Patient-reported outcome surveillance in older cancer survivors: Using the SEER-MHOS linked data resource

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Cancer in older adults

- Adults 65 years account for approximately 60% of all cancer diagnoses
- 43% of older adults with cancer diagnoses survive more than 10 years
  - 17% survive more than 20 years from initial diagnosis
- With more effective therapies and earlier detection, the number of older cancer survivors will grow
  - Limited research that on the health related quality of life (HRQOL) of older cancer survivors
Cancer prevalence

Parry et al., 2011
PRO surveillance and quality improvement

Recommendation 8: Quality Measurement

– Goal: Develop a national quality reporting program for cancer care as part of a learning health care system.
Surveillance Epidemiology and End Results (SEER) Cancer Registries
SEER-MHOS Data Linkage
SEER-MHOS Data Linkage

- Linkage of cancer registry data (SEER) to patient-reported measures from the Medicare Health Outcome Survey (MHOS)
- Linked data are the records of individuals in both the SEER (through 2009) and MHOS data sets, plus all additional MHOS data for the years 1998-2011
Goals of SEER-MHOS

- Create an ongoing dataset for use by NCI, CMS, and external investigators
- Collect valid and reliable data on PROs that may be used to promote research and policy:
  - Outcomes Research and Surveillance
  - Health Plan Quality Improvement
    - Eg. Star Ratings Program
SEER Registry Initiation Date
- 1973-75 SEER
- 1988-92 SEER
- 2000 SEER Expansion (also part of CDC-NPCR)

*Alaska Native and Arizona American Indian are not part of SEER-MHOS.
Variables available in SEER-MHOS

<table>
<thead>
<tr>
<th>SEER Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cancer incidence and survival</td>
</tr>
<tr>
<td>• Month/year of diagnosis, site of cancer, histology, grade, and stage</td>
</tr>
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<td>• Follow-up vital status</td>
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### Variables available in SEER-MHOS

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<td>• Cancer incidence and survival</td>
<td>• HRQOL: SF 36 v2, VR 12</td>
</tr>
<tr>
<td>• Month/year of diagnosis, site of cancer, histology, grade, and stage</td>
<td>• Activities of daily living</td>
</tr>
<tr>
<td>• Initial surgical and radiation treatment within 12 months of diagnosis</td>
<td>• Comorbidities</td>
</tr>
<tr>
<td>• Follow-up vital status</td>
<td>• Depressive symptoms</td>
</tr>
<tr>
<td>• Demographics</td>
<td>• Number of unhealthy days</td>
</tr>
<tr>
<td></td>
<td>• Health behaviors: Smoking</td>
</tr>
<tr>
<td></td>
<td>• HEDIS effectiveness of care measures</td>
</tr>
<tr>
<td></td>
<td>• Urinary incontinence</td>
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<tr>
<td></td>
<td>• Physical activity management</td>
</tr>
<tr>
<td></td>
<td>• Bone Density Scanning</td>
</tr>
<tr>
<td></td>
<td>• Demographics</td>
</tr>
<tr>
<td></td>
<td>• Fall risk management</td>
</tr>
</tbody>
</table>
## Health-Related Quality of Life (HRQOL): SF-36 Scales

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Component Summary (PCS)</td>
<td>Summary measure, includes: PF, RP, BP, VT, SF, RE, MH and GH</td>
</tr>
<tr>
<td>Physical functioning (PF)</td>
<td>10 questions on how health limits performance of physical activities.</td>
</tr>
<tr>
<td>Role-physical (RP)</td>
<td>4 questions on the extent to which the physical health limits work/usual activities</td>
</tr>
<tr>
<td>Bodily pain (BP)</td>
<td>2 questions on severity of pain and extent to which pain interferes</td>
</tr>
<tr>
<td>General health (GH)</td>
<td>5 questions on current health status, susceptibility to disease, and expectations for health in the future.</td>
</tr>
<tr>
<td>Mental Component Summary (MCS)</td>
<td>Summary measure, includes: MH, RE, SF, VT, GH, BP, RP, and PF.</td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>4 questions on energy and fatigue</td>
</tr>
<tr>
<td>Social functioning (SF)</td>
<td>2 questions on limitations in normal social functioning due to health</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>5 questions on mental health dimensions.</td>
</tr>
<tr>
<td>Role-emotional (RE)</td>
<td>3 questions on whether emotional problems have interfered with work/usual activities</td>
</tr>
</tbody>
</table>
MHOS 2.0: Switch from SF-36 to VR-12 in 2006

VR-12:

- Shorter, 14-question survey
- Reduces respondent burden and survey costs while producing results similar to 36-item survey
- Developed, tested, and implemented by Veterans Administration in multiple studies
- Validated conversion formulas allow comparisons with earlier 36-item survey
- In progress: mapping 8 scales from SF-36 to VR-12
Number of SEER-MHOS Participants

Completed 1+ MHOS Survey(s) (1,665,298)

Linked to SEER (95,273)
  - One MHOS Survey (52,572)
  - 2+ MHOS Surveys (43,151)

