SWISS CANCER SURVIVAL STATISTICS: QUALITY OF VITAL STATUS FOLLOW-UP

M Lorez[1], A Bordoni[2], C Bouchardy[3], S Dehler[4], S Ess[5], G Jundt[6], I Konzelmann[7], F Levi[8] and V Arndt[1]

[1]National Institute for Cancer Epidemiology and Registration (NICER), Zurich, Switzerland. [2]Ticino Cancer Registry. [3]Geneva Cancer Registry. [4]Cancer Registry of Zurich/Zug. [5]Cancer Registries of St. Gallen/Appenzell and Grison-Glarus. [6]Cancer Registry of Basel-Stadt/Basel-Landschaft. [7]Valais Cancer Registry. [8]Neuchâtel Cancer Registry.

Background

- Completeness of registration of deaths is rarely investigated. However, even modest levels of unregistered deaths may lead to overestimation of survival, especially long-term survival and in circumstances of poor prognosis [1].
- Substantial efforts are taken to obtain the vital status of cancer patients in Switzerland. Since cantonal health authorities adopt different policies regarding access to population registries, follow-up procedures are quite heterogeneous (from regular automated data linkage to sporadic project-related follow-up by mailing letters to a large number of regional offices).

Objectives

- To compare survival estimates in eight Swiss population-based cancer registries with different follow-up procedures by focussing on diagnoses with poor prognosis.

Data and Methods

We included malignant primary diagnoses from 1999 to 2008 for stomach (ICD-10 C16), colon/rectum (C18-C20), liver/bile ducts (C22), pancreas (C25) and trachea/bronchus/lung (C33-C44). Cases were provided by eight regional cancer registries, labelled A to H for reasons of anonymity. Cancer registries recorded all incident cancer cases diagnosed in their resident population and assessed cases' survival by active and/or passive follow-up until end of 2011. We used the assumption that cases survived up to end_2011 if life-status was neither dead nor lost.
Relative survival (RS) was derived for consecutive time intervals of increasing length after diagnosis during which the hazards were assumed to remain constant. RS was calculated as the ratio of the observed survival of cancer cases and the expected survival of persons in the general population matching on age, sex, calendar year of death and residence. Expected cancer survival was estimated using the Ederer II method. RS ratios were estimated using the strs command (v1.3.7) [2] written for the Stata Statistical Software.
Funnel plots [3] were constructed using the mean log(RS) as target value and thresholds of +/-2 times (95% control limits, CL) and +/-3 times (99.8% CL) of the SE of log(RS).

A. Follow-up procedures adopted by Swiss cancer registries

Regional cancer registry	Diagnosis period 1999-2008; Follow-up to 2011: Passive follow-up (linkage to official vital statistics) periodicity / scope	Active follow-up periodicity / scope / method	%FU incomplete# Stomach	Colon/ rectum	Liver	Pancreas	Lung
A	each year / on all cases	each year / on all cases / on-line access	0	0	0	0	0
B	each year / on all cases	each year / selected cases** / postal enquiries	8	9	2	1	3
C	each year / on all cases	each year / on all cases / on-line access	0	0	0	0	0
D	each year / on all cases	each year / on all cases / on-line access	0	0	0	0	0
E	each year / selected cases only*	each year / selected cases** / postal enquiries	11	26	6	3	5
F	not every year / on all cases	sporadic / on all cases / postal enquiries	13	21	5	5	7
G	each year / on all cases	each year / on all cases / on-line access	0	0	0	0	0
H	each year / on all cases	each year / on all cases / postal enquiries	5	14	3	0	3

*: Only if cancer was mentioned in as cause of death in the death certificate.
**: Selected for year of diagnosis (e.g. five years before present).
#: Cases with vital status alive, but with latest follow-up > 6 months before end of 2011. Lost-to follow-up excluded.

Tab. 1. Swiss population-based cancer registries generally carry out passive as well as active follow-up at least once per year on all diagnoses in the database. If linkage to official vital statistics serves predominately for case finding (registry E) or is not repeated every year (F), some deaths might be missed. Active follow-up can compensate for this, but the problem remains if active follow-up is carried out on selected cases only (B and E) or is not repeated each year (F) or must rely on postal enquiries (B, E, F, and H).
We conclude that under-registration of deaths is a potential problem in registries E and F, flagged in red for highest % of cases with missing or outdated active follow-up. Both registries together contribute about 40% of diagnoses to the pool on which Swiss national survival statistics are based.

B. Quality indicators

Regional cancer registry	DCO [%]* Stomach	Colon/ rectum	Liver	Pancreas	Lung	MV [%]** Stomach	Colon/ rectum	Liver	Pancreas	Lung	TNM M missing [%]# Stomach	Colon/ rectum	Liver	Pancreas	Lung
A	3.5	0.9	6.3	10.1	2.4	95	98	47	61	90	6	3	19	17	7
B	2.1	0.5	1.6	2.3	0.8	94	96	50	63	90	17	3	26	14	8
C	not available					98	98	58	70	91	21	6	69	23	21
D	0.5	0.7	1.5	2.1	0.5	98	96	48	69	91	3	2	7	4	3
E	3.0	2.9	5.6	8.1	3.1	95	96	67	72	91	37	8	72	53	34
F	3.8	2.6	13.5	22.0	3.5	96	97	85	77	96	13	4	26	25	18
G	0.9	0.2	0.3	1.1	0.3	94	97	72	78	91	not available				
H	0.0	0.2	1.7	0.9	0.4	95	96	56	66	90		30	not available		

*: Diagnoses based on death certificates only (excluded from survival analysis).
**: Diagnoses based on microscopic verification.
#: Insufficient TNM information to infere the M status.

