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Citation for final published version:

Pak, Hei Yi, Lansdown, Andrew, Taylor, Peter , Rees, Aled Daffyd , Davies, John and Hayhurst, Caroline 2020. Acromegaly and the information gap: patient perceptions of the journey from primary to tertiary care. *Endocrine Connections* 9 (10) , pp. 971-977. 10.1530/EC-20-0335

Publishers page: <http://dx.doi.org/10.1530/EC-20-0335>

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1 Acromegaly and the information gap: patient perceptions of the journey from
2 primary to tertiary care

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20 **Short Title:** Acromegaly and the information gap

21 **Word count** (excluding abstract): 3031

22 **Keywords:** Acromegaly, long-term impact, qualitative, patient perspective

23

24 **Abstract:**

25

26 **Objective:** Acromegaly is a rare condition and there is often a long path to diagnosis for many
27 patients. We sought to explore patient's perceptions and understanding of acromegaly, to examine
28 the quality of communication and find gaps in the information provided at diagnosis.

29

30 **Design:** A prospective study using qualitative research methodology and grounded theory. A semi-
31 structured interview was conducted with 18 patients treated for acromegaly in a single tertiary centre
32 and verbatim transcripts were thematically analysed for overarching themes.

33

34 **Results:** 18 patients with acromegaly were interviewed. The mean age of participants was 52 (range
35 30 – 72). Four overarching themes emerged; (1) Patients rely on online resources to understand
36 acromegaly in the time between diagnosis and tertiary care clinic; (2) There is not enough support
37 available for patients; (3) Patients have a basic understanding of acromegaly and associated
38 conditions, but the long term impact is underestimated; 4) Patients initially felt intimidated by the
39 multidisciplinary team panel, but overall found it useful.

40

41 **Conclusion:** Acromegalic patients have a strong need for information at the point of initial diagnosis,
42 in particular online resources and interaction with other experienced patients. Wider dissemination
43 of patient educational resources into primary and secondary care settings may improve overall
44 patient satisfaction, treatment adherence and subsequent health care provider-patient relationships.

45

46

47

48

49

50 Introduction

51 Acromegaly, usually due to a benign pituitary adenoma, is a rare condition that has profound effects
52 on all aspects of the body¹. Besides causing soft tissue growth, excess growth hormone is associated
53 with co-morbidities such as hypertension, cardiomyopathy, diabetes and cancer². Acromegaly can be
54 a challenging condition to identify and patients may often be diagnosed late³. By the time they
55 attend clinic, patients may have already developed significant health problems, with significant
56 impact on both quality of life and life expectancy^{4,5}. Additionally, diagnostic delay often shapes
57 patients' attitudes to health care professionals, which impacts on the quality of communication and
58 subsequent treatment adherence^{6,7}.

59

60 In UK practice, often a secondary care endocrinologist or the primary care physician conveys the
61 diagnosis to the patient before referral to a tertiary centre multidisciplinary team (MDT). This model is
62 increasingly the gold standard of pituitary care in North America and Europe^{8,9}. Therefore, it is
63 anticipated that patients are informed of their diagnosis and given background information prior to
64 their tertiary clinic appointment to discuss treatment options, including pituitary surgery, medical
65 treatment with somatostatin analogues or radiotherapy. However, with an incidence of only 3.8 per
66 million population¹⁰, many primary care and secondary care physicians may lack experience with the
67 condition. Studies of the diagnostic pathway in acromegaly identify the point of diagnosis disclosure
68 as critical in establishing patient- healthcare provider trust^{6,11}. Additionally acromegaly patients are
69 often reluctant to share concerns or questions with healthcare providers at initial consultation⁶.

70 However, there are few studies focusing on how information should be provided and how

71 information resources are used by patients.

72

73 Through qualitative research, this study aims to gain a better appreciation of patients' experiences
74 with the diagnosis of acromegaly. We sought to identify gaps in patient information in the pathway

75 to treatment, in order to improve future communication and to identify the support resources
76 required and when they are needed.

