

Measuring the Outcomes of Health Care

The outcomes of health care can be defined in many ways. In the biomedical sense, outcomes represent the result of a disease process. Biomedical research focuses on understanding the mechanisms behind diseases so that interventions can be made to improve outcomes by changing the natural course of the disease. Outcomes can also refer to the end results of care, which you measure to assess the effectiveness of a particular clinical management approach, either medical or surgical. These outcomes can be positive or negative.

Our understanding of what constitutes a “good” or “successful” outcome can change over time as medical care improves. For example, for children born with critical heart disease, the natural history of the disease has been death in infancy. Since the first surgery was performed on a child with critical heart disease in 1944, innovations in surgical treatment strategies for congenital heart disease have altered children’s survival trajectory significantly. Today, more children survive than die from congenital heart disease. Survival has become the expectation and, as a result, attention has shifted to children’s developmental and physical abilities throughout their lives. This is true of cancer as well, as now many cancers are viewed as chronic diseases. So, with medical advances comes an evolution of what success means for a person needing help with a health problem.

In addition to medical advances, an evolution in our expectations for well-being and quality of life has also influenced what success looks like in health care. A good example is when hospice care is viewed as an option for people who may not want extreme end-of-life efforts using treatments with unknown results. Sometimes the outcomes are unknown for different treatment modalities or there are choices among treatments, so patient preferences and values come into play. It’s important to recognize that as medical science and health care evolve, so will the outcomes that we measure.

Measuring the Outcomes That Matter Most to People

Elizabeth Teisberg and Scott Wallace developed the Capability, Comfort, and Calm outcome measurement framework after aggregating a decade’s worth of research from talking to people about their lived experience

managing their health.¹ A part of the discussion included learning about the outcomes that mattered most to them. What they found was that the outcomes that matter most to people tend to fall into three domains: capability, comfort, and calm.

Capability is your ability to do the things in life that are important to you – the things that make you *you*. Better functional outcomes enable you to live the life that you want to live. Here are some examples of capability:

1. Running a marathon after an ACL (anterior cruciate ligament) tear
2. Walking your child to school without feeling dizzy
3. Being intimate with a partner
4. Being able to see in order to read and drive
5. Going to work
6. Dancing at your child's wedding

Comfort is freedom, to the extent possible, from pain or emotional and mental suffering. If we look again at the World Health Organization's definition of health,² we can see how achieving capability and comfort align to physical, mental, and social well-being respectively.

Calm is the ability to receive care in the least disruptive way possible during the course of daily life. In other words, it's less mayhem, less wasted time, and less hassle. It reflects patient experience and extends beyond the hospitality of the clinic or hospital to the experience of navigating life with the condition and care.

This framework is positively framed and reorients us to improving health. It centers our efforts on what the person needs and what their goals are for health – not necessarily the disease, and not necessarily what the health care system needs. This framework enables us to orient our measurement and improvement efforts around achieving health and the outcomes that matter most to patients. It also allows us to reframe existing measurement efforts into a framework that facilitates measuring the results of health care. Furthermore, the Capability, Comfort, and Calm outcome measurement framework can be adapted through time as medicine and health care evolve.

To begin measuring outcomes, you need to know which outcomes are important to people. Why did they seek help to begin with? Often one can elicit the outcomes that matter by asking people what are their health goals. Why did they come to see you? What questions are they asking?

This can be applied to a variety of settings, including those in which the people seeking care are well. In the case of health screenings, for example, providers use a set of screening questions to ask children with asthma if their asthma is under control. The goal, of course, is for the child to be able to function in school and play without symptoms of asthma. The measurement here should be tracking the asthma screening score for each child to see how their asthma is being managed over time.

Measure at the Individual Patient Level

To determine if care helped a person, outcome measurement must be at the level where the care was provided: the individual. I can't emphasize this enough. Many quality and patient experience measures are gathered at the level of a care unit, clinic, or doctor. For example, patient satisfaction surveys seek to measure the patient's experience with the health care system and not the individual care delivery outcomes. While the survey items address many elements that could resemble measures of calm, they do not assess individuals with distinct medical conditions and rarely focus on life beyond the care received at a facility or through telemedicine. Instead, the survey asks individuals to assess the hospitality and other characteristics of the setting in which they received care as opposed to if and how care supported and enabled them to live their life.

The US Centers for Medicare and Medicaid Services (CMS) star ratings, which gauge the performance of American hospitals, are another example of measures that do not measure at the right level or assess the results of care for a particular disease.³ This is problematic in many ways. For example, if a hospital is great at cancer care and below average at cardiac care, is it a great hospital, a below-average hospital, or an average hospital? How should a family seeking cardiac care for a loved one compare hospitals using the star rating?

Health care outcomes are achieved one patient or family at a time, and this requires measurement at the individual patient level.

Measure Outcomes across the Care Cycle

Keep in mind the full cycle of care when measuring. Think about what is happening in a person's life beyond the walls of the health care setting.

Often the measurement of outcomes takes place after a health care intervention to determine how things turned out. Outcomes can and should also be measured *during* the course of care. In speech therapy, physical therapy, and treatments for many anxiety disorders, measurements can be made to track progress during care to ensure that progress is being made toward a goal, with treatment adjusted in real time as needed. For example, a group of psychologists at Cincinnati Children's Hospital Medical Center found a way to track session by session if children with obsessive-compulsive disorder were making progress in treatment. Children or their parents (if the children were unable) indicated how successful they were feeling at controlling or managing their condition by characterizing their ability to focus on school and work, and to enjoy playtime with friends. The care team measured these outcomes throughout the child's care cycle to inform treatment decisions, with the goal of always aligning therapeutic interventions with patient success. And by measuring outcomes more frequently, the psychology team identified provider variation

in results, adopted best practices for achieving better results, and ultimately improved the children's life at school, home, and play more quickly and more effectively than they had previously (A. Madore, K. Carberry. Developing a New Tool to Measure OCD Treatment Progress at Cincinnati Children's Hospital Medical Center. Unpublished case, Value Institute for Health and Care at the University of Texas at Austin, 2020).

References

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