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Impact of acromegaly on sexuality of men and women Impacto da acromegalia na sexualidade de homens e mulheres

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Resumo | O objetivo deste estudo é descrever os impactos psicológicos da disfunção sexual devido à acromegalia e verificar se há diferenças na influência da patologia de forma específica na atividade sexual de ambos os gêneros. Foi feito um estudo retrospectivo de corte transversal, utilizando o questionário AcroQol (Acromegaly Quality of Life Questionnaire) em 71 pacientes do estado da Bahia diagnosticados com a patologia. Os principais resultados evidenciam correlação significativa entre o desconforto com a autoimagem após o diagnóstico, e os impactos na atividade sexual dos acromegálicos. Em média, 33,8% da amostra, incluindo homens e mulheres, relataram sentir dificuldades em manter relações sexuais. No que se refere à libido, os homens afirmaram ter pouco desejo sexual devido à acromegalia (30,4%), já nas mulheres, mais da metade (54,2%) referiu diminuição do desejo sexual após o diagnóstico. Como principais conclusões do estudo, percebeu-se que quase metade da amostra nunca teve dificuldade para manter relações sexuais devido à acromegalia, enquanto mais da metade das mulheres e um terço dos homens referiram diminuição da libido. Identificou-se também que não apenas a questão hormonal interfere na disfunção sexual, mas aspectos emocionais e psicológicos.

Palavras-chave: Acromegalia; Disfunção; Sexual; Psicologia.

Abstract | The aim of this study is to describe the psychological impacts of sexual dysfunction due to acromegaly and to verify if there are differences in the influence of the pathology of specific form in the sexual activity of both genders. A retrospective cross-sectional study was conducted using the AcroQol (Acromegaly Quality of Life Questionnaire) questionnaire in 71 patients from the state of Bahia diagnosed with the pathology. The main results show a significant correlation between the discomfort with the self-image after the diagnosis, and the impacts on the acromegalic sexual activity. On average, 33.8% of the sample, including men and women, reported experiencing difficulties in having sex. As for libido, men reported having low sexual desire due to acromegaly (30.4%), while in women, more than half (54.2%) reported decreased sexual desire after diagnosis. As main conclusions of the study, it was found that nearly half of the sample never had difficulty in maintain sexual relations due to acromegaly, whereas more than half of women and a third of men reported decreased libido. It has also been identified that not only the hormonal issue interferes with sexual dysfunction, but also emotional and psychological aspects.

Keywords: Acromegaly; Dysfunction; Sexual; Psychology.





Introduction

Acromegaly is a chronic, rare, and insidious disease caused by an excessive secretion of growth hormone (GH), due to a benign tumor located in the pituitary gland, affecting women and men between 30 and 50 years. This disease presents higher mortality and morbidity rates in relation to the healthy population (Abreu et al., 2016; Varadhan, Reulen, Brown & Clayton, 2016), due to the secondary damage it causes in other systems, such as the cardiovascular, or metabolic system and possible cases of cancer (Matta et al., 2008, Melmed et al., 2013).

Among the clinical conditions are excessive acral growth, soft tissue swelling, arthralgia, maxillary prognathism, mild hyperglycemia, headache, sleep apnea, hypertension, sexual dysfunctions, and menstrual disorders (Melmed, 2006).

These typical facial and acral changes develop insidiously, and although they are visibly identifiable, they are not easily associated with the pathology, either by the patients or by the health team (Vilar, Vilar, Lyra, Lyra & Naves, 2017). Hence, there is a delay between the time symptoms appear and when the diagnosis is actually made (Melmed, 2006). Therefore, an early diagnosis and fast treatment of comorbidities could prevent long-term complications (Melmed et al., 2013) and irreparable damage (Matta et al., 2008; Lavrentaki, Paluzzi, Wass & Karavitaki, 2017).

Due to the macroadenomas, which are benign and slow-growing tumors, measuring more than 1 centimetre (Ribeiro, Rocha, Almeida & Rocha, 2014), acromegaly problems can be observed in women, such as decreased secretion of some pituitary hormones, like gonadotrophin, which may result in decreased libido, menstrual dysfunction with or without galactorrhea, and dysregulation of prolactin levels (Fochesatto Filho & Barros, 2013). As for men, there may be a decreased sexual desire, testosterone production and erectile dysfunction (Llanes et al., 2017).

