

Health Informatics

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Big Data- Enabled Nursing

Education, Research and Practice

Health Informatics

This series is directed to healthcare professionals leading the transformation of healthcare by using information and knowledge. For over 20 years, Health Informatics has offered a broad range of titles: some address specific professions such as nursing, medicine, and health administration; others cover special areas of practice such as trauma and radiology; still other books in the series focus on interdisciplinary issues, such as the computer based patient record, electronic health records, and networked healthcare systems. Editors and authors, eminent experts in their fields, offer their accounts of innovations in health informatics. Increasingly, these accounts go beyond hardware and software to address the role of information in influencing the transformation of healthcare delivery systems around the world. The series also increasingly focuses on the users of the information and systems: the organizational, behavioral, and societal changes that accompany the diffusion of information technology in health services environments.

Developments in healthcare delivery are constant; in recent years, bioinformatics has emerged as a new field in health informatics to support emerging and ongoing developments in molecular biology. At the same time, further evolution of the field of health informatics is reflected in the introduction of concepts at the macro or health systems delivery level with major national initiatives related to electronic health records (EHR), data standards, and public health informatics.

These changes will continue to shape health services in the twenty-first century. By making full and creative use of the technology to tame data and to transform information, Health Informatics will foster the development and use of new knowledge in healthcare

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Big Data-Enabled Nursing

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To my family; and nursing's honor of the bold authentic voices of the patients, families and communities.

Connie W. Delaney

In memory of Betty R. Weaver, a mother who supported her daughter to follow her dream.

Charlotte A. Weaver

To Edward, my loving husband, who supported, listened, critiqued, and edited.

Judith J. Warren

To my father, John Clancy, who convinced me to become a nurse 40 years ago and it has been a wonderful journey ever since.

Thomas R. Clancy

To the patients and caregivers whose frustration with technology creates opportunities for big data visualization to enhance the effectiveness and efficiency of healthcare quality, including its processes, structures and outcomes.

Roy L. Simpson

Foreword 1

The idea of big data brings up the old saying “water, water, everywhere and not a drop to drink”. It may be wise to add that “drowning in data” is also of concern. The sheer volume and velocity of data has exploded with electronic information systems, the global internet, software and hardware technology, the cloud and use by almost everyone. The idea of big data has grown rapidly. Even with the advances in methods of collection, analysis, and reporting, the usefulness of data has not grown as rapidly. The vision of how data will add to knowledge and wisdom has initiated high interest and dreams of answering major questions to guide multiple current issues, challenges and decisions. Most professional and general public publications include discussions of big data addressed from perspectives of clinical care, science, business, education, travel, finance, marketing, and quality determinants.

In this important book pioneering authors address several important considerations and hopes for the creation, generation and use of big data particularly from the perspectives of the science and delivery of health care. The book is written as basic information for those who are becoming interested and for those who already have an interest in how big data can add to information and knowledge of importance to them. More specifically the authors describe how each individual, group, or nation might conquer, contribute to, and use big data to inform their own questions about science, practice, education, policy, organization, resources, and quality.

Researchers have and will continue to generate large amounts of data in many formats, at all levels and in every corner of the world. There is an increasing and urgent need to better understand how to capture, store, manage, analyze and share data to further knowledge and foster new discovery. Likewise, those who deliver and pay for care continue to generate large amounts of clinical, administrative, policy, and cost data to inform the decisions made by each individual or group. And the recipients of the decisions made by these groups have keen interest as buyers, patients, funders, and policy makers. Thus both those seeking the big picture and those seeking more specific targets can easily be blurred by the thousands of data elements.

Big data is of importance to many types of stakeholders. Biomedical, clinical, health services, economics, and population are examples of researchers. Serious

expectations are proposed for precision medicine with the aim to cure major diseases like cancer, Alzheimer's, AIDS and genetic disorders. Physicians, nurses, physical therapists, dentists, psychologists and other health professionals have need for specific data of importance to their practice. This need for specific data only increases when specialty areas are considered. Further stakeholders are hospitals, home care, long-term care, mental health, public health and hospice organizations. Patients and consumers are major stakeholders with needs for data tailored to specific conditions and situations. Ownership, governance, payers, and policy makers increase the complexity of essential data. Recently, community social determinants data have been identified.

