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Disseminating the best available evidence: New challenges in public reporting of health care

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Abstract:

As a direct benefit of the Health Care Reform Act (2010), concerted effort has been deployed to define and characterize the process by which the best available evidence for diagnosis or treatment intervention prognosis can be obtained. The science of research synthesis in health care has established the systematic research protocol by which randomized clinical trials and other clinical studies must be reviewed and compared for the level and quality of the evidence presented, as well as the consensus of the best available evidence synthesized and shared. This process of systematic review yields a reliable and valid approach in comparing different interventions and strategies to prevent, diagnose, treat and monitor health conditions in terms of efficacy, and or of effectiveness. The resulting bioinformation outcome of comparative effectiveness and efficacy research review of the available clinical data is expressed as a consensus of the best available evidence, which finds its way in evidence-based clinical practice guidelines, standards of care and eventually, in policies: hence, the acronym CEERAP (comparative effectiveness and efficacy review and policy). The methodological and the procedural criteria that determine and regulate the public reporting dissemination of this sort of bioinformation, and the extent of benefit to the patient's health literacy, which have remained a bit more elusive to this date, are investigated and discussed in this paper.

Keywords: Best available evidence, systematic review, comparative effectiveness and efficacy review and policy (CEERAP), evidence-based decisions, dissemination, public reporting, health literacy.

Background & Description:

The Health Care Reform Act of 2010 advocates innovative health care modalities whose foundations rest on translational science. The Act proposes dynamic transactions between translational researches - the bridge between the patient and the fundamental clinical and biological evidence obtained from the samples and biopsies of the patient - and translational effectiveness - the utilization of the best available evidence obtained by research synthesis in specific clinical settings.

In the context of translational effectiveness, it is now generally accepted that a patient's health literacy reflects the individual's ability to read, understand, comprehend and use healthcare bioinformation. The importance of health literacy is widely accepted because it empowers the patient to become an active participant (i.e., locus of control, motivation) in the process of understanding the seriousness of the diagnosis, of making decisions (i.e., self-efficacy) regarding treatment protocols, and of following instructions for treatment (i.e., compliance).

The U.S. Department of Health and Human Services defines health literacy as "...the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness..." [1]. Several variables modulate health literacy, starting from socio-educational status, to age, ethnicity, gender, language proficiency and comprehension in certain cultural groups. In fact, even in the wake of the health Care Reform Act of 2010, which has expressly called for patient centered outcomes research (PCOR), low health literacy remains among one of the most formidable and largely under-addressed public health issues and it still form a barrier to clinical practice that aims to improve health care quality and outcomes. In fact, low health literacy still forms today a gargantuan barrier to clinical practice that aims to improve health care quality and outcomes. In addition, the lack of precision to predict health literacy, the administrative burden and the inability of existing measures to estimate health literacy at a population level, continues to hamper its rigorous and robust assessment.

Research has shown that multivariate models permit a more accurate estimation of the meta-construct of health literacy than single predictors. While complex, these approaches can be applied effectively to readily available administrative or census data to produce estimates of average health literacy and identify communities that would benefit most from appropriate targeted interventions in specific clinical settings, and to address poor quality care and outcomes related to low health literacy [2]. Standardized and targeted training strategies can be effective in building stronger relationships with stakeholders, particularly when designed to customize practice-based content and curriculum delivery to patient's optimal cognitive learning mode and preferences [3].

Case in point, the Rapid Estimate of Adult Literacy in Medicine (REALM) was developed to incorporate dental and medical terms into an 84-item Rapid Estimate of Adult Literacy in Medicine and Dentistry (REALM-D) measure, and was validated against a 48-item health beliefs and attitudes survey in a sample of 200 culturally diverse dental clinic populations in the Los Angeles area. This survey evinced that minority non-white participants have significantly lower REALM-D as well as a lower total scale scores at each level of difficulty compared to white participants. Also, participants whose main language was not English had significantly lower REALM-D scores compared to those with higher level of education and more robust oral health literacy [4]. In brief, it is evident that health literacy requires a multi-pronged approach for the assessment of: 1) appropriate dissemination of relevant and appropriately packaged bioinformation; 2) skills to gather and comprehend health bioinformation; 3) comprehension of at least some degree of bioinformation, health and medical glossary; 4)

understanding diversity of means and platforms for public reporting and dissemination of bioinformation.

