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Original Research

# Death certificate only proportions should be age adjusted in studies comparing cancer survival across populations and over time

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**Abstract** ***Background:*** The proportion of cases notified by death certificate only (DCO) is a commonly used data quality indicator in studies comparing cancer survival across regions and over time. We aimed to assess dependence of DCO proportions on the age structure of cancer patients.

***Methods:*** Using data from a national cancer survival study in Germany, we determined age specific and overall (crude) DCO proportions for 24 common forms of cancer. We then derived overall (crude) DCO proportions expected in case of shifts of the age distribution of the cancer populations by 5 and 10 years, respectively, assuming age specific DCO proportions to remain constant.

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***Results:*** Median DCO proportions across the 24 cancers were 2.4, 3.7, 5.5, 8.5 and 23.9% in age groups 15–44, 45–54, 55–64, 65–74, and 75+, respectively. A decrease of ages by 5 and 10 years resulted in decreases of cancer specific crude DCO proportions ranging from 0.4 to 4.8 and from 0.7 to 8.6 percent units, respectively. Conversely, an increase of ages by 5 and 10 years led to increases of cancer specific crude DCO proportions ranging from 0.8 to 4.8 and from 1.8 to 9.6 percent units, respectively. These changes were of similar magnitude (but in opposite direction) as changes in crude 5-year relative survival resulting from the same shifts in age distribution.

***Conclusions:*** The age structure of cancer patient populations has a substantial impact on DCO proportions. DCO proportions should therefore be age adjusted in comparative studies on cancer survival across regions and over time.



## 1. Introduction

Monitoring of cancer survival by cancer registries is a key component of cancer control. Studies comparing cancer survival across different countries, such as the EUROCARE project, have been instrumental in disclosing gaps in cancer control and motivating and strengthening efforts to overcome them [1–9].

High and comparable quality of cancer registry data is a prerequisite for valid interpretation of comparative analyses of cancer survival. A frequently used quality and completeness indicator is the proportion of cancer cases notified by death certificate only (DCO) [10,11]. DCO cases are typically cases with poor prognosis who had limited contact with the health care system [12,13]. DCO proportions depend on multiple factors, including but not restricted to prognosis of the cancer under investigation, completeness of and legal basis for high quality registration at lifetime, access to and quality of information on death certificates, and efforts put in trace-back of patients first notified by death certificate [13]. DCO cases are typically included in the registry databases with their date of death as a proxy date of diagnosis. Because their true date of diagnosis and survival time is unknown, DCO cases are commonly excluded from registry-based survival analyses, which may lead to overestimation of survival [14–16]. To enhance comparability of survival estimates, it has become standard to report DCO proportions along with survival estimates in cancer survival studies.

For most cancers, survival decreases and DCO proportions increase with age of the cancer patients [8,13,17]. To make cancer survival comparable across populations with different age distributions of cancer cases, age standardised rather than crude cancer survival proportions are commonly reported [1–9]. By contrast, DCO proportions are commonly reported as crude proportions. In this manuscript, we assess the implications of this practice for comparative cancer survival analyses.

## 2. Methods

Our analyses are based on data from the German Cancer Survival Project, details of which have been reported elsewhere [18,19]. Briefly, data from 11 population-based cancer registries from 1997 and later years are included, covering a population of approximately 27 million people (one third of the German population). For this analysis we selected patients aged 15 and older with the 24 most common cancers diagnosed in 2002–2006 and followed with respect to survival until the end of 2011. This was the most recent 5-year cohort of patients for whom complete information on 5-year survival was available at the time of analysis.

All analyses were carried out separately for each of the 24 cancers. We first described the patients with respect to their numbers and age distributions, their overall (crude) and age specific 5-year relative survival, and their overall (crude) and age specific DCO proportions. Relative survival rather than absolute survival is reported according to standard practice in population-based cancer survival studies. It is calculated as the ratio of observed survival and expected survival of a group of people from the general population with the same age and sex distribution. Expected survival was calculated according to the Ederer II method [20] using general life tables from Germany stratified by calendar year, age and sex. Age groups for age specific analyses were 15–44, 45–54, 55–64, 65–74 and 75+, which correspond to the age groups proposed by Corazziari et al. for age standardisation of cancer survival proportions for most cancers [21].

We then simulated situations in which the cancer patients were 5 or 10 years younger, or 5 or 10 years older than the patients actually diagnosed in 2002–2006. For simplicity, we just subtracted or added 5 or 10 years from each patient's age, and derived the expected age distribution of the 'rejuvenated' or 'aged' cancer populations using the aforementioned age categories. This procedure ensures differences in mean age