Utilizing Big Data in Cancer Care

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KEYWORDS

• Big data • Oncologic outcomes • Electronic health records • Clinical databases

KEY POINTS

- Scientific research has turned toward analyzing large amounts of data to advise clinical practice, and ideally develop individual, patient-driven care plans.
- Several computing technologies have been developed to assist with this large amount of data, but global clinical usage is still far from reality.
- Electronic health records are a gold mine of information, but combining information into useable formats across multiple health care systems continues to be a hurdle.

HISTORY

The amount of data being digitally collected and stored is growing exponentially. Historically, scientific research was centered around generating new data by performing individual basic science experiments to answer specific questions related to cancer care. Because patients may receive care at multiple institutions within a region, "single-site" studies may underrepresent or overrepresent key clinical features. Integrating health records across care delivery sites is critical to developing a more comprehensive and accurate picture of cancer care delivery. Over the recent decades, data mining has grown exponentially, and a new era of scientific research has emerged, focused on clinical outcomes. This has led to the informatics age, where attention must be turned toward using the information that is being collected daily from clinical events and episodes of care. This is becoming ever more possible with the use of high-throughput supercomputers. The science of data analysis is concurrently advancing, with the goal of enabling organizations and health care systems to harness this information and convert it to usable knowledge, and ideally personalized clinical decision-making.[1] Computer scientists use the term "big data" to describe this evolving technology.

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The concept of recording and quantifying aspects of complex work environments to improve performance (ie, separate "signal from noise)" has been around for at least 150 years. In 1918 Walter Shewhart of the Western Electric Company at the Hawthorn Works plant near Chicago used schematic control charts to stress the importance of reducing variation in the manufacturing process. Ernest Codman initiated the idea of following patients to determine if their diagnoses and treatment were correct in the early 1900s. Ultimately, this process lead to formal review systems used to apply an assessment as to whether patient care could have been improved by differing decision-making.[2] One can now clearly see that this concept set the foundation for generating and maintaining data on patient characteristics, care, and treatment outcomes, which ultimately led to the formation of quality improvement programs and processes that are known today.[3] Harnessing new technologies to use this insurmountable amount of collected data will be the foundation of medical decision making in the future.

GROWTH OF DATA

Big data has been used in several industries, such as retail. Wal-Mart and Amazon use supply chain analytics to maintain profit in low-margin retail, which has led these retailers to be leaders in mass merchandising and on-line retailing, respectively.[4] In computing, for example, Google customizes individual searches based on previous World Wide Web data, and in so doing maintains World Wide Web history from millions of Google accounts and individual World Wide Web browsers. This information is used in more tactile, positive ways, such as in 2009 when Google identified an influenza outbreak based on individual symptom searches across the United States. Their analysis decreased the interval to Centers for Disease Control and Prevention reporting by 1 to 2 weeks.[5] The influenza case study serves as an example of the health care potential that can be unleashed by analyzing and using collectable data.

Health care laws and federal incentives promoting the use of electronic health records (EHRs) have led to a dramatic increase in electronic clinical data. EHRs contain quantitative data (eg, laboratory values), qualitative data (eg, text-based documents), and transactional data (eg, records of medication delivery). Much of these data are unstructured and therefore difficult to search through. One estimate suggests that 80% of business-related data exist in an unstructured format, with similar estimates for health care data.[6] This leads to the era of big data and the task of using these data for positive clinical outcomes, where it has not been harnessed before. Researchers and public health officials have expressed interest in data linkage; however, linking EHR data across institutions requires a balance between data availability and privacy. The Federal Health Insurance Portability and Accountability Act, along with the more recent Omnibus rule, provide clear specifications on what constitutes protected health information (PHI) and procedures for securing PHI. The application of big data to cancer care has informed practice and evolved for decades, and will undoubtedly continue to unfold. Next is a review of several forums through which these data have been collected and reviewed to address clinical questions.

Institutional Data

Data analytics began with individual researchers reporting treatment outcomes for providers and institutions as case series. These cases series provided a foundation for clinicians to understand how patients were treated at various institutions, but provider variability, at times, prevented duplication of results. As an extreme example, MD Anderson created the Oncology Expert Advisor, which includes information from all patients with cancer who were treated in the history of the institution and has served

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