Journal of Clinical Anesthesia 40 (2017) 117–118

Contents lists available at ScienceDirect

Journal of Clinical Anesthesia

Editorial

Fishing for answers in an ocean of data: The potential for big data analytics to enhance our knowledge of the complex regional pain syndromes

In an era of expanding costs and declining reimbursement, the healthcare industry has dramatically expanded the collection of demographic and clinical data to facilitate billing efficiency and maintain financial solvency. Electronic health data collection has primarily emphasized the capture of diagnostic coding, medication delivery, laboratory utilization, and procedural interventions to support third party reimbursement claims, improve efficiency, and provide transparency. Although much of the electronic stored data was never directly intended to answer clinical questions, or guide clinical care, the use of data analytics has created opportunities to winnow through the vast data collections and pull out useful insights into previously unrecognized patterns of common and uncommon medical disorders [1–3]. Drawing from broad national and even international population data sets, we may finally be able to accurately characterize rare "orphan" disorders, such as complex regional pain syndromes, type I (CRPS).

CRPS is a rare painful condition, characterized by severe pain out of proportion to the inciting injury, usually trauma involving an extremity, and which persists beyond the anticipated healing period [4]. Evidence of edema, changes in regional skin blood flow, or abnormal sudomotor activity in the affected area must be present. The incidence rate for CRPS in the United States is unknown, but estimated at affecting only 0.0055% of the population [5]. Due to the rarity of the disorder, clinical studies of CRPS are often limited to individual case reports or small series of 1–30 subjects. This picture has been further complicated by the lack of a definitive diagnostic testing or defined pathology to clearly establish the diagnosis. CRPS remains a diagnosis defined by excluding any other etiologic cause [5]. Although the syndrome was well described by Mitchell in wounded soldiers during the Civil War era, it has been described by many names, defined in part by the nature of the inciting injury, the location of the injured part, and by the medical specialist providing care [6–7]. Under the auspices of the International Association for the Study of Pain (IASP) in 1994, the terms CRPS type 1 (without obvious nerve injury) and CRPS type 2 (with obvious nerve injury) were first introduced as more descriptive names for the commonly used names, causalgia and reflex sympathetic dystrophy, shoulder hand syndrome, and Sudek's atrophy [7–10]. Adoption of the CRPS terminology has been gradual, with clinical adoption lagging behind the medical literature, but this is rapidly changing [7].

In this issue, Elsharydah et al. give us our first glimpse at the potential benefits of big data analysis with respect to the epidemiologic characteristics of CRPS type 1 [11]. The authors examined the demographics and comorbidities of CRPS type 1 drawn from a nationwide inpatient sample of patients with a diagnosis of CRPS. Their data were obtained from a sample of 33,406,123 patients, from which 22,533 patients were identified with CRPS. Although their data are primarily descriptive demographics, and provide little insight into causality, treatment response, or even the presence of active disease, it reveals the potential for large, electronic data sets to better define risk factors and associations for various disease states! The use of big data to attempt to answer clinical questions represents a paradigm shift from the scientific method where instead of isolating a single testable variable in a controlled experiment, large swaths of data are evaluated for statistical associations. Critical to collecting the clinically useful diagnostic and therapeutic information, is the ability to ask the right questions and collect the necessary responses.

Efforts to refine and foster the adoption of meaningful outcome measures have been fomented by researchers and pain societies, such as the IASP CRPS Special Interest group, which is supporting efforts to develop an international core outcome measurement set for complex regional pain syndrome clinical trials designated COMPACT [12]. Incorporating standardized questionnaires, defined clinical assessments, and defined outcomes into patient records will eventually lead to a common language, enabling more effective analysis, and more useful data sets to characterize the natural history of the disease, risk factors, and other predictive data. Even more exciting is the potential to evaluate and identify effective and ineffective therapies, eventually taking it to the genomic level and a personalized course of therapy for the individual patient. Most of our current outcome data and conceptions of the natural history of CRPS, is based on the limited information obtained from small scale clinical reports. We still have a far way to go, but the potential for improved patient care is well within reach. After years of fishing for answers with a single pole, we can now cast a wide net to harvest far greater amounts of clinical information and improve our understanding and treatment of this difficult pain malady.

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7 April 2017
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