77

78

79 Patients and Methods

80

81 Study design:

82 A prospective qualitative study using a single semi-structured interview with patients diagnosed with
83 acromegaly referred to a single regional tertiary pituitary centre.

84

85 Participants:

86 All patients aged over age 18 that had attended the pituitary multi-disciplinary pituitary clinic at the
87 University Hospital of Wales with a biochemically confirmed diagnosis of acromegaly were invited for
88 interview by telephone and provided with written information about the study. Interviews were
89 conducted via telephone or face to face.

90

91 Data collection and analysis:

92

93 Data collection and analysis in this qualitative study was based on grounded theory where ongoing
94 data analysis leads to further questions to refine evolving theories¹². As such interviews are
95 conducted until no further themes emerge and saturation is reached¹³. This allowed systematic
96 generation and development of theories by being alert to emerging themes¹⁴, prompting adding new
97 questions to the interview guide. An initial interview guide was developed and subsequent questions
98 added as new themes emerged during the study (Table 1).

99 Each interview was recorded on tape and transcribed verbatim by the interviewer. Then, the

100 transcripts were re-read to get an impression of the patients' experiences. Thematic analysis was

101 conducted first through open coding, to separate the data into segments which relate to one idea,
102 then through axial coding, to combine similar ideas into overarching themes ¹⁵.

103 Demographic data for each participant was collected including age, mode of presentation and region
104 of presentation.

105

106 Ethical considerations:

107 This study was approved by the Cardiff and Vale University Health Board Specialist Services clinical
108 board as a service evaluation and all participants provided verbal consent.

109

110 Results

111 25 patients were invited for interview. 18 patients were interviewed and data saturation was reached
112 as the final interviews did not produce any new themes ¹⁶. The mean age of participants was 52
113 (range 30 – 72); the mean age at diagnosis was 48 (range 26 – 72). **Table 2** outlines the patient
114 demographics. 11 patients (61%) were diagnosed by an endocrinologist in their local hospital, 1
115 patient received the diagnosis from an orthopaedic surgeon after referral for carpal tunnel syndrome
116 and 4 (22%) were diagnosed by their primary care physician.

117

118 **Thematic analysis**

119 Analysis of the interviews produced 4 overarching themes:

120

121 *1) Patients rely on online resources to understand acromegaly in the time between diagnosis and tertiary*
122 *care clinic.*

123 Since acromegaly is a rare disease, patients may be entirely unaware of the condition and hence are
124 surprised when they are given the diagnosis. Most patients felt they were not given enough

125 information at diagnosis, which is usually delivered by their local endocrinologist or general practitioner

126 (GP). Instead, they received the most information from the tertiary MDT clinic, as expected for a rare
127 disorder. Only five patients reported that printed resources would have been useful at diagnosis.

128

129 *“It wasn’t brilliant. There’s not a real pamphlet and nothing that was explaining it. It was literally, ‘you
130 got acromegaly’ ... most of it was done by myself, reading online about it.”*

131

132 *“Possibly a leaflet about... explaining things. And as I say, what the pituitary gland does and the whole...
133 some of the terminology ... of the various things that were going on.”*

134

135 Given delays between obtaining the diagnosis and attending the tertiary care clinic the greatest
136 information need is between appointments. All patients, except one, had searched online to learn more
137 about acromegaly. All patients who searched online did so as soon as they heard about their diagnosis.
138 However, many reported having to filter out what they read online as there is an overwhelming amount of
139 information available and some can be distressing for patients to see.

140

141 *“When I googled it and there was very outdated..... there was a man with a gigantic jaw. When you
142 google things, you can get lost.”*

143

144 Many patients used the National Health Service website Health A-Z (www.nhs.uk) to find information on
145 acromegaly. Other resources which patients reported using are online groups such as on Facebook groups,
146 forums, videos, podcasts and blogs. To find information, patients used google with the search terms
147 ‘Acromegaly’ or ‘Pituitary Tumour’. Five patients reported they found a number of North American
148 resources online, for example, websites and video interviews, but few specific to the United Kingdom or
149 their region. Patient videos and websites from the UK may be more relevant and reassuring for the
150 patients in this study.

