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Lessons from rare diseases: pathophysiology of stress-related diseases and organization and evaluation of care for patients with Cushing's syndrome

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LESSONS FROM RARE DISEASES

Pathophysiology of stress-related diseases and organization and evaluation of care for patients with Cushing's syndrome

1. Mortality remains increased despite biochemical cure in Cushing's disease. (*this thesis*)
2. In reporting outcome measures, not only the efficacy but also the safety and quality of transsphenoidal surgery in Cushing's disease should be taken into account, in order to appreciate the clinically important balance between remission and complications. (*this thesis*)
3. Screening all patients with chronic central serous chorioretinopathy for Cushing's syndrome is not indicated. (*this thesis*)
4. Instead of psychological interventions targeting personality traits in patients with chronic central serous chorioretinopathy, disease specific support programs addressing coping mechanisms might be more useful. (*this thesis*)
5. Hair cortisol concentrations are not useful in monitoring central serous chorioretinopathy disease activity. (*this thesis*)
6. The current practice variation in thromboprophylaxis management among the European Centers of Expertise endorses an unmet need for randomized controlled trials and registries to establish the optimal anticoagulant regime for patients with Cushing's syndrome. (*this thesis, M. Fleseriu et al, Lancet Diabetes Endocrinology, 2021 (9): 847-75, panel 2, R.A. Feelders et al, Pituitary, 2022 (25): 746-749*)
7. When Magnetic Resonance Imaging is unable to visualize the Adrenocorticotrophic Hormone producing pituitary adenoma in case of Cushing disease, molecular PET imaging may allow to identify and localize the causative lesion and could therefore play an important role in the pre-operative workup of patients with Cushing's disease. (*W.A. Bashari et al, Pituitary, 2022 (25):709-712*)
8. Patients biochemically cured from Cushing's syndrome often still do not feel well and experience an impaired quality of life. Patient education and awareness of the physical and psychological aftermath, as well as psychological interventions could ameliorate quality of life of both the patients and their families, and could reduce health costs. (*C.D. Andela et al, European Journal of Endocrinology, 2017 (177):59-72, F Albarel et al, European Journal of Endocrinology 2020 (183):551-559, S.M. Webb et al, Pituitary, 2022 (25):768-771*)
9. Shared decision making increases therapy compliance and patient satisfaction, reduces overtreatment, and does not lead to poorer health outcomes. (*K. Niburski et al, Patient 2020 dec;13(6):667-681, D. Stacey et al, Cochrane Database Syst Rev 2017 apr 12;4(4):CD001431*)
10. If doctors want to obtain happiness, they should attempt to find purpose and pleasure in their lives. This is, after all, the formula most other humans follow to find happiness. (*adapted from Dr. Allan Peterkin, 2017*)