A few years ago I was invited to present at the First International Interdisciplinary Conference on Big Data held in Singapore. I proposed that big data was not big enough especially from the perspective of nursing practice and nursing science and from the perspective of patients, families and communities. Our experience with data for decades has been focused on classifications of diseases and medical procedures. Data about the assessment, problems, interventions, and outcomes of nursing care are invisible. It was and still is a challenge to find essential patient data from the perspective of nurses in electronic information systems, data warehouses, repositories and the cloud. There was surprise and agreement from engineers and computer scientists at the conference. Unfortunately, this state exists even with extensive work on a Nursing Minimum Data Set and a Nursing Minimum Management Data Set as well as work on international and national development of nursing terminologies and vocabularies. This is a serious limitation and challenge to meeting the goal of advancing nursing science and nursing practice. It is also a serious limitation for all interdisciplinary efforts to generate and use data.

The potential value of big data has created intense interest from the creators and users to be sure that what is of importance to each is included in big data. A current challenge is the desire to have a longitudinal plan of care for each patient. Each stakeholder wants to include a very specific type of data important to a specific practice. Data of importance to another is often considered clutter and makes the information/decision support system time consuming and of little use. Also a challenge and of keen interest is that each piece of data is clearly defined, and is valid and reliable. Highly reliable evidence-based care to ensure quality, safety, and value in health care clinical decisions needs to be supported by accurate, timely and up to date clinical information. Missing data on care not delivered or care data not delivered is of great importance as part of the search for best care. All stakeholders need to accelerate the integration of best knowledge into a care decision.

SNOMED CT and LOINC represent international and nationwide work on reference and clinical terminology that are helping achieve the goal of having standardized interoperable data. This should help the goal that each stakeholder uses the same data element with the same concept. Researchers and clinicians often use different terminology. This quest is no small challenge because of the many areas of science, technology, clinical care, administration, policy development, and the broad variety of health delivery systems and the populations who are the participants in health care.

Each part and chapter of this book has comprehensive descriptions of the evolution of data and knowledge discovery methods that span qualitative as well as quantitative data mining and other methods. Multiple examples are included. There are opportunities and challenges as the data grows in scale, complexity, volume, variety and velocity. Opportunities also expand with the rapid growth of new approaches to data management, analysis, and sharing and with further development of technology (hardware and software).

When all is said and done, the value of big data to patients will depend on how well their care can be delivered and received. A most important question may be precision medical diagnosis and treatment using a wide range of data. Or it may be that cost or community safety is a top question. On the other hand, important concerns may include questions regarding their immediate and long-term care. Big data will not be of much interest to patients having such very personal problems as unmanaged pain, pressure ulcers, lack of information to inform self-management, nausea, vomiting, falls with injury, hospital acquired infections, and uncoordinated care if not included in big data sets.

There is still much to learn about what really contributes to outcomes of value to stakeholders. Use of big data holds promise for advancing health care, research methods, education and policy. This book is a major contribution to that learning.

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Foreword 2

Big data science has to be the concern of all nurses. The 21st-century question for every health professional is: How do you promote transformational change in which the emphasis is not on transitory, isolated performance improvements by individuals, but on sustained, integrated, comprehensive advancement of the whole? The turn-of-the-century focus on bridging the quality divide, with its emphasis on re-engineered care processes and effective use of information technology, has been replaced by the wish to create the continuously learning healthcare systems (LHS) described by the Institute of Medicine. The LHS can analyze all aspects of the care experience for real-time decision-making by patients and clinicians alike. In the space of a dozen years, the stress has moved from simply establishing and using the electronic health record to analyzing all aspects of the care experience for new insights which might involve mining a host of previously unconnected data bases (e.g., quality-safety benchmarks, cost accounting, environmental hazards, admission-discharge records, and so forth).

