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Original Research

Quality analysis of population-based information on cancer stage at diagnosis across Europe, with presentation of stage-specific cancer survival estimates: A EUROCARE-5 study

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Abstract ***Background:*** Cancer registries (CRs) are fundamental for estimating cancer burden, evaluating screening and monitoring health service performance. Stage at diagnosis—an essential information item collected by CRs—has been made available, for the first time, by CRs participating in EUROCARE-5. We analysed the quality of this information and estimated stage-specific survival across Europe for CRs with good data quality.
Data and methods: Sixty-two CRs sent stage (as TNM, condensed TNM or extent of disease) for 15 cancers diagnosed in 2000–2007. We assessed the quality, partly by comparing stage

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according to the three systems. We also developed procedures to reconstruct stage (categories: local, regional, metastatic and unknown) using information from all three systems, thus minimising the amount of missing information.

Results: Moderate-to-excellent stage concordance was found for practically all 24 CRs, for which it was possible to compare at least two staging systems. However, since stage was often incorrectly assigned, and information on the presence/absence of metastases was often lacking, data on only 7/15 cancers from 34/62 CRs (15 countries) were of sufficient quality for further analysis. Cases diagnosed ≥70 years had more advanced (or lacking) stage– and worse stage-specific survival than those <70 years.

Conclusions: Many European CRs collect and record reasonably accurate stage information. Others have difficulties. Both the completeness of primary data and the accuracy of stage coding need to be improved in order for CRs to fulfil their expanding roles in cancer control. We propose our stage reconstruction/checking procedures as a means of fully exploiting the stage information provided by EUROCARE CRs. More advanced (or lacking) stage at diagnosis plus poorer stage-specific survival in the elderly are worrying.

1. Introduction

Cancer registries (CRs) are fundamental sources of population-based information for assessing cancer incidence, survival and prevalence; evaluating mass screening efficacy [1] and monitoring health service quality [2]. It has long been recognised that cancer stage at diagnosis is an essential item of information to be collected by all European CRs [3]. For the first time, many CRs participating in EUROCARE-5 sent in stage at diagnosis information with their records. Thus, new quality control procedures had to be developed to evaluate this information to help decide what data could be used and what had to be discarded. The present study describes these new procedures, and their use to assess the quality, comparability and completeness of the stage information, and presents the first Europe-wide analysis of stage distribution and stage-specific survival for selected cancers and CRs, for which stage information was ascertained to be of sufficient quality.

2. Materials and methods

2.1. Data

The EUROCARE-5 protocol [4] asked CRs to send full data—specifically including information on stage at diagnosis—on adult (aged ≥15 years) patients diagnosed in 2000–2007, and followed up to December 2008, with one of 13 solid cancers. Several CRs also sent stage information on lung and vagina-vulva cancers enabling their inclusion in the data quality analyses. The 15 solid cancers thus investigated were primary malignancies of breast, colon, rectum, stomach, lung, skin melanoma, thyroid, uterine cervix, uterine corpus, ovary, vagina, prostate, testis, urinary bladder and kidney, as defined elsewhere [5].

Ninety-four of the 99 adult EUROCARE-5 CRs collect data on the 15 cancers. However, the following CRs did not send any stage information: national registries of Denmark, Iceland, Sweden, Scotland and Malta; all French registries except the Burgundy registry; 11 of 29 Italian registries and three of nine Spanish registries. These 32 registries (Supplementary Table 1 [Table S1]) are not considered further.

We assessed stage information for the remaining 62 CRs from the following countries: Finland and Norway (northern Europe); England, Wales, Northern Ireland and Ireland (United Kingdom and Ireland); Austria, Belgium, France, Germany, Switzerland and The Netherlands (Central Europe); Croatia, Italy, Portugal, Slovenia and Spain (Southern Europe) and Bulgaria, Czech Republic, Estonia, Latvia, Lithuania, Poland and Slovakia (Eastern Europe).

The protocol specified that stage could be provided in one or more of three forms. The preferred and most detailed was the standard tumour-node-metastasis (TNM; according to the fifth/sixth TNM edition [6,7]); the next most detailed was condensed TNM, as specified by the European Network Cancer Registries (ENCR) [8]; the least detailed was summary extent of disease (EoD) [8]. EoD is used by CRs to summarise stage by indicating how far a cancer has spread from its point of origin, using all available information [9]. EoD categories are local, regional, metastatic and unknown, with hybrid categories regional/metastatic (R/M) for cancers that are not local but whose regional versus distant status is unclear; and local/regional (L/R), for cancers without distant spread but whose local versus regional status is unclear. The protocol did not specify clinical versus pathological stage, but if both were available, registries were asked to send pathological stage.

We analysed stage information quality after excluding T0/Tis cancers and cases discovered at autopsy or known only from the death certificate (DCO/autopsy). The following aspects were scrutinised: (a) missing stage information (as defined in Table 1); (b) concordance between TNM, condensed TNM and EoD, when at least two of these were provided; (c) distribution