

Cushing's, coping and quality of life

Cushing's disease (CD) and Cushing's syndrome (CS) are rare illnesses in which the body is flooded by an excess of the hormone cortisol, leading to characteristic and severe symptoms, among them central weight gain, easy bruising, diabetes mellitus, hypertension and depression. In CD, cortisol overproduction is triggered by a benign tumor of the pituitary gland, which produces a hormone stimulating the adrenal glands to produce cortisol. In CS, the most common cause of cortisol oversecretion is a benign cortisol-producing tumor of the adrenals themselves.



Fig. 1. A classification of coping styles from the Freiburg questionnaire on coping with illness, FK-LIS, categorized by their effect on quality of life in the presented study. Muthny FA (1989) Freiburger Fragebogen zur Krankheitsverarbeitung. Beltz Test GmbH, Weinheim

Cushing's is a chronic illness, which is likely to change a person's life in many ways. Patients may have had symptoms from excessive cortisol levels for many years before Cushing's was suspected and finally confirmed. Diagnosis is oftentimes followed by surgery and may also involve being on medication or receiving radiotherapy. The illness is likely to have affected one's appearance, physical and mental abilities and independence. Studies on patients with Cushing's demonstrate that their quality of life oftentimes remains impaired years after successful treatment even though the disease itself may be well-controlled or in long-term remission.

This is where "coping" comes in. In psychology, coping is defined as a person's own conscious effort to deal with difficult situations, life periods and also illnesses. The ways by which this is accomplished are called coping strategies. Some coping strategies help to overcome problems

more easily. They are called positive (= adaptive) coping strategies, whereas others, which are negative (=maladaptive) may even reduce a person's quality of life further.

Research on patients with diseases such as cancer, multiple sclerosis or diabetes mellitus has shown that patients with negative ways of coping have a worse quality of life and more depression than those who have more positive coping strategies. In order to find out whether the coping strategies used by Cushing's patients relate to quality of life, we sent out questionnaires on quality of life, depression, embitterment and coping strategies to more than 300 patients with Cushing's disease treated at three major German neurosurgical university centers; 176 of these patients returned completed questionnaires and were included in the analysis.

Our patients answered the questionnaires on average almost seven years after their last pituitary surgery. Nevertheless, at the time of the study, 21.8% of patients suffered from anxiety, 18.7% experienced an above-average feeling of embitterment, compared to the reference values of healthy people, and 13.1% suffered from depression. Our statistical analysis showed that patients who often used negative coping strategies had higher levels of anxiety and embitterment, depression, and a significantly poorer quality of life. In fact, poor coping strategies were robust and strong predictors of psychosocial impairment, whereas other patient and illness related factors had no such influence. Figure 1 gives an overview of the investigated coping strategies and their relation to quality of life in patients with CD.

In our eyes, this finding has a large implication for patients with Cushing's, because coping is a behavior that can be modified. Positive coping styles can be learned or reinforced. While there are up to now no special programs to help Cushing patients cope with the particular aspects of their disease, most beneficial coping strategies are universally useful. Examples include learning to look at obstacles in a positive way, accepting the illness or building on social support and communication. Counseling may help in determining what coping strategies a person currently uses and developing positive coping strategies, if needed. The results of our study indicate that the development of positive coping strategies can be one way to gain back quality of life despite the limitations a chronic illness like Cushing's may cause.

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