Tab. 2. Critical values potentially biasing survival analyses are marked in red (DCO ≥10%; outlier in MV; missing TNM metastasis status ≥25%). DCO levels were generally low, except for registry F which does not perform trace-back. Microscopic verification was comparable between registries, with an unusually high proportion for liver cancer in registry F. Information on disease progression (TNM) were often missing, especially in registry E.

C. Outlier identification using Funnel plots

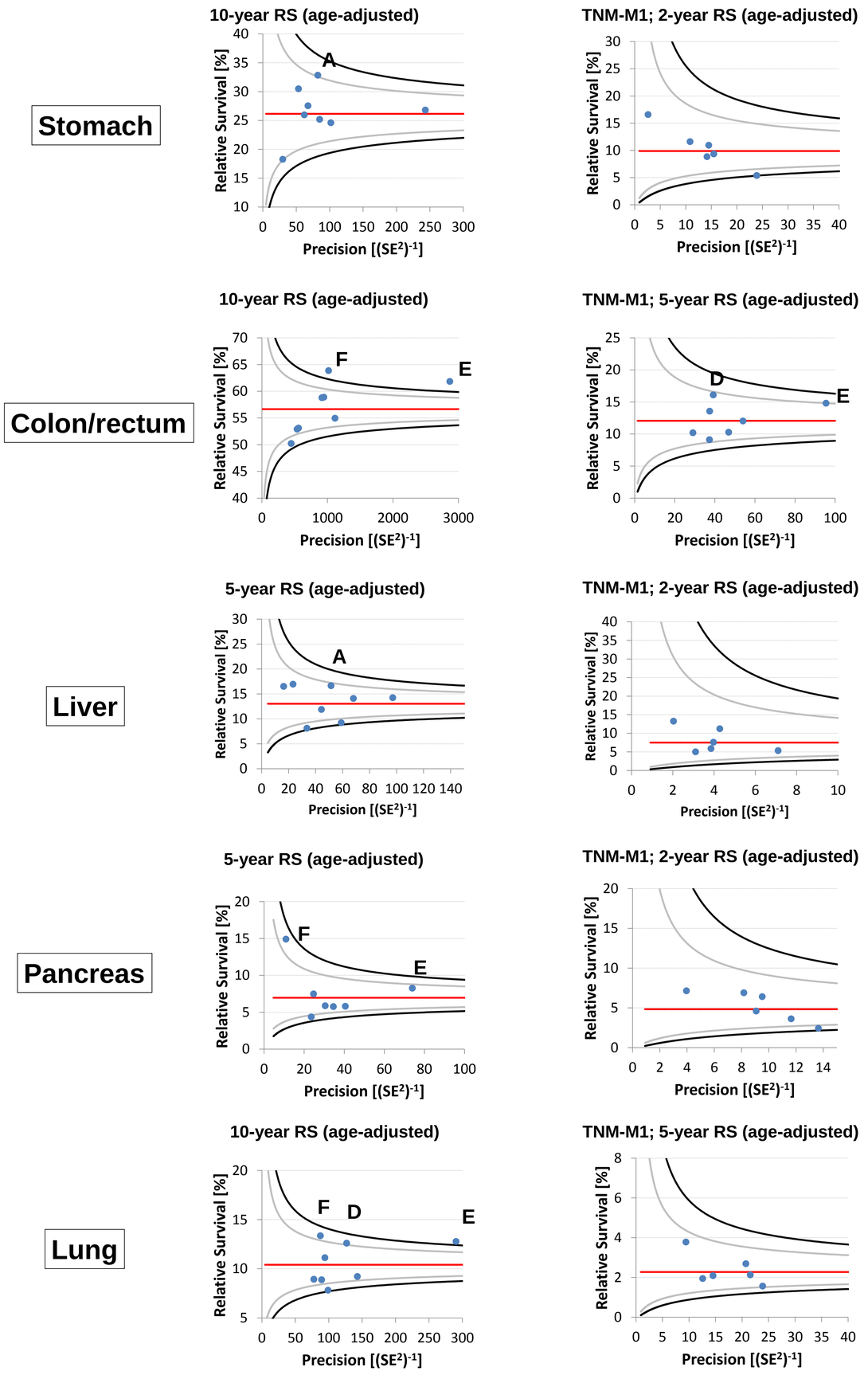

Fig. 1. Funnel plots (Target value in red; 99.8% CL in black; 95% CL in grey)

- Left sided funnel plots compare relative survival at least 5 years post diagnosis. Registries E and F are systematically flagged with unexpected high survival.
- Funnel plots on the right take possible case mix effects by disease progression into account. Differences between registries disappeared, except for colorectal cancer. This suggests that unexpected high survival arose mainly from differences in stage at diagnoses.

Summary

- We compared survival in eight population-based cancer registries under conditions sensitive to incomplete registration of deaths: long-term survival, disseminated disease; assuming patient survival in the absence of registered death.
- Significant survival differences in age-adjusted survival coincided with follow-up procedures that potentially under-register deaths.
- Additionally restricting analysis to M1 stages reduced differences in survival. But high levels of missing TNM information limited our ability to control for disease progression.

Conclusion

- Under-registration of deaths possibly occured in registries E and F, warranting further investigation.
- We continue to adopt the conservative approach to censure survival times to the date of last contact in the absence of reported death for publication of Swiss survival statistics on pooled data.

References

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