CASE REPORT

"Nothing About Me Without Me": New Perspectives on Case Reports

简介 也不了解我，没有我：病例报告的新视角

Nada sobre mí sin mí: nuevas perspectivas sobre los informes de casos

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This issue of *Global Advances in Health and Medicine* offers three perspectives on the treatment of a patient diagnosed with breast cancer, including the patient's perspective. Hopefully, this will become more common. These perspectives offer a snapshot summary of 5 years of treatments and follow-up visits and provide insight into the choices that shaped the outcomes for this patient. Patients need to be able to jointly control and share the information in their personal health records. Diane Plamping of the Center for Innovation in Health Management (www.cihm.leeds.ac.uk) has eloquently called for increased transparency and patient participation with the phrase "nothing about me without me."¹ This approach is uncharacteristic of most healthcare systems today and challenges our linear and procedure-centric analysis of data.

In 2012, more than 35 000 clinical trials and 27 000 case reports have been reported on pubmed.gov, the US National Library of Medicine's electronic access portal.² And some medical journals, such as *BMJ Case Reports*, *Global Advances in Health and Medicine*, and the *Journal of Medical Case Reports*, have developed detailed author guidelines. Yet case reports often are overlooked in the design of clinical trials or the development of clinical practice recommendations. Why is this, when practitioners have been reporting on patient outcomes for years? One reason is that standardized reporting guidelines do not exist, medical records are often unavailable, and the quality of case reports is inconsistent.^{3,4} As a result, this information is routinely considered anecdotal and insufficiently rigorous to inform clinical trials or guide clinical practice.

Yet randomized controlled trials (RCTs) also have limitations. High-quality clinical trials may have a high internal validity, but this may work against the ability to apply their results in the real-world practice of medicine. And the provider-patient relationship, a key factor in the real-world practice of medicine, often is overlooked. The conclusion of many systematic reviews (based on the more than 18 000 RCTs published annually) is that the overall evidence is insufficient to guide clinical practice.⁵ Case reports—like comparative effectiveness research—offer the possibility of providing signals of effectiveness and harms and informing clinical trials.

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Recommendations Moving Forward

- Tailor all medical decisions to the individual patient.
- Increase patient involvement and control in all medical decisions.
- Provide transparency about medically related decisions from interventions to outcomes and costs to adverse events.
- Include patient-centered care as a key component in all phases of professional training

the development of new models for the systematic collection and reporting of patient encounter information from healthcare professionals and patients. This includes health research reporting guidelines for case reports to improve their quality, transparency, and completeness.⁶ This will strengthen the link between clinical expertise and external evidence in healthcare delivery—the cornerstone of the practice of evidence-based medicine.⁷ In October 2012, the University of Michigan and *Global Advances in Health and Medicine* co-hosted a 2-day consensus meeting with 20 participants to develop general health research reporting guidelines for case reports (called the CARE Guidelines). The work of this group will be published in the near future.

Case reports offer a real-world perspective on the system-wide change required to address some of the global healthcare issues, particularly the challenges of chronic disease. Historically, case reports have described an unusual presentation or treatment of a disease. Diseases, drugs, and treatment have been first described in case reports and only later identified and evaluated by the scientific community. Leveraged by technology, healthcare professionals are progressing toward systems-oriented and individualized approaches to care. Patients are also increasingly reporting their outcomes. If case reports from practitioners are combined with patient reports and records as advocated by organizations such as Cancer Commons (www.cancercommons.org), Patients Like Me (www.patientslikeme.com), and the Norwegian International Registry of Exceptional Courses of Disease, treatment might become more patient-centered.⁸

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