

Designing value-based health systems for patients: The example of pain control and palliative care

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Health systems strengthening efforts have focused on enhancing performance without significant attention to what value means to the ultimate users of the system—patients. Generating metrics that can better drive health systems in a manner that places patients at the core is an ethical, health and economic imperative. In fact, measures that comprehensively assess patient experiences, preferences and outcomes, can improve

accuracy in priority-setting and promote the delivery of value-based care.

Take palliative and end-of-life care, for example. The value of alleviating health-related suffering is not fully captured in outcome measures that consider only if a patient dies, if they become more productive, or the extent to which they are cured of ailments. This skews priority setting in ways that should be obvious to anyone who has been a patient. How much would you value or be willing to pay for having a tooth extraction with instead of without medication to dull the pain? Or if your child's broken arm has to be set, are you willing to consider an option where she experiences severe pain even if this does not change the ultimate outcome of the break? Imagine waking up after a mastectomy—without pain medication—and trying to breathe. Or, consider a loved one dying of cancer that has metastasised to the bone, is it imaginable that they would live their last days without morphine?

Providing pain medication in these circumstances does not change the health outcome for the patient—they die—but it does radically improve the patient's and family's experience of suffering, and their quality of life. The trouble is, most outcome metrics would provide no value for these interventions.

Addressing health-related suffering can have positive externalities, including in non-health areas. But these are also seldom measured or accrued in considering the full benefits—or positive outcomes—of a health intervention.

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Alleviating suffering at end-of-life eases the burden on the caretaker and family as well as on the patient and can help prevent complicated grief and ease the bereavement process. Moreover, these interventions are not gender neutral but rather proactively support women, who are often the primary caretakers.

A knowledge gap currently exists due to limited data collected from patients with poor outcomes because such patients die and there is a shorter window to capture relevant information. Advocacy efforts to inform change are blunted by the truncated sample of patients from whom data is available. A full accounting of benefits—the positive outcomes—to patients and people can dramatically change the cost-effectiveness calculation around a health intervention. This manner of approaching health systems is in line with a diagonal approach—using disease-specific interventions to drive through systemic changes.

This approach is pro-poor, which is valuable because the voice of poor patients is rarely heard and concern for them is not at the forefront of systems policy and planning.

Anecdote cannot be effectively projected to policy. Rather, systematic measurement of patient and person value around healthcare is a tool that is much

needed to promote evidence-based advocacy and better experiences of care for everyone.

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