Big data is not only of importance to nurse informaticians and health services researchers, but to all who aspire to leadership positions in practice, education, research, and policy. Nursing leaders have highlighted the need for nurses to know enough about big data that they can appreciate its relevance to care coordination. Nurses need to be cognizant of technologic developments if they are educators or deans so they can be futuristic about program planning and faculty recruitment. Nurses need to understand enough about how big data can give them insights into health risk differences. Consider, for example, the challenge of designing population-based care for urban and rural women in a particular country. Nurses need to recognize the promise and potential perils of big data if their research is concerned with advancing symptom management.

As we know, leadership isn't just what you can do yourself, but encompasses what you can get done. Do you know enough about trends and the changing nature of health care to hire people with the right skills sets and ask pithy questions of experts who are telling you that your organization should be moving in a particular direction? Do you know how technology-mediated interventions might increase patient engagement and adherence in your clinical setting, so that you can start to

move your setting in that direction? Nurse leaders in all settings and at all levels need to be familiar with big data science, and big data needs to be shaped so it asks the questions of concern to care giving. This major volume on big data science can, therefore, be of use to those nurses already concerned with these matters, and I believe it can also be valuable as an immersion in futures thinking for those who don't know enough currently about how to address the informatics revolution underway. If you are trying to get your head around how to handle the tidal wave of data, the increasing concern about figuring out the social determinants of health, or the transformation taking place in how we think and work, then this book is must reading.

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Preface

This book's purpose is to engage all of nursing in the potential that big data analytics holds for advancing our profession and the discipline of nursing spanning practice, operations, research, academics, industry, and policy. The book includes big data state-of-the-art-and-science reviews, as well as applied chapters and case study exemplars in nursing using big data analytic methods and technology. In this book, we celebrate the early adopters and the transformative initiatives in play at health-care organizations, vendors, payers and academia. We also aim to present the opportunities for nursing's impact in this new, emerging knowledge-driven world.

Nursing research historically adopted qualitative methodologies with purposive sampling and quantitative methodologies with small sample sizes because access to patients or large study populations was constrained. Clinical trials, bench research, epidemiology studies and large data methods were in the medical domain and used traditional biostatistical analyses. However, the digitization of medical records and payers' claims data has redefined population studies and made large databases available to all disciplines. In the United States, large payer data has been amassed and organizations have been created to welcome scientists to explore these data to advance knowledge discovery. Health systems' electronic health records (EHRs) have now matured to generate massive databases with longitudinal trending. The learning health system infrastructure is maturing, and being advanced by health information exchanges (HIEs) with multiple organizations blending their data, or enabling distributed computing. The evolution of knowledge discovery methods that use quantitative data mining and new analytic methods, including the development of complex data visualization, are enabling sophisticated discovery not previously possible. These developments present new opportunities for nursing, and call for skills in research methodologies that can best be further enabled by forging partnerships with data science expertise spanning all sectors. Recognizing that these new opportunities also call for reassessment of all levels of academic preparation of nursing professionals from pre-licensure through post-doctoral training, parts of this book are dedicated to nursing education and competencies needed at all levels.

This book represents the first big data/data science book in nursing to be published worldwide. It succinctly captures the state of big data and societal context,

provides exemplars to establish a foundation for nursing's response to the big data science frontier and provides multiple pathways for driving nursing's future. Accordingly, we organized the book into five parts with the goal of introducing the core concepts of big data and data science in Part I with examples that relate to nursing as well as other industries. Part II brings in the new and emerging technologies that make big data analytics possible, and illustrates through case studies and references to initiatives currently happening. These two foundational parts also provide state-of-the-art/science reviews that are written by fellow nurses with an eye to demystifying and removing any intimidation that might surround this field.