A cohort study from Turkey (Celik et al., 2013) evaluated sexual dysfunction in 57 acromegalic patients and the association between activity of the

disease, complications, psychological aspects, and quality of life. Evidence was shown that, regardless of the activity of the disease, the rates of sexual dysfunction and depression in acromegalic women are higher than that of healthy patients (46 in the control group).

The excess of growth hormone (GH), in turn, has been associated with behavioural, psychopathological and personality changes (Sievers et al., 2009). In a European study, a high prevalence of emotional disorders was reported in subjects with acromegaly, when compared to people affected by other pituitary adenomas and compared to healthy subjects (Matta et al., 2008). Individuals with acromegaly more often showed social isolation, demotivation and fatigue than subjects from other control groups (Imran et al., 2016).

According to Silva, Castro & Chem (2010), difficulties in intimate and interpersonal relationships can be observed in people experiencing significant changes of the body. Social avoidance behaviour could become visible, such as a reduction of the number of social relations, isolation and feeling of embarrassment, after the diagnosis of acromegaly.

This pathology can also lead to neuropsychological changes, such as disorders in cognition, symptoms of anxiety, interruption of interpersonal relations, distortion of self-image, and personality changes due to weakening of self-esteem (Katznelson et al., 2014; Yedinak & Fleseriu (2014),

As the study by Leon-Carrion et al. (2010) revealed, from neurophysiological and neuropsychological exams of the main neurocognitive domains, symptoms of depression were found in 62.5% of the evaluated patients, of which 50% presented mild depression and 12.6% presented moderate depression. Richert, Strauss, Fahlbusch, Oeckler & von Werder, (1986), analyzed 31 patients with active acromegaly in the preoperative period. Identified were psychopathological symptoms, including affective disorders, such as dejection, irritability, increased appetite and loss of libido.

Thus, the systemic complications caused by the pathology can lead to impairments in the quality

of life (Webb & Badia 2016), impacting several contexts and experiences of the subject, as already explained previously. The study by Llanes et al. (2017) showed the aesthetic, psychosocial and emotional impacts on women's sexuality, since they revealed to feel less attractive, less feminine and limited in the possibility of forming sexual, affective and marital bonds, limiting their intimacy with their partners. The authors also suggest that the sexual impact on women, due to acromegaly, results in a decreased or lost sexual desire, since they see sexual activity and sexual availability as a fundamental basis for the relationship.

In men, Llanes et al. (2017) a repercussion in the sexual life was presented regarding the discomfort of the aesthetic impact of the disease, leading to the decrease of the sexual desire due to difficulties of getting an erection, causing a lower frequency of sexual activity, in order to avoid the "failure". Therefore, difficulties in interpersonal relationships and distortion of self-image caused by acromegaly may imply a healthy sexual functioning of the patient.

There is also a concern in males about the sexual satisfaction of partners, according to the authors mentioned above, since they believe that not "responding" sexually is a hindrance to continue to be admired and respected by their female partners.

In this sense, the implication of the psychological symptoms in people with acromegaly, especially anxiety and depression, can be perceived, which can interfere in the sexual activity of the patients. This can affect their relationships, body image, self-esteem, self-image, as well as have an effect on other social and professional contexts of life. For this reason, this study has become relevant since it can broaden the view of health professionals towards acromegaly, going beyond the signs and symptoms when perceiving the dimension of the psychological and emotional implications that can affect several areas of the patient's life and the way they relate to the world.

It is necessary to emphasize that although the literature points out the relation between acromegaly and sexual dysfunction, the studies in this approach are scarce, especially from the perspective of the subjects who suffer from this problem, as pointed out by Llanes et al. (2017). This study intends to contribute to the broadening of discussions on the subject, aiming to describe the psychological impacts of sexual dysfunction due to the diagnosis of acromegaly and to verify if there are differences in the influence that this pathology specifically has on the sexual activity of both genders.

