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More concerns and stronger beliefs about the necessity of medication in patients with acromegaly are associated with negative illness perceptions and impairment in quality of life*



Cornelie D. Andela^a, Nienke R. Biermasz^a, Adrian A. Kaptein^b, Alberto M. Pereira^a, Jitske Tiemensma^{a,c,*}

^a Department of Medicine, Division of Endocrinology and Center for Endocrine Tumors Leiden (CETL), Leiden University Medical Center, Leiden, The Netherlands

^b Department of Medical Psychology, Leiden University Medical Center, Leiden, The Netherlands

^c Psychological Science, University of California, Merced, CA, United States

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ABSTRACT

Objective: Patients with acromegaly can be treated with surgery, radiotherapy and/or medical treatment. In general, patients' beliefs about medication are associated with illness perceptions, a contributory factor of Quality of Life (QoL). At present, there are no quantitative studies on medication beliefs in patients with acromegaly. Here, we aimed to examine possible associations between medication beliefs, illness perceptions, and QoL. Furthermore we aimed to explore whether illness perceptions of patients with remission of acromegaly receiving medical treatment differ from patients without medical treatment.

Design: Cross-sectional evaluation of 73 patients with remission of acromegaly (n = 28 patients with medication, n = 45 without medication). The Beliefs about Medicines Questionnaire (BMQ), Illness Perception Questionnaire-Revised (IPQ-R), EuroQoL-5D, and AcroQoL were used for the assessment.

Results: Stronger beliefs about the necessity of medical treatment and stronger concerns about the adverse effects were associated with attributing more symptoms to acromegaly, perceiving more negative consequences, and having a stronger belief in a cyclical timeline (BMQ, all P < 0.05). Stronger beliefs about the necessity of medical treatment were associated with a worse disease-specific QoL (BMQ, P < 0.01). Patients with medical treatment perceived a more chronic timeline of their disease, compared to patients without medical treatment (IPQ-R, P = 0.002).

Conclusion: Negative medication beliefs were related to more negative illness perceptions and worse diseasespecific QoL. Patients receiving medical treatment for acromegaly tend to perceive a more chronic timeline of their disease, compared to patients with remission without medical treatment. These psychological factors need to be taken into account when treating patients and developing a psychosocial education program aiming to improve QoL.

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1. Introduction

Acromegaly is characterized by exposure to elevated growth hormone (GH) levels, most frequently due to a GH-producing pituitary adenoma. Patients are usually treated with transsphenoidal surgery and sometimes by additional radiotherapy. When this treatment is not (completely) successful, or when surgery and/or radiotherapy is not preferred, patients can be medically treated with somatostatin analogs (SA) (e.g. Octreotide, Lanreotide) and/or a GH receptor antagonist

E-mail address: jtiemensma@ucmerced.edu (J. Tiemensma).

(e.g. Pegvisomant). Patients with acromegaly report impairments in Quality of Life (QoL) [1,2], which may persist even after long-term remission [3,4]. These persistent impairments have been (partly) attributed to comorbidities, such as osteoarthritis [5], musculoskeletal pain [6–8], and psychopathology [9]. Besides physical factors, Tiemensma et al. elucidated psychological factors (i.e. negative illness perceptions) which were related to QoL impairments in patients after long-term remission of acromegaly [10].

Recently Gurel et al. carried out structured interviews that explored patients' perceived impact of acromegaly. These interviews revealed that patients did not feel "cured" after treatment, particularly when patients realized they had to take medication for the rest of their life. The use of medication resulted in confusion between being a patient and being a person. Furthermore, patients had to make specific injection schedules to plan their medication around work, travel, and big events, in order to minimize the negative influence of side-effects on everyday

 $[\]star$ Précis: Patients with acromegaly report concerns and strong beliefs about the necessity of medication, which are related to more negative illness perceptions and impaired QoL.

^{*} Corresponding author at: University of California, Merced, SSHA, Psychological Science, 5200 North Lake Road, Merced, CA 95343, United States.

life [11]. A previous focus group study carried out by our group elucidated medicine beliefs and illness perceptions in patients with acromegaly. Specifically, during these focus group conversations patients reported that they experienced the use of injections as awful [12] (for illustrative, unpublished quotes, see Table 1). These two qualitative studies point toward the potential existence of negative beliefs about medicines in patients medically treated for acromegaly. Furthermore, it illustrated the need for self-management skills in patients with acromegaly in order to minimize the negative influence on their daily life.

Beliefs about medicines can be quantitatively assessed by using the Beliefs about Medicines Questionnaire (BMQ) [13], which assesses beliefs about *necessity* and *concerns* of taking a specific medicine. Until now, there are no quantitative studies available about beliefs about medication for acromegaly (i.e. SA) and beliefs about medication in general in patients with acromegaly.

The important influence of beliefs about medicines on illness perceptions, coping strategies, and therefore QoL, is demonstrated in the Common-Sense Model of self-regulation (CSM) [14]. This model describes how individuals come to understand their illness and how they develop coping strategies. The model comprises three stages. During stage one, illness perceptions are identified and organized around five categories: identity, cause, timeline, consequences, and cure/control. These illness perceptions determine coping strategies (stage two). The third stage comprises the appraisal of these coping strategies. Recently, the extended CSM was formulated by including beliefs about medicines. Specifically, it was demonstrated that beliefs about medicines were associated with illness perceptions in patients with chronic diseases (e.g. asthma [15]), adrenal insufficiency [16]. In addition, beliefs about medicines have also been found to be predictive of self-management behavior, such as adherence to medication [15,17].

