Health-Related Quality of Life in Pituitary Diseases

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KEYWORDS

• Pituitary diseases • Quality of life • Cushing syndrome • Acromegaly • Prolactinoma • Nonfunctioning pituitary adenoma • Hypopituitarism

KEY POINTS

- Impaired health-related quality of life (QoL) is observed in pituitary diseases.
- Even after endocrine control of acromegaly and Cushing disease, impaired QoL persists.
- Hypopituitarism, affecting 1 or more hormones, tends to worsen QoL further.
- Some physical and psychological factors have been identified as determinants of impaired health-related QoL in patients with pituitary diseases.

INTRODUCTION

Health-related quality of life (QoL) is a concept that refers to individual well-being. It is based on how a particular individual feels, responds, and functions in daily life. Individuals value their QoL, taking into account their expectations, standards, and goals, as well as emotional, physical, and social aspects of their lives, which might be affected if a disease is present.

QoL is usually measured by 2 types of questionnaires: generic and disease-generated or disease-specific. In both, the patients should evaluate how they self-perceive their general health status through several possible ratings (ie, excellent, very good, good, slightly bad, bad). Generic questionnaires have the advantage of being useful in any population, so comparisons can be made between patients with different diseases and normal individuals (**Table 1**). Alternatively, disease-generated

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Table 1
Examples of generic and disease-generated questionnaires

Generic Questionnaires	Disease-Generated Questionnaires for Pituitary Diseases
The Nottingham Health Profile[1]	CushingQoL for Cushing syndrome[5,6]
The Psychological General Well Being Scale[2]	AcroQoL for acromegaly[7]
The EuroQol (including the EQ-5 Dimensions and EQ-Visual Analog Scale)[3]	AGHDA (Adult Growth Hormone Deficiency Assessment)[8] or QLS-H (Questions on Life Satisfaction–Hypopituitarism) for growth hormone deficiency[9,10]
The Short Form 36[4]	

questionnaires are more sensitive in identifying dimensions most affected by the disease (eg, improvement after treatment) (see **Table 1**).

Evaluation of a patient's QoL is important to highlight the patient's viewpoint on clinical aspects often not considered by clinicians, to favor a better perception of high-quality medical care, to improve physician-patient relationships, and to contribute to therapeutic decisions based on evidence and cost-efficacy. Moreover, it allows selection of treatments that not only attain biochemical control but also optimize QoL.

CUSHING SYNDROME

The clinical features associated with hypercortisolism in patients with Cushing syndrome (CS) seem to be a strong determinant of well-being and QoL. QoL questionnaires used together with specific evaluations of cognitive functioning or depression have shown impaired QoL in CS, mainly in active patients.[8,11,12] However, cured patients with CS failed to normalize their QoL, even long-term after control of hypercortisolism.[12,13] Complex pharmacologic treatments, need for frequent medical checkups, and concerns about future health deterioration as a result of comorbidity also negatively affect QoL.[13]

Patients with CS most often complain of fatigue/weakness (85%), changes in physical appearance (63%), emotional instability (61%), cognitive problems (mainly poor memory [49%]), depression (32%), and sleeping difficulties (12%).[14] These problems in patients with CS cause negative effects on family life, partner relations, and work/school performance.[14] Furthermore, a retrospective report showed low scores on questions regarding employment status and work capacity in patients with CS both before and after treatment.[15] Although after treatment, 81% of patients with CS were working, 11% were retired because of disability, 5% were retired because of age, and 3% were on sick leave at the time of answering the questionnaire.[15]

The mechanism through which CS determines impairment of QoL is probably multifactorial, involving physical, medical, and psychological factors (**Fig. 1**). Impaired QoL has not been found to correlate with modality of treatment (pituitary or adrenal surgery or pituitary irradiation), duration of follow-up after biochemical remission, disease duration, or severity of hypercortisolism.[8,13] A European-wide study reported that depression was the only negative predictor of the QoL score (using CushingQoL [Cushing Quality of Life Questionnaire]), whereas other variables such as delay to diagnosis, diabetes, or hypertension did not significantly influence it.[16] Patients with CS show more emotional problems (depression and anxiety) and slower recovery after surgery than other patients with pituitary adenomas.[17] Most patients with CS have depression or emotional lability, especially if they are older, women, and have severe hypercortisolism. Psychopathology (mainly atypical depression) was more prevalent