Methods

The present study is characterized as a cross-sectional retrospective study, with a quantitative approach. The sample consisted of 71 patients with acromegaly from the state of Bahia. Patients were of both genders, over 18 years of age, and being treated at the Neuroendocrinology Outpatient Clinic of CEDEBA. Participants' diagnoses were confirmed by laboratory exams and images that were included in medical records of the referral clinic. Patients with an inability to respond to the questionnaire used in this study were excluded from the sample.

It is important to emphasize that this research is part of the main project entitled "Rare Diseases: Comprehensive Care, Evaluation and Social Support", approved by the Ethics and Research Committee of the Bahian School of Medicine and Public Health (EBMSP) in May 2016, with CAAE number: 56840516.4.0000.5544. All study participants signed the Term of Free and Informed Consent (FPIC) according to Resolution 466/12 of research involving human subjects.

Data collection

The AcroQol (Acromegaly Quality of Life Questionnaire) was used to measure the quality of life of people with acromegaly. The questionnaires were offered in the waiting rooms of the clinic or during the anamnesis of the psychology service from April 2014 to July 2017.

This instrument was created for the use of clinical screening and routine monitoring of patients with acromegaly, designed as a self-administered questionnaire. It is composed of 22 items, assessing

physical and psychological aspects and impact of the disease on personal relationships (Badia, Webb, Prieto & Lara, 2004).

Passos (2013) shows that each AcroQol item is answered with a score ranging from 1 to 5, where 1 corresponds to the worst quality of life and 5 to the best quality of life (Likert scale). Depending on the question, the respondent evaluates their quality of life according to the degree of frequency (always, most of the time, sometimes rarely and never) or the degree of agreement with the item (totally agree, quite agree, no agree or disagree, disagree somewhat and agree nothing).

Data analysis

Descriptive analysis and statistical tests were performed using the Statistical Package for Social Sciences (SPSS 23.0). The results were presented in tables with descriptive measures (mean, maximum, minimum, standard deviation and standard error, suitable for quantitative variables) and frequencies (absolute and relative) for qualitative variables. Normal distribution analysis was performed on the quantitative variables of continuous distribution by the Kolmogorov-Smirnov test. Univariate analysis was performed using the chi-square test and the Student's T test for the comparison between the gender groups and the scores of the sexual dysfunction subscale. The Pearson test was used to analyse the correlation between sexual dysfunction and self-image scores. The level of significance is 5% (p < 0.05).

To describe the psychological impacts of sexual dysfunction due to the diagnosis of acromegaly, a subscale was considered, in other words, a partial score derived from the sum of questions regarding the evaluation of aspects of sexual dysfunction. Although the 22 AcroQol questions were used for the quantitative analysis of this study, 2 items were separated: "I have problems to have sexual relationships because of acromegaly" and "I have a low sexual desire due to acromegaly." It should be noted that these items are answered on a frequency scale. In addition, another item of AcroQol investigated symptoms of depression: "I feel depressed after the diagnosis," to assess the impact of this aspect on sexuality.

In order to assess discomfort with body image in the context of sexuality in acromegalic patients, a correlation was also made between the change in self-image after diagnosis (feeling "ugly" and feeling "awful" when I see myself on photos) with the difficulty related to maintaining sexual relationships after diagnosis, both items answered by AcroQol.

Results and discussion

It was noticed that both men and women, presented a similar sociodemographic profile, as shown in Table 1. The majority resides in the interior of the state of Bahia, studied until high school, and receives up to 1 minimum wage.

Table 1. Sociodemographic characteristics of patients with acromegaly in the state of Bahia, Brazil.

Variables	Male (N=23) X (±SD) or %	Female (N=48) X (±SD) or %	Total (N=71) X (±SD) or %
Age	46,9 (±12,10)	50,18 (±13,18)	49,58 (±12,89)
Residence (City)	Interior (70,8%)	Interior (59,2%)	Interior (63%)
Schooling	High School(57,1%)	High School (45,8%)	High School(49,3%)
Income	1 salary (52,4%)	1 salary (64,6%)	1 salary (60,9%)

In addition, it was noticed that in the distribution of sexual dysfunction subscale scores (Table 2), there was not a big difference between the means of men and women. However, the scores of the two subscales measured in this study (Table 3) show that the participants obtained above-average results, considering the possibility of a minimum and maximum score in AcroQol.

