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Agreement between different survey instruments to assess incident and prevalent tumors and medical records – results of the Heinz Nixdorf Recall Study

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ABSTRACT

Objective: The validity of participants' self-reports via questionnaires or interviews in epidemiological studies remains questionable. We examined the agreement of tumors, reported via different survey instruments, with medical records.

Methods: Within the Heinz Nixdorf Recall Study, comprising 4814 subjects aged 45–75 years, tumors were assessed via different survey tools at baseline and 8-year-follow up (FU): personal interviews (CAPI), self-administered questionnaires (SA-Q), physical examinations, short questionnaire/non-responder questionnaire (S-/N-Q) and telephone interviews. Information on each self-reported tumor was coded via ICD-10, WHO-Version 2010, and evaluated against medical records.

Results: During FU, 95% of 1083 self-reported incident tumors in 623 individuals, at baseline, 65% of 473 prevalent tumors in 406 individuals could be evaluated. Agreement of the main assessment tools, CAPI and SA-Q, with medical records was 90.1% and 88.4% (FU) and 91.0% (baseline-CAPI).

Best agreement was in tumors of prostate (baseline-CAPI: 97.8%; 5-year-FU-CAPI: 96.9%, SA-Q: 95.7%) and breast (baseline-CAPI: 93.2%; 5-year-FU-CAPI: 100.0%, SA-Q: 98.8%).

Discussion: Agreement of CAPI and SA-Q with medical records was good. To assess incident tumors, SA-Q emerged as favorable, as it is least expensive and easy to be applied. Especially for tumors of prostate and breast, cost-intensive and time-consuming validation with medical records may not be necessary.

1. Introduction

Assessment tools like questionnaires or interviews are commonly used in epidemiological studies [1]. However, validity of these self-reports remain questionable as several aspects may influence their accuracy. Retrospectively assessed information in cross-sectional studies require a long period of recall and may, thus, lead to biased information [2,3]. Missing expert knowledge may result in mistaken information or improperly applied terminology [4–6]. During an interview, atmosphere and the kind of questions may affect the accuracy of answers [7,8].

So far, most epidemiological studies evaluate self-reports from CAPI or, more often, SA-Q, by comparison with medical records. Especially in cancer studies, record linkage with cancer registries is also common [9–12]. However, comparison with medical records is costly and time-consuming and cancer registries are not always available or their data may not be complete. Thus, our aim was to examine which assessment tool might result in the best agreement between self-reported tumors and medical records.

2. Methods

The Heinz Nixdorf Recall (Risk Factors, Evaluation of Coronary Calcium and Lifestyle) Study, an ongoing population-based prospective cohort study of the Ruhr area in Germany, started in the year 2000. Initially, 4814 males and females, aged 45–75 years, were recruited for study participation per random sample at the registry offices of Bochum, Mülheim/Ruhr and Essen. Baseline response was 55.6% [13]. The study predominantly aimed at the prediction of incident myocardial infarction and cardiac death by means of established and new risk factors [14]. Another objective was the assessment of other diseases, i.e. tumors, and overall mortality. The ethical commission of the Medical Faculty of the University Duisburg-Essen has approved the study. Study participants gave informed consent. The present analysis focused on two study phases: (1) incident tumors during 8-year-FU and (2) prevalent tumors at baseline.

2.1. Enquiry of study participants

Study participants were asked for tumors by applying the following assessment tools at different time points: CAPI at baseline and 5-year-FU-survey and, furthermore, annually mailed SA-Q during 8-year-FU.

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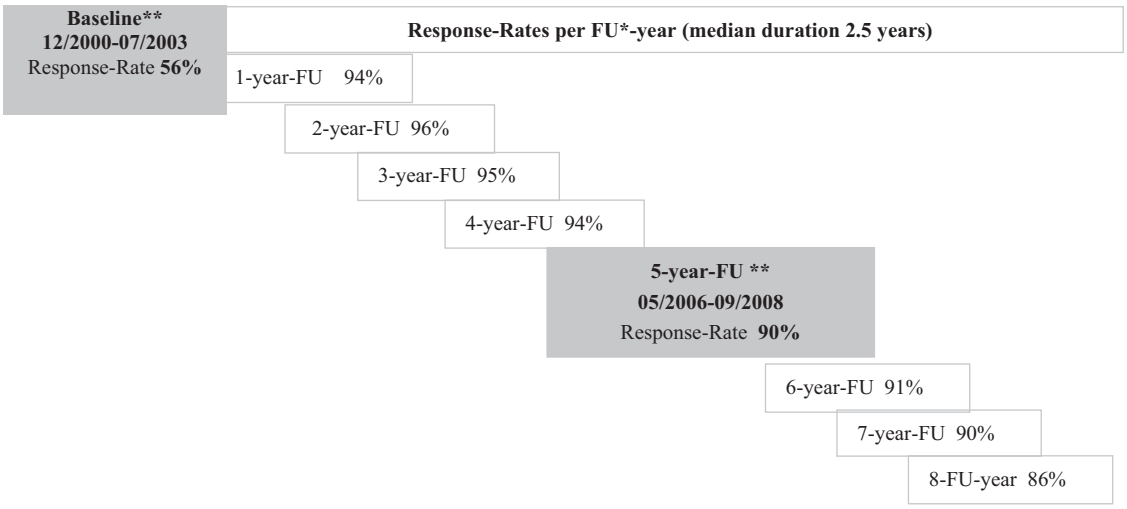

