

The burden of cancer in Austria

Estimating cancer prevalence with data from the Austrian National Cancer Registry

**3rd Autumn Meeting of the research group
„Young Demography“**

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Why Prevalence?

- of primary interest for health care planning and resource allocation
- Identifies the burden of a disease or health-related events on the population and health care system
- Represents new and old cases alive on a date or period, incidence describes newly diagnosed cases during a given time period
- Prevalence is a function of incidence and survival

Introduction

- ~ 36,000 people newly diagnosed with cancer every year in Austria
- Cancer is second most common cause of death in both sexes
- Importance in cancer is increasing in view of ageing population
- Epidemiology of cancer incidence, mortality and prevalence plays key role in health reporting
- However, systematic information on cancer prevalence unavailable in Austria → objective of this presentation!

Schedule of the talk

1. Short description of the Austrian national cancer registry
2. International evidence on cancer prevalence
3. Practical considerations for Austria
4. Estimation of prevalence
 - * Point prevalence
 - * Partial prevalence
 - * Period prevalence
5. Findings
6. Discussion
7. Concluding Remarks

1. Austria's cancer registry

- = population based, applies to all resident in Austria
- Major goal: publication of cancer incidence numbers (i.e. newly diagnosed cases per year)
- The 1969 Cancer Statistics Act and the 1978 Cancer Statistics Ordinance provide the statutory basis for the Austrian cancer registry
- All hospitals (private and public) are obliged to send all new cancer diagnoses to Statistics Austria (paper or electronical)
- Report form includes standardized information on the patient (name, adress, birth date) and the tumour (histology, behaviour, grading)

1. Austria's cancer registry

- Four regional registers: Carinthia, Salzburg, Tyrol and Vorarlberg → collect, administer and forward the cancer reports to Statistics Austria
- Only textual specification of diagnoses from the hospitals and regional registries are accepted
- Currently coding according to ICD 0-3 (International Classification of Diseases for Oncology, third version), for publication recoded to ICD 10
- The data-collection process as well as the utilisation and plausibility-checks are following international recommendations (IACR, ENCR)
- Reasonable completeness of data can be assumed for 1983 and onwards → linkage of cancer registry and causes of death statistics

1. Austria's cancer registry

- DCO-rate as most important indicator for completeness of data (DCO = Death Certificate Only)
- Below 10% since 1997 ... IARC threshold... GOOD QUALITY!
- Publication of incidence data: ry+2(3) years, 2007 out now
- Database is dynamic, no final results, constantly allowing for updating all former years
- Publication of a new report-year is always representing a snapshot of the database
- Standard analysis available in the internet: incidence per 100.000, ASR, cumulative rates → highly aggregated
- Prevalence is not part of our standard publications!

2. International Evidence

- Approach to estimate cancer prevalence is based on a wide range of interacting factors regarding
 - data quality
 - length of follow-up and
 - completeness of data-collection
- Diverse interpretations of prevalence within „cancer community“
- NORWAY: systematically collects cancer information since 1952
- Records are supplemented with information on patient's vital status → high level of completeness and validity
- Annually publish data on incidence, survival and prevalence
- Prevalence = proportion of a population with a disease at a given point in time
- lifetime and partial prevalence

2. International Evidence

- GLOBOCAN 2002 is a database using data from the Descriptive Epidemiology Group of IARC provided by cancer registries from all over the world for the reference year 2002: incidence data, statistics on cancer survival
- Data does not allow for directly following the patients' vital status → method to indirectly estimate prevalence by combining new cancer cases and survival probability per country, sex, age-group and cancer-site
- Approach applied by Slovenia and Robert Koch Institute

- EUROPREVAL is first Europe-wide project to estimate prevalence
- Data provided by Eurocare-study (incidence and survival)
- Assumption: cancer is an irreversible disease
- Point prevalence = proportion of individuals who have ever been diagnosed with cancer still present in the population at a given time point

3. Practical Considerations for Austria

- Employ incidence and follow-up data collected by population-based cancer registry
- The Austrian cancer registry currently contains ~ 1,071,000 reported tumours, featuring ~ 36,000 new cases per year
- Basis for prevalence estimates will be incidence data between 1983 and 2004 → Includes 769,560 cancer cases (malignant invasive cases, incl DCO-cases)

3. Practical Considerations for Austria

- Handling of multiple tumours
 - Of those 769,560 tumours, 642,364 were first tumours, equivalent with the number of cancer patients
 - Length of follow-up period is 21 years → direct method to estimate prevalence will be employed
- Assumption: once diagnosed with cancer, an individual remains a cancer patients until death

