Patient Viewpoint

Clinical Commentary on “Certain Uncertainty: Life After Stroke From the Patient’s Perspective”

Emily C. O’Brien, PhD; Ying Xian, MD, PhD; Gregg C. Fonarow, MD; DaiWai M. Olson, PhD, RN; Lee H. Schwamm, MD; Adrian F. Hernandez, MD, MHS

Patient engagement is a fast-evolving area of research. The Patient-Centered Outcomes Research Institute grants have fueled a renewed interest in developing approaches that incorporate generalizable patient perspectives. Although most clinical researchers recognize the importance of addressing outcomes that matter to patients, the fact remains that most grant proposals are built on aims chosen by doctors and scientists. Patient-Centered Research into Outcomes Stroke Patients Prefer and Effectiveness Research (PROSPER) represents a departure from this longstanding paradigm in 2 important ways. First, the questions, concerns, and outcomes we plan to tackle have been generated by patients, for patients. Second, stroke survivors and stakeholders are part of the PROSPER team and regularly engage in an iterative process to ensure that patient-centered outcomes remain the primary focus for this study.

Developing the goals and hypotheses for the PROSPER study was an eye-opening experience that prompted reflection; it challenged the way each of us thinks about outcomes research. After carefully outlining a set of questions in what we considered to be highly relevant topic areas, our investigative team presented these for feedback to a group of stroke survivors. It quickly became apparent that our plan, although well-intentioned, was far too narrow. Yes, stroke survivors were concerned about long-term survival, but they were equally concerned about the quality of that survival and the potential for recovery beyond 3 months or 1 year (i.e., the typical time points in stroke outcomes research). We knew regaining functional status was an important component of recovery, but we did not realize how much depression, anxiety, and fatigue weighed on many stroke survivors’ minds. So we revisited our aims, overhauled our data collection plan, and ensured that our goals were not only informed by patients but also aligned with the issues that patients cared about the most.

We are fortunate to be partnering with 3 stroke survivors, who are active members of a research team that is committed to candid ongoing discourse to ensure that the patient’s voice continues to guide PROSPER. We are excited to see the enthusiasm that our patient partners have brought to the table. PROSPER represents a new level of collaborative research, and we encourage other clinical researchers to be open to this type of direct patient feedback. Although the process is humbling at times, it is also incredibly rewarding. We are committed to exploring the process of directly involving stroke survivors in the design, conduct, and analysis phases of research. We think that this type of involvement will result in more well-informed, thoughtful, and compelling conclusions than ever before.

Acknowledgments
We thank Erin Hanley, MS, Duke Clinical Research Institute, for editorial assistance and article preparation. She did not receive compensation for her assistance apart from her employment at the institution where the study was conducted.

Sources of Funding
This work was supported by an award (CE-1304-7073) from the Patient-Centered Outcomes Research Institute.

Disclosures
Dr O’Brien, Dr Xian, and Dr Olson have no relevant conflicts to report; Dr Fonarow reports serving as a member of the Get With The Guidelines (GWTG) steering committee, receiving significant research support from the National Institutes of Health, and being an employee of the University of California, which holds a patent on retriever devices for stroke; Dr Schwamm reports being the principal investigator of an investigator-initiated study of extended-window intravenous thrombolysis funded by the National Institute of Neurological Disorders and Stroke (clinicaltrials.gov/show/NCT01282242) for which Genentech provides alteplase free of charge to Massachusetts General Hospital as well as supplemental per-patient payments to participating sites, serving as chair of the American Heart Association/American Stroke Association Get With The Guidelines stroke clinical work group, serving as a stroke systems consultant to the Massachusetts Department of Public Health, and serving as a scientific consultant regarding trial design and conduct to Lundbeck (international steering committee, Desmoteplase in Acute Ischemic Stroke [DIAS] 3, 4 trial) and Penumbra (data and safety monitoring committee, Separator 3D trial); and Dr Hernandez reports receiving a research grant from Amgen, Bristol Myers Squibb, GlaxoSmithKline, Janssen, Novartis, and Portola Pharmaceuticals, and receiving honoraria from Amgen, GlaxoSmithKline, Janssen, and Novartis.
Clinical Commentary on "Certain Uncertainty: Life After Stroke From the Patient's Perspective"
Emily C. O'Brien, Ying Xian, Gregg C. Fonarow, DaiWai M. Olson, Lee H. Schwamm and Adrian F. Hernandez

Circ Cardiovasc Qual Outcomes. 2014;7:970; originally published online November 11, 2014; doi: 10.1161/CIRCOUTCOMES.114.001484
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2014 American Heart Association, Inc. All rights reserved.
Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circoutcomes.ahajournals.org/content/7/6/970

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Circulation: Cardiovascular Quality and Outcomes can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Circulation: Cardiovascular Quality and Outcomes is online at:
http://circoutcomes.ahajournals.org//subscriptions/