The German neuroendocrine tumour (NET) registry: Epidemiology of neuroendocrine tumours and data quality

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Introduction

No epidemiological data of NET are available in Germany. Thus, the AG NET/DGE introduced the German NET Registry in 9/2003. First data of the registry are presented.

Methods

A NET specific database was constructed. 5903 specialists (gastroenterology, endocrinology, oncology) were invited to participate. Centres (C) had to treat at least 5 pts with NET to be included in the database. C are grouped according to the number of pts treated: small (SC), medium (MC), large (LC), very large (VLC): 5-10/11-20/21-100/>100 pts, resp. C are visited by 2 study nurses, patient files are analysed and data transferred to the database. Only pts with a diagnosis of NET after 1.1.1999 are included. To evaluate the data quality, data were retrieved from the German NET-Registry database. Data were analysed according to the documentation of diagnosis, histology, imaging, biochemical investigations and therapy.

Results

As of 10/2006 136 C participate, 13 C have already been visited. All are university clinics (Fig 1). Pts are cared for by specialists of internal medicine, surgeons or by both specialists at one C (Fig 2) 904 pts (452 t), 57 ys (13-87) (median, range) at diagnosis are evaluated. MEN-1 pts (N=30) are younger at diagnosis (44 ys, (24-64)). Tumours are classified as foregut, midgut, hindgut, cancer of unknown primary (CUP) and no classification available (Fig 3). Functioning tumours are identified in 222 (25%) pts. Mean follow-up is 1y (0-7), with more than 1 visit documented in 72%. Mortality is 8% during follow-up, with a median survival time of 1 y (0-5) (Fig 4). Data Analysis: Diagnosis.

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In addition, the data base reflects the structure of care, provided in Germany. Despite the observational character of the NET-registry changes are already implemented with respect to the organization.

Conclusion

The German NET-registry is an effective tool to analyse epidemiological data of NET pts. However, as the number of pts included is still rather low, definite data await the inclusion of larger numbers. In addition, the data base reflects the structure of care, provided in Germany. Despite the observational character of the NET-registry changes are already implemented with respect to the organization of patient care. Documentation was almost complete with respect to diagnosis. However, important histological data were poorly documented, as were some imaging procedures considered essential in these tumours. Documentation of different therapies was highest in very large centres. The number of pts per centre did not significantly influence the quality of the documentation. Further information: www.net-register.org