4. Estimation of Prevalence

■ POINT PREVALENCE

- Follow the direct method of estimating the total prevalence presented in Capocaccia et al. (2002) and Micheli et al. (2002) as used in the EUROPREVAL study
 - We define point prevalence as the proportion of existing cases at one point in time
 - This number is corrected by an estimate for non-registered cases still alive: Completeness Index R
- Correction factor, the completeness index R, is an estimate of non-registered cases alive
- R takes the value of 1 when all prevalent cases are fully observed, and approaches 0 as the proportion of prevalent cases that are observed decreases

4. Estimation of Prevalence

- POINT PREVALENCE → Total Prevalence
- N_{tot} = total prevalence, sum of the observed prevalence plus the unobserved prevalence
- N_{obs} = observed prevalence, proportion of patients diagnosed after the start of registry activity i.e. 1983, can be directly calculated from the registry data and who were still alive at the given reference date

$$N_{\text{tot}} = N_{\text{obs}}/R$$

- R is influenced by the registration period as well as the age slope of cancer incidence

4. Estimation of Prevalence

■ POINT PREVALENCE

- Point prevalence as of 31 December 2004 by sex

	Sex	Cases observed (a)	Cases alive (b)	Completeness Index R (c)	Total prevalent cases (d)	Population (per 100 000)(e)	Total Prevalence (x 100 000) (f)
Malignant Neoplasms C00-C97*	Total	642,364	265,593	0.89	298,419	81.74	3,650
	Men	306,984	112,194	0.89	126,061	42.06	2,997
	Women	335,380	153,399	0.89	172,358	39.69	4,342

* All malignant neoplasms, C00-C97, incl. DCO-cases, excl. Carcinoma-in-Situ cases as well as C44.

