Patient-generated Data:
A Double-edged Sword

by Elizabeth Lerner Papautsky, PhD

My father died in the critical care unit as a result of blood clots in his lungs after residents reintubated him when he had a panic attack in the middle of the night. The information that he had a low platelet count as a side effect of a cancer drug he was taking as part of a clinical trial had fallen through the cracks every time new clinicians came into his room. Although I had reminded them of this information daily to ensure that he received regular infusions as prescribed by his oncologist, the clinicians on the night shift did not consider this information.

Patients and their caregivers need to have formal mechanisms in place to deliver clinically relevant information to clinicians. Given their continuity across the care continuum[1] and their experience with and potential expertise about the disease and its treatment,[2] patients and caregivers are in the position to contribute to a more comprehensive clinical picture that may help mitigate medical error[3] and even to bring to light adverse events that go undetected by clinicians.[4, 5]

Recently, the conversation has turned to formal mechanisms to enable patient contributions through patient-generated health data (PGHD). According to the Office of the National Coordinator for Health Information Technology (ONC), PGHD are "health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern."[6] PGHD can range from biometric data (e.g., blood glucose monitoring, blood pressure readings, cholesterol levels) to history, symptoms, lifestyle behaviors, observations, results, and objective interpretations of health status changes.[7] The recognition that patients' and caregivers' contributions are integral to quality care is promising. However, it is a double-edged sword because providers' use of PGHD has not been systematically studied, and therefore no formal policies or guidelines for the capture and use of these data are available. Currently, the Office of the National Coordinator for Health Information Technology is progressing toward developing a policy framework and incorporating PGHD into electronic health records (EHRs). Because of the massive amount of patient information that already resides in EHRs, which contributes to medical errors with devastating consequences,[8] the capture and delivery of PGHD should be carefully examined and considered to inform the design of technology and processes for their use.

A formal solution to deliver potentially clinically relevant information to healthcare providers might have helped save my father's life. However, such solutions should take into account the theoretical understanding of biases and decision-making processes underlying clinicians' use of information, clinicians' workflow, the information management workload, and design and usability from a human factors perspective.

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Notes

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8. Makary, Martin A., and Michael Daniel. "Medical Error—the Third Leading Cause of Death in the US." *BMJ* 353 (2016): i2139.