

# Comparative Effectiveness Research: Stimulus for Better Patient Care

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**A**n elderly man is diagnosed with lymphoma. Aggressive therapies could cure his disease, but would they negatively impact his quality of life? A young woman is being treated for diabetes. Is her treatment regimen framed by perverse financial incentives or by the various treatment options that consider the full breadth of the human experience?

President Obama recently signed into law a bill appropriating \$1.1 billion for comparative effectiveness research (CER), which evaluates the impact of different treatment options for a given medical condition. Deciding exactly how this money will be spent is the question of the day. The National Health Council (NHC) sees this research as an important first step in providing patients with the comprehensive information they need to participate in decision making about every aspect of their care. However, we are concerned about the potential impact of CER on patients if the research and subsequent dissemination of information are carried out improperly.

The NHC provides a united voice for the more than 125 million people with chronic diseases and disabilities and for their family caregivers. Its membership is comprised of approximately 115 national health-related associations and businesses, including 50 of the nation's leading patient advocacy organizations such as the American Heart Association, the March of Dimes, and American Diabetes Association.

The principles of good science and evidence-based medicine should guide CER policy. As defined by Dr David Sackett, evidence-based medicine means integrating individual clinical expertise, the best evidence, and individual patients' predicaments, rights, and preferences to make healthcare decisions.<sup>1</sup> To achieve these aims, CER research efforts must incorporate the needs of individual patients.

The NHC has conducted several nationwide, telephone focus groups to gauge the public's understanding of the concept of CER. What we learned is patients believe that evidence-based medicine is valuable, important, and something they would like their health providers to use. We also heard loud and clear that patients and their family caregivers are vehemently opposed to a "one size fits all" approach to medical care. They want treatment plans that consider an individual's specific health conditions, history of treatments and side effects, and goals for health outcomes and quality of life.

The best clinical medicine will not necessarily result in the best outcome if a patient's life circumstances are not taken into consideration—especially circumstances that can't be changed (eg, genetics) and those that impact quality of life.

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The best treatment option for most patients with the same diagnosis simply might not work for others with a different genetic structure. For example, some mental health patients or people diagnosed with epilepsy may

be highly sensitive to medications, making it difficult to set the right combination or dosage.

Comparative effectiveness research must involve various subpopulations to address the genetic differences of patients. For years, data extrapolated from research done on white men were applied to women and minorities. For example, low-fat diets, daily aspirin to prevent heart attacks, and cholesterol-lowering drugs were determined to be beneficial based on tests involving men but not women. In some cases, ethnic differences have been discovered by chance when patients had an unexplained reaction to a drug.<sup>2,3</sup> An inclusive process will help to create buy-in and foster transparency among the public.

Quality-of-life circumstances also can influence treatment plans. Consider a man in his 50s who drives a bus. If a particular medication is determined to be the most effective method for treating his condition but it makes him drowsy or confused, he won't adhere to the treatment plan because the medication interferes with his ability to make a living. The clinically second-best treatment might be more effective if a patient is more likely to adhere to his or her treatment regimen.

Too often the benefit of a treatment option is defined by length of life rather than quality of life. Consider 2 women with breast cancer. A woman in her 40s wants to live a long life and see her children grow up. A woman in her 80s with the same cancer diagnosis may be more concerned about her quality of life in the here and now.

If the genetic predisposition and quality-of-life circumstances of patients influence the success of a particular treatment option, then the health delivery system needs a means for identifying these qualifiers at the point of intake, when patients present at a physician's office, hospital, or local clinic. The Guided Care program of the

Lipitz Center for Integrated Health Care is one model for people with chronic conditions. Following a comprehensive assessment and planning process, a Guided Care nurse educates patients and families, monitors their conditions, and coordinates the efforts of health professionals, hospitals, and community agencies to be sure no important health-related need slips through the cracks.<sup>4</sup> The initial assessment is the touch point for involving patients in the decision process and ensuring they are not subjected to the cookie-cutter approach to healthcare.

We need better-quality, uniform tools that will lead us down the right path to CER's ultimate goal: better information that will lead to better outcomes.

People with chronic diseases and disabilities have told us through our research that they support evidence-based medicine. But they feel equally strongly that CER should not dictate treatment decisions. Comparative effectiveness research done right—factoring in the science, the delivery system, and the patient—can bring new knowledge and understanding to patients and providers.

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