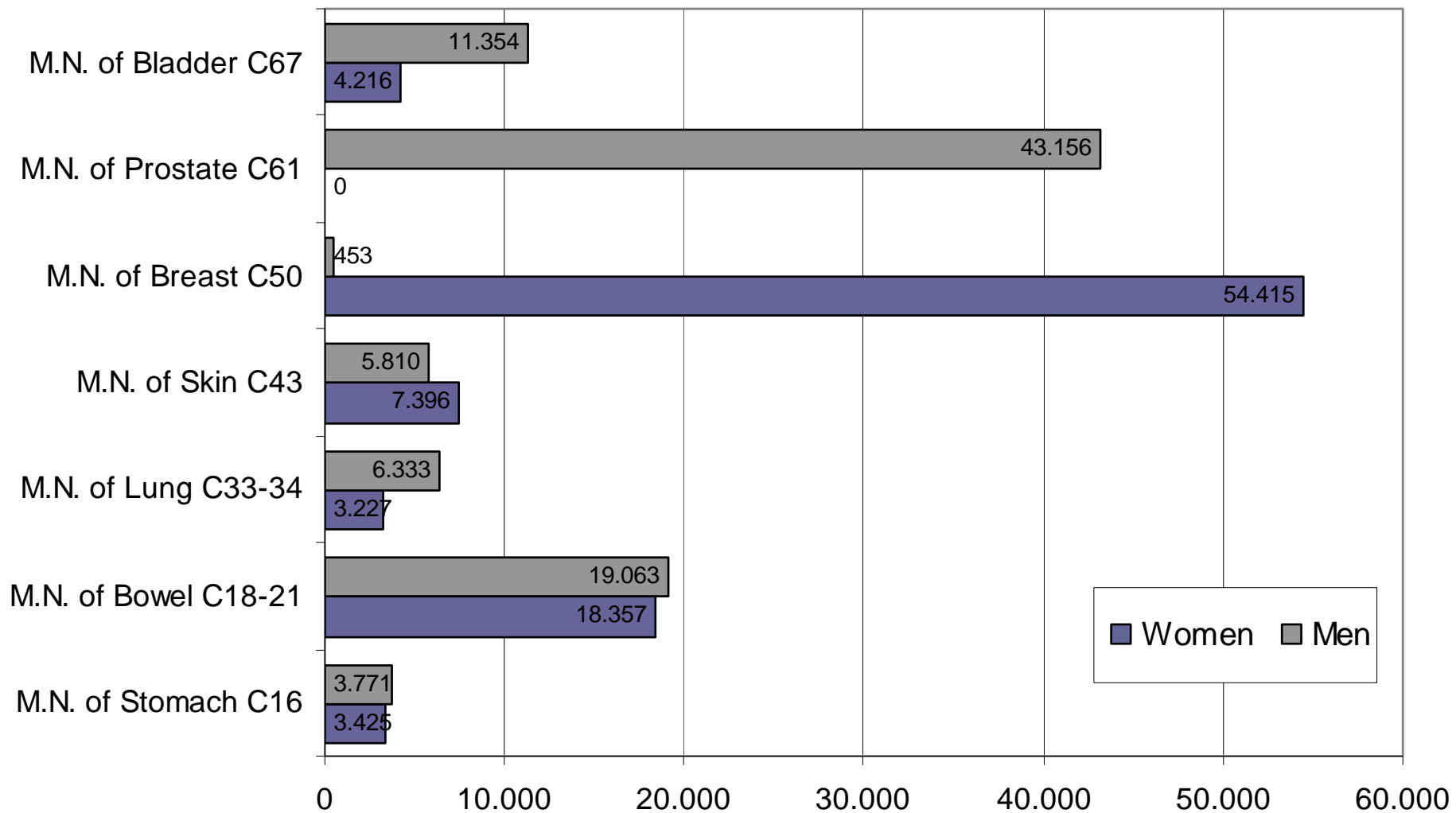
4. Estimation of Prevalence

■ POINT PREVALENCE

- 3.6 out of 100 Austrians have had a previous cancer diagnosis until the reference date
 - Contrary to the proportion of new cases (incidence) in men and women, there are more prevalent cases among females compared to males at the end of 2004
- dominant role of breast cancer

