Perceived Quality of Life in Acromegaly: results from a tertiary UK Centre

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Introduction

Patients with acromegaly are frequently left with long-term adverse sequelae. Cross-sectional evaluation of health-related quality of life (HR-QoL) in patients with acromegaly using both generic and specific questionnaires has confirmed HR-QoL to be severely impaired [1, 2]. Female gender, ageing, disease duration, joint symptoms and prior radiotherapy [2] have been suggested to impact negatively on HR-QoL. The most severely impaired domain of HR-QoL is reported to be appearance. Patients with active acromegaly show a similar magnitude of impairment of HR-QoL compared with those in remission [2].

Methods

We prospectively collected data from patients with acromegaly, who have been followed-up in the Endocrine Clinics at Leeds Teaching Hospitals. The disease-specific questionnaire, AcroQoL, and the generic psychological general well-being schedule (PGWBS) were used to evaluate QoL in our cohort. The AcroQoL is a disease specific questionnaire consisting of 22 items which cover physical and psychological aspects. The latter can be divided into the domains of appearance and personal relationships. Higher scores reflect better quality of life [3]. The PGWB index is a generic questionnaire consisting of 22 questions evaluating 6 different aspects (positive well-being, general health, depression, self-control, anxiety and vitality). As with the AcroQoL higher scores reflect better health [4]. Participants were asked to complete the questionnaires twice within a space of five years. Data relevant to patients' history of acromegaly were also collected. Biochemical disease control was defined as GH<2mcg/l (or <6miu/l) and IGF-I within the reference range for the patient's age.

Results

Baseline responses were collected from 58 patients (mean age 55.5±12.7 years), previously treated for acromegaly. Baseline mean GH and IGF-1 values for the entire cohort were 1.53±2.07mcg/l and 102.1±51% of the upper limit of normal (ULN) respectively. Mean duration of GH control in our cohort was 5.1±4.8 years, whereas for IGF-1 this was 4.0±4.4 years. Patients with pituitary hormone deficiencies have been on the appropriate hormone replacement therapy at the time of completion of the questionnaires. Patients' characteristics for the entire cohort are shown in Table 1.

Follow-up responses were obtained from 23 patients. The mean time interval between the two set of responses was 5.4±0.36 years. For this subgroup, mean GH and IGF-1 at follow-up were 0.76±0.75mcg/l and 110.4±54.3% of ULN respectively (versus 1.6±2.4mcg/l and 110.5±64.7% of ULN at baseline). Table 2 summarises the characteristics for this subgroup of patients.

AcroQoL mean total score at baseline was 67.8±18.4 (52.0%). The domain of appearance was the most under-marked, while the highest scores were noted in the personal relationships domain (Table 3). For the subgroup of 23 patients, no significant difference was found in the baseline and follow-up AcroQoL scores (64.2 vs 65.7, p=0.58).

Table 1. Summary of the characteristics of all patients who provided with responses to the questionnaires at baseline (N=58). Numbers in brackets represent percentages. Numbers in years represent mean values with their standard deviations. IGF-I values are shown as percentage of the upper limit of normal (ULN %).

Characteristic	Patients (%)	Characteristic	Patients (%)
Gender		**Radiological evidence of residual disease**	
• Male	31 (53.4%)		
• Female	27 (46.6%)	• Yes	36 (62.1%)
Age (years)	54.5±13.1	• No	22 (37.9%)
Treatment modalities		**Characteristic**	**Number of years**
• Transsphenoidal surgery	51 (87.9%)	**Active disease duration**	11.5±7.8
• Radiotherapy	28 (48.2%)	**Duration of GH control** (GH<2 mcg/L)	5.1±4.8
• Medical therapy	33 (56.9%)		
Pituitary dysfunction following therapy		**Duration of IGF-I control**	4.0±4.4
• LH/FSH deficiency	23 (39.7%)	**Test**	**Mean value**
• ACTH deficiency	21 (36.2%)	**GH** (mcg/L)	1.53±2.07
• TSH deficiency	15 (25.9%)	**IGF-I** (ULN %)	102.1±51%
• ADH deficiency	1 (1.7%)		

Results (cont'd)

