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1 **ACROMEGALY IN REMISSION : A VIEW FROM THE PARTNER**

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19

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26

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31 dictionary defining each field in the set, will be made available upon reasonable request to the
32 corresponding author.

33 **Ethics approval:** Informed written consent was obtained from all patients to participate in the study,
34 which was approved by the ethics committee of Aix Marseille University.

35 **ABSTRACT**

36 **Purpose** A relative can be an asset in dealing with chronic illnesses such as acromegaly where quality
37 of life is altered even after remission. However, it has been shown that quality of life of caregivers
38 can also be impacted. Our main objective was to explore the consequences of acromegaly in
39 remission in the patient-relative dyad in a matter of quality of life and self-esteem.

40 **Methods** In this observational study, to better characterize the perception of the disease by the
41 partner, patient's body image and self-esteem were evaluated from the patient's point of view
42 (n=27) and from the relative's using the same questionnaires with modified instructions. The patient
43 and the partner were also asked to fulfil quality of life, anxiety/depression and coping strategies
44 questionnaires.

45 **Results** The relative had an overall accurate estimation of the patient's body image using Stunkard
46 figurines. However, there were wide variations between the patient's and the relative's answers for
47 self-esteem and body perception. The relative's quality of life was not altered and was significantly
48 higher in the social domain than for the patient.

49 **Conclusion** Despite inter-individual changes between the patient's and the relative's view, our results
50 show that the relative should be educated in all the steps of the management of acromegaly, to help
51 him/her better understand the disease and support the patient.

52 INTRODUCTION

53 In chronic diseases, health-related quality of life has become an increasingly important aspect of
54 patient care [1]. For instance, patients with active as well as controlled acromegaly report an
55 impaired quality of life, linked to the duration of the disease, the necessity of a prolonged medical
56 treatment, a history of radiotherapy or persistent symptoms such as joints complaints [2–4]. The
57 partner (family member or close friend) can also be impacted by the chronic disease of the patient
58 [5]. Indeed, it has been thoroughly described with dementia and cancer patients [6–8]. Furthermore,
59 when evaluated with various generic scales such as HAD and SF-36, chronic kidney disease patients
60 and relatives showed the same level of anxiety and depression [9].

61 To the best of our knowledge, the patient-relative dyad in pituitary disease has only been studied in
62 two qualitative studies [10] [11]. For instance, Andela *et al.* conducted focused groups interviews to
63 explore the partners' perspective. They found that the partners had negative beliefs about
64 medication and felt that they had to make adaptations of their own behaviour for their ill partner
65 [11]. In both studies, partners asked for more information about the disease and additional guidance.
66 However, consequences on the dyad in acromegaly has never been specifically studied from a
67 quantitative point of view.

68 The main objective of this study was to determine the partner's perception of acromegaly in
69 remission via an original approach in which we asked him/her to imagine what the patient had
70 answered in terms of body image and self-esteem. Secondary objectives were to determine the
71 quality of life of the partner, as well as anxiety, and depression (comparing it with the patient's
72 characteristics), and the coping strategies of the dyad.

73 **PATIENTS AND METHODS**

74 A prospective monocentric, non-interventional study was conducted in the Tertiary reference Center
75 of La Conception Hospital, Assistance Publique Hôpitaux de Marseille, France.

76

77 **Patients and partner/family member**

78 Patients aged 18-80 years, in remission and/or controlled by a pharmacological treatment for 1-10
79 years, were recruited while doing their follow-up at our department between September 2019 and
80 June 2020. Remission was defined as follows: Normal age and sex matched - insulin-like growth
81 factor (IGF-1) levels, random growth hormone (GH) < 1 ng/mL and/or a nadir GH level after OGTT <
82 0,4 ng/mL. Patients were considered controlled if they had normal IGF-1 levels and random GH < 1
83 ng/mL on medical treatment. Patients with known cognitive deficiency could not be included. The
84 partner and/or family member was chosen by the patient.