4. Estimation of Prevalence

POINT PREVALENCE



4. Estimation of Prevalence

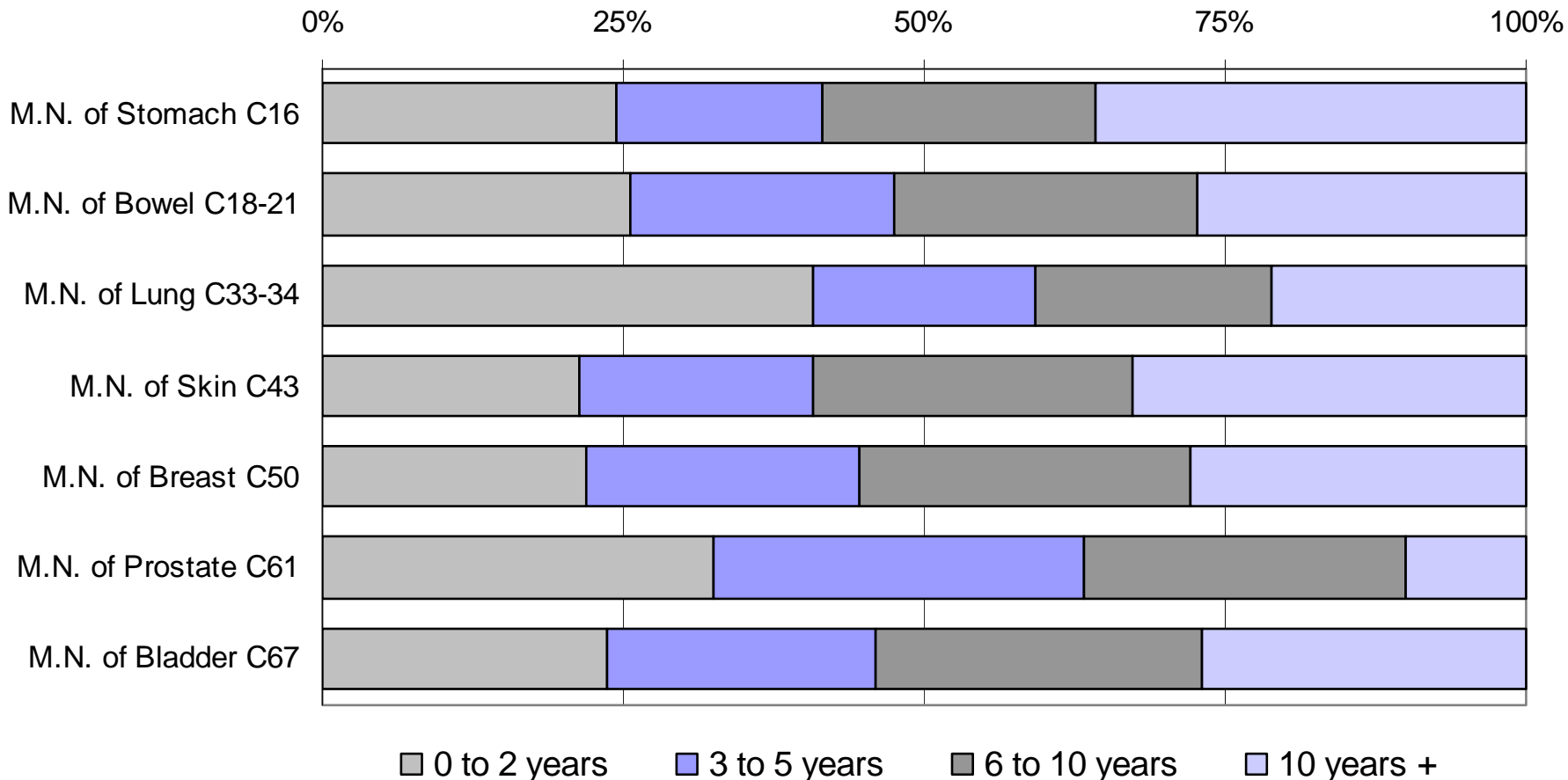
■ PARTIAL PREVALENCE

- Prevalent cancer cases are a highly heterogeneous group in terms of health status
- Stratification the results of the point prevalence according to the number of years spent after being diagnosed with cancer
- Helps classifying prevalent cases by disease stage → distinguish the recently diagnosed patients from those who need clinical follow-up and those who can be considered cured
- Important step towards the development of specific indicators of health care needs for specific sections of the (cancer-) population
- Directly obtained from the follow-up of registered cancer patient's vital status
- 2-year, 5-year and 10-year partial prevalence

4. Estimation of Prevalence

■ PARTIAL PREVALENCE

- Partial prevalence as of 31.12.2004 by cancer sites and time since diagnosis



4. Estimation of Prevalence

■ PARTIAL PREVALENCE

- At the end of the year 2004 there were 265,593 living cancer patients, thereof 112,194 men and 153,399 women, 3.2% of the Austrian population
- Up to 2 years since diagnosis: most acute demand on the health care (24%)
- Patients diagnosed 2-5 years ago need less intensive care (21%)
- One fifth of all living cancer patients have a diagnosis 6-10 years old
- Cancer sites with particularly good or bad survival chances result in an according figure
→ comparably high lethality of lung cancer vs. breast cancer

4. Estimation of Prevalence

■ PERIOD PREVALENCE

- Ratio of person months spent by cancer patients during one year (1.1.2004 - 1.1.2005) and the person months of the general population in 2004 (=person months of exposed to risk)
- Result = Proportion of the Austrian population affected by cancer at any time in 2004 by age-group and cancer site
- a total of 3,113,701 cancer months spent by all cancer patients combined (old and new cases) during the year 2004

total number of person months spent in 2004 by the general population in Austria which amounted to 98,096,796
(8,174,733x12)

4. Estimation of Prevalence

■ PERIOD PREVALENCE

- Results for Austria: Period prevalence in 2004 by age-groups and sex

			Absolute numbers per 100 000									
			Age-groups									
Malignant Neoplasms C00-C97*	Sex	Total	0 - 4	5 - 14	15 - 24	25 - 34	35 - 44	45 - 54	55 - 64	65 - 74	75 - 84	85 +
	Total	3,174	46	126	239	654	1,437	2,714	5,145	9,302	12,827	18,847
	Men	2,754	52	138	230	393	765	1,619	4,489	10,430	17,282	27,823
	Women	3,571	40	113	248	915	2,128	3,800	5,764	8,364	10,472	15,842

* All malignant neoplasms, C00-C97, incl. DCO-cases, excl. Carcinoma-in-Situ cases as well as C44.

5. Findings

- **Sex**

For all cancer sites combined, prevalence in women was higher than in men (100 : 73)

- **Age**

Prevalence is increasing with age. The largest proportion of all prevalent cases were aged 85 years and older

- **Time since diagnosis**

24% of all prevalent cases consisted of patients who had their cancer diagnosis within 2 years of the index date

- **Prevalence by site**

Female breast cancer had the highest prevalence, accounted for ~34% of prevalence in Austrian women.

In men, prostate cancer accounted for ~38% of the total prevalence

6. Discussion

- Different approaches to estimate prevalence and thus describe the burden of cancer have specific interpretational implications
- Partial prevalence the most applicable measure in the context of health care planning
- 21-year follow-up period: high completeness can be assumed
- However, we had to account for these unobserved cases and estimate their impact on the prevalence
- Presented results not yet corrected and likely to be incomplete in terms of identifiable cases lost to follow up → cases should be reviewed and re-checked on their vital status by consulting additional data sources (e.g. insurance data) to avoid an overestimation of the total prevalence

7. Concluding Remarks

- Compare different period prevalences for different index years → increasing prevalence?
 - Due to population ageing and advances in cancer treatment result in increasing proportion of cancer patients living longer
 - Role of screening and early detection → inflation of incidence and prevalence?
 - Micheli et al (2002): high cancer prevalence is associated with low general and infant mortality and with high gross domestic product and high total expenditure on health
- Increase of cancer prevalence in Austria?
- Rising demand for social and health care services!

Thank you very much for listening!