Endocrinología, Diabetes y Nutrición 70 (2023) 445–447

Endocrinología, Diabetes y Nutrición

www.elsevier.es/endo

EDITORIAL

Quality of life in pituitary diseases

Calidad de vida y patología hipofisaria

Susan M. Webb[a,b,c,*], **Elena Valassi**[c,d,e]

[a] *Servicio de Endocrinología, Hospital Sant Pau e IIB-Sant Pau, Grupo de Investigación en Patología Hipofisaria, Barcelona, Spain*
[b] *Departamento de Medicina, Universitat Autònoma de Barcelona, Barcelona, Spain*
[c] *CIBERER Unidad 747, Instituto de Salud Carlos III (ISCIII), Madrid, Spain*
[d] *Servicio de Endocrinología, Hospital e Institut de Recerca Germans Trias i Pujol, Badalona, Barcelona, Spain*
[e] *Universitat Internacional de Catalunya (UIC), Barcelona, Spain*

I want to be well! This is what patients express when their doctor declares them to be ''cured''. But this is not typically the case for most patients who have been successfully treated for a pituitary disorder, i.e., once the hormonal dysfunction has been resolved, particularly if it is a patient diagnosed with Cushing's syndrome, acromegaly or hypopituitarism. In the case of hypercortisolism, it extends to all Cushing's syndromes, whether of pituitary, adrenal or ectopic origin.[1] Why? The diagnostic delay of several years typical of most pituitary disorders determines a long exposure to hormonal dysfunction, be it hypercortisolism, excess GH/IGF-I or lack of pituitary hormones (hypogonadism, hypothyroidism, lack of cortisol or GH). This leads to the onset of specific multi-organ morbidity (skeletal, muscular, cardiovascular, neuropsychological, etc.), which often improves, but does not normalise, with replacement therapy for the deficient pituitary axes. In their day-to-day lives, patients have a poor perception of their health and experience a deterioration in their quality of life.[2]

This poor quality of life has become particularly evident in the last two decades, when, thanks to advances in neurosurgical techniques and the availability of effective medical treatments, it is now possible to control most pituitary dysfunctions. Furthermore, the availability of specific questionnaires that address the dimensions that are affected by the various diseases has informed healthcare professionals of realities that are frequently ignored at clinical visits, but are crucial for the patient.[2] For instance, constant fatigability, pain or limitations doing daily tasks, whether professional, social or family-related, stress intolerance, emotional incontinence or memory problems that make it difficult to continue performing activities that require high executive capacity. All of this would explain reduced employment and more sick leave, even up to six years before the diagnosis of hypercortisolism.[1,3,4]

It is expected that reducing the diagnostic delay, and therefore exposure to hormonal dysfunction, would have a favourable impact on quality of life and residual morbidity. However, it is very likely that some limitation preceding the onset of the pituitary problem would persist, beyond general ageing itself, which is already associated with osteoarthritis, increased cardiovascular risk and memory deficits.

How can we help these patients to manage their perception of loss of quality of life? It is important that they have realistic information about their disease, available treatments and the disease course or long-term prognosis, as these are chronic processes with long survival rates. The

* Corresponding author.
E-mail address: webbsusan4@gmail.com (S.M. Webb).

availability of information of varying degrees of reliability on the Internet today means many patients can understand the reality of their disease better than they could a few decades ago. If they are aware of what can happen and of the probable discomfort or limitations, it will be easier to accept and adapt to the new post-disease reality. But the opinion of the expert professional, responding to any questions that may come up, encouraging the patient to adapt to the new situation with hopefulness, and relativising some aspects that are difficult to interpret, is fundamental for the patient to perceive a good experience in the treatment received, an increasingly important aspect when assessing the excellence and quality of healthcare services. In fact PROMs (patient-reported outcome measures) and PREMs (patient-reported experience measures) are increasingly used to assess the quality of clinical care.[5,6]

Markers of poorer quality of life include older age at diagnosis, lower educational level, female gender, depression at diagnosis or chronic pain, including headache.[2] Two recent Scandinavian epidemiological studies found more neuropsychiatric abnormalities, worse cognitive function and poorer long-term quality of life in patients with Cushing's syndrome than in the general population, which only partially improved after treatment.[1,3] There is greater consumption of psychotropic drugs (anxiolytics, antidepressants and hypnotics) and opioid analgesics in the five years prior to diagnosis compared to the control population, which persists in the following five years; this contrasts with the consumption of drugs for hypertension and type 2 diabetes, which reduces after controlling hypercortisolism.[3] Therefore, following the diagnosis and treatment of Cushing's syndrome, clinicians should pay the same level of attention to mental health as to hypertension or diabetes to improve the long-term prognosis and quality of life of their patients.