Table 2. Distribution of AcroQol partial scores and clinical characteristics of patients with acromegaly in the state of Bahia, Brazil

Variables	Male (N=23) X (±SD) or %	Female (N=48) X (±SD) or %	Total (N=71) X (±SD) or %	
Subscale Sexual Dysfunction	6,6 (±3,2)	6,0 (±2,8)	2-10 pts (min-max)	
Subscale Self-image	19,1 (± 6,0)	17,2 (±6,0)	6-30 pts (min-max)	
Diagnostic Time (years)	4-10 (52,2%)	>10 (31,3%)	>7 (51,4%)	
Performed surgical treatment	79,2%	90%	86,4%	
Feeling depressed after the diagnosis	8,7%	20,8%	16,9%	

With regard to "feeling depressed after the diagnosis", the scores presented a low percentage, in both women and men. Although the specific instruments for assessing depression have not been applied, this data is clinically relevant, but also reveals that the sample shows little association with the diagnosis of acromegaly. However, it should be emphasized that this inference does not necessarily indicate that respondents are not depressed.

On the other hand, it is worth mentioning that the sample is inserted in a psychoeducational group in the Neuroendocrinology clinic of CEDEBA. Therefore, access to information and dialogue about the impacts of acromegaly, such as sexual dysfunction, the construction of coping strategies and acceptance of change, may have been developed during the group process. These aspects may have interfered in the choice of responses when AcroQol was applied and, consequently, in the scores of the subscales.

Llanes et al. (2017) affirm that some individuals reported not to be negatively affected regarding sexuality, after the diagnosis of acromegaly, and they associate this aspect with the influence of acceptance of physical changes as part of the natural course of life, recognizing the benefits. The author also shows the association with the functional

and healthy dynamics of the couple, since solid relationships, with the presence of children and life projects built together, as well as openness in dialogues on sexual issues, provide conditions for a lower psychosocial- and emotional impact.

As for the categories "difficulty in having sexual relations associated with acromegaly" and "lower sexual desire due to acromegaly", explored in AcroQol within the subscale of sexual dysfunction, it was noticed that slightly more than a third of the total sample (men and women) reported difficulty in having sexual relationships after the diagnosis. This study aimed to know the impact of the disease specifically on sexual activity of both genders. Therefore, the gender analysis was performed in an attempt to cover the peculiarity of the acromegaly interference in the sexuality of men and women. Although the literature describes that each gender experiences sexuality in a different way, this sample presented similar results regarding "having difficulties to have sex after the diagnosis", however, if we look at the category "decreased sexual desire after diagnosis "there was a certain distance between the answers given by the genders, with a higher percentage of women agreeing with the statement, compared to the answers of males (Table 3).

Table 3. Distribution Subscale AcroQol - Sexual Dysfunction

Variables	Male (N=23)	Female (N=48)	Total (N=71)	P Value*
Difficulty having sexual relationships after diagnosis	34,7%	33,3%	33,8%	0,06
Do not experience difficulty in having sexual relationships after diagnosis	47,8%	45,8%	46,5%	0,06
Perceived lower sexual desire after diagnosis	30,4%	54,2%	46,5%	0,22
No lower sexual desire perceived after diagnosis	26,1%	20,8%	22,5%	0,22

^{*} Statistical Significance (p < 0,05)

Regarding libido, men reported having a low sexual desire due to acromegaly (30.4%), while in women, more than half (54.2%) reported decreased sexual desire after diagnosis. This data may be associated with the mean age of the sample (Table 1), since these patients may be influenced not only by acromegaly, but also by the climacteric state itself, which refers to a biological phase of life and occurs before and after menopause, which can cause hormonal changes in women.

In Brazil, 60% of women report having decreased sexual activity after menopause (Lorenzi, Baracat, Saciloto & Padilha, 2006). And although sexual complaints occur at any time during reproductive life, the climacteric phase allows them to be more vulnerable to sexual dysfunction, due to a wide range of factors, such as the difficulties in the emotional and social aspects, which are characteristic of this phase (Pinto Neto, Valadares & Costa-Paiva, 2013, Cabral et al. al., 2006). Thus, the effects of acromegaly are a factor to be added in relation to the possible impacts that the female patient may suffer in her sexuality.