PGWBS scores were significantly lower in the patient group compared with reference population, both at baseline [median score 71.5 (IQR 52.0-86.5) vs 89.5 (IQR 81.0-95.75), p<0.001] and follow-up [median score 61.0 (IQR 46.0-83.0) vs 89.5 (IQR 81.0-95.75), p<0.001]. Baseline and follow-up PGWBS scores were not statistically different for the subgroup of 23 patients (Table 4). Positive well-being, general health and vitality were the mostly under-marked domains. Multiple linear regression analysis using the AcroQoL and PGWB scores as dependent variable and patient's age, gender, active disease duration, GH and IGF-I values at the time of questionnaire completion, presence of other pituitary hormone deficiencies, treatment modalities used for the acromegaly control, duration of GH and IGF-I control and radiological evidence of residual disease following treatment, as independent variables, did not reveal any factors predictive of patients' QoL scores.

Table 2. Clinical characteristics for the subgroup of patients (N=23) who have completed the QoL questionnaires both at baseline and follow-up (mean time interval 5.4±0.36 years). Numbers in brackets represent percentages. Numbers in years represent mean values with their standard deviations. IGF-I values are shown as percentage of the upper limit of normal (ULN %).

Characteristic	Patients (%)	Characteristic	Patients (%)
Gender		**Radiological evidence of residual disease**	
• Male	10 (43.5%)		
• Female	13 (56.5%)	• Yes	10 (43.5%)
Age at baseline (years)	56.7±9.9	• No	13 (56.5%)
Age at follow up (years)	62.2±10.0	**Characteristic**	**Number of years**
Treatment modalities		**Active disease duration**	11.5±7.8
• Transsphenoidal surgery	23 (100%)	**Duration of GH control** (GH<2 mcg/L)	4.66±4.5
• Radiotherapy	14 (60.9%)		
• Medical therapy	13 (56.5%)	**Duration of IGF-I control**	3.77±3.9
Pituitary dysfunction following therapy		**Test**	**Mean value**
• LH/FSH deficiency	9 (39.1%)	**GH at baseline** (mcg/L)	1.60±2.4
• ACTH deficiency	8 (34.8%)	**IGF-I at baseline** (ULN %)	110.5±64.7%
• TSH deficiency	7 (30.4%)	**GH at follow-up** (mcg/L)	0.76±0.75
• ADH deficiency	0 (0.0%)	**IGF-I at follow-up** (ULN %)	110.4±54.3%

Table 3. Breakdown of the scores for the different domains of the AcroQoL questionnaire. Results are presented as mean scores with their standard deviations and refer to the baseline responses for the entire patient cohort (N=58).

Domain	Actual mean score	Max possible score
Physical	23±7.5	40
Appearance	20±6.3	35
Personal relationships	25±6.2	35
Total score	68±18.4	110

Table 4. Comparison of the PGWB scores between patients at baseline (N=58) and control group and between patients at baseline and follow-up (N=23, mean time of follow-up 5.4±0.36 years). Results are presented as median scores with their interquartile ranges.

Comparison in the PGWB scores between patients at baseline (N=58) and controls		
	Median score	P-value
Patients	71.5 (IQR 52.0-86.5)	<0.001
Controls	89.5 (IQR 81.0-95.8)	
Comparison between patient PGWB scores at baseline and follow-up (N=23)		
	Median score	P-value
Baseline	69.5 (IQR 51-82.5)	0.6
Follow-up	64.5 (IQR 46-82)	

Conclusions

Our results demonstrate impairment of QoL in patients with acromegaly compared with the control population. Long-term follow-up of treated patients failed to show any change in QoL scores despite biochemical disease control. Physical aspects of the disease such as appearance, vitality and positive well-being were found to be the most underscored domains, with arthropathy and fatigue being the main factors affecting patients' general health. A more holistic approach, potentially in a multi-disciplinary setting involving clinical psychologists, should be implemented for the long-term management of patient with acromegaly.

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17 ECE
3-GP-19
Pituitary basic and neuroendocrinology
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DOI: 10.3252/pso.eu.17ece.2015
Poster presented at: ECE2015 16-20 May 2015 DUBLIN, IRELAND 17th EUROPEAN CONGRESS OF ENDOCRINOLOGY
PosterSessionOnline.com