An empathic environment, which encourages perceived difficulties to be expressed and addressed, has been shown to be very therapeutic for those affected. Offering an educational programme to pituitary patients that promotes their autonomy and self-care improves their satisfaction and perception of their health, and encourages the pursuit of new goals, such as increasing knowledge, sharing experiences and improving self-esteem.[7] The fact that patients' quality of life did not improve after the educational programme is probably due to the fact that it was offered several years after diagnosis, emphasising the need to promote self-efficacy in the year following diagnosis and treatment; the most problematic year. Another intervention programme aimed at both patients and their partners that addressed psychosocial dimensions, such as self-efficacy, the need for support, perception of the disease, approach to problems and improving quality of life, succeeded in improving mood, self-efficacy and vitality; partners reported improvements in anxiety and depressive symptoms.[8] In addition, a similar programme can help maintain an acceptable quality of life by reminding patients that they are not to blame if they do not meet their daily goals and to consider more realistic expectations at work, in their social lives and at home.[9]

As experts in this disease, it is our responsibility to make the administrative and legal authorities aware of the potential persisting consequences for physical and mental health after a pituitary disorder. A reduction in working hours, incapacity for work or early retirement may be fully justifiable both in the case of jobs with a large physical component, due to fatigability and the greater risk of fractures, and in jobs with high academic or professional demand, due to reduced memory and perceived executive ability.[2,10]

Funding

This study received no specific funding from public, private or non-profit organisations.

Conflicts of interest

Susan Webb has received fees for consultancy or participation in training sessions promoted or financed by HRA, Ipsen, Novartis, Pfizer, Recordati Rare Diseases and Sanofi. She received unrestricted funding for clinical research projects or implementation of HRA assistance programmes.

Elena Valassi has received fees for consultancy or participation in training sessions promoted or financed by HRA, Ipsen, Recordati Rare Diseases and Sandoz. She received unrestricted funding for HRA clinical research projects.

References

1. Ebbehoj A, Søndergaard E, Jepsen P, Stochholm K, Lundsgaard Svane HM, Madsen M, et al. The socio-economic consequences of Cushing's syndrome: a nationwide cohort study. J Clin Endocrinol Metab. 2022;107:e2921–9, http://dx.doi.org/10.1210/clinem/dgac174.
2. Webb SM, Santos A, Aulinas A, Resmini E, Martel L, Martínez-Momblán MA, et al. Patient-centered outcomes with pituitary and parasellar disease. Neuroendocrinology. 2020;110(9-10):882–8.
3. Bengtsson D, Ragnarsson O, Berinder K, Dahlquist P, Edén-Engstrom B, Ekman B, et al. Psychotropic drugs in patients with Cushing's disease before diagnosis and at long-term follow-up: a nationwide study. J Clin Endocrinol Metab. 2021, http://dx.doi.org/10.1210/clinem/dgab079.
4. Webb SM, Valassi E. Quality of life impairment after a diagnosis of Cushing's syndrome. Pituitary. 2022;25:768–71.
5. Webb SM, Kristensen J, Nordenström A, Vitali D, Amodru V, Wiehe LK, et al. Patient journey experiences may contribute to improve healthcare for patients with rare endocrine diseases. Endocr Connect. 2022;11(12):e220385, http://dx.doi.org/10.1530/EC-22-0385.
6. Valassi E, Chiodini I, Feelders RA, Andela CD, Abou-Hanna M, Idres S, et al. Unmet needs in Cushing's syndrome: the patients' perspective. Endocr Connect. 2022;11(7):e220027, http://dx.doi.org/10.1530/EC-22-0027.
7. Albarel F, Pellegrini I, Rahabi H, Baccou C, Gonin L, Rochette C, et al. Evaluation of an individualized education program in pituitary diseases: a pilot study. Eur J Endocrinol. 2020;183(6):551–9.
8. Andela CD, Repping-Wuts H, Stikkelbroeck NMML, Pronk MC, Tiemensma J, Hermus AR, et al. Enhanced self-efficacy after a self-management programme in pituitary disease: a randomized controlled trial. Eur J Endocrinol. 2017;177(1):59–72.

9. Santos A, Webb SM. Coping with Cushing's disease: the patients' perspectives. In: Laws ER, editor. Cushing's Disease: An Often Misdiagnosed and Not So Rare Disorder. New York: Elsevier; 2017. p. 169–85. Academic Press.

10. Martel-Duguech L, Alonso-Pérez J, Bascuñana H, Díaz-Manera J, Llauger J, Nuñez-Peralta C, et al. Intramuscular fatty infiltration and physical function in controlled acromegaly. Eur J Endocrinol. 2021;185:167–77, doi.org/10.1530/EJE-21-0209.