Patterns of Ovarian Cancer Care and Survival in a Midwestern State

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Presenter Disclosures

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No relationships to disclose
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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.
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.
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 by 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.
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)
Case exclusion criteria:

- Autopsy;
- Death certificate only;
- Synchronous tumors.
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.
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
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.
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.
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.
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.
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.
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.
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).
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.
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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