From SSS 1977 To SSS 2000: A Preliminary Analysis of the Data Implications of Changes in Registry Item Codes

Jerri Linn Phillips
Elaine Collins
Laura Stephenson
Susan Van Loon
Background

- SEER Summary Stage 1977
  - Intended as a derivative of EOD
  - Not updated as EOD evolved
  - Not updated as timing rules changed

- Since then, SSS 1977 Guidelines used for direct coding in many states
  - Instructions incomplete for that task
SEER Summary Stage 2000

- Changes made to EOD since 1977
- Specific timing rules
- Comprehensive instructions amenable to direct coding
- Specific codes for all primary sites and histologies
- No conversion between SSS 1977 and 2000
The Question

- What data implications accompany the transition from SSS 1977 to SSS 2000?
Specific Issues

- Differences in SSS 1977 and SSS 2000 values for same cases
- Quality of existing registry SSS 1977 data
- State-to-state consistency of SSS 1977 coding
Method

3 central registries reabstract lung and female breast cancers diagnosed in 2000
- Sites important to cancer control
- Sites have large numbers of cases in redefined stages
- Staging issues differ between the two sites
- 2000 prior to introduction of SSS 2000, but recent
Method

Cases:
- Invasive carcinoma
- Reported by in-state hospitals that provided first course treatment
- Random sample of 200 cases from each site selected from eligible cases from each central registry
**Method**

- Abstracting by Central Registry CTR staff
- Modified AbstractPlus on registry laptops
  - Identification items available to abstractors
  - Coded SSS 1977, SSS 2000, date of surgery, all text fields relevant to those codes
  - Extraction program stripped identifying information used in field to create submission file
- Central registry consolidated information submitted separately and matched for analysis
Notes on Reabstracting Projects in the HIPAA Environment

- Most abstracting took place before HIPAA
- All 3 states provided information from the NAACCR website
- All 3 states provided supporting information from state laws
- 2 facilities required the state to go through IRB procedures
Recommendations for Projects in the HIPAA Environment

- Need to identify the person in the facility who is responsible for receiving supporting information
- State can prepare a form in advance to place in patient record to state who reviewed the record, when and why
- Once at the facility, approach the tumor registrar who can provide introductions
Method

Central registries
- Differed in data collection and quality control operations
- All mature, and all had collected SSS 1977 for several years
- All used SSS 1977 for publications
- All collected text during 2000, but it was not available for all cases
What if state registry SSS 1977 distributions were different?

- Unequal proportion unknown
  - committee observed major known/unknown differences in committee member states
  - could represent difference in coding requirements
  - lung: differences in coding or facility work-up?

- Unequal local/regional/distant distribution
  - could represent difference in coding procedures
  - breast: screening effect or differences in coding?
State-to-State Consistency: Registry SSS 1977 Coding
Breast Cancer

Known/Unknown: no sig difference
Local/Regional/Distant: p < .05
State-to-State Consistency:
Registry SSS 1977 Coding

Lung Cancer

Known/Unknown p<.05
Local/Regional/Distant no sig difference
Presenter’s note: Due to a series of unavoidable computer problems, one registry had not completed its reabstracting at the time of this presentation. As a consequence, all of the remaining graphics are based data for 2 registries only. All data are to be considered preliminary in this presentation.
What if registry SSS 1977 differed from the reabstracted?

- Coding: were SSS 1977 Guidelines followed when registry data were collected?
  - familiarity with SEER EOD changes
  - “rule of thumb” coding vs. “by the book”

- Registry data are consolidated
  - possible inter-facility discrepancies
  - consolidation procedures themselves
First Look at Registry vs. Reabstract SSS 1977 Stage

Breast

Registey Stage

Reabstracted Stage

- Unknown
- Distant
- Regional
- Local
First Look at Registry vs. Reabstracted SSS 1977 Stage

Lung

Reabstracted Stage

- Unknown
- Distant
- Regional
- Local

Registry Stage

- Local
- Regional
- Distant
- Unknown
First Look at SSS 2000 Compared to SSS 1977

Breast Cancer

SSS 1977

SSS 2000

Unknown
Distant
Regional
Local
Breast Cancer Changes

Localized (ignored in the definition) to Regional – Extension
  adherence
  attachment
  fixation
  induration
  thickening (skin changes)
Distant to Regional – Nodes
  ipsilateral infraclavicular (subclavicular)
First Look at SSS 2000 Compared to SSS 1977

Lung Cancer

SSS 2000
- Unknown
- Distant
- Regional
- Local

SSS 1977
Lung Cancer Changes

Localized to Regional:
- multiple masses/separate tumor nodule(s) in the SAME lobe
- tumor of main stem bronchus <2.0 cm from carina

Localized to Distant
- separate tumor nodule(s) in different lobe

Distant to Regional
- aorta
- brachial plexus from superior sulcus
- chest (thoracic) wall
- diaphragm
- pancoast tumor (superior sulcus syndrome)
- parietal (mediastinal) pleura
Comparison of Distributions

Breast: 2 Registries
Comparison of Distributions

Lung: 2 Registries
Points to Consider: Preliminary

- The nature of the effect of changing from SSS 1977 to SSS 2000 may depend on your registry’s procedures for collecting SSS 1977.
- The type and direction of the effect is likely to reflect a compounding of changes and may not be easily deduced from summarized changes in coding definitions.
- Specific differences may be few.