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Institutionen för medicinsk epidemiologi och biostatistik

Cancer Patient Survival in Sweden – theory and application

AKADEMISK AVHANDLING

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ABSTRACT

Cancer patient survival in Sweden is generally increasing, and Sweden compares well in an international perspective. Despite these achievements, there are nevertheless socio-economic and regional differences in survival that need to be addressed to meet the intentions of the Swedish Health and Medical Service Act. The Act emphasises good health and access to care for the entire population where priority shall be given to those in the greatest need of care. The new organisational structure for oncological care that is now being implemented, with Regional Cancer Centres as central nodes in a network in their respective health care region, will hopefully be able to address these inequalities and take the past achievements in cancer patient survival even further.

The quality and completeness of the Swedish Cancer Register is high. There are nevertheless areas regarding procedures for reporting incident cases to the regional registries and registration that need to be reviewed as a certain degree of under-reporting does exist. The under-reporting appears to be systematic rather than random as it is site-specific, increases with age, and non-reported tumours are often without histopathological verification. For most uses in epidemiology, the degree of under-reporting will be without significant consequences, but to a varying degree, it will have implications for specific research questions. The accuracy of the cancer register should be monitored on a continuous basis rather than in the ad-hoc fashion that has been done so far. This is also the method recommended by the International Agency for Research on Cancer and in guidelines from the Council for Official Statistics at Statistics Sweden.

Two studies in this thesis evaluate period-based and cohort-based analyses ability to predict long-term survival for recently diagnosed cancer patients. Both studies show that period analysis gives better prediction of the future true survival, particularly when not all of the available information is used for the cohort analysis. The first of these two studies was the first systematic evaluation of period analysis that was independent of the researchers who proposed the method. Previous evaluations had mainly been performed using data from the Finnish Cancer Registry. This study had a significant role in demonstrating the utility of period analysis, which has since become an established method in population-based survival analysis. The second study is the first prospective evaluation of the ability of period analysis to predict future survival.

Relative survival is defined as the observed survival of the cancer patients divided by the expected survival of a comparable group from the general population, *free from the specific cancer under study*. However, as expected survival is usually calculated from general population life tables these estimates are biased. This bias is generally ignored since mortality among individuals with a specific cancer is regarded as a small negligible part of the total mortality of the general population. To estimate the size of this bias the Swedish computerised population registers were used to calculate expected survival both including and excluding individuals with cancer. A simple method to correct for this bias using cause of death statistics was also evaluated. The results show that the bias is often sufficiently small to be ignored for most applications, especially for cancers with high or low mortality and for younger age groups. However, for older age groups and for common cancers the bias can be greater than one percent unit, and even larger for all cancer sites combined. The proposed method to correct for this bias seems to work well, and it may often be sufficient to use cause of death statistics for one recent year to gain a satisfactory correction to the bias.