AcroVoice: Understanding how patients with acromegaly define their condition and make treatment decisions

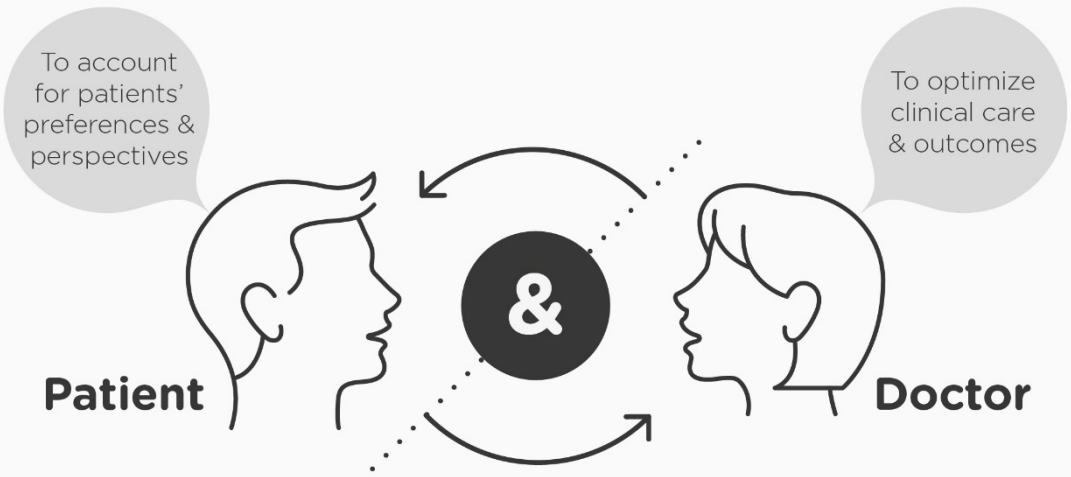
Date of summary: 9 January 2019

Study start date: November 3, 2017 Study end date: July 17, 2018

Why is this study important?

- This study looked at which factors are important to patients with acromegaly for defining how active the condition is, and for making treatment decisions.
  - *Patients with acromegaly may have different perceptions of these factors than doctors and other healthcare professionals.*
  - *The patients in this study showed a deep understanding of their condition and their treatment needs.*
  - *It is important for doctors and healthcare professionals to know what matters to patients, and to have conversations to actively involve them in their care.*
- This study emphasizes the importance of personalized care. It also shows that shared decision making between patients and their doctors is important in making treatment decisions.

Patients with acromegaly should feel comfortable talking with their doctor and sharing their opinions



What is acromegaly?

- Acromegaly is a rare condition in which the pituitary (a small gland below the brain) produces too much growth hormone.
    - The most common cause of acromegaly is a pituitary tumor.
    - Patients with acromegaly can experience fatigue, sweating, swelling, and changes in their appearance, which may interfere with their everyday function and affect their quality of life.
    - The most serious consequences of acromegaly are type 2 diabetes, high blood pressure, increased risk of cardiovascular and cerebrovascular disease, and arthritis.
        - If not treated properly, acromegaly can result in serious illness and premature death.

What did this study look at?

- In this study, called AcroVoice, researchers used telephone interviews and an online survey to understand how patients with acromegaly define disease activity and treatment success.
- In the telephone interview, patients identified five factors they considered to be important in describing disease activity:
    - Two clinical factors: the size of the pituitary tumor, and the levels of a hormone called insulin-like growth factor I (IGF-I for short), which can be elevated in patients with acromegaly.
    - Three patient-centered factors: related health conditions, symptoms, and quality of life.
- In the online survey, participants in AcroVoice looked at descriptions of patients with acromegaly, with varying degrees of disease activity, which had been invented by the researchers.
    - One questionnaire asked participants to review 20 patient descriptions and to indicate whether, and to what extent, a change in treatment was needed.
    - Another questionnaire asked participants to look at 15 pairs of patient descriptions and to choose which patient was “doing better” from each pair.
- This summary describes how important the two clinical factors and three patient-centered factors were for patients with acromegaly in defining how active the condition is, and in making treatment decisions.