151

152

153 *"I think the ones I remember were NHS UK, also the pituitary foundation and there seems to be a lot of*
154 *academic stuff from America but if I remember rightly I started looking at sort of threads and help*
155 *groups but it was just full of... it was the worst stories, you know, so I decided not to read about it*
156 *anymore. I thought it would help but actually really didn't, so I stuck with the facts, the clinical facts."*

157

158 When asked if they had enough information to support treatment decisions, the majority of patients felt
159 that initially they thought surgery was the only option, but learning about the procedure and alternative
160 options helped put them at ease. With information patients felt confident in the team treatment
161 recommendation.

162

163 **2) *There is not enough support available for patients***

164 All participants reported they would have liked to receive more support, as GPs are often unable to help
165 with issues relating to acromegaly.

166

167 *"because they know you're under specialists, they can't help you because they just don't know."*

168

169 Patients find the ability to contact an endocrine nurse specialist for advice reassuring but this is often only
170 available at the tertiary centre, following specialist referral.

171

172 *"there is an endocrine nurse centre there. Because I know the consultant will get back to you, but he*
173 *very busy doing wards, doing the clinics, sometimes there is no one else that's in, to offer any advice."*

174

175 Importantly, patients expressed they would have liked to talk to treated patients, to get a better sense of
176 what is happening and what they are about to go through. Meeting other people with acromegaly and
177 reaching out to support groups could be an invaluable source of support for the patients.

178

179 *"Maybe meeting other people who has had it and have been cured for it... so you know what they've*
180 *been through, what to expect. That would have been helpful."*

181

182 Earlier signposting in the primary or secondary care setting to online resources and support groups in
183 important in the patient pathway.

184

185 *"Maybe like the pituitary foundation, maybe it would have been best if I would... been told to... contact*
186 *the pituitary foundation you know? To chat with them or the pituitary nurse... That would have been*
187 *very good actually."*

188

189 **3) *Patients have a basic understanding of acromegaly and associated conditions, but the long term***
190 ***impact is underestimated***

191

192 Despite feeling they lacked information, the majority of patients were aware acromegaly was associated
193 with a growth hormone-secreting pituitary tumour and soft-tissue growth. Almost all patients stated there
194 was not enough information given about the long-term outlook of acromegaly, but they were aware of the
195 hormone imbalance and the physical changes that would occur if left untreated. The knowledge of other
196 long-term complications of acromegaly was variable, but the majority of patients were able to name
197 several.

198

199 *"All I know it is ... it causes the growth hormones to... grow, which umm... make my fingers swell up*
200 *and... and my feet ... uhh, and obviously part of my face"*

201

202 *"If it's not treated, it can cause shortening of life, umm, you heart can grow and your diabetes could*
203 *get worse, you can have strokes, you can have a risk of heart attacks..."*

204

205 *"Well, the heart problems, the diabetes or the bowel problems, I don't know any more than that."*

206

207 In the beginning, patients assumed that they would be cured after the surgery and would be normal again.

208 They may not have realised that they will still require follow up for recurrence, and may still suffer from

209 symptoms after surgery, for example, headaches and fatigue.

210

211 *"It's just, I can't see an end to it, I don't feel like there will ever be an end to it. You still gotta be*

212 *checked after. But I can't see a light at the end of the tunnel..."*

213

214 *"It wasn't explained that this might not be the end of it, you might need to have another operation and*

215 *it might not... I think I was naïve a little bit then, I hadn't realised that."*

216

217 Acromegaly had a varied long term impact on patients, 50% felt the disease had not greatly impacted their

218 lives and were able to get back to normal following surgery. However, for the remainder the experience

219 was life-changing and they still struggle with work and relationships despite successful treatment. Many

220 patients reported ongoing problems with depression and anxiety.

