editorial

Measure Me, Don't Judge Me: Patients as Objective Contributors to Performance Status Measurement

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Shortly after the introduction of antineoplastic therapies in the 1940s, it was recognized that not all patients with cancer tolerated chemotherapy equally. One of the major determining factors was functional status; bedbound or otherwise moribund patients did particularly badly. In an attempt to standardize functional status, the first performance status scale, now known as the Karnofsky performance status (KPS), was introduced in 1948.[1] This was followed a decade later with the introduction of a scale by Zubrod et al[2] that was later adapted into the Eastern Cooperative Oncology Group performance status scale in 1982.[3] These scales are universally accepted, and their reporting in the medical record is considered a core quality element by the Quality Oncology Practice Initiative.[4]

In most types of cancer, functional status is the determining factor for both conventional treatment and clinical trial eligibility. It is often also a primary driver of prognosis independent of treatment.[5] Common examples include the determination of transplantation eligibility in patients with multiple myeloma and the definition of a frail subset of patients with non–small-cell lung cancer.

Although lesser known than his work on defining the KPS, Karnofsky was aware of the distinctions between subjective and objective measurements.[6] As demonstrated by numerous studies[7-10] that have shown highly variable levels of agreement between two observers measuring performance status, performance status scales must be considered subjective to at least some degree. Nevertheless, strict cutoffs for performance status are routine for clinical trial eligibility and are one of the putative driving forces of low clinical trial enrollment among adults.[11,12] As one of the authors of this editorial (L.S.) can attest through reading her own notes, KPS can fluctuate without any clear reason. In her own words:

There have just been two times in my life when a clinician judged my KPS as anything lower than 90. The first time was 2 weeks after I had surgery to remove a recurrent grade II astrocytoma. The second time was roughly 8 years later during a new patient evaluation with a neuro-oncologist.

In both instances, I was given a KPS of 80, which means one is "restricted in physically strenuous activity but (is) ambulatory and able to carry out work of a light or sedentary nature—e.g., light house work or office work."[13] *This narrative perfectly captures my abilities after a craniotomy but is a puzzling evaluation when applied to me today.*

My first KPS of 80 was scored after having gone through a craniotomy to debulk my tumor in February 2009. I was left with a small bit of damage in the left parietal lobe and went through months of occupational and physical therapy wherein I relearned how to walk and balance. During the 6-month period after surgery, I was barred from driving as a result of seizure activity, graduated from a walker to a cane, and my husband was told to "watch me" in the kitchen in case I were to cut or burn myself and not feel it.

The second KPS of 80 came as a bit of a surprise in May 2017. In the 8 years that passed since that second brain surgery, my physical abilities had grown by leaps and bounds. After completing a regime of 24 months of temozolomide chemotherapy in 2011, I began working with a personal trainer at a gym with whom I continue working to this day. My physical and cardiovascular strength is better than it was before my brain tumor diagnosis, and I have easily managed holding full-time work after recovering from surgery. In addition, my antiepileptic medication is suppressing seizures, so I am able to drive, and my husband has decided to be the chef of the house so I don't have to worry about the dangers of the kitchen.

Knowing all of that, why would I be given the same KPS 8 years after my last brain surgery? From my perspective, the KPS is subjective to the clinician's observations, even though they are not with the patient 100% of the time. The KPS is based on a conversation and examination that

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lasts, at most, 45 minutes. After meeting me, how did my new neuro-oncologist decide 80 is appropriate for me? Didn't she hear me tell that story about my recent conquest of bench pressing 115 pounds? That's a far cry from the postcraniotomy rule to "not lift anything heavier than a soup can."

In the accompanying study by Gupta et al,[14] the authors explore the possibility of using physical activity monitors as an objective surrogate of clinician-determined performance status. Gupta et al[14] hypothesize that wearable trackers, such as the Fitbit, Jawbone, or Apple Watch, have the potential to objectively measure the long-term physical activity in people receiving therapy for cancer. Indeed, they found a highly statistically significant and marked difference in the number of steps recorded by patients with Eastern Cooperative Oncology Group performance status scores of 0, 1, or 2. Furthermore, the authors found that the number of steps recorded was positively correlated with the Functional Assessment of Cancer Therapy–General and negatively correlated with the Quick Inventory of Depressive Symptoms–Self-Rated and the Brief Fatigue Inventory.

Whereas the preliminary findings of the study by Gupta et al[14] are compelling, some caution is in order. The number of patients studied is relatively small and mostly female. Physical activity monitors must be worn to record, and current technology cannot readily differentiate between a device forgotten on the bedside versus a bedbound patient. Fewer than one half of patients used their activity monitor for every day that they were on the study, and several patients had a large discrepancy in the days on study versus days using the monitor. Median days on study was slightly more than 60 days; it is unknown whether adherence to activity monitoring would persist in studies with much longer time horizons. It must also be acknowledged that certain patients or patient populations may not be willing to be monitored by devices,[15] and this could exacerbate existing disparities in clinical trial enrollment.

Given that physical activity monitors are likely to complement—not replace—existing methods of performance status assignment, let us return to L.S.:

Why do I care about a KPS that is incongruous with my lived experience? When it comes down to it, I care because in a health care setting my medical record is my identity, and in the future could mean the difference between being accepted into a clinical trial or not being a desirable candidate. My clinical notes are the narrative of my patient history and story. Notes were originally designed as a communications tool between doctors to remind them about a patient's condition and plan for treatment. If my doctor were to become unavailable, the next person who pulls up my chart will review it to create a picture of me in his mind, and he will have that idea in his mind upon meeting me. Looking through my prior notes, this might have actually been the culprit behind my KPS of 80 in 2017.

Fortunately, physical activity monitoring is not the only area of medicine seeing increased patient participation. The reason that L.S. could easily review her notes in the first place was because she requested a complete copy of her medical record when she was transitioning her care from one neuro-oncologist to another after a change in health insurance. Access to 8 years of her medical record provided L.S. an opportunity to review her clinical notes for the first time and sparked her curiosity for what lies within notes that may be helpful to patients and their care partners during their medical journey; however, none of the practices at which she obtained care participated in OpenNotes,[16,17] an increasingly prevalent concept that allows clinician-generated notes to be shared through patient portals in near real time. In the future, OurNotes[18] will take this concept one step further by allowing patients and families to easily suggest corrections to errors in existing notes and to perhaps coproduce notes with their clinicians.

In conclusion, the article by Gupta et al should pave the way toward larger prospective studies that assess the incorporation of physical activity monitors into the design of clinical trial eligibility and monitoring. As with the provocative findings by Basch et al[19] where patient-reported symptoms tied to e-mail alerts led to an overall survival benefit, it is possible that passively collected data through physical activity monitors could play a major role in the future care of oncology patients.

DOI: https://doi.org/10.1200/CCI.18.00029
Published online on ascopubs.org/journal/cci on April 30, 2018.

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AUTHOR CONTRIBUTIONS

Conception and design: All authors
Data analysis and interpretation: All authors
Manuscript writing: All authors
Final approval of manuscript: All authors
Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/jco/site/ifc.

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ACKNOWLEDGMENT

The viewpoints expressed in this editorial are those of the authors and do not necessarily reflect the views of their employers.

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