Fig. 1. Heinz Nixdorf Recall Study – study phases and response rates (baseline – 8-year-FU). This figure presents the different study phases (baseline and FU-years) and their response rates.

Fig. 1 illustrates the study phases and the response rates of 5-year-FU-survey and SA-Q.

2.2. Basic assessment tools, regularly applied to all participants (SA-Q) and to those attending the study center (CAPI)

Both, CAPI and SA-Q included cancer-specific questions: any kind of physician-diagnosed cancer ever (prevalent tumors via baseline-CAPI) and during the past five years (incident tumors via 5-year-FU-CAPI) and within the last 12 months (incident tumors via SA-Q) (all free text). Tumors occuring within the first 5 FU-years could also be reported in the 5-year-FU-CAPI (which actually had been assumed). Furthermore, the CAPI-question 'did a doctor diagnose you with cancer within the past 5 years' was considered as a control question. In baseline-CAPI participants were asked whether a physician had ever diagnosed cancer and if so, when and what kind of cancer had been diagnosed. In 5-year-FU-CAPI, participants, who had reported a cancer in baseline-CAPI, were asked if a new tumor diagnosis had occurred during the past five years. Participants, who did not report a cancer in baseline-CAPI, were asked if a physician had diagnosed a cancer during the past 5 years. In SA-Q participants were asked whether a physician had diagnosed cancer within the last 12 months and if so, when and what kind of cancer had been diagnosed. In the same way, non-specific questions in both, CAPI and SA-Q, aimed at further diseases, hospitalization and surgeries.

2.3. Additional assessment tool, regulary applied to all participants attending the study center: -physical examination-

Physical examination was part of baseline and 5-year-FU in line with a stress electrocardiogram. In addition to cardiac status, any indication of cancer (e.g. breast ablation) was also documented.

2.4. Additional assessment tools, applied to certain participants only: -short questionnaire/non-responder questionnaire (S-/N-Q)-

During the 5-year-FU, a S-Q was applied for participants unable to visit the study center due to e.g. disease and a N-Q for individuals denying further study participation. Both tools included cancer-specific questions.

2.5. Telephone interview with certain participants or relatives

A standardized telephone interview was conducted, if individuals were unable to visit the study center at 5-year-FU or to complete the annual SA-Q due to serious disease or death.

2.6. Screening of participants' self-reports

Basic and additional assessment tools were screened for tumor-relevant information in cancer-specific questions. Non-specific questions were screened in case of "hidden" information, i.e. self-reported surgery turned out to be a tumor according to medical records. In case of missing questionnaires or lacking relevant information, participants were contacted by phone. Participants' unattainability or death resulted in the request of address or death certificate.

2.7. Validation process of tumor diagnosis

In case the screening of the assessment tools indicated an incident or prevalent tumor, an ICD-10-Code (ICD-10 C00–D48, WHO 2010) was derived from the self-reports. Then, further information was obtained via medical records, interviews with the attending physicians and death certificates. Thereafter, an ICD-10-code was derived from this information and compared to the code derived from the self-report. Those reports – per different assessment tools – with the most detailed information and best plausibility regarding a single tumor were chosen as 'best information'. Both, 'best information' and self-reports via distinct assessment tools were validated against medical records. Additionally and independently, cancer death cases were validated by an external expert group, the Criteria and Endpoint Committee (CEK) (Fig. 2).

2.8. Statistical analyses

The percentage of agreement between self-reported tumors and medical records was calculated via crosstabulation on neoplasm-group-level (three-digit-ICD-10-code): firstly, by the "best information" of distinct assessment tools, secondly, by each tool separately, and, thirdly, by combined tools (CAPI-SA-Q) for