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NET REGISTER

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Clinicopathological characteristics and long-term outcome of gastrointestinal neuroendocrine tumours in Germany

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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 analysis of single subentities 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.

As novel and effective therapeutic modalities come into focus appropriate classification and therapeutic stratification become more and more important. In recent years NET-registries have been founded in several countries[7,8] and here we report the results from the German NET-registry[9].

Aim of the study:

In a nationwide survey (figure 1) the German registry for gastrointestinal NET collected data from patients with histologically proven NET diagnosed since 1999. 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:	62.75 yrs
median age:	65 yrs (range 21-96 yrs)
mean follow-up:	2.15 yrs
median follow-up:	2.1 yrs

Figure 2:
Primary tumour localization

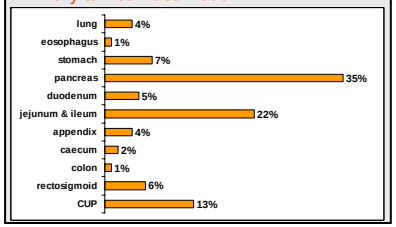
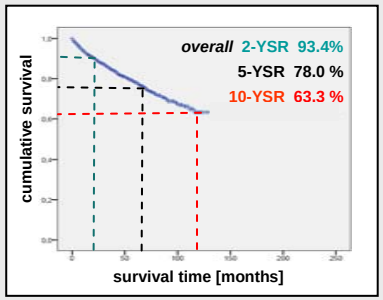


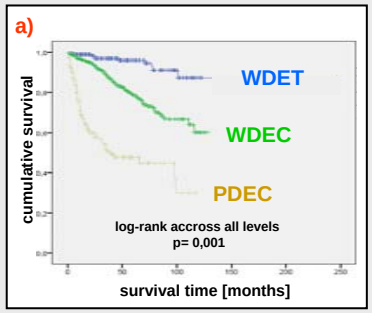
Figure 3:
- Results of overall survival analysis (a)
- Prevalence of specific hormone hypersecretion syndromes (b) and
- metastasis at initial diagnosis in the cohort (c)



b)

Hormone hypersecretion syndromes n= 403	
Carcinoid syndrome	41.0 %
Insulinoma syndrome	38.0 %
Zollinger-Ellison syndr.	15.0 %
Glucagonoma syndr.	4.0 %
Verner-Morrison syndr.	2.0 %
Somatostatinoma syndr.	0.4 %

Figure 4:
Survival analysis according to
- WHO- classification (a) and
- Grading according to ENETS (ki-67) (b)



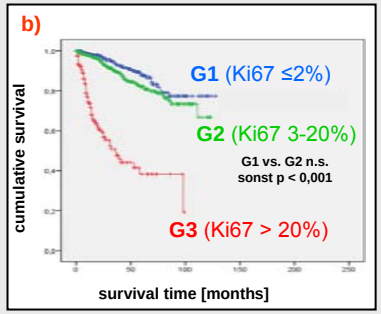
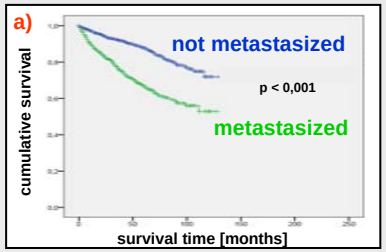
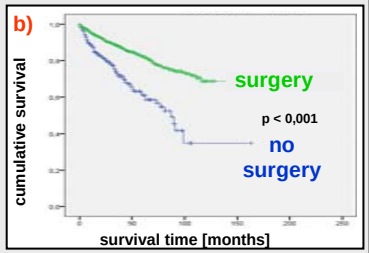
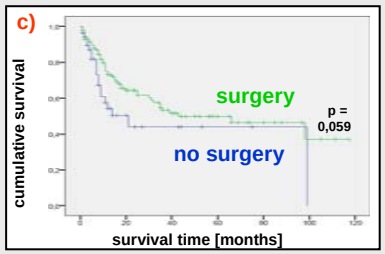
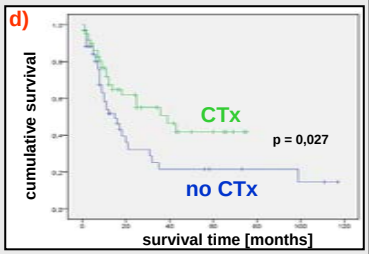


Figure 5: Results of survival analysis according to status of metastasis at initial diagnosis (a) , Outcome of surgical therapy in WHO-1 (= WDET/C; b) and WHO-2 (= PDEC; c) as well as outcome of chemotherapy in WHO-2 (= PDEC; d)









Conclusions:

- Preferentially pancreatic, small bowel and CuP-NET are reported to the NET-registry.
- Carcinoid, insulinoma and Zollinger-Ellison's-syndrome are the most frequent functional syndromes.
- Overall and tumor specific survival rates in Germany are very good when compared to published cohorts.
- Prognosis in NET is based on histopathological classification according to WHO grading as well as grading according Ki-67 and the metastastic status at initial diagnosis.
- Improved survival was seen in surgically resected NET-patients and advanced PDEC treated with chemotherapy.
- Large cohorts of rare tumors provide valuable information on prognosis and treatment results.

Methods:
Data from 2009 patients with NET were collected by specifically trained study nurses by structured extraction from clinical source documents after informed consent had been obtained and entered into a data base (Microsoft Access)[9]. Data analysis was performed and statistical assessment using SPSS 15.0.

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