85

86 **Data collection and conduct of the study**

87 After being selected by the endocrinologist in charge of each patient in the Department, patients
88 were contacted by mail. Informed written consent was obtained from all patients to participate in
89 the study, which was approved by the ethics committee of Aix Marseille University. The following
90 data were collected for each patient: socio-demographic data (including age, gender, education level,
91 profession, marital status), medical data (medical history, comorbidities), acromegaly data
92 (therapeutic course, current treatment, hormonal deficits).

93

94 Patients and relatives were asked to fill in the following questionnaires:

- 95 - Quality of life assessment using : First, the French version of the generic scale WhoQoL-BREF
96 developed in 1998 [12] and translated in 2010 by Baumann *et al.* [13]. It allows the
97 evaluation of quality of life in several areas like "physical health", "psychological health",

98 "social relations" and "environment". Secondly, the only disease-specific scale in acromegaly
99 called AcroQoL [14] for patients only.

100 - Anxiety and depression evaluation with the Hospital Anxiety and Depression scale (HAD)
101 developed by Zigmond *et al.* in 1983 [15] and validated in French by Lepine *et al.* in 1985
102 [16]. This scale has the particularity of studying both the anxiety and the depression
103 components. It includes 14 items rated from 0 to 3. Seven questions refer to the anxiety
104 component and seven others to the depressive component, giving two scores.

105 - Self-esteem was evaluated with Rosenberg's questionnaire, developed in 1965 [17] and
106 translated in 1992 [18].

107 - Body image perception using the Image Body Questionnaire (IBQ), a French questionnaire
108 developed by Bruchon-Schweitzer in 1990 [19] and figurines by Stunkard, Sorensen and
109 Schlusinger (patients were asked to choose the figurine that they believed to be closest to
110 their representation of themselves) [20].

111 Of note, we studied the relative's perception of the patient's body image using the same
112 questionnaires (Rosenberg's questionnaire, IBQ and figurines by Stunkard, Sorensen and Schlusinger)
113 with modified instructions, and without knowing the patient's answers. This technique has already
114 been used in the literature to study the perception of the patient's quality of life by the relative in
115 chronic diseases [21], particularly in cancer and neurological diseases like strokes where it can be
116 useful since the patient's communication is impaired [22] [23].

117

118 **For the patient-relative dyad:**

119 We also explored the coping strategies, defined as cognitive and behavioural efforts to deal with a
120 stressful situation, using the Brief Cope situational scale. The version we used was translated and
121 validated in French by Muller *et al.* in 2003 [24]. It includes 14 different coping dimensions (active
122 coping, planning, using instrumental support, using emotional support, venting, behavioural
123 disengagement, self-distraction, self-blame, positive reframing, humour, denial, acceptance, religion

124 and substance use). We used a French version regrouping these dimensions in 4 coping strategies :
125 Seeking social support (including emotional support, instrumental support, venting and religion),
126 positive thinking (including humour, positive reframing and acceptance), avoidance (including
127 behavioural disengagement, self-distraction, substance use, denial and self-blame), problem solving
128 (including active coping and planning) [25].

129

130 **Statistical analysis**

131 We first performed a descriptive analysis of the population. Quantitative variables were expressed as
132 median with interquartile ranges or means with standard deviation; qualitative variables were
133 expressed as proportions and percentages. We considered each QoL score as a variable of interest:
134 the four QoL scores of the WHOQoL-BREF (physical, psychological, social and environmental scores)
135 and the total score of the AcroQoL. The same analysis was performed for the partner. Body image
136 questionnaire, Stunkard figurines score and Rosenberg's questionnaire evaluations made by the
137 partner were correlated with the evaluations of the patients. Data analyses were performed using
138 Prism version 8.4.3 (GraphPad software, LLC). p-values < 0.05 were considered significant and all
139 statistical tests were two-tailed.

140 **RESULTS**

141 Thirty-five patients were contacted; twenty-seven patients (15 women and 12 men) agreed to
142 participate, and were enrolled in this study. The epidemiological and socio-cognitive characteristics
143 of the patients are reported in table 1. Most patients had familial support, and were educated to a
144 middle to high level. Three patients (n=3/27, 11.1%) had a disabled worker status. Regarding the
145 partner and/or family member, 77.7% of the relatives were partners, 22.2% were children.

