Untangling Health Trajectories among Patients with Sepsis

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The work by Jones and colleagues published in this month's *AnnalsATS* (pp. 904–913) is a sobering illustration of an extremely common disease process that creates a disruptive ripple effect across the boundaries of healthcare facilities and people's lives (1). They show that nearly 45% of all hospital deaths in their health system are caused by sepsis and that close to a third of survivors were readmitted within a month, also often due to infection. Those readmitted were more likely to be elderly, to have comorbid conditions, and to have experienced an admission preceding the index hospitalization. This chronically acutely ill population has been a focus of attention for many reasons, including the fact that their long-term functional and cognitive outcomes remain poor despite national hospital-based initiatives and overall improvements in survival (2).

Yet here we see a snapshot of the perpetually twisting trajectories of acute and chronic illness, recovery, and decline. Most hospital-based clinicians cannot easily observe the sum total of each patient's comings and goings, perhaps optimistically assuming that a transition from the intensive care unit (ICU) to the ward is simply the beginning of an ascension to health status normality (3). Perhaps the same could be said for clinicians based in post-acute care facilities—or in the clinic for that matter. To borrow a popular metaphor, in our increasingly specialized and fragmented health system we are all blinded, perceiving our own side of the elephant only by feel, until work such as Dr. Jones' begins to unveil the bigger picture.

Although some will justifiably question whether these poor outcomes in post-acute

care are modifiable, this analysis illustrates they are associated with significant mortality and undoubtedly with poor quality of life and other important patient-centered outcomes. Despite disappointing attempts to improve long-term outcomes among high-risk ICU survivors (4), improving survivorship remains an imperative for our specialty and medicine as a whole.

Many have suggested strategies focused on acute and post-acute care that could be helpful, such as peri-discharge risk profiling for adverse outcomes (e.g., a frailty phenotype), care coordination/patient navigators/discharge coordinators, accountable care organizations and bundled payments, palliative care involvement in post-acute care (itself hampered by payment issues), and finally more research focused on the outcomes of post-acute care (5–7). Jones and colleagues document a high rate of hospice discharge after sepsis readmission (13.3%), suggesting, for example, that enhanced advanced care planning in the intervening post-acute setting could mitigate some degree of resource utilization and suffering associated with readmissions. Implementing any of these strategies, though, will take collaboration, focus on a shared vision, and leadership as well as, of course, aligned financial incentives.

Jones and colleagues document the remarkable complexity of many patients' transit across multiple health care facilities and providers, wherein it seems that there is nobody piloting the ship. Having interviewed hundreds of ICU survivors over the years, I continue to be struck by patients' and families' uniform perception of a disconnected system that chews them up in an academic ivory tower hospital and then spits them back out to their beloved

primary care doctor who has no clue about what happened to them in the hospital or nursing home. Here, the health care leader is hopelessly handicapped by the limitations of a disconnected digital health care informatics system where nothing is shared and data sit in isolated silos, unable to be tapped for the most sensible clinical tasks.

Therefore, we advocate for another "trajectory management" solution that combines an "old school" practice structure with evolving technology that refocuses on the real matter at hand: what does the patient need? To this, we reply, "a doctor." To be more specific, a single clinician who serves as a health team leader for every patient, who knows his or her story best, and who is digitally connected to the patient through supportive electronic health records and robust patient interfaces. The clinician's patient dashboard would display each patient's "health timeline" auto-populated with healthcare interactions, both good (e.g., improving disease control or health-maintenance activities) and bad (ICU on ventilator with septic shock) as well as graphical displays of health status and symptom trajectories. Software could be developed to alert the clinician about care transitions or health trajectory changes, enabling an efficient mobilization of outreach services, disease management teams, or navigators. Steeper trajectory declines or increases in symptoms could help activate proactive palliative care as well.

A similar dashboard would also improve acute care clinicians' awareness of their patients' baseline functional status and premorbid disease state. Being able to easily view data on patients' postdischarge

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trajectory would also improve the accuracy of the clinician's perception of outcomes. "Unveiling the elephant" in real-time clinical practice could improve the quality of care in many ways, including counseling patients and family around treatment options.

Collecting such novel data will be facilitated by a proliferation of mobile information technologies increasingly able to engage patients and harness the data they generate. We could start by allowing patients to report their perceptions of health and functional status through patient-reported outcomes measures that are integrated with

electronic health records (8) or passive data collection from sensors such as the rapidly proliferating wearable health monitors (9). Such data could then be aggregated to enrich observational studies, such as this one with patient-centered outcomes, but also to comparative effectiveness or even pragmatic and efficient prospective trials to elucidate the best methods for caring for this needy population. This vision will require significant work aligning health information technology, legal, and privacy issues, but the infrastructure is emerging to allow us to realize this result in the near future.

But back to the fine article by Jones and colleagues. We applaud their skillful description of the remarkable scale and breadth of the impact of sepsis, a challenge to acute and post-acute care venues alike and one that is apparently equally distributed to some extent across the range of illness severity. They highlight one of our society's greatest clinical problems and one that will surely command our attention for years to come. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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