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Measuring What Matters to Patients



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Healthcare is entering a new era driven by competition on value—meeting patients’ needs as efficiently as possible. Thomas H. Lee, MD, the Chief Medical Officer of Press Ganey with more than three decades of experience in healthcare performance improvement as a practicing physician, discusses pinpointing and addressing the most significant causes of patient suffering while also collecting and using data to drive improvement in healthcare organizations.

The concept of patient-centered care is becoming increasingly clear to healthcare providers; it is nothing more and nothing less than organizing around meeting patients’ needs. Patients’ needs are not organized in patients’ minds in accordance with the traditional structure of medicine, which is based on various types of clinical expertise such as surgery and gastroenterology. Patients are not focused on whether individual clinicians are competent or reliable in their various roles; patients assume this competence exists, and they are usually correct.

These points lead to a conclusion that is disruptive for the measurement of performance in healthcare: the spotlight should be on the patient,

not the provider. Clinicians’ reliability is important, of course, but it is a means to an end. The end is defined by whether patients’ needs are met.

My colleagues and I think that the goal of reducing patient *suffering* is consistent with most organizational mission statements and the motivations of virtually all healthcare clinicians and other personnel. The word suffering is an emotional one, of course, and one reason to use it is that it compels a response. However, the goal of performance *measurement* is not to make clinicians feel guilty; it is to help them respond to patients’ needs with reliability.

Can suffering be measured? What I learned from my career in clinical research is that if something is important, you will figure out how

to measure it as well as possible. Even if the issue is difficult to measure, such as quality of life, pain, or functional status—the ability of people to do the things they want to do—you approach the issue with discipline and methodological rigor. You frequently need to collect data from many patients, knowing that they will give widely varying responses. But if you collect enough data and calculate the average, you will get valuable information.

The famous story of the British statistician Francis Galton and the oxen at the country fair offers valuable insight. In 1906, Galton went to the annual West of England Fat Stock and Poultry Exhibition and observed a competition in which people tried to guess what the weight of a fat ox would be after it was slaughtered and prepared for sale as meat. Nearly 800 people made guesses. Some were “experts” (butchers or farmers), but many were “non-experts” (regular citizens). The guesses varied widely, of course, but the average was only one pound off from the actual weight.

What Galton realized is that in any guess, there is information plus error. If that error is random and you average the responses from many people, the errors cancel out, and what you are left with is information. This insight is described in the book *The Wisdom of Crowds*, in which James Surowiecki shows how groups of people are often smarter than the smartest individual.

The implication for the measurement of suffering is that if this enormous, complex issue is broken down into various components and information is collected from enough patients, providers can understand how their patients are suffering and try to reduce that suffering. There are many different types of suffering, of course; physical pain is just one of them. Therefore, the first critical step toward measuring suffering is to break it down into various types of unmet needs so that providers can organize themselves to address them.

My colleague Deirdre Mylod has been a key thought leader behind work to deconstruct suffering. Patient suffering can be categorized as

inherent to the patient’s medical condition and associated treatment or as avoidable, resulting from dysfunction in the care delivery process¹ (**Table 1**).

The inherent suffering that patients experience before and after receiving a diagnosis may be unavoidable because of their specific medical problems. The role of providers is to anticipate, detect, and mitigate that suffering. Pain, other symptoms, and loss of function are just a few types of inherent suffering. Fear, anxiety, and distress over loss of autonomy are also of enormous concern to patients, sometimes even more than pain itself.

Inherent suffering also encompasses the impact of treatment for the patient’s condition. Medications and procedures can cause side effects, pain, discomfort, loss of function, and unwelcome changes in appearance even when they ultimately lead to recovery. Some pain cannot be eliminated. Some procedures will always be uncomfortable. Often, what providers can do to mitigate such suffering is help patients understand what to expect so that they are not frightened by the unknown.

If inherent suffering is driven by patients’ conditions and their necessary treatments, avoidable suffering has nothing to do with their diseases and everything to do with the way healthcare providers are organized. Poor coordination of care, excessive waits for appointments, uncertainty about what will happen next, and ineffective care transitions all erode patients’ trust and lead to anxiety, frustration, and fear. All these dysfunctions are preventable even if they seem beyond the control of individual personnel.