Table 4. Association of Self-image and Sexual Difficulties

Self-image	Sexual Dysfunctions	Correlation Coefficient (r)	P Value*
"Feeling ugly after diagnosis"	"Difficulties in having sexual relations"	0,33	0,004**
"Feeling awful when seeing themselves on photos"	"Difficulties in having sexual relations"	0,34	0,003**
"See yourself different in the mirror"	"Difficulties in having sexual relations"	0,12	0,33
"Notice large body parts"	"Difficulties in having sexual relations"	0,06	0,58
"Feeling looked at because of physical appearance"	"Difficulties in having sexual relations"	0,15	0,22
"Feeling looked at because of physical appearance"	"Have a low sexual desire"	0,11	0,37
"Feeling ugly after diagnosis"	"Have a low sexual desire"	0,13	0,26
"Feeling awful when seeing themselves on photos"	"Have a low sexual desire"	0,16	0,19
"See yourself different in the mirror"	"Have a low sexual desire"	0,39	0,74
"Notice large body parts"	"Have a low sexual desire"	-0,21	0,86

^{*}P values calculated using Pearson's test

^{**} Statistical Significance (p < 0.05)

According to Hannickel, Zago, Barbeira & Sawada (2002), self-image is one of the main aspects in relation to self-esteem, thus, it impacts attitudes and emotions of individuals. It is also known that sexuality can also be influenced by self-esteem, since libido and sexual activity include the subject's perception of their own body. Thus, according to the data in Table 4, a significant correlation was verified between a change of self-image after diagnosis (feeling "ugly" or feeling "awful" when they see themselves on photos) and the category "difficulty in having sex after diagnosis". The correlations, although weak (r = 0.33 and r = 0.34) indicate that the changes in the self-image associated with the symptomatology of the disease have interfered with the self-esteem of the acromegalic patient, which may have led to the change of sexual behaviour of a part of the sample.

As additional data to the dimensions explored in the subscale of sexual dysfunction, it was observed that 90% of the sample has tumors greater than or equal to 1 cm, and could be characterized as macroadenomas. In this sense, the size of the tumor may be an aspect affecting the hormonal picture of the patient with acromegaly, being a high value marker that helps differentiate the clinical and hormonal aspects on the sexual question.

Final considerations

From what was found throughout this study, it is possible to conclude that not only the hormonal question interferes with libido but also emotional aspects and one's self-image. Thus, there are multiple intercurrent factors in sexual dysfunction due to acromegaly.

In this sense it is relevant to insert patients with acromegaly in psychotherapeutic treatment, either individually and/or in psychoeducational groups, because there are many psychological repercussions associated with the disease. The participation of patients in a psycho-educational group aimed

at acromegaly is shown as a facilitating aspect in the treatment, especially regarding the possibility of sharing experiences with other patients. Other benefits are the possibility to express oneself and sharing coping strategies in a group, family support, and the possibility to start a dialogue on issues that are not always discussed openly in clinical practice, such as sexuality.

It is considered important to opt for an interdisciplinary approach in treatment, including family and community support, as in this way it could strengthen the patients' social support. Thus, it is suggested that the emotional and psychological issues are given attention and are worked on, catalysing the coping process of the disease and easing its repercussions, as it is beneficial to both the patient and family. These interventions help the insertion of new practices to improve life habits and help prevent the emergence and/or aggravation of psychological conditions related to acromegaly.

Nowadays, it is known that subjective or self-reported questionnaires may not be sensitive to subtle psychiatric disorders. Therefore, a limitation of this study is that there was no specific assessment to evaluate the symptoms of depression and anxiousness, only the AcroQol self-report scale was used to evaluate these items in the sample.

In addition, there is the fact that the topic of sexuality may have been viewed by the participants of the study as a subject they are not used to talk about, and patients may have been embarrassed by the questions regarding sexual dysfunction. Therefore, the responses of both men and women may have been incomplete or false negative, since this issue is still seen as a taboo for many people.

Conflict of interest disclosure

There is no financial-, legal-, or political conflict involving third parties (government, corporations and private foundations, etc.) for any aspect of this study.

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