146 We asked the relative to determine the self-esteem score that the patient would obtain by filling in
147 the same questionnaire as he/she was the patient. Eight relatives considered the patient to have a
148 very low or low self-esteem (vs. 6 when completed by the patient), while 13 (vs. 12 when fulfilled by
149 the patient) considered the patient to have a high or very high self-esteem (p=0.348). We asked
150 every relative to depict the Stunkard body that would be given by the patient: the median estimated
151 Stunkard body score was 5 [1-8], which was not significantly different compared to the patient's
152 answers (p= 0.171 in comparison with the patient). The same non-significant difference was
153 observed for the IBQ (p=0.549). However, as shown in Figure 1, though the overall differences in
154 these parameters were not significant between the patient's and the relative's view, there was a
155 wide variation when taken from an individual viewpoint: except for Stunkard scores (r=0.792,
156 p<0.001), both Rosenberg and IBQ scores were indeed not correlated between the patient and the
157 relative (r=0.203 and r=0.080, respectively).

158 Regarding the socio-cognitive characteristics of the partner, the quality of life median scores of the
159 WhoQoL-BREF were 69 [31-100] for physical, 69 [25-88] for psychological, 75 [44-88] for social
160 relationships and 75 [44-88] for environmental. When comparing with patients' Who-QoL (data not
161 shown), there was no significant difference for all but one parameter, social relationships, for which
162 there was a median gain of 19 points in the relative questionnaire (p=0.0435). Two family members
163 (7.4%) had a HAD-anxiety score above 8 (likely anxious), while 1 (3.7%) had a score above 11 (certain
164 anxiety). According to the HAD depression scale, 1 family member (3.7%) had a depression score
165 above 8 (likely depressive), and 1 (3.7%), a score above 11 (certain depressive). Regarding these

166 scores, we found no significant difference between the patient and the family member ($p=0.247$).

167

168 Finally, the adaptation strategy preferentially adopted by the dyad was positive thinking. Problem

169 solving came in second position, and seeking social support in third.

170

171 **DISCUSSION**

172 Illness perceptions can be different between a patient suffering from a chronic disease and his/her
173 relative. In acromegaly, we showed that the patient's relative had a global accurate estimation of the
174 patient's body image using the Stunkard scale. However, even though there was no statistical
175 difference between the patient's IBQ and Rosenberg scores and the partner's, there were major
176 differences when taken individually as shown in Figure 1. To our knowledge, this facet of the dyad
177 has never been evaluated in our field. Using the same method for advanced cancer patients,
178 caregivers seem to give an adequate evaluation of the patient's body dissatisfaction and associate it
179 to the weight loss due to their disease [26]. Body image is only mentioned by the patient in the few
180 studies available about the patient-relative dyad in pituitary disease. Therefore, we speculate that
181 family members of acromegaly patients are not fully aware of the consequences of body changes on
182 their relative's self-esteem. As a matter of fact, in the focus groups conducted by Andela *et al.*,
183 partners expressed viewing their relative differently but for other reasons such as changes in their
184 relationship (partner becoming the counsellor or carer) or differences in coping mechanisms. Both
185 patients and partners reported difficulties in communicating about the disease with doctors and their
186 social network, resulting in a decrease of social interactions [11]. Accordingly, seeking social support
187 only came in third place on our results of the Brief cope. This may be explained by the fact that
188 acromegaly is a rare disease, little known by the medical community and general population.
189 Dunning *et al.* explored experiences of patients with pituitary disease and their partners by
190 monitoring chat room discussions and they observed that patients discussed more openly about
191 physical changes, appearance and feelings among their peers than with their family or friends [10].
192 Moreover, in an online survey conducted on the Carenity website, patients expressed the need to
193 share experiences with other patients in discussion groups and that acromegaly be better known
194 from their relatives [27]. Taken together, this suggests that we should use body image as a starting
195 point to discuss the particularity of acromegaly either in consultation or in education programs [28].

