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The Gravity of Weight

## The Turmoil of Uncertainty

Living with illness can create a state of suspended animation.

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### KEY POINTS

- Uncertainty is a subjective, cognitive state that can affect emotions and behavior.
- Research has tried to quantify the state of uncertainty but it's mainly qualitative, unlike risk and probability, which are statistical.
- Uncertainty is pervasive among patients and caregivers of those with medical illness but some have a higher tolerance for it than others.



"No matter how much confusion or uncertainty we experience—even in sickness or danger..." by English artist Elizabeth Wang, 2005. Private collection.

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"When faced by uncertainty, we all oscillate wildly between panic and dismissal—as I was to discover when my cancer was first diagnosed," writes English neurosurgeon Henry Marsh in *And Finally: Matters of Life and Death* (2022). Marsh continues, "One of the worst aspects of being a patient is waiting—waiting in drab outpatient areas, waiting for appointments, waiting for the results of tests and scans—living in a kind of 'suspended animation.'"

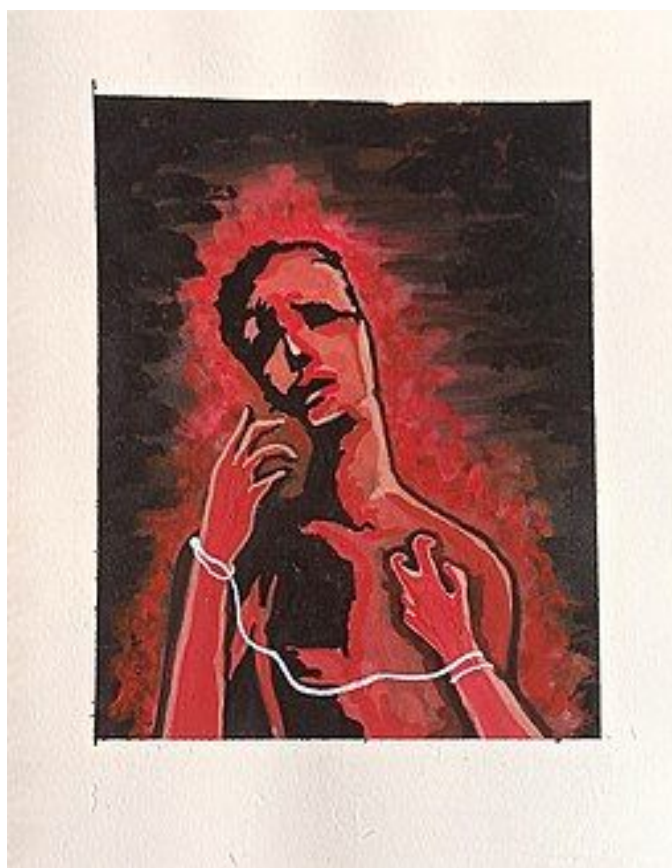
"Patients want certainty, but doctors can only deal in uncertainty," writes Marsh. Only reluctantly could his physician quote him probabilities when Marsh learned of his prostate cancer and it became "increasingly difficult" to

deny that his body "was past its *Best Before* date."

Researchers have attempted to develop scales to quantify uncertainty, but there are "no clear validated cut-offs" to define its levels. Fundamentally, then, uncertainty is a subjective cognitