

# Outcome Dimensions in Pediatric Palliative Care

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Most acute minor and moderate illness episodes unfold as a linear journey, from health to illness, and, one hopes, back again. In this simplest of illness models, outcomes exist along a single dimension, such as the length of illness or the probability of full recovery. As illness becomes more chronic or severe, the corresponding model of illness becomes more complicated as the dimensions of outcomes increases. Length of time away from normal activities or in the hospital, along with the probability of complications or survival, provide different views of outcomes. When the subjective aspects of the illness experience, such as symptom distress or quality of life, are incorporated into the illness model, the dimensionality of the model rises substantially.

All of which is to say that just as a stick figure is not an accurate drawing of an individual human, the simple model of illness is not an accurate rendition of the real multidimensional disorder. Nevertheless, the simple model can be extraordinarily useful. Medical science progresses by working with tractable models of health and disease. For this purpose, the simplest sufficient model is optimal. Trouble arises, however, when we conflate the scientific usefulness of the simple illness model with the requirements of clinical care of ill individuals.

This is especially true for palliative care. We need good outcome measures to advance the science of palliative care, but we also need to remain mindful of simplifications that separate science from clinical care.

Regarding scientific outcome measures, Friedel et al<sup>1</sup> in the current issue of *Pediatrics* report on their systematic identification of instruments used to assess pediatric palliative care interventions. Their findings are sobering: among a dearth of instruments, those that exist lack even basic psychometric evaluations. Additionally, children who receive palliative care are heterogeneous, varying in age, illness severity, and proximity to end of life. We therefore need accurate outcome measurement methods across a combination of the above-mentioned features. If such methods existed, we could rigorously determine if a specific intervention (such as a medication) improves a specific outcome (such as pain) for a defined group of patients (such as patients with a specified level of neurologic impairment from a degenerative disease process).

Regarding clinical care, scientific findings based on simple illness models can be vitally important, but the simple illness model itself is insufficient for 3 reasons, essentially each a meta-dimension that fleshes out a more comprehensive illness model.

First are preferences. Individual patients and parents differ regarding how they value various outcome dimensions, which in turn affects the therapeutic tradeoffs they view as “good” or “acceptable.” For example, some patients in pain dislike taking medications or dislike pain medication side effects such as sedation and are willing to experience higher levels of pain. Findings from the pain intervention study imagined above

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would need to be viewed through the lens of an individual patient's (or parent's) set of preferences to determine if providing the intervention would likely result in "better." Now imagine that we were to measure the outcome using a generic pediatric quality-of-life instrument but with no accounting for the preferences of a given patient or family across the multiple dimensions and used this to guide therapy. The result would be the opposite of personalized care.

Second are perceptions, especially self-perception. All subjective aspects of an illness experience are measured on the basis of perceptions. As pediatric clinical investigators, we are staunch advocates for self-reported outcomes: children 8 years of age and older, who are developmentally capable and not significantly impaired by their illness, can<sup>2</sup> and should self-report their experience, even at the end of life.<sup>3,4</sup> Perceptions do, however, raise new challenges, such as when parents perceive a child's level of pain differently or when one's perceptions

of a given situation change not because of the situation changing per se but rather because of a change in one's internal frame of reference or mindset. Such are the challenges and subtleties of navigating the clinical care landscape.

Third is time. Outcomes can be set at a point in time, yet the illness experience unfolds as an area under the curve of living. A child's last moments do not sum up the preceding life. Neither does the time from disease onset to death. Palliative care, although attending to the dying process, is fundamentally concerned with living: how to live best in the face of serious, progressing illness. This illness experience often unfolds in phases, during which the preferences and perceptions of patient and parents may change, consequently shifting the definition of a "desired" outcome. To capture this, we need a personalized integrative outcome measure.

So, let's agree to forge ahead and improve pediatric palliative care measures to advance our scientifically based therapeutic

knowledge base but at the same time stay respectfully aware of the current separation between these measures and the provision of high-quality care.

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