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Carcinoma of endocrine organs: Results of the RARECARE project

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Abstract The rarity or the asymptomatic character of endocrine tumours results in a lack of epidemiological studies on their incidence and survival patterns. The aim of this study was to describe the incidence, prevalence and survival of endocrine tumours using a large database, which includes cancer patients diagnosed from 1978 to 2002, registered in 89 population-based cancer registries (CRs) with follow-up until 31st December 2003. These data give an unique overview of the burden of endocrine carcinomas in Europe.

A list of tumour entities based on the third International Classification of Diseases for Oncology was provided by the project Surveillance of rare cancer in Europe (RARECARE) project. Over 33,594 cases of endocrine carcinomas were analysed in this study.

Incidence rates increased with age and were highest in patients 65 years of age or older. In 2003, more than 315,000 persons in the EU (27 countries) were alive with a past diagnosis of a carcinoma of endocrine organs. The incidence of pituitary carcinoma equalled four per 1,000,000 person years and showed the strongest decline in survival with increasing age. Thyroid cancer showed the highest crude incidence rates (four per 100,000 person years) and was the only entity with a gender difference: (female-to-male ratio: 2:9). Parathyroid carcinoma was the rarest endocrine entity with two new cases per 10,000,000 person years. For adrenal carcinoma, the most remarkable observations were a higher survival for women compared to men (40% compared to 32%, respectively) and a particularly low relative survival of 24% in patients 65 years of age or older.

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More high quality studies on rare cancers, with additional information, e.g. on stage and therapeutic approach, are needed and may be of help in partly explaining the observed variation in survival.