NET REGISTER

ulrich-frank.pape@charite.de

GASTROINTESTINAL NEUROENDOCRINE TUMOURS: Tumour characteristics and long-term clinical outcome in the German NET-registry

S. Maasberg[1], A. König[2], A. Rinke[2], M. Anlauf[3], B. Isermann[4], C. Auernhammer[5], N. Begum[6], H. Mönig[6], P. Goretzki[7], U. Plöckinger[1], U.-F. Pape[1]

[1]Med. Dept., Div. of Hepatology & Gastroenterology, Charité Campus Virchow Clinic, University Medicine Berlin, [2]Dept. f. Gastroenterology, Endocrinology & Metabolism, University Clinic Marburg, [3]Institute of Pathology, University Clinic Düsseldorf, [4]Dept. of Medicine I, Div. of Endocrinology & Metabolism, University Clinic Heidelberg, [5]Med. Dept. II, University Clinic Großhadern, Munich, [6]Med. Dept. I & Dept. of Genral Surgery, University Clinic Schleswig-Holstein, Lübeck, [7]Dept. Of Surgery, Lukas-Hospital, Neuss, all Germany
for the participating centers of the German Registry of Neuroendocrine Gastrointestinal Tumours (NET-Registry)

Background:

Prognosis of neuroendocrine tumours (NET) has been difficult to predict due to heterogenous tumour biology, various classification systems, and lack of reliable and recent data due to the rarity of these tumours. Some prognostic factors have been identified[1-3], however, either mostly single center-based surveys or focus on single subentities of these analyses limit the value of their results. On the other hand, population-based analyses[4-6] are limited by the inclusion of cases with differently classified NET and a lack of NET-specific details.

In recent years NET-registries have been founded in several countries[7,8] and here we report the results from the German NET-registry, which is associated withe the German Society for Endocrinology (DGE)[9]. In a nationwide survey including solely data from NET diagnosed since 1999 the German registry for gastrointestinal NET has strived to accumulate and analyze factors which influence prognosis in NET.

Aim of the study:

The German NET-registry collected data from patients with histologically proven NET from all over Germany (figure 1). Epidemiological, histopathological and clinical data as well as information on outcome results were obtained and analyzed.

Results:

Figure 1: Participating centers of the German NET-registry

Table 1:
Basic data in the German NET-registry

number of included cases:	2009
♀:♂	964:1045
mean age at initial diagnosis:	56.4 yrs
median age at initial diagnosis:	58 yrs (range 14-93)
mean follow-up:	2.34 yrs
median follow-up:	1.53 yrs (range 1d-13.6yrs)

Figure 1:
Age distribution at initial diagnosis

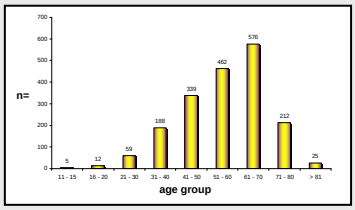
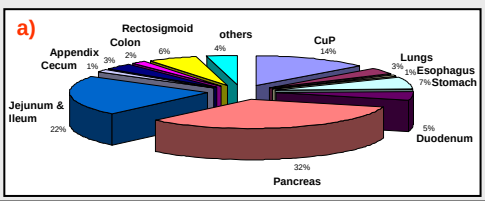
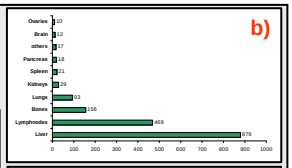


Figure 2:
Primary tumour localizations (a), observed metastatic localizations (b) and prevalence of specific hormone hypersecretion syndromes (c) in the cohort

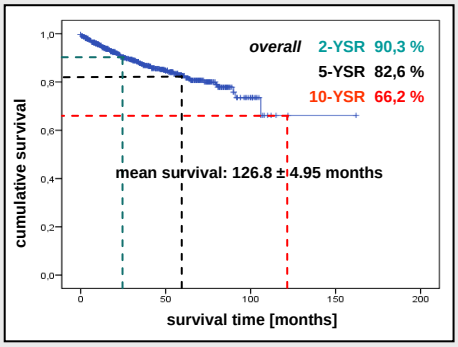




Hormone hypersecretion syndromes c)

Carcinoid syndrome	30.9 %
Insulinoma syndrome	8.1 %
Zollinger-Ellison syndr.	6.2 %
Glucagonoma syndr.	2.3 %
Verner-Morrison syndr.	0.8 %
Somatostatinoma syndr.	0.4 %
Cushing syndr.	0.4 %

Figure 3: Results of survival analysis in the whole cohort



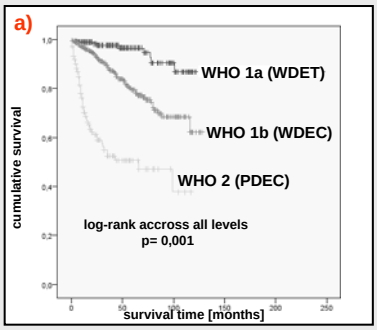
rate of distant metastasis: 68%

2nd neoplasm: 12 %

death rate: 9%
tumor-related death rate: 49%

overall	NET-related survival	
95.2 %	97.1 %	1-YSR
90.3 %	93.7 %	2-YSR
82.6 %	85.4 %	5-YSR
66.2 %	70.1 %	10-YSR

Figure 4: Results of survival analysis stratified according to WHO classification (a) or grading [Ki67- or mitotic-index, ENETS] (b)



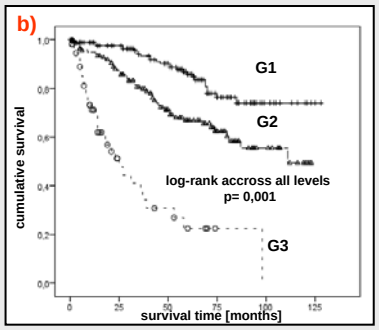


Table 2: Therapeutic modalities in the cohort (a) and success rates of surgery (b)

a) Tx-mode	total	as 1st-line-Tx	b) resection status	total	as 1st-line-Tx
surgery	1836	1370	R0	504	438
medical Tx	1155	320	R1	154	134
radionuclide Tx	411	61	R2	67	54
ablative Tx	185	15	RX	84	68

Conclusions:

- The German NET-registry reports data from> 2000 pts. with NET mostly of the GI-tract from 21 centers in Germany.
- A preference of metastatic as well as pancreatic and small bowel NET is reported.
- Carcinoid syndrome, hyperinsulinemic hypoglycemic neuro-glycopenia (insulinoma syndrome) and Zollinger-Ellison syndrome are the most frequent functional syndromes.
- Survival rates in this cohort with initial diagnosis since 1999 are very good when compared to historical cohorts.
- Stratification according to WHO classification or to grading according to Ki67-index identify significant prognostic subgroups.
- Analysis of this large cohort reveals improved survival in NET-patients with modern management strategies.

Methods:

Data from 2045 patients with NET were collected by specifically trained study nurses by structured extraction fromclinical source documents after informed consent had been obtained and entered into a data base (Microsoft Access)[9]. Data analysis was performed after structured data extraction and statistical assessment using SPSS Version 15.0.

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Acknowledgements:

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