Collecting data that distinguish inherent from avoidable sources of suffering allows organizations to understand where patient needs have not been met and provides insight into what steps need to be taken to close that gap. Current questionnaires that measure patient experience do not directly ask patients about their level of suffering. However, they do ask patients to evaluate attributes of care, and those measures demonstrate

Table 1 : Deconstructing Suffering: Sources and Examples

Unavoidable Suffering (Provider's Goal: Mitigate)		Avoidable Suffering (Provider's Goal: Eliminate)
<ul style="list-style-type: none"> • Symptoms of disease including pain 	<ul style="list-style-type: none"> • Post-operative pain 	<ul style="list-style-type: none"> • Unnecessary pain resulting from failure to identify and treat the source
<ul style="list-style-type: none"> • Loss of functioning (temporary or permanent) 	<ul style="list-style-type: none"> • Loss of functioning (temporary or permanent). • Side effects 	<ul style="list-style-type: none"> • Undesirable outcomes, such as hospital-acquired conditions and readmission due to failure to follow evidence-based practice
<ul style="list-style-type: none"> • Fear or anxiety arising from the implications of the diagnosis for health functioning 	<ul style="list-style-type: none"> • Fear or anxiety regarding outcome of treatment • Fear or anxiety due to unfamiliar processes, disruption in daily life, and loss of control 	<ul style="list-style-type: none"> • Misdiagnosis, delay in diagnosis
		<ul style="list-style-type: none"> • Fear or anxiety due to poor coordination and teamwork, lack of respect shown to patient, and loss of trust in providers
		<ul style="list-style-type: none"> • Unnecessary waits and delays in treatment. Poor adherence to discharge instructions and medication regimens resulting from inadequate communications and coordination

where patients view their care as optimal versus less than optimal.

Suboptimal experiences help providers understand where patients' needs are not being met.

Table 2 organizes the measures into needs that stem from inherent suffering and from avoidable suffering. Although the examples are derived from the inpatient setting, the constructs are relevant to all types of patient care.

For example, patients have an inherent need for information. Uncertainty is unnerving and causes suffering. Survey questions on the extent to which physicians and nurses kept patients informed, the clarity of the communication, and the effectiveness of conveying to patients the side effects and purposes of tests and treatments provide insight into how well this need is being met.

There is an important and fundamental difference between organizing patient experience data around provider reliability and organizing

it around patients' unmet needs. With the former and more traditional approach, the analyses describe the overall reliability of physicians, nurses, and other personnel. With the latter, the data are analyzed around different types of patients' needs.

These needs vary with a patient's condition, of course. An emerging trend is to segment patients into groups defined by condition. Patients with the same condition tend to have shared needs that can be best met by multidisciplinary teams organized around that condition. For example, congestive heart failure (CHF) patients endure a chronic, progressive, yet unpredictable disease course that results in needs for information that are different from the needs of patients with other diagnoses. Being aware of differing needs can help clinicians communicate more effectively with CHF patients to help them better understand their diagnosis and care plans. Patients with Parkinson's

Table 2: Examples of Patient Needs in the Inpatient Setting

Inherent Patient Needs Arising from Disease and Treatment	Patient Needs that Stem from Dysfunction in Care Delivery
As a part of having a health condition or receiving treatment, patients have a need for:	When dysfunction exists, patients develop a need for:
Pain control	Courteous/respectful interactions
Skilled care providers	Reduced wait times
Preparation for discharge	Comfortable environment
Information	Adequate amenities
Personalization	Service Recovery
Empathy	
Choice	
Privacy	
Responsiveness	

disease, diabetes, and other chronic conditions also have specialized information needs. It is thus important to collect, analyze, and report data for the levels at which accountability can be created and improvement can occur.

REFERENCES:

1. Deirdre E. Mylod and Thomas H. Lee, "A Framework for Reducing Suffering in Healthcare," *Harvard Business Review*, November 14, 2013. Accessed August 7, 2015, <https://hbr.org/2013/11/a-framework-for-reducing-suffering-in-health-care>.

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