

ACROCOVID II: an international survey on acromegaly management more than 1 year into the COVID-19 pandemic era

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BACKGROUND

- Acromegaly is a rare chronic endocrine condition, which requires management by a multidisciplinary team^{1,2}
- The real-world impact of COVID-19 on care for people with acromegaly has not been fully established^{3,4}
- The 2020 ACROCOVID survey revealed substantial negative impacts on all aspects of care during the early stages of the global pandemic³

OBJECTIVE

- The ACROCOVID II survey aimed to improve the understanding of the pandemic's ongoing effect on care pathways, and the need for changes in delivery of, and access to, care

METHODS

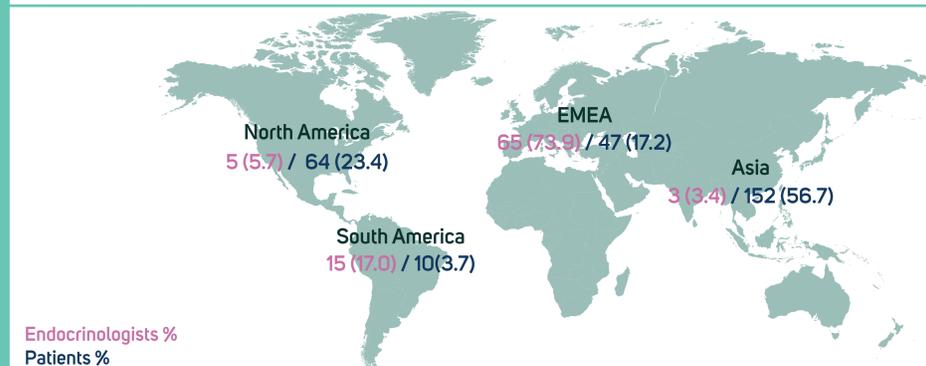
- Two surveys were created, targeting people with acromegaly and endocrinologists, respectively
- Questions were drafted with input from patients, patient advocates, and endocrinologists
- Surveys were available in six languages (English, German, Spanish, Portuguese, Russian, and Simplified Chinese)
- The surveys were hosted on a commercial platform (4C Research Solutions) from April 26 to July 6, 2021
- Dissemination was supported by a global social media campaign

RESULTS

Demographics, SARS-CoV-2 infection, and vaccination

- Most respondents with acromegaly (N = 273) were from Asia while most endocrinologists (N = 88) were from Europe (Figure 1)

Figure 1: Regional distribution of respondents



Endocrinologists: N = 88; Patients: N = 273; EMEA: Europe, Middle East and Africa

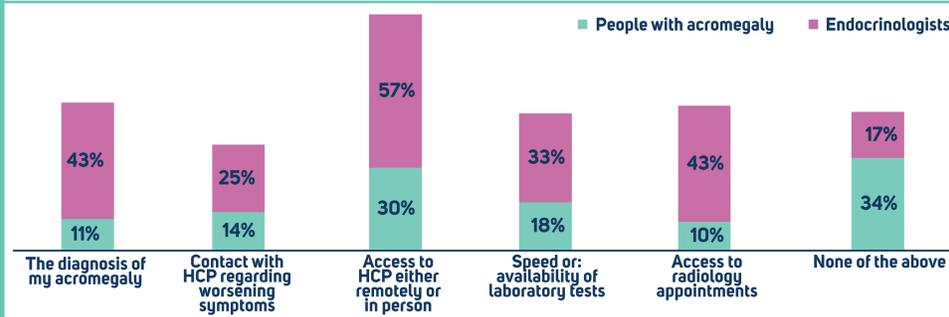
- Most respondents with acromegaly were female (68.9%) and were aged between 31 and 50 (79.1%), with a similar number aged ≤ 30 (9.9%) or ≥ 61 (11.0%)
 - Close to half of patients (46.2%) were diagnosed with acromegaly ≤ 5 years ago, 27.1% were diagnosed 6–10 years ago, 12.5% 11–15 years ago, and 14.3% > 15 years ago
- Most endocrinologists worked in a general endocrinology practice (53.4%), rather than a pituitary centre (46.6%)
 - A fifth of endocrinologists (20.5%) had ≥ 100 patients under their ongoing care, 40.9% cared for between 21 and 100 patients, and 38.6% ≤ 20 patients

- Confirmed SARS-CoV-2 infection during the pandemic was uncommon amongst respondents with acromegaly (2.9%)
 - Close to half of respondents with acromegaly had been vaccinated (46.2%), though prioritization due to an acromegaly diagnosis was uncommon (7.0%)
 - Conversely, 26.1% of endocrinologists reported that acromegaly patients were part of vaccine priority groups in their country and 25.0% suggested early vaccination for all such patients

Effects of the pandemic on care

- Most endocrinologists (62.5%) felt people with acromegaly were at high risk during the pandemic
- Just over half of patients sought or were offered advice regarding care during the pandemic (53.5%) and the vast majority of endocrinologists received queries or provided advice (94.3%)
- Close to half of respondents agreed that the pandemic had made it harder to live with acromegaly (47.3%)
 - A minority of both people with acromegaly (25.3%) and endocrinologists (13.6%) reported continuing their in-person care appointments as usual
 - However, only 41.4% of people with acromegaly and 46.6% of endocrinologists felt their relationship with their care team/patients was negatively affected
 - Reduced access to endocrinologists (39.2%) and primary care physicians (36.6%) were the most commonly reported barriers to care-team members
 - Endocrinologists were more likely than people with acromegaly to report issues related to specific aspects of care (Figure 2)

