Patterns of Ovarian Cancer Care and Survival in a Midwestern State

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Presenter Disclosures

Jeannette Jackson-Thompson

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No relationships to disclose

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Acknowledgments (cont'd)

- We would like to thank MCR-ARC Quality Assurance staff and the staff of facilities throughout Missouri and other states' central cancer registries for their dedication and desire for continuous quality improvement and submitting their reportable cases to MCR-ARC.
- We particularly want to thank staff of the 50 facilities that participated in this project for their willingness to take on extra responsibilities to make this project a success.

Background

- Ovarian cancer:
  - 8th most common cancer among U.S. women; and
  - 5th leading cause of cancer deaths.
- No effective early detection available.
- Prevention exists for genetically-related cases, but
  - These are a small proportion of all cases.

Background (cont'd)

- Effective treatment reduces mortality.
- Treatment by a gynecologic oncologist (GO) can result in longer survival.
- MO and other Midwestern states:
  - High rates of ovarian cancer, but
  - Limited number of GOs available to deliver guidelines-based treatment.

Objective of Study

- Measure outcomes (survival) following treatment and assess whether receipt of guidelines-based treatment differs by patient sociodemographic factors or treating physician characteristics.

Objective of Presentation

- Describe methods used to achieve study objective and challenges encountered in undertaking MCR's first survival study.

Methods

- Participating states (Missouri, Iowa & Kansas) followed a data collection protocol developed CDC.
- Protocol was designed to collect:
  - Existing central cancer registry (CCR) data items;
  - Data elements collected & abstracted by reporting facilities but not reported to the CCR; Data elements in the medical record but not abstracted (& often new to abstractor); and
  - Facility-specific data items.

Methods (cont'd)

- Case selection criteria were based on:
  - Residence at diagnosis (Missouri)
  - Sex (Female)
  - Age (18 - 89)
  - Primary site (Ovary (C56.9), Fallopian Tube (C57.0) or Primary Peritoneal (C48.1-C48.8) AND 1st primary)
  - Behavior (Malignant (3))
  - Histology (8000 – 8576 or 8930 – 9110)
  - Year of diagnosis (2011 or 2012)

Methods (cont'd)

- Case exclusion criteria:
  - Autopsy;
  - Death certificate only;
  - Synchronous tumors.

Methods (cont'd)

- 450 cases were randomly selected from hospitals reporting to MCR with a target N = 335, & 115 available for replacement.
  - c. 50 of 120+ hospitals in MO
  - Total 3-state sample = 1,000
- We imported existing MCR data into a customized version of CDC software.

Methods (cont'd)

- Data to be requested from hospitals included:
  - Select comorbidities that could influence treatment choice;
  - FIGO* stage & staging procedures;
  - More detailed treatment data than usual for a registry (e.g., chemo cumulative dose and routes, cytoreduction procedures and outcomes, etc.); and
  - Data on recurrence.

* International Federation of Gynecology & Obstetrics

Methods (cont'd)

- We developed a data collection plan:
  - Request treatment data and data on recurrence from hospitals:
    - Develop spreadsheet for data entry by hospital registrars (initial plan had been to have hospitals enter data in software);
    - Send spreadsheet securely to each hospital;
  - Review responses securely sent from hospitals;
  - Enter data into software;
  - Perform QA (including follow-back to facilities);
  - Securely upload cases to CDC's contractor; and
  - Receive and respond to CDC contractor QA feedback for all cases, making corrections/changes if/as needed.

Methods (cont'd)

- Plan also included asking for facility information:
  - Whether surgery of chemo was given by a gynecologic oncologist (GO);
  - Great Circle Distance from patient residence at diagnosis to diagnosing and to treatment facilities;
  - Facility size (beds);
  - CoC affiliation;
  - Rural/urban location;
  - Teaching/non-teaching status; and
  - Facility ownership.