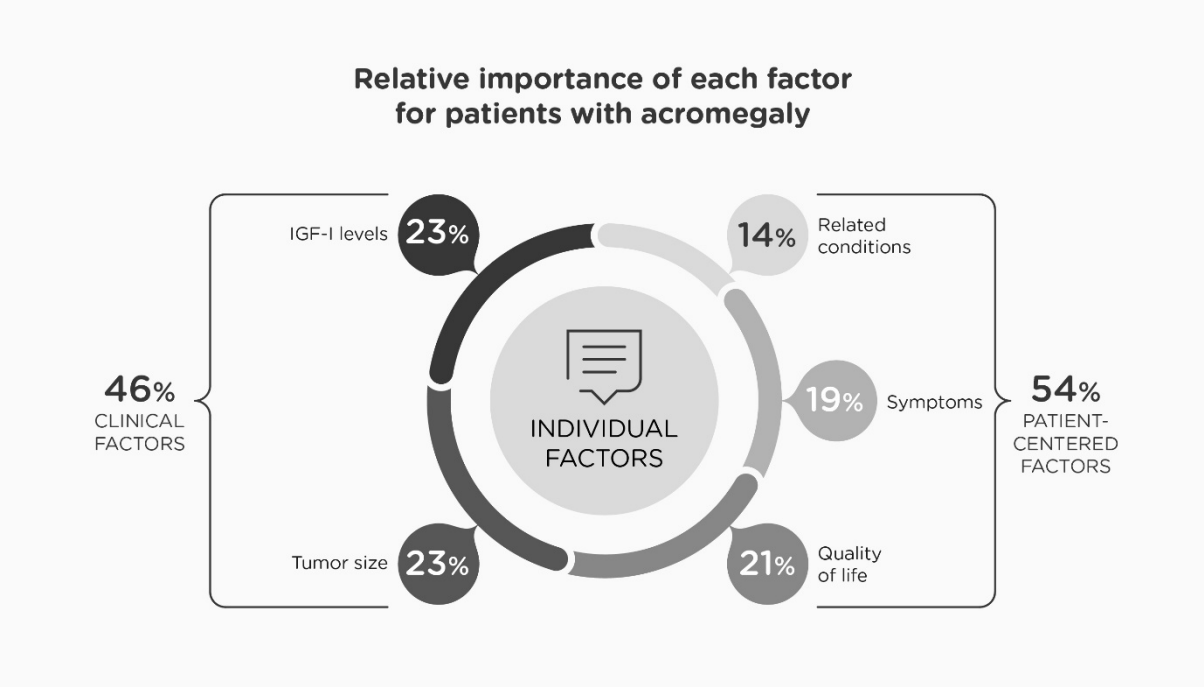
Who took part in this study?

- Advocacy and support groups came together to find patient volunteers to participate in the AcroVoice study.
- One hundred patients with acromegaly in the USA and Canada took part in the study.
    - More than half of them were women (65%).
    - Their average age was about 48 years.

- On average, they had been diagnosed with acromegaly for around 10 years.
- Overall, they had a high level of education and around half had a university degree.
- They were taking different treatments for acromegaly, including octreotide, lanreotide, pegvisomant, bromocriptine, cabergoline and/or radiation.
    - Some patients were taking more than one treatment at a time.

What were the results of this study?

- The clinical and patient-centered factors were important to patients with acromegaly.
    - All five factors were important to patients when deciding whether, and to what extent, changes in treatment were needed.
    - All five factors were important to patients when deciding how well a patient was doing overall.



What were the main conclusions reported by the researchers?

- Patients with acromegaly should feel empowered to express their needs and opinions, and to receive treatment that takes their preferences and perspectives into account.
- In the AcroVoice study, patients with acromegaly valued both clinical factors (tumor size and IGF-I levels) and patient-centered factors (related conditions, symptoms, and quality of life).
- A similar study, called ACRODAT, which was carried out with doctors who treat acromegaly, concluded that the two clinical factors were more important to doctors than the three patient-centered factors.

How could this study benefit patients with acromegaly?

- The AcroVoice study shows that patients' opinions need to be considered to ensure that they receive the best possible care.

How to use this summary to help patients and doctors talk about this research

- **Question from patient to doctor:** How does this research support my involvement in decisions about my care?
- **Question from doctor to patient:** How relevant is this research to what matters most to you?

Are there any plans for future studies?

- No other studies by this team of researchers are currently planned.

Who sponsored this study?

Pfizer Canada.

The researchers would like to thank the patients who took part in this study, and the Atlantic Acromegaly Support Group, the Vancouver Acromegaly Support Group, the Alberta Pituitary Patient Support Group, the University of Alberta Hospital, and the Acromegaly Community for their help in identifying eligible patients to take part in this study.

The full title of this article is:

AcroVoice: Eliciting the Patients' Perspective on Acromegaly Disease Activity

You can find the full article here: https://link.springer.com/article/10.1007%2Fs11102-018-00933-9. You can access the full article for free.

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