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Titel des Beitrags: The German NET-registry: an audit on the diagnosis and therapy of neuroendocrine tumors.

Abstract: AIMS: Clinical experience with neuroendocrine tumors (NETs) is difficult to acquire because they are rare and heterogeneous. The impact of guidelines on the care for NETs is not known. The German NET Registry compiled information for Germany pertaining to three questions: who provides care for NET patients; does the care comply with proposed guidelines, and are the results comparable to those described in the literature? PATIENTS AND METHODS: Between 2004 and 2007 data on 1,263 patients from 21 centers were compiled in a dedicated database. RESULTS: Tumor location, age and sex compared well with published data. Most patients were cared for in centers with more than 100 (47.9%) or between 20 and 99 patients (46.1%). Imaging (magnetic resonance tomography, computer tomography, ultrasound) was available for 79% of the patients, specific laboratory tests for 67%, somatostatin receptor scintigraphy for 56%, and pathology findings for 79%. High-quality pathology reports were rare (2%). Sufficient documentation was mostly found in large centers. Surgery was the first-line therapy in 70.9%, while medical therapy was the second-line therapy in 45.7% of the patients. Median follow-up was 2.8 (0.4-6.4) and median overall survival was 2.5 (0.34-6.3) years. CONCLUSIONS: Most patients were referred to large specialized centers.
Those centers adhered best to published guidelines for NETs. However, there are still significant deficiencies in the documentation of diagnostic results, mainly with regard to pathology reports. Therapeutic strategies were comparable between centers. The data provide a basis for future studies assessing improvements in documentation, diagnosis and treatment of NET.

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