Methods (cont'd)

- Plan included calculating patient residence based on Census data:
  - County-level urbanicity (RUCC2013);
  - Tract-level education level (% of residents with less than high school, high school, college or graduate education); and
  - Tract-level median income.

Methods (cont'd)

- Plan also called for creation of a separate abstract if there if the cancer recurred to include:
  - Type and date of recurrence; and
  - Any second course of treatment.

Methods (cont'd)

- January – February 2018:
  - Tested processes using two of c. 50 hospitals as pilot sites.
    - Securely sent (SecureTransmIT application), patient and protocol procedural documents
    - Received data back from pilot hospitals via secure transmission & entered in software.
    - Sent data to CDC contractor via secure transmission;
    - Received feedback from the CDC contractor; and
    - Made adjustments as needed.

Methods (cont'd)

- March – June 2018
  - Securely sent a list of patients & procedures to remaining sites, including:
    - Cross walk of ICD-9 & -10 codes for comorbidities;
    - Study dictionary; and
    - Encouraging letter of introduction from MCR Director.
  - Securely received requested data from hospitals;
  - Conducted 2 rounds of QA:
    - 1) completeness/consistency of incoming data, then
    - 2) after entering data in software, check of data entry accuracy and consistency.
  - Sent data securely to CDC contractor.

Results - Process

- 27 cases were excluded.
  - Any case needing to be excluded had to be explained to & cleared by Westat after discussion with CDC.
  - Reasons for exclusion included:
    - Correction of original abstract dates resulting in synchronous primaries or found to have been reported with wrong behavior (actually /1 borderline tumors);
    - First course of therapy out of state without authority for study follow back (most of excluded cases were for this reason);
    - Charts not available due to hospital merger or closing
    - Findings of remote histories of other cancers.
- Reserve cases were utilized to maintain study strength & meet target (N = 335).

Results – Process (cont'd)

- Number of cases per facility ranged from one to more than 70.
- Facilities were allowed to spread their reporting evenly over multiple months:
  - Some needed reminders or extensions;
  - Several facilities needed multiple reminders to comply with data submission timelines.
  - Only one facility could not fulfill our request for cases (did submit 2/3 of cases)

Results – Process (cont'd)

- 44% of cases had recurrences.
- 25% of submitted forms required follow-back one or more times to:
  - Clarify an entry; or
  - Contact another involved facility to complete the needed information.
- Overall response from contributing registries was good:
  - Facility staff like to know data they collect are used.
  - They seemed glad to participate in a study that might impact patient care in their regions if disparities found.

Conclusions/Discussion

- We encountered a variety of data collection challenges. These included:
  - Unknowns in data fields due to age of data and charts or part of charts being unavailable:
    - Archived (due to patients death and age of data);
    - Physician retirements & practice closings;
    - Chemo administration details not available in EMR;
    - Paper charts archived;
    - Software changes in EMR making some details inaccessible;
    - Restricted access – registrars not authorized to view original records from before a facility merger.

Conclusions/Discussion (cont'd)

- Additional data collection challenges:
  - Registrars collecting unfamiliar data – had to depend on supplied data dictionary to decide how to code or ask questions.
  - A tracking spreadsheet needed to be designed and maintained to track by facility the many steps involved and to provide a crosswalk for Study ID vs. Abstract ID assigned in the software.
    - It also identified cases for which a recurrence abstract was created.
    - A separate tab recorded up to 3 provider/ facility addresses for every case so that Great Circle Distance could be calculated.

Conclusions/Discussion (cont'd)

- This was a very labor-intensive project for both hospital and CCR staff.
- Conference calls with the CDC contractor & all 3 states every 2 weeks were valuable:
  - Lots of questions on issues encountered & clarifications needed.
  - Software and required fields improved as a result.
  - The number of fields required to be tracking for recurrences was lessened.
  - Some case extraction problems were overcome and edits were improved over the course of the study.

Researchers

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