196 Relatives of acromegaly patients do not seem to have an altered quality of life. We also found a
197 difference of 19 points between the patient's and the relative's social WhoQoL score which contrasts
198 with previous findings [5]. However, it should be interpreted with caution considering the high
199 variability of answers and the size of our cohort. Indeed, acromegaly is a rare disease and finding a
200 family member willing to participate reduces the number of participants. A review of the literature
201 published by Stenberg *et al.* identified difficulties experienced by family caregivers of cancer patients
202 like fatigue, sleep disturbance, anxiety or mood disturbances highlighting the burden of caregiving
203 responsibilities [7]. Using specific scales like the Caregiver Burden Scale (CBS) and the Caregivers
204 Quality of Life Index-Cancer (CQOLC), another study found that caregiver burden increased with
205 anxiety, depression and poorer quality of life and that these results were similar to those reported in
206 other chronic conditions like chronic heart failure [8]. Furthermore, some findings in chronic kidney
207 disease show that patients and caregivers have similar scores in the mental and social domains of
208 quality of life score [9]. We cannot fully compare our results as we are the first to analyse the
209 relative's quality of life in pituitary disease. Nonetheless, we can hypothesize that results might be
210 different around the diagnostic of acromegaly when there are more outpatient visits, exams, and
211 hospitalisations and therefore a higher burden for the partner.

212 Our study has a main limitation, which is the fact that we were not allowed to analyse the medical
213 history of the partners/family members as they were not inpatients of our institution. We thus
214 cannot exclude that comorbidities might have biased the results of the 2nd part of our study, ie. their
215 sociocognitive characteristics. However, the way we evaluated our main criterion, was based on a
216 direct comparison of the perception of the disease by the partner and the patient, was not biased by
217 this medical history. Moreover, as a pilot study, we only included a small number of patients, and our
218 results will have to be confirmed by studies on a larger number of patients. Finally, we decided to
219 include patients controlled by medical treatments or cured by surgery: even if we acknowledge that
220 quality of life is probably different between these 2 groups of patients, this should not modify our
221 main criterion.

222 To conclude, our study is the first to analyse the consequences of acromegaly of the patient-relative
223 dyad in a matter of quality of life and self-esteem. Partners appeared to have an accurate estimation
224 of the patient's body image. However, they were not fully aware of the consequences of body
225 changes on their relative's self-esteem. It is thus proposed that discussing body image may be used
226 as a starting point in dealing with the patient's perception of the disease. Both patients and relatives
227 reported a decrease in social interactions although seeking social support was not a preferential
228 coping mechanism. Education programs should therefore consider a specific approach not only
229 centred on the patient, but also on the familial environment. In a disease such as acromegaly in
230 which physical and psychological sequelae can likely remain for years after remission,
231 endocrinologists will probably increase the overall acceptance of the disease by involving the
232 relatives.

233

234

235 **LEGEND TO TABLES AND FIGURES**

236

237 **Table 1:** Epidemiological and socio-cognitive characteristics of the patients. All values are presented
238 in effectives (n) and percentages (%) or median and Interquartile Range [IQR]

239

240 **Table 2:** Psychological characteristics of the patient and relative. Values are presented in median and
241 Interquartile Range (IQR). ^aScore > 8 possible symptomatology, > 11 certain symptomatology. ^bscore
242 < 25 very low, 25–31: low, 31–34: in the average, 34–39: high, > 39: very high. ^cResults of the four
243 factors Brief-COPE with transformed score from 0 to 100

244

245 **Figure 1:** Correlation scores between the patient and the relative for Rosenberg, Body image and
246 Stunkard scores: The relative was asked to fulfil the questionnaire as if he was the patient.
247 Overestimation by the relative: 50% for the Rosenberg, 45.8% for the IBQ and 19.2% for Stunkard's
248 figurines. Underestimation: 42.3%, 54.1% and 38.4% respectively. Accurate estimation: 7.7%, 0% and
249 42.3% respectively.

250

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