Pituitary disorders FACTSHEET

Information on Pituitary disorders with a view to labour market participation (a project to improve participation potential in work processes)

This factsheet is intended for health-professionals and insurance assessors. This factsheet briefly describes the essence of Adrenal Insufficiency, Pituitary Disorders and Cushing's Syndrome in relation to labour/work participation. More information on adrenal disorders can be found on AdrenalNET.EU These fact sheets were developed in the year 2021/2022 in a project of BijnierNET/AdrenalNET in the Netherlands. It was a ZonMw funded project. No rights can be derived from this (translated) document. Copyright belongs to BijnierNET/ AdrenalNET (April, 2024).

Etiologie

Pituitary disorders are rare. The most common pituitary disorder is a hypophyseal adenoma[1]. Often, a pituitary adenoma is non-functional. However, the adenoma can also produce excess hormones, such as prolactin (prolactinoma), growth hormone (acromegaly) or adrenocorticotropic hormone (ACTH, Cushing's disease).

Other disorders of the pituitary gland include hypophysitis (usually autoimmune mediated or as a complication of oncological immunotherapy), infarction or haemorrhage of the pituitary gland (Sheehan syndrome, apoplexy) and so on (see also www.hypofyse.nl/aandoeningen/) only in dutch.

Pituitary disease and its treatment can lead to pituitary dysfunction in which one or more hormonal axes fail: (pan)hypopituitarism.

Symptoms

The symptoms of pituitary disorders are usually caused by mass effect or by hormonal dysregulation. A large lesion in the pituitary gland can lead to vision problems due to compression of the chiasma opticum or compression of the cranial nerves in the sinus cavernosus. In addition, the space-occupying effect may cause headaches. The hormonal dysregulation can consist of a deficiency or a surplus of pituitary hormones.

A deficiency of pituitary hormones can lead to adrenal cortex insufficiency (see adrenal cortex insufficiency factsheet for more information), hypothyroidism, hypogonadism, growth hormone deficiency and a diabetes insipidus. Each type of hormone failure is accompanied by specific symptoms, such as fatigue, coldness and weight gain in the case of hypothyroidism, tiredness, loss of muscle strength, mood symptoms and apathy in the case of hypogonadism and thirst and polyuria in the case of diabetes insipidus. Combined failure can also lead to nonspecific symptoms, with fatigue, reduced energy and workload capacity, mood swings and stress sensitivity being common.

An excess of pituitary hormones is also accompanied by specific symptoms, such as nipple flooding and hypogonadism in the case of prolactinomas; fatigue, excessive sweating, headache, joint complaints, mood impairments and changes in appearance in the case of acromegaly, and weight gain, muscle and skin atrophy in the case of Cushing's syndrome (see Cushing's factsheet for more information).[2-4]

With both hormonal failure and hormonal overproduction, psychological and cognitive complaints such as mood problems, emotional instability, increased sensitivity to stimuli and concentration and memory impairments frequently occur[5-6]. It is not unusual for these to persist or at least continue for a long time after treatment has been started.

Treatment

Treatment varies for each type of disorder and may include pituitary surgery, radiotherapy of the pituitary, drug treatment or hormone supplementation. Combined treatment is often needed, either from the beginning or in the event of a recurrence. Patients are therefore usually monitored by an endocrinologist for life.

Hormonal failure is usually permanent and is treated with hormonal supplementation. The dosage of hormonal substitution varies from patient to patient. It takes some time (months to years) to find the optimal dosage schedule for a patient. Despite optimally adjusted suppletion treatment, a proportion of patients retain residual complaints and symptoms, as mentioned above.[5-6]

Hypopituitarism is a chronic condition: patients remain dependent on a daily intake of medication (usually 3 times daily) for the rest of their lives and have to undergo periodic medical check-ups. The condition also requires lifestyle adjustments (stress

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instruction, adaptation of workload). In particular, adrenal hormone and antidiuretic hormone (ADH) requirements for diabetes insipidus can be variable and need to be adjusted for stress, illness and weather conditions. There is often a learning curve for these patients to learn how to cope with hormone loss.
It is therefore important to realise that patients usually go through an individual and mostly intensive medical process and that the multidisciplinary treatment team has to take several medical aspects into account: vision, tumour, hormone excess and failure, as well as comorbidity caused by hormone excess. In addition, regular psychosocial counselling and some form of rehabilitation are needed.

Employment

Although there are large differences between patients, it is no exception for patients to experience problems with labour market participation[7]. The treatment process is often long-term, as described above. Recovery proceeds in several stages and may take years, with persistent symptoms (such as reduced exercise tolerance and cognitive impairments) possibly remaining even after reaching hormonal stability.
Despite careful adjustment to optimise hormonal supplementation, the quality of life of patients with pituitary disorders remains on average lower than that of the healthy population.[5] This indicates that it is impossible to perfectly mimic the complex physiological hormonal secretion of the pituitary gland with current substitution options. Studies show that patients with adequately treated hypopituitarism score worse on average in terms of physical, social and mental functioning as well as vitality.[5-6] In addition, residual symptoms vary enormously from patient to patient.
Some patients experience little or no limitation in daily life, while others are severely impacted by physical and mental fatigue for example, or by memory and concentration disorders and other psychological symptoms. It is not easy to predict which patients will continue to have residual symptoms and which patients will experience no limitations from their condition. A 2018 Dutch study shows that - on average 11 years after diagnosis - 28% of patients (18-65 years) no longer had a paid job after treatment of a pituitary tumour.
In particular, patients diagnosed with Cushing's disease, acromegaly, (pan)hypopituitarism and those who had had radiotherapy were more likely to be unemployed[7].
Some patients suffer permanently - and often to varying degrees - from specific impairments. These include reduced cognitive and/or physical stamina, needing longer recovery times, reduced workload capacity and in particular reduced endurance. Neuropsychological testing does not always objectify cognitive impairments at the individual level, while group studies do identify some deviation. In our experience, however, short or longer term workload capacity testing in a practical setting, as carried out by occupational rehabilitation centres, makes the impairments and limitations clearly 'visible' even in the individual with symptoms. The use of such work diagnostic capacity testing can help the patient get a better view and grip on the perceived limitations and specific impairments and how to deal with them. It can also provide guidance on re-integration and adjustments in terms of working circumstances, working conditions, working content and working relationships.

Points of attention for the occupational and insurance physician

- Pituitary disorders are rare conditions with diverse symptom patterns that require patient-specific treatment.
- A patient with hypopituitarism is dependent on hormonal substitution for life.
- After diagnosis, it takes time to find the optimal dosage regimen for an individual patient.
- The long diagnostic delay and the duration of the treatment process added to the lengthy recovery period can cover well over two years.
- On average, the quality of life of patients with pituitary disease is lower than that of the healthy population. In addition, residual symptoms vary greatly from person to person.
- It is not easy to predict which patients will continue to have symptoms despite adjusting hormonal supplementation as optimally as possible and which patients will experience no impairment from their condition.
- It may well be that energy levels and mental functioning fluctuate throughout the day and differ from period to period.

Coordination and consultation:

In complex situations, it can be beneficial to arrange for written information exchange or verbal coordination between the treating practitioner and the relevant occupational / insurance physician - always, of course, with the consent of the patient/ employee.

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This information in this factsheet may be subject to changes or improvements. New versions will be posted on the project website: www.werkwijzer.online
This website is only in Dutch.