the Pituitary Foundation for ages. When I did, I realised that the hospital had given me steroids without...a steroid card...I didn't know I needed to wear a medic alert bracelet...the Pituitary Foundation have really opened my eyes on how to look after myself... I was wondering around without extra pills and I was going without a cortisone injection...so if I had of collapsed that would have been it” P3.</p>
Sub-theme: Reducing isolation	<p>“You're talking to somebody who knows what you mean,... You do not have to start from scratch... can pick up handy tips...” P1.</p> <p>“It made me realise I wasn't alone. I found the forum, endocrine nurse and the online booklets extremely helpful until I was made redundant and can no longer afford the membership” S135.</p> <p>“...giving my wife the opportunity to talk to other carers” P2.</p> <p>My sister called pit foundation and asked for advice on how the family could support me S403.</p>
Overarching theme of geography and the relationship to theme two	<p>“Oh it helps me understand the condition, understand what to do about it, understand the effects of the medication...it helps me to find the specialist medics that I should see...It helps me feel not alone and having the nurse at the end of the support it just so reassuring...” P9.</p> <p>“I have used information sheets to think about the preparation for going on holiday and potential emergencies” S641.</p>

Table 4: Supporting quotations for theme 3 and overarching theme

Theme	Supporting Quotations
Theme 3: Attendance at support groups	<p data-bbox="719 339 2056 408">“I think the only negative thing is getting folk to come to meetings um but that’s not so much a problem now with a group leader” P5.</p> <p data-bbox="719 427 2018 496">“I think the balance needs to be made between patient stories and local support groups and medical issues and treatments.” S196.</p> <p data-bbox="719 515 1749 552">“I’m glad that they are there but...I haven’t had much more to do with them” P9.</p> <p data-bbox="719 571 2040 639">“We are all very different people. Some of us are more sociable than others I suppose and some of us are more inclined to go elsewhere, to pick others brains or ask for help” P7.</p>
Overarching theme of geography and relationship to theme 3	<p data-bbox="719 668 1861 737">“Their condition is diagnosed. It’s at that point that they need to know about the Pituitary Foundation...there aren’t support groups everywhere...there’s lots of gaps” P4.</p> <p data-bbox="719 756 2047 825">“Finding time to attend groups as they were a fair drive away. Maybe big groups move to smaller more local groups” S404.</p> <p data-bbox="719 844 2018 954">“I do get copies of their newsletter emailed and it does help to know that some of the problems that I have...that other people with similar conditions are feeling the same way. So just knowing that is helpful...” P7.</p> <p data-bbox="719 973 2033 1042">“Seeing other patient stories, getting comms from the Foundation has made me feel I’m not alone, or just odd, that others have been in exactly same situation...” S84.</p>

Table 5: Indicative quotations for theme 4

Theme	Supporting quotations
Theme 4: Finding the foundation	<p>“There was certainly nothing when I realised I was a pituitary patient and I firmly thought at that point that it needs something” P4.</p> <p>“The Pituitary Foundation I didn’t know about initially, the endocrine team didn’t tell me about it ...” P1.</p>
Sub-theme: publicity	<p>“...targeting places where patients are likely to be...like doctor’s surgeries, hospitals that type of thing, citizen advice bureaus, and places like that would be another way to make sure there are information leaflets about the pituitary where potential patients are.” P7.</p> <p>“for endocrine clinics to be more upfront giving out information.... if you had a little...card that you would put in your wallet just with the basic contact details of the Pituitary Foundation I think that might help...if you got them early enough they would probably be quite keen, that’s when you need the information...” P9.</p> <p>“So many don’t know what pituitary gland is and how it works. Awareness needed in GP surgeries” S467.</p> <p>“...its quite a long time since I heard of any media coverage within magazines etc...” P8.</p> <p>“not enough general awareness, posters for G.P surgeries/helpline numbers etc” S229.</p>
Overarching theme and relationship to theme 4	<p><i>“I think I was playing on the internet and found the Pituitary Foundation and discovered that they had gotten a lot of written information...” P9.</i></p> <p><i>“The key issues I think is persuading endocrinology and neurology departments to actually publicise their existence...I think there is an education problem there with the people that have direct interface with those with pituitary conditions, seemingly not being terribly aware or not being terribly interested...” P6.</i></p>