A New Era in Cancer Surveillance

Leveraging the Cancer Registry to Measure & Improve the Quality of Cancer Care

Dennis Deapen, DrPH
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How Do You Do Consumer Research?

- Cars? ConsumerReports
- Hotels? tripadvisor
- Restaurants? yelp
- Cancer Treatment? Dr.Google
Despite the “Information Age”…

Patients navigate uncertain waters in choosing a cancer provider….but there are opportunities now to help.
Background: Cancer’s Burden on California and the Nation

- Cancer is the second leading cause of death in the United States and by 2030 will be the first.

- In California this year, there will be an estimated 155,920 new cancer cases and 56,000 cancer deaths, and the numbers are increasing.

- With earlier detection and better treatment there are now many people living after cancer treatment: Over 14 million in the US and over 1 million in California.

- The costs of cancer care are skyrocketing. National expenditures for cancer care are projected to increase to $173 billion by 2020, up from $72 billion in 2004.
Problem #1: The quality of cancer care is variable.

- Up to 1 in 3 patients treated with chemotherapy do not receive a treatment regimen that is consistent with current medical evidence and best practices.¹

- Patients are often hospitalized during treatment due to side-effects avoidable with less toxic treatments and appropriate supportive care.²

- Patients frequently get tests and treatment they do not need, putting them at risk of side-effects, and imposing additional care burden and cost.³

Problem #2:

- There is no publicly available, meaningful information on cancer care quality by identified provider.
Patients navigate uncertain waters in choosing a cancer care provider because they have no information on the quality of cancer care.

Providers do not have the information they need for quality improvement.

Payers do not have useful data about care quality to help them incent care improvement and make informed networking/contracting decisions.

Policymakers lack provider-specific information about variation in cancer care quality across the state that could inform policymaking.
Institute of Medicine: A New Course for a System in Crisis

Care often is not patient-centered, many patients do not receive palliative care to manage their symptoms and side effects from treatment, and decisions about care often are not based on the latest scientific evidence.

IOM recommendations to improve the quality of cancer care include:

The need for a quality reporting program with meaningful quality measures across the nation.

Cancer Registries can lead the way!
We have a unique opportunity to inform decision making…

- Cancer registries are an established and invaluable resource (other diseases struggle with accurate case identification)
- New health care informatics and technology
- Multidisciplinary cancer care teams looking for ways to improve the quality of cancer care

Cancer Registries are the Only Source of Information on all Patients
# Workgroup Members

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Workgroup’s Charge

- To examine the barriers and opportunities for leveraging the California Cancer Registry (CCR) for measuring and improving the quality of cancer care

- This vision specifically includes the public reporting of cancer quality metrics by provider to allow for improved decisionmaking by patients, plans, providers, and others
Cancer Registries Could…

- Be used for quality of cancer care assessment
- Be merged with other existing data sources like claims data and electronic health records (EHRs) to get at medical care utilization, medication use, and imaging
- Provide better and more transparent information for patients, providers, payers, and other stakeholders to inform decisionmaking and the quality of cancer care
Capacity for Linkage Already Exists

SEER-Medicare Database: What Have We Learned?

- Mammography is underutilized in older breast cancer survivors who are at high risk of recurrence
  
- The number of procedures performed by a surgeon is related to their patients experiencing urinary complications
  
- Can estimate medical costs associated with colorectal or rectal cancer by stage (graph at right)

Limitations of Medicare Data

- Limited clinical information about treatment dosage and regimens
- Persons < 65 years not included
- Radiation and chemotherapy treatment data incomplete
Issues for Consideration

- Technical
- Stakeholder concerns
- Legal and regulatory
Issues for Consideration

Technical

- Timeliness and rapidity of reporting
- Data capture and physician workflow
- Relevant domains of quality of care measures
- Costs
Issues for Consideration

Stakeholder Concerns

- Provider entities may be sensitive about making quality of care/performance data available to public

- Patients are concerned about their privacy
Issues for Consideration

Legal and Regulatory

- Current California Cancer Registry Statute prohibits public release of provider names
Leveraging State Cancer Registries to Measure and Improve the Quality of Cancer Care: A Potential Strategy for California and Beyond

Recommendations

Create a system of public reporting that will improve cancer quality care and health outcomes, while protecting confidentiality and trust among the state cancer registry, providers, payers, and patients.

1. The State of California and its Department of Public Health should expand (through legislation if necessary) the mandate for the CCR beyond public health surveillance to include use of registry data for quality measurement and public reporting.

2. The CCR, other relevant state agencies, and health care payers in the state should work toward developing a system for routinely linking CCR data with health insurance claims data.

3. A strategy should be developed for linking clinical data contained in health system EHRs and the CCR; cancer care providers should be deeply involved in this effort.
Projected Impact

- Improved transparency of the quality of care
- Better information for patient choices
- Opportunity for patients to be engaged in decisionmaking
- Added value to cancer registry program, where investments have already been made
- Addresses health disparities
Launching into the next era of cancer research

- Public health officials, Policymakers
- Patients & Families
- Payers, Insurers
- Providers - physicians, health plans, others
- Researchers
Acknowledgements

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