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

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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 (ie, 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.

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