Table 1

Illustrative quotes on medication l	beliefs and illness	perceptions in	acromegaly.

Medicine beliefs:	I take very intense medications, which is difficult.		
concerns	I noticed, toward the end of my injections, that my sleep problems increased. My body would start functioning differently when my injection would wear off.		
	I find information about side effects very important. I thought those side effects were very severe.		
Illness perception: identity	I believe I am just tired earlier and experience stress faster. You are more sensitive to stress, which has an impact on your physical well-being, I think. Your central nervous system must be damaged here and there because of the illness, it is almost inevitable.		
Illness perception: consequences	It had a huge impact. You are working, you have a house, you have a good job, and all of a sudden you are ill. In the meantime, you basically lost your entire life. It is very two-sided of course. On the one hand, you are happy to know where your symptoms came from after getting the diagnosis. Subsequently, you undergo surgery, which goes well, and afterwards you are happy you are still alive, you can finally do all the fun things you haven't done in years, because I was always working and very busy. Afterwards, you still have a body that doesn't want to even though you want it to. That is difficult sometimes.		
Illness perception: timeline	You feel like you may have been cured because the values normalized so the surgery was successful, but the damage that preceded this is permanent so you obviously have damage somewhere. Permanent damage, that troubles me the most. You may not actually be sick, but you do have a disease as a result. And you keep that with you for the rest of your life, so to what extent are you cured?		

Unpublished quotes from a recent focus group study of our department. The main results are described in [12]. During the focus groups patients with acromegaly reported concerns about their medication, and perceptions about the identity of their disease, the consequences and the timeline.

In the present study, we aimed to assess the contribution of beliefs about medicines to illness perceptions and QoL in acromegaly. We examined possible associations between beliefs about medication, illness perceptions, and QoL in patients with remission of acromegaly. Considering the extended CSM we hypothesized that beliefs about medication are associated with illness perceptions and QoL. Furthermore, we evaluated whether there are differences in illness perceptions and QoL between patients with remission of acromegaly receiving medical treatment and patients without medical treatment. Considering the potential negative effect patients may perceive when taking medication for acromegaly [11,12], we hypothesized that patients medically treated for acromegaly have more negative illness perceptions and more impairments in QoL compared to patients in remission without medical treatment.

2. Patients and methods

2.1. Design

Patients with acromegaly were invited to fill out questionnaires on medication beliefs, illness perceptions, and QoL. Patients were asked to complete the questionnaires at home and return them in a prepaid envelope. Inclusion criteria were adult patients (age > 18 yr) and remission defined by strict biochemical criteria (see below for details) for at least 1 year. Institutional Medical Ethics Committee approved the protocol.

2.2. Patients

A clinical chart review of 156 patients with acromegaly was performed. All patients were in biochemical remission for at least 1 year at the time of the present study. We invited these patients to fill out the questionnaires. Seventy-three patients (47%) refused to participate for several reasons (e.g. too busy, old age, debilitating disease). Eightythree (53%) patients returned the questionnaires and filled out at least one questionnaire. Seventy-seven of these patients (49%) completed both the *Beliefs about Medicines Questionnaire*, as well as the *Illness Perception Questionnaire*. Patients with acromegaly who used medication other than somatostatin analogs (SA), i.e. dopamine agonists (n = 2), or Pegvisomant (n = 2) were excluded from the analysis because of the low power for separate analyses. Therefore, a final number of 73 patients (47%) were included in the present study. Sixty-five of these patients (42%) also filled out QoL questionnaires. For an overview of this process, see Fig. 1.

The diagnosis of acromegaly had been established by clinical signs and symptoms, and by biochemical tests, including insufficient suppression of GH during the glucose tolerance test and increased IGH-I levels for age. Normal serum IGF-I levels for age and serum GH levels below 1.9 µg/liter defined biochemical control of acromegaly for all patients and, in patients without SA treatment, also by suppression of GH levels (<0.38 µg/L) during glucose tolerance test [18]. Remission was reconfirmed at yearly intervals. Pituitary function was monitored and pituitary hormone replacement was prescribed dependent on the results of the yearly evaluation of pituitary functions. In case of corticotrope insufficiency, documented by insulin tolerance test (ITT) or CRH test, hydrocortisone was prescribed (20 mg/d divided into 2-3 dosages). Evaluation of GH deficiency was performed by ITT or GHRHarginine test, only in patients under the age of 70 years and only after at least 2 years of remission. Somatotrope insufficiency was treated with rhGH replacement, aiming at IGF-I concentrations in the normal range for age. In addition, free T4 and testosterone levels (in male patients) were assessed. If results were below the lower limit of the respective ranges, substitution with L-T4 and/or testosterone was prescribed. In the case of amenorrhea and low estradiol levels in premenopausal women, estrogen replacement was provided.

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