Agreement between self-reported and central cancer registry recorded prevalence of cancer in the Alaska EARTH study

Sarah Nash\(^1\) (slnash@anthc.org), Gretchen Day\(^1\), Vanessa Hiratsuka\(^2\), Garrett Zimpelman\(^3\), Kathy Koller\(^1\)

\(^1\)Community Health Services, Alaska Native Tribal Health Consortium, \(^2\)Research Department, Southcentral Foundation

Background

Population health status data can be collected from multiple sources, including self-report or the medical record. The central cancer registry provides an additional source of data collected from multiple healthcare facilities that have been compiled and curated by trained professionals.

Reliance on self-reported health status information can be challenging due to error associated with participant recall. Understanding the accuracy and validity of these self-report measures is critical to the use of these data.

A recent study of the Alaska Education and Research Towards Health (EARTH) cohort (1) suggested that cancer was among the most accurately self-reported health conditions in this study population, but did not examine whether this varied by cancer site.

Aims

The primary aim of this study was to determine agreement between self-reported and tumor registry-recorded site-specific cancer diagnoses among Alaska EARTH cohort study participants.

Our secondary aim was to determine whether agreement varied by select demographic factors.

Methods

The Alaska EARTH study was part of a multi-site cohort to examine risk factors for cancer among American Indian/Alaska Native (AI/AN) people. The study collected medical history information from participants recruited 2004-2006. The Alaska EARTH cohort, and this study, was approved by the Alaska Area IRB, and participating tribal institutions.

We linked data from the Alaska EARTH cohort with cancer history information from the SEER Alaska Native Tumor Registry (ANTR), using key identifying information (Name, DOB, SSN). We identified individuals with first primary cancers diagnosed between 1969 and study enrollment.

We calculated measures of agreement including sensitivity, specificity, positive and negative predictive values (PPV, NPV), and kappa values.

We examined whether agreement varied by cancer site, age, sex, rural/urban residence, and primary language spoken at home (English or AI/AN language). Logistic regression was used to estimate associations of these factors with “incorrect reporting”. All statistical tests were two-sided with \(\alpha = 0.05\). All statistical analyses were performed with SAS version 9.4 (SAS Institute, Cary NC).

Results and Discussion

Table 1. * Agreement for cancer (all sites), as well as the leading cancer sites among Alaska EARTH participants was good. Self-report was more specific than sensitive. Agreement measures were higher for female breast and prostate cancers than for colorectal cancers.

<table>
<thead>
<tr>
<th></th>
<th>Prevalence</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
<th>PPV (%)</th>
<th>NPV (%)</th>
<th>Kappa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ANTR</td>
<td>Self-report</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cancer (All sites)</td>
<td>99</td>
<td>140</td>
<td>86.9</td>
<td>98.5</td>
<td>60.0</td>
<td>99.6</td>
</tr>
<tr>
<td>Breast (F)</td>
<td>34</td>
<td>33</td>
<td>85.3</td>
<td>99.8</td>
<td>84.8</td>
<td>99.8</td>
</tr>
<tr>
<td>Colorectal</td>
<td>14</td>
<td>21</td>
<td>78.6</td>
<td>99.7</td>
<td>52.4</td>
<td>99.9</td>
</tr>
<tr>
<td>Prostate (M)</td>
<td>7</td>
<td>8</td>
<td>100.0</td>
<td>99.9</td>
<td>75.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*For the purpose of these comparisons, ANTR was considered the reference.

Women [OR (95% CI): 2.8 (1.49 – 5.31)] and participants older than 50 years at the time of study enrollment [OR (95% CI): 2.5 (1.53 – 4.42)] were more likely to report their cancer history “incorrectly”. There was no association of “incorrect reporting” with rural/urban residence, or primary language spoken at home.

Of those who reported a cancer that was not recorded in the ANTR (n = 54), 43 (80%) were women. Of those cancers women incorrectly reported, 56% were cervical cancers, and a further 21% were other female-specific cancers. Cervical cancers may be more likely than other sites to be confused with non-malignant diagnoses such as cervical dysplasia.

Examing agreement measure specifically for colorectal cancers, we found that agreement was lower among those aged 50+ years at enrollment, and those with greater than a high school education. Like cervical cancers, colorectal cancers may be more likely confused with non-malignant diagnoses such as advanced polyps, especially since these diagnoses may also require treatment. Such confusion may be more likely to occur among those who receive screening (aged 50+ years, higher education).

Conclusions

Good agreement between self-reported and registry-recorded cancer history may reflect the high quality of cancer care within the Alaska Tribal Health System (ATHS). The ATHS places high value on patient-provider relationships and delivery of culturally-appropriate care.

These results may also have health literacy implications. Clinicians within the ATHS may want to modify discussions with patients and family members about cancer, and particularly precancerous (non-malignant) diagnoses. Our results also suggest certain population subgroups may benefit from health literacy interventions to increase understanding of cancer diagnoses and treatment.

Acknowledgements

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