

# Patient experience of living with acromegaly in the United Kingdom

Antonia Brooke\*, Jacqui Lyttle\*\*, Lynne Goss\*, Lou Pobereskin\*\*\*, South West Peninsula Endocrinology Network

\* Royal Devon and Exeter Hospital, Exeter; \*\* JSL Consulting & Associates Ltd.; \*\*\* Derriford Hospital, Plymouth

## Introduction and objectives

Previous studies have shown patients with acromegaly frequently have a delayed diagnosis, psychological difficulties and long term morbidity. The objectives of this project were to ascertain patient opinion on:

- The overall patient pathway from initial diagnosis, subsequent treatment, and on-going management
- Engagement with healthcare professionals and patient groups
- Willingness and ability to travel

## Methods

- 104 patients within 10 years of active treatment for acromegaly, from the South West Peninsula Endocrinology Network in the UK (involving 5 acute hospitals and 1 neurosurgical centre), were invited to participate
- 61 patients (34M, 27F) were interviewed to explore the experience of living with acromegaly
- Semi-structured Interviews were conducted by an independent consultant (60-120 min each) in the patient's own home
- 52 (85%) patients had surgery for their acromegaly

Hospital	Population	Invited	Participated
Barnstable	165,000	3	3
Exeter	450,000	21	16
Torbay	275,000	17	10
Plymouth	700,000	43	23
Truro	383,000	20	8

Figure 1: Number of patients participating from each hospital under one neurosurgical centre

Year of diagnosis	Number interviewed
Pre-1993	8
1994 - 2003	11
2004 - 2013	42

Figure 2: Year of diagnosis

## Results: grouped into 7 common themes (selected quotes used for illustration)

### 1. Diagnosis

- 56 (92%) experienced a significant delay from symptoms to diagnosis, but prompt effective secondary care treatment
- Patients felt a lack of awareness of the condition within primary care and its effect on them long term
- "The attitude and knowledge of my GP could have been improved. I presented with problems for more than two years and all the tell-tale signs were missed."

### 2. Support and communication for surgery

- Patients interviewed felt that the impact of surgery on their lives was not well explained, the surgical experience traumatic
- "There appears to be a disconnect between the medical and surgical management."
- "I was given no choices for surgery, no choices for treatment."
- "Surgery was the most terrifying experience of my life and I would have benefited from someone holding my hand."
- "Nurses were overworked and reliant on bank staff. I had no privacy and the attitude of nurses was apathetic."
- "After being discharged we were on our own! I felt as though the strings had been cut."

### 3. Medical treatment

- 36 (59%) were on additional medical treatment and had issues with the ordering, dispensing (late delivery) or administering of the drug (delayed appointments).
- The majority on Somatostatin analogues had the practice nurse injecting (only 4 had self-administration at home), with lack of technique from nurses in 2 cases resulting in waste.
- "I have a real issue getting my medication. I fully understand the importance of it but do not feel the practice nurse sees it in the same way."
- "I am happy with my injections, but know they cost a lot of money."
- "Poor communication between pharmacy, clinic, ordering injections and administration of drug which could be improved."

### 4. Endocrine Specialist involvement

- Overall patients were satisfied with the care they received and after diagnosis had rapid investigation and treatment.
- Those in contact with a 'specialist' consultant or an endocrine nurse specialist felt most supported
- 52 (85%) felt they had access to a consultant who understood the condition
- "I feel my care is superbly coordinated, due to the excellent team working between the consultant and specialist nurse."
- "It was an example of the NHS at its best. From initial attendance at my GP through to final diagnosis it was superb. Consultant is quite outstanding."
- "All of my care plan was very well coordinated – specialist nurse was excellent and very efficient and could not explain too much."
- "I feel I have excellent access to the consultant, who clearly understands my condition, never too much trouble."
- "My consultant has recently changed and I do not feel that my relationship or support is as good."
- "My consultant retired and my review appointments are now with registrars, who are not 'au fait' with the condition or my history, and I have to relay all my medical information time and time again."
- 62% had access to a specialist nurse (and 81% felt experience enhanced as a consequence)
- 10 patients didn't realise they had access to ESN outside clinical trial
- Those without contact with an endocrine nurse specialist felt their care might have been compromised as a result.
- Many thought a key worker (nurse) would be of benefit
- "I have excellent support from the specialist nurse, and feel things have been much improved since I have started seeing her."
- "I think I would benefit from seeing the specialist nurse. I would not want to encroach on valuable consultant time."

### 5. Psychological support

- Most patients felt a lack of psychological support at diagnosis and early treatment
- "We had total unawareness of depression relating to the condition, and I really feel this needs further development for other patients. Psychological support is crucial for newly diagnosed patients."
- "It was such a lonely period. I was acting all the time I was at work, but in despair when I got home."
- "Nurses should have some form of training to deal with patients re the psychological impact of traumatic surgery."
- "Whilst all my physical needs were met, what I cannot live with is no psychological awareness of patients' problems."
- "I have at times felt very isolated and I feel like a monster."

### 6. Information

- There was no consistent approach to providing information in each centre
- Patients felt unprepared for the life-long effect of their condition and some inadequately prepared for surgery.
- 53 (87%) patients felt they understood about their condition now, many felt this took a long time with extensive personal research
- 67% had been offered written information
- 69% had looked on websites
- 61% were aware of patient groups, but:
  - only 20% had joined or sourced information from one
  - 15% attended a meeting (despite a desire to help others with acromegaly)
- "My diagnosis was difficult to take in, and I did not feel it was communicated well initially – I would have benefited from more support and information."
- "I do understand my condition now but only as a consequence of my own research."
- "I was given extensive information by the hospital concerning my treatment, but not about my condition."

### 7. Travelling for treatment

- 46 (75%) would be willing to travel anywhere in the UK to receive treatment (25% to next available hospital) if not available locally.
- Although many felt involved in decision-making, few had been offered choice (but would value their consultant's advice).
- Most patients would take decision on whether to travel based on advice from their consultant
- "If you cannot get it locally we would travel. If your health is at stake, I would be willing to travel anywhere."

## Conclusions

- This is the largest acromegaly qualitative patient experience study undertaken in the UK, reflecting the issues of living with acromegaly
- Patients overall were happy with their clinical care and ongoing medical management and feel well supported
- Patients highly valued the support and input from their endocrinology team
- Patients who had access to a specialist nurse highly valued their support
- Overall patients did not see travel as a barrier to accessing quality healthcare if they had the choice
- Common themes were observed across all hospitals.
- Although all patients were under active disease management, some patients had initial treatment many years ago and systems have significantly changed.
- New common pathways and information sheets are now in development.