

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

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Introduction:

NET are rare. 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 built. 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.

Results:

As of 10/2006 136 C participate, 13 C [1 SC with 9 (1%), 3 MC with 45 (5%), 7 LC with 370 (41%) and 2 VLC with 480 (53%) pts, resp] have been visited. All are university clinics. Pts are cared for by specialists of internal medicine, surgeons or by both specialities at one C (N=564, 62%, 204 23% and 136 15% resp.).

904 pts (452 f), 57 ys (13-87) (median, range) at diagnosis are evaluated. MEN-1 pts (N=30) are younger at diagnosis [45 ys, (24-61) 9, MEN-1 vs sporadic NET, $p < 0.0001$). Tumours are classified as foregut, midgut, hindgut, cancer of unknown primary (CUP) and no classification available (52%, 29%, 5%, 12.5 and 2%, resp.) Functioning tumours are identified in 222 (25%) pts. Mean follow-up is 1y (0-7), with more than 1 visit/pt documented in 72%. Mortality is 8 % during follow-up, with a median survival time of 1 y (0-5).

Discussion:

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.