221

222 4) *Patients initially felt intimidated by the tertiary multidisciplinary clinic, but overall found it useful.*

223

224 Patients reported being given minimal warning before attending the MDT of the nature of the clinic.

225 Therefore some of them felt shocked to see a large group of clinicians and nurses in the room. They were

226 put at ease quickly and have generally benefitted from the team meeting.

227

228 *"It was useful I guess, you had the input of a lot of different specialists at the same time, so yeah. It*

229 *was intimidating but it was also reassuring to know that there was... more than one person looking at*

230 *your case."*

231

232 *“Well only when you go in and you see seven people sitting there and they’re all, you know, professors*
233 *and consultants... they were absolutely fine... but it’s a bit intimidating just to see that panel...”*

234

235 Patients benefit from meeting the whole team that will guide them through their treatment and follow-up,
236 however providing information prior to the clinic on the team members and roles would be useful.

237

238 Discussion

239

240 Using qualitative research methods to explore the needs of patients newly diagnosed with acromegaly in a
241 primary or secondary care setting demonstrates the need for high-quality, relevant online resources and
242 local support networks. The internet is being used increasingly by patients to research their health
243 conditions ^{17, 18}. This has been shown to affect the patient’s beliefs and potentially change their decision
244 about treatment ¹⁹. Our study shows that patients diagnosed with acromegaly turn to online resources
245 early after initial diagnosis to learn more about their condition. Interestingly, patients appear much more
246 reliant on online information and patient-to-patient interaction than the traditional printed information
247 leaflet.

248

249 However, patients may be overwhelmed by what they might find online and, quality of information on the
250 internet may be substandard ²⁰. Our cohort highlighted the importance of online materials and groups
251 being regionally specific to them. Ideally, patients would like to be provided with reliable online resources
252 at initial diagnosis and guidance to help them make sense of the information ²¹. In a similar study by Gurel
253 et al ⁶, 19 patients participated in online and face-to-face interviews aimed at understanding the impact of
254 a diagnosis of acromegaly. They demonstrated a strong desire for education about the disease at
255 diagnosis, noting the diagnosis seemed to ‘fuel a thirst for knowledge’ in all participants ⁶. As in our study,
256 participants emphasized the need for patient-patient interaction as part of their quest for knowledge and
257 a desire to take control of their disease, highlighting the need for access to support groups. Plunkett and
258 Barken ¹¹ suggest strategies to facilitate the patient-healthcare professional relationship throughout the

259 treatment pathway and highlight the provision of educational and emotional support resources at the
260 initial diagnosis meeting. Such resources include The Pituitary Foundation (www.pituitary.org.uk). In
261 particular, their support groups and peer support programme may address the patients' needs to speak
262 with more experienced acromegalic patients and encourages the exchange of health information ^{18, 20, 21}.
263 Video presentations by similar patients, such as the UK acromegaly meetup, could be helpful for newly
264 diagnosed patients (UK Acromegaly Meetup 2017: Patient stories - Rachel and Carolyn.
265 <https://youtu.be/llqHT-FheMA> , accessed 27.03.20).

266 Internationally The Pituitary Society (www.pituitary-society.org), Acromunity.com and
267 Acromegalycommunity.com provide resources and access to support groups. However, in a study to
268 assess communication practices among endocrinologists, Polanco-Briceno et al²² reported only 14% of
269 respondents routinely recommended educational resources or programs to patients and only 44% were
270 aware of these resources. Additionally, most physicians in the study did not have dedicated nurse to
271 discuss these topics with patients.