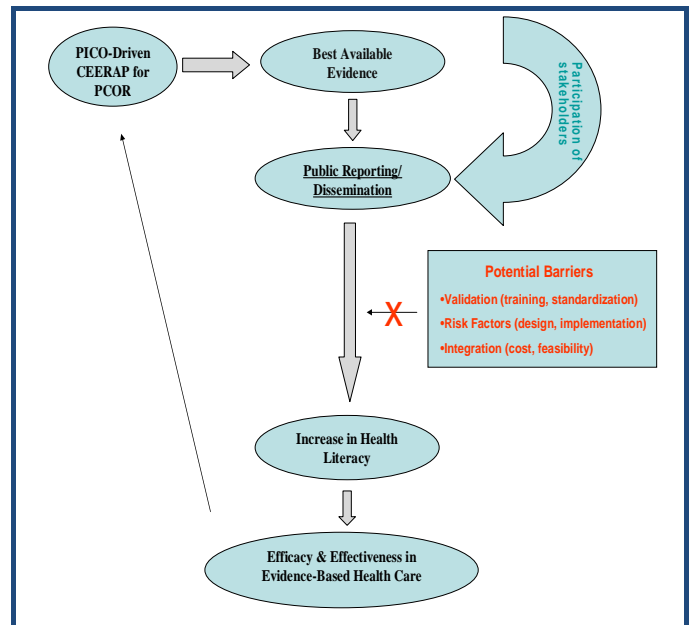


Figure 1: Patient-Centered Outcomes Research (PCOR): Implications of Public Reporting for Health Literacy Outcomes: Crafting a consensus statement via the PICO question, driven through a systematic scientific process that is characterized by comparative effectiveness and efficacy research and analysis for practice (CEERAP) in a patient-centered outcome research (PCOR) modality leads to the Best Available Evidence by a mechanism that involves feedback from the stakeholders. The process ensures that the resulting best available evidence will optimally serve patients and caregivers in empowering them in the clinical decision-making process. This usually involves engaging them to compare different interventions and strategies. The best available evidence must be effectively disseminated through a bioinformation Public Reporting/Dissemination step, which can involve systemic data collection, analysis and final dissemination to public audience. The best available evidence obtained through the CEERAP protocol and dissemination leads to increased health literacy, which in turns will enhance efficacy and effectiveness in evidence-based health care, because the consensus of the best available evidence feeds into evidence-based practice guidelines, standards of care and policies. In this concerted process there are potential barriers that hinder the final outcomes, and now require active study. These may include validation issues (i.e. training, standardization), risk factors (i.e. design, implementation) and integration (i.e. cost, feasibility).

A distinct conceptualization of health literacy assessment, the National Assessment of Adult Literacy (NAAL), a US nationally representative assessment of English literacy among American adults age 16 and older defines functional health literacy as the ability to read, understand, and act on health information in everyday life. In the NAAL categorization format, patients may be: 1) *Proficient* if able to perform the complex activities involved in searching and comprehending health information (10-12% of the US adult population); 2) *Intermediate* if capable of conducting moderately difficult tasks for finding basic health-related facts (about 50% of the US adult population); 3) *Basic* if

only able to comprehend the information in a clearly written pamphlet; and 4) *Below Basic*, if barely capable to follow a set of short instructions. These individuals have limited English literacy.

NAAL confirms that language and culture are serious barriers to health literacy for at least 5% of the US adult population (and larger proportions in certain States, such as California, and certain city neighborhoods, such as East Los Angeles, the San Fernando Valley, etc.). Qualitative and quantitative assessments, derived from the NAAL rating scale and adapted specifically to health literacy, can be useful and sensitive measures of health literacy [5].

In brief, the context of patient-centered outcomes research renders it unavoidable and critical to have fully validated and reliable instruments to measure health literacy, and to follow-up interventions that target its increase. It is primarily for this reason that current trend of health care research have led to the development of several paradigms designed to increase health literacy through structured and systematic bioinformation at the national level, such as the AHRQ Center for Education and Research on Therapeutics (CERTS).

The 2004 goal set by President Bush on universal Electronic Health Records (EHRs) was followed, within less than a decade, by the recent Health Care Reform Act of 2010. Taken together, these political efforts are witnessed of the extraordinary emphasis that has been given to efficiency, patient-centered outcomes research, and comparative efficacy and effectiveness research modalities in the first part of the XXI Century. Thus today, the best available evidence is integrated into appropriately revised clinical practice guidelines and standards of care and eventually evidence-based health care policies. The focal point of patient-centered outcomes research consists of the systematic scientific process that is characterized by comparative effectiveness and efficacy research and review for practice and policy, often represented by the acronym CEERAP.

Emanating from the CEERAP core is the process of evidence based decisions, which always benefits from active participation by all stakeholders, including the patient and the caregivers. In order to empower the stakeholders to fully participate in this essential stage of health care, the best available evidence obtained through CEERAP must be effectively disseminated in a manner that enriches the cognitive schemata of the patients, or in other words, significantly increases the patient's health literacy. Certain blocks and limitations still exist that hinder the process (**Figure 1**).

Novel and improved modes of dissemination of the best available bioinformation could be designed and tested. We have proposed a system based on the principle of the web architecture [6], as one possible means to provide fast, reliable and global dissemination service [7]. Nevertheless, the fact remains that the challenge of reporting and disseminating science and health care bioinformation to the public is as complex and unresolved as critical current trend of health care is to this date, as it is a critical current trend of health care.

In conclusion, it is fair to recognize that the "science of public reporting" has a noble history that begun at least a quarter century ago [6], although traces of its importance can be found in the work of Paracelsus and Galen. But, our efforts in this domain are far from being exhausted, and much work remains to improve seamless public reporting.

The challenge of public reporting of bioinformation today refers to the concerted process to provide specific bioinformation, such as the best available evidence emerging from CEERAP in a patient-centered outcome research modality, to stakeholders and health care consumers, in order to empower them to rate and compare providers, interventions and health care variables ranging from standards of quality, cost, coverage, risk, success rate, and etc. The science of public reporting has now evolved into a process that must include systematic data collection and analysis, and final dissemination to a public audience [6-9]. Current trends dictate that public reporting not only must be an instrument of dissemination of the best available evidence obtained through the CEERAP protocol, but must also ensure increased health literacy.

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