Introduced throughout all five parts is the important principle of using partnerships and building teams that include big data analytics experts and data scientists in order to have the clinical and technical skill mix needed. The days of the single researcher, analyst, or single domain team are being called into question for their relevancy and efficiency. Recognizing that all missions—academic, research, practice, policy—are transformed by big data, Part III focuses on research. Specifically, this part dives into the complexity of disease, advancement of networks to increase access to large data capacity, and actual application of data analytics to drive transformation of the healthcare system. Taken together, Part III's chapters show the potential of nursing's engagement in big data science to transform the science by the new knowledge generated and its application in practice, education and policy.

The last two parts attend to applied current state exemplars for nurse executives to have reference roadmaps, competencies needed at all levels, and a look at the near future impact for healthcare delivery, education and research. Throughout Part IV and V, “readiness” is directed at those who own change across the sectors: those who teach our next generation of nurses; the health policymakers who support change through regulations, guidance and funding; and nurse executives who define care strategies within their healthcare organizations. Front and center to all these sectors within the near future big data world is the critical state of the nursing workforce. Part V includes a description of quantity, emergent roles, education and appropriate certification and credentialing that “readiness” for the changes afoot will require.

A theme throughout the book is the goal of having “sharable and comparable” nursing data, and the need for standards to make this possible. While nursing is making progress on having adequately matured, codified terminologies to represent nursing concepts, actions and outcomes across all care domains, we are not there yet. The tactics used to compensate for this current state are reflected in the chapters and case studies presented in Part IV and V. Interoperability and data standards are the key challenge of our times and will continue to have intense focus. Standards that work for all are not just U.S. challenges, but rather extend worldwide; and thus, the significance of a global world permeates these invitations for engagement, transformation and empowered nursing.

In summary, this book is applicable to all nurses and interprofessional colleagues in all roles. We deliberately constructed the content and selected the applied

examples and case studies so that the book can serve as a technology reference, or a “101 Intro” to big data for all nurses, and most importantly, a “how to” guide for planning your own big data initiatives. We hope that you will use the book broadly for continuing education purposes as well as for educational curricula; but above all, we hope that you read and enjoy the book!

Connie W. Delaney
Charlotte A. Weaver
Judith J. Warren
Thomas R. Clancy
Roy L. Simpson

Acknowledgments

The idea for this book grew out of many nursing and interprofessional dialogues about big data and data science's growing presence throughout the healthcare industry including research, education and policy. The need for a "big data and nursing" book emerged from multiple conversations that happened in the context of the University of Minnesota School of Nursing's annual Big Data and Nursing conferences that started in June 2013. From these rich interchanges, we recognized a pressing urgency to bring the potential of big data analytics into all the domains of nursing—practice, operations, research, academics, industry, and policy. More sobering was the discovery that there were no books in the marketplace in 2016 that specifically focused on nursing and big data. So our biggest "thank you" goes to all the authors and co-authors of the many chapters and case studies that make up this book. As early contributors in this first nursing publication on the topic worldwide, these authors bravely stepped forward to share their work and to lay out candidly how they are bringing big data applications into their respective domains.

In addition, we owe thanks to many others for helping us bring this body of work to you. To start at the beginning, we want to acknowledge the debt we have to the annual Big Data and Nursing Knowledge Conference Steering Committee Members who have worked diligently to ensure that we had this annual gathering without which the ideas, content and contributors for this book would not have happened. Bonnie Westra and Lisiiane Pruinelli served as the organizing principals, aided by Susan Matney, Joyce Sensmeier, Daniel Pesut, Nancy Ulvestad and four of the book editors. A number of organizations also contributed by sponsoring representatives to the annual conferences and those include: American Nurses Association, American Association of Colleges of Nursing, American Medical Informatics Association, National Institute of Nursing Research, Trinity Health, Hospital Corporation of America, and University of Minnesota Medical Center. Cerner Corporation and OptumLabs™ Scott Regenstein, Greta Bagshaw and William Crown were instrumental partners as fellow researchers, book contributors and data science experts who willingly shared knowledge and guidance.

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Connie W. Delaney
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Roy L. Simpson

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