

The German neuroendocrine tumour (NET) registry: Quality of data documentation

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Introduction: The German NET Registry (NR) was established in 9/2003. It aims to document the diagnostic and therapeutic situation of all NET-pts in Germany. The evaluation will allow for improved interdisciplinary cooperation, diagnosis and therapy. As of 10/2006, 904 pts in 13 centres have been included.

Methods: A NET database was developed. 5903 specialists (gastroenterology, endocrinology, oncology) were invited to participate. Centres (C) had to treat at least 5 NET pts. C are grouped according to the number of pts: 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, files are analysed and data transferred to the database. All pts with a NET-diagnosis after 1.1.1999 are included. Diagnostic, histologic, imaging, biochemical and therapeutic data were documented.

Results: At present 136 C participate, 13 C have been visited [1 SC with 9 (1%), 3 MC with 45 (5%), 7 LC with 370 (41%) and 2 VLC with 480 (53%) pts, resp]. 904 pts (452 f), 57 ys (13-87) (median, range) at diagnosis, are included. Tumors were classified as foregut (52%), midgut (29%), hindgut (5%), CUP (12%) or not classified (2%). Documentation of diagnosis, functionality, tumor location were available in 896 (99%), 222 (25%), 780 (86%) pts. MEN-1 was documented in 30 (3%), excluded in 60 (7%) and not documented in 814 (90%). Somatostatin receptor scintigraphy (SRS) was documented in 566 (62%) pts. 349 pts w/o SRS were classified as foregut (60%), midgut (24%), hindgut (5%), and CUP (7%). Imaging (sonography, CT, MRT) was documented (times per pt): 1.7 in SC, 3.5 in MC, 1.8 in LC and 2.8 in VLC. Biochemistry was documented at least once per pt. in 619 (69%). The 1st treatment (Tx) was surgery, medical Tx, radioreceptor Tx or ablative Tx in 651 (72%), 170 (19%), 10 (1%), 8 (0,9%) of the pts. 65 (7%) pts had no Tx. Pts were treated with up to 6 different Tx. The number of Tx – but not the type of Tx - correlated positively with the number of pts treated per C. Mean follow-up was 1y (0-7), with more than 1 visit/pt in 72%. Mortality was 8 %, with a median survival time of 1 y (0-5).

Discussion: The NR reflects the structure of care in Germany. Documentation was almost complete for diagnosis, but poor for histological data and imaging. On the basis of these results and the ensuing discussions, improvements of documentation and interdisciplinary care organisation are being implemented in the participating centres.