

Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2018;



SPECIAL COMMUNICATION

Turning Data Into Information: Opportunities to Advance Rehabilitation Quality, Research, and Policy

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Abstract

Attention to health care quality and safety has increased dramatically. The internal focus of an organization is not without influence from external policy and research findings. Compared with other specialties, efforts to align and advance rehabilitation research, practice, and policy using electronic health record data are in the early stages. This special communication defines quality, applies the dimensions of quality to rehabilitation, and illustrates the feasibility and utility of electronic health record data for research on rehabilitation care quality and outcomes. Using data generated at the point of care provides the greatest opportunity for improving the quality of health care, producing generalizable evidence to inform policy and practice, and ultimately benefiting the health of the populations served.

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Over the past 2 decades, health care quality and safety have risen to the forefront of health policy and research. Landmark reports such as the 2001 Institute of Medicine's *Crossing the Quality Chasm*, together with the National Quality Strategy a decade later, aligned hundreds of organizations, individuals, and stakeholders toward 3 national aims: improved health, higher-quality care, and affordable care.^{1,2} Despite national support of these 3 aims, advances in rehabilitation practice, policy, and research are not in harmony. Policies are established without adequate empirical

authors and do not necessarily represent the official views of the funding sources. Disclosures: none. evidence and yet are directing changes in practice.³ Many clinical guidelines lack sufficient evidence.⁴ Quality improvement at the service level is not always disseminated or designed to be generalizable.⁵ Research is said to take a decade or more to be implemented,⁶ and that which is implemented in many cases cannot be measured or monitored for population-level health benefit. In this special communication, we define quality, apply the dimensions of quality to rehabilitation, and describe the "untapped potential" of electronic health record (EHR) data used to guide local quality improvements that can also be optimized to generate real-world evidence and to inform policy. Then we illustrate this untapped potential with a case example. We describe an in-depth evaluation of the feasibility and utility of using EHR data for stroke rehabilitation research in a multisite collaborative network. Use of data generated at the point of care provides the greatest opportunity for improving the quality of health care, producing generalizable evidence to inform policy and practice, and ultimately benefiting the health of the populations we serve.

0003-9993/18/\$36 - see front matter © 2018 by the American Congress of Rehabilitation Medicine https://doi.org/10.1016/j.apmr.2017.12.029

Study Performed: Carolinas Rehabilitation, Carolinas HealthCare System (Department of Physical Medicine and Rehabilitation); Duke Health (Duke School of Medicine, Duke School of Nursing, Duke Regional Hospital)

Presented in part as an abstract at the American Congress of Rehabilitation Medicine, November 14, 2013, Orlando, Florida.

Published in Archives of Physical Medicine and Rehabilitation, 2013;94:e53. Supported in part by National Institutes of Health/National Institute of Nursing Research (grant no. P30NR014139); Carolinas HealthCare System Cannon Research Center; and Duke University School of Nursing. The contents of this article and conduct are solely the responsibility of the

Dimensions of quality: Priorities in rehabilitation

Greater attention to improving the health delivery system is useful when all involved have the same end goal. To improve the quality of care and improve the long-term outcomes of populations served, health delivery organizations, including those that provide rehabilitation services, refocused in 2001 to improve 6 dimensions of health care. Care needs to be equitable, patient-centered, effective, safe, timely, and efficient.¹ Applied to rehabilitation (table 1), these dimensions provide a clear action plan for measurement and improvement. Providers of rehabilitation care have some of the richest and most contextual information regarding patients' health and functioning. These data are extremely valuable for each domain of quality. In many cases, however, their use is reserved to individual patients rather than populations. Consequently, learning across patients and subgroups is minimal and improvements in quality are limited. There is a tremendous opportunity in optimizing use of EHR data at the population level to improve quality, inform policy, and generate real-world evidence, particularly from rehabilitation services where the data are richest with measures of what matters most to patients.