Not linked to SEER/no cancer reported (1,315,772)
  - SEER Area survey (279,479)
  - Non-SEER area (1,036,293)
<table>
<thead>
<tr>
<th>First Cancer</th>
<th>Total # of linked Patients (N)</th>
<th>Baseline Survey (N)</th>
<th>Baseline and Follow-up Surveys (N)</th>
<th>Survey Before and Survey after Dx (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>19,727</td>
<td>19,598</td>
<td>8,657</td>
<td>1,352</td>
</tr>
<tr>
<td>Breast</td>
<td>16,388</td>
<td>16,264</td>
<td>7,679</td>
<td>992</td>
</tr>
<tr>
<td>Colorectal</td>
<td>11,127</td>
<td>11,061</td>
<td>4,839</td>
<td>698</td>
</tr>
<tr>
<td>Lung and bronchus</td>
<td>7,823</td>
<td>7,756</td>
<td>2,728</td>
<td>434</td>
</tr>
<tr>
<td>Gynecological Cancers</td>
<td>5,171</td>
<td>5,134</td>
<td>2,351</td>
<td>201</td>
</tr>
<tr>
<td>Bladder</td>
<td>4,757</td>
<td>4,723</td>
<td>2,028</td>
<td>330</td>
</tr>
<tr>
<td>Melanomas -- skin</td>
<td>4,338</td>
<td>4,302</td>
<td>2,032</td>
<td>283</td>
</tr>
<tr>
<td>Kidney and Renal pelvis</td>
<td>1,874</td>
<td>1,859</td>
<td>784</td>
<td>150</td>
</tr>
<tr>
<td>Non-Hodgkin's lymphomas - nodal</td>
<td>1,893</td>
<td>1,877</td>
<td>775</td>
<td>119</td>
</tr>
<tr>
<td>Stomach</td>
<td>1,029</td>
<td>1,026</td>
<td>366</td>
<td>53</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1,294</td>
<td>1,284</td>
<td>427</td>
<td>47</td>
</tr>
</tbody>
</table>
**Strengths**

- Adequate sample sizes for many cancer sites
- Ability to look at change over a two-year period
- Compare individuals with and without cancer
- One of largest data sources on PROs of older adults with cancer

**Limitations**

- Linkage is limited to select SEER registry areas
- SEER treatment data limited to first few months of therapy
- No data on Medicare enrollees in fee-for-service
- No data on non-Medicare populations
- Survey sampling frame not designed around time since diagnosis
SEER-MHOS Public Use Data Resource

The data were made available to the public by application in 2008. Since then:

- 19 data use agreements
- 16 publications
Findings:
PCS lower in survivors of certain cancers, particularly multiple myeloma and pancreatic cancer.

Adjusted Physical (PCS) and Mental (MCS) scores

Kent et al., (2014), Cancer
Adjusted Physical (PCS) and Mental (MCS) scores in bladder cancer survivors by time since diagnosis

Findings:
PCS lower in bladder cancer survivors, persisting up to 10 years after diagnosis

Fung et al., (2014), *J of Urology*
Findings: Changes in HRQOL in prostate cancer survivors sensitive to time since dx

Reeve et al. (2012), Cancer
Changes in HRQOL among breast cancer survivors by treatment type

Findings:
Greater PCS declines in health among women with breast cancer than controls, across treatment types

Stover et al. (2014), Cancer
Additional Findings

• HRQOL in colorectal cancer patients – Quach et al., 2014, *Cancer*
  • Declines in physical HRQOL
  • Greatest decrements in recently diagnosed and those with stage III and IV
  • Greater odds of major depressive disorder than controls

• Differences in HRQOL among prostate, breast, colorectal cancer across racial/ethnic groups - Pinheiro et al., In Review
  • Pre-dx, non-Hispanic Whites better HRQOL than minorities
  • Post-dx, some gaps in HRQOL across racial/ethnic groups narrowed
Sample research questions using SEER-MHOS data

1. How has HRQOL and other patient reported outcomes among older cancer patients changed over time?
2. What types of comorbidities occur among older patients with specific types of cancer?
3. How does functional status predict mortality and survival among older cancer patients and survivors?
4. Has the Medicare Star Ratings program affect enrollment/retention of cancer patients in MAOs, and if so, does this differ from older individuals w/o cancer?
5. Are there regional, geographic, and/or health plan effects on the health status of cancer patients/survivors in MAOs?
1. Send e-mail to: SEER-MHOS@hcqis.org
2. Use the MHOS flag in SEER*Stat to determine sample sizes of individuals with specific cancers, just released.
3. Come to the NCI Booth tomorrow (Tues) 1:30-2:30pm to talk with me about SEER-MHOS research ideas!
SEER-MHOS Partners:

- National Cancer Institute (NCI)
- Centers for Medicare & Medicaid Services (CMS)

With technical assistance from:

- Health Services Advisory Group (HSAG)
- Information Management Services, Inc. (IMS)
Coming soon… SEER-CAHPS

- Data linkage between SEER and the Consumer Assessment of Healthcare Providers and Systems (SEER-CAHPS)
- CAHPS data exists for both MA and Fee-for-Service (FFS)
- Linkage contains SEER cancer registry data, responses to the CAHPS survey, and Medicare Claims data (FFS only)
SEER-CAHPS: Priority research questions

- Do perceptions of care differ among Medicare beneficiaries with and without cancer?
- To what extent do cancer patients’ care experiences vary by racial and ethnic groups?
- Do patients’ care experiences vary by increasing chronic illness burden?
- How are patients’ care experiences associated with health care utilization at the end of life?
- Do cancer patients’ care experiences vary by time since diagnosis?
When performance is measured, performance improves. When performance is measured and reported back, the rate of improvement accelerates.

-Pearson’s Law
Thank you
MHOS Administration Timeline

• Each spring, a random sample of Medicare beneficiaries is drawn and surveyed from each MAO with a minimum of 500 enrollees
• Two years later, the baseline respondents are surveyed again (i.e., follow up measurement).
• *Cohort 1* was surveyed in 1998 and was resurveyed in 2000, etc.
• 1998-2006: MAO baseline sample size was one thousand; 2007-sample size increased to twelve hundred.
• 1998-2008, members required to be continuously enrolled in their MAO for 6 months; 2009 restriction waived.
• 1998-2009, beneficiaries with End Stage Renal Disease (ESRD) were excluded. Effective 2010, those with ESRD are no longer excluded.