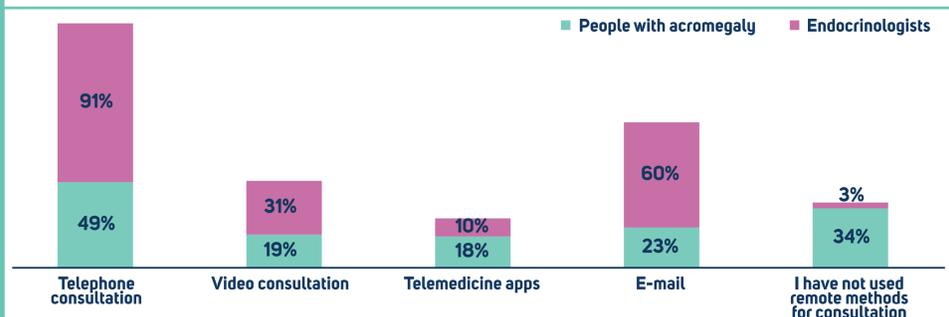
Figure 2: Aspects of care negatively affected during the pandemic according to respondents



HCP: healthcare professional

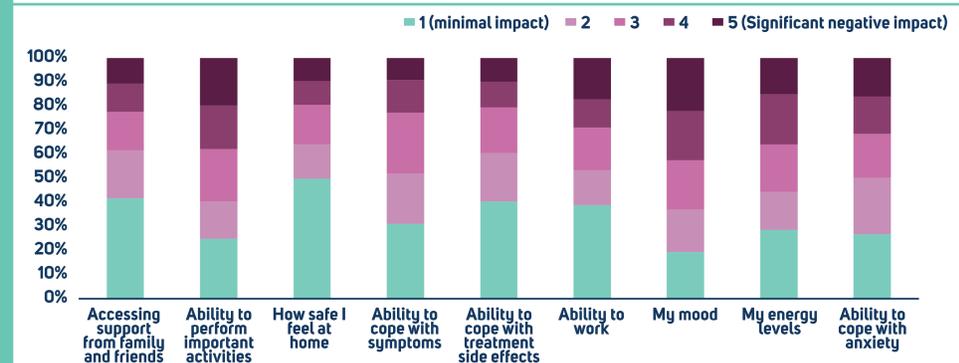
- Endocrinologists were more likely to have used most types of remote consultation than individuals with acromegaly (Figure 3)
 - 49.5% of those with acromegaly and 42.4% of endocrinologists agreed that remote consultation had improved communication during the pandemic, 23.6% and 23.5%, respectively, disagreed
 - 50.0% of those with acromegaly and 69.4% of endocrinologists agreed they would continue to use remote consultation post-pandemic, 19.8% and 11.8%, respectively, disagreed

Figure 3: Remote methods of consultation used during the pandemic according to respondents



- 28.9% of people with acromegaly and 25.0% of endocrinologists reported a treatment change was delayed during a period of poor biochemical control
 - Increases in intervals between somatostatin receptor ligand (SRL) injections and delayed medical treatment after surgery were reported by 16.1% and 15.0% of respondents with acromegaly, respectively
 - 23.9% of endocrinologists recommended a change to self/partner injections of SRLs, and 26.1% could not change dose of medication in symptomatic patients due to an inability to assess IGF-1 levels
 - Surgery was delayed in 46.9% of people with acromegaly for whom it was scheduled, and 73.9% of endocrinologists had delayed surgery on at least one occasion
- 53.8% of respondents with acromegaly reported a negative effect on their financial situation due to the pandemic, and there were broad effects on other aspects of life (Figure 4)
 - People with acromegaly most commonly reported increased use of medical websites (41.8%), patient advocacy groups (36.3%) and Facebook communities (34.8%) for support or information

Figure 4: Effect of the pandemic on different aspects of day-to-day life



STRENGTHS AND LIMITATIONS

- This was an open online survey and there was no opportunity to verify the veracity of answers nor the identity of those filling out the survey
- The large contingent of Chinese respondents (N = 142; 52%), herein, reported substantially more positive experiences in coping with their acromegaly than those of other regions, perhaps due to low levels of infection/restrictions following severe lock downs

CONCLUSION

- Our data suggest the COVID-19 pandemic is substantially affecting the clinical care of acromegaly, despite few confirmed SARS-CoV-2 infections in respondents with acromegaly
- Physicians appear to be embracing the 'new normal' by creating a novel continuum of care better suited to the presumed post-COVID-19 environment
- Routine care, including screening for complications, biochemical and imaging monitoring, and medication adjustments, should continue during the pandemic to avoid a rise in non-COVID-19-related morbidity and mortality in chronic rare conditions such as acromegaly
- The ability of respondents with acromegaly to maintain their relationships with their care team and the desire of to continue the use of remote communications post-pandemic suggest a potential positive shift in care patterns for this rare disease

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DISCLOSURES

MF Grants/scientific consultancy with Chiasma, Crinetics, Ionis, Ipsen, Pfizer, Recordati. MG, MM & SK - none to declare

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