272

273 Qualitative research is becoming more popular in surgical and medical practice ²³, as it can provide an
274 insight into the social aspects of being treated for a disease from the patient's perspective ²⁴. To date most
275 qualitative research in acromegaly focuses on diagnostic delay and treatment adherence ^{7, 25}. A study by
276 Sibeoni et al ⁷ conducted with 18 participants revealed the lack of awareness in the medical community as
277 a significant factor for a diagnostic delay. **Most patients had interactions with many healthcare**
278 **professionals who did not recognise or believe the symptoms being reported, which in turn drives a thirst**
279 **for knowledge at diagnosis and shapes subsequent attitudes towards doctors** ⁶. Sibeoni et al⁷ also reveal
280 the psychosocial elements of a delayed diagnosis of acromegaly and suggest that endocrinologists should
281 be involved in addressing the psychological impact of the condition together with support of mental
282 wellbeing.

283

284 A study with a focus group of 6 acromegalic patients to explore patient perceptions of disease impact
285 presented a wide variety of causes for a reduced quality of life in patients with acromegaly ²⁶. Some issues

286 discussed in the focus group correlate with those reported by patients in our study. These include fatigue,
287 mental health problems and worries about fertility ²⁶. These issues are not covered in available disease
288 specific quality of life questionnaires. In their study, they advise clinicians to be more aware of these
289 problems in order that appropriate support may be provided ²⁶. It is clear that patients focus initially on
290 the immediate treatment and resolution of symptoms such as fatigue, headaches and joint pain, but pay
291 little attention to the potential long term implications or need for future multimodal therapy ⁶. When and
292 how patients should receive this information and how they will process it is not clear. However our study
293 and that of Gurel et al ⁶ suggest this is most likely to have an impact when discussed in a patient-to-patient
294 forum.

295

296 Despite a clear benefit from a multidisciplinary team approach to the management of pituitary disease ^{9,27},
297 patients find the experience intimidating. Although not all centres will adopt a joint MDT clinic with
298 multiple clinicians; in our practice we find it beneficial to facilitate discussion between the patient,
299 endocrinologist, surgeon and radiation oncologist to explore all treatment options. Prior contact from a
300 specialist nurse or written information detailing the team members and their roles may help ease some
301 anxiety and improve subsequent treatment adherence and overall satisfaction ¹¹.

302

303 Overall, despite increasing awareness of acromegaly and a recent reduction in the delay to diagnosis ⁴,
304 most patients are diagnosed in non-specialist centres with limited access to specific support resources.
305 There is a need for clear signposting to up-to-date online resources that patients feel is relevant to them
306 both factually and geographically. Our study demonstrates this should occur prior to attendance at the
307 specialist tertiary centre together with a need for supporting education on acromegaly in primary and
308 secondary care.

309

310 Limitations:

311

312 This study involves patients from a single centre and results drawn from the study may not apply to other
313 patient groups and/or internationally. Nevertheless, conclusions drawn from this study may still be
314 relevant for other centres to better appreciate the needs of patients with acromegaly. In any qualitative
315 study the interviewer's ideas and assumptions can bias the outcome; however, the semi-structured format
316 and open questions should have allowed the patients to speak freely about their experience and concerns.

317

318 Conclusion

319 The study demonstrates some of the challenges faced by patients with acromegaly and gives us an insight
320 into knowledge of their condition and what information and support they require. It highlights a need for
321 better communication with patients as well as guidance for online searching. There is a clear need for the
322 provision of information at the point of initial diagnosis in whatever care setting that may be made. The
323 wider education and dissemination of appropriate online resources will improve subsequent health care
324 provider-patient communication and ultimately improve treatment satisfaction and quality of life.

325

326 **Declaration of Interest:** There is no conflict of interest that could be perceived as prejudicing the
327 impartiality of the research reported

328 **Author Contribution Statement:** HP, CH and AL devised the study, HP undertook interviews, HP, CH
329 and JSD reviewed thematic analysis, all authors contributed to manuscript preparation and review

330 **Funding:** This research did not receive any specific grant from any funding agency in the public,
331 commercial or not-for-profit sector.

332

333

334 **References:**

335

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