Untapped potential of EHR rehabilitation data

The World Health Organization considers health information systems 1 of the 6 essential building blocks of high-functioning health systems.⁸ Health information technology in the United States was accelerated in 2009 with the creation of the Health Information Technology for Economic and Clinical Health Act.⁹ This legislation established milestones for implementation and stimulated the adoption of EHRs and supporting technology. EHR implementation was to support use of electronically captured data to improve health care quality, safety, and efficiency. To reach these goals for data use, implementation of EHRs requires its own plan-do-study-act process improvement cycles to maximize utility.¹⁰ No EHR is perfect from the start, nor can it meet the needs of all stakeholders. Although these goals for using electronic data at the point of care and to improve the health of populations are slowly becoming reality, rehabilitation research and policy affecting rehabilitation makes little use of EHR data.

Several national practice-based research initiatives are leveraging EHR data across organizations under a unifying purpose. For example, the National Institutes of Health Health Care Systems Collaboratory was designed to engage health care systems to use clinical and operational data for pragmatic clinical trials in an effort to improve the efficiency, relevance, and generalizability of study findings.¹¹ Similarly, the Patient-Centered Outcomes Research Institute funded the National Patient-Centered Clinical Research Network with 33 partner networks.¹² Of these, 20 are patient-powered research networks, governed by patients and their partners, and 13 are clinical data research networks based in health care systems such as hospitals, integrated delivery systems, and federally qualified health centers.

List of abbreviations:

EHR electronic health record EQUADR Exchanged Quality Data for Rehabilitation PSO patient safety organization These collaborative data networks are important infrastructures that leverage clinical and research experts to address coding and standardization, privacy and proprietary considerations, quality, and access to already-collected data available from a variety of sources. Studies that evolve from these networks are more efficient than replicating studies in multiple locations and are likely to include more variations in treatment patterns and outcomes than would be available in any one data source or site. This means the results are more likely to be generalizable and more useful to patients and clinicians. However, few of these national networks have focused on post-acute care services such as inpatient rehabilitation. Both of these transformational initiatives are built on collaborating partnerships; neither includes rehabilitation in its leadership or as a primary focus in any of its partner's projects. This is an area where rehabilitation providers, researchers, and consumers could become more involved.

The rehabilitation community has become more engaged with population-specific registries. The Spine Quality Outcomes Database created by the American Academy of Physical Medicine and Rehabilitation and American Association of Neurosurgical Surgeons, and the cardiovascular registries supported by the American College of Cardiology provide a platform for clinical, research, and policy expert collaboration. The data in these registries are used to examine the delivery and outcomes of care. The research generates the evidence needed to strengthen clinical practice guidelines and direct policy. Registries also allow participating organizations to compare the delivery of care and outcomes across members. Variation in care can be informative. For example, delays in the initiation of home-based therapy may signal several areas of access for further investigation. Highperforming organizations can be invited to share strategies. The common data framework standardizes the language of data being used to measure and monitor population-based improvements over time. These are several of the benefits to participating in registries. There are also some disadvantages. For rehabilitation providers, population-based registries dissect the total population of patients served, meaning that the advantages of participating in the registry are applicable to only a select segment of patients. It is also difficult to measure improvements when testing or spreading one strategy or intervention to other populations. This can be as simple as a new piece of equipment or as a complex as a care pathway. Different data networks and registries serve different purposes for different people.

EHR readiness for rehabilitation research network use: Case example

Leveraging EHR data across organizations opens a new space for health services research, including rehabilitation-focused pragmatic clinical trials and implementation research.¹³ The only rehabilitation-specific quality database in the United States that integrates clinical data from different organizations is the Exchanged Quality Data for Rehabilitation (EQUADR) network. EQUADR is accredited by the Agency for Healthcare Research and Quality as a patient safety organizations whose primary mission and function are to improve patient safety and health care quality.¹⁴ The EQUADR network supports member inpatient rehabilitation facilities and units to securely submit data to compare performance with similar rehabilitation programs, share best practices among members, and receive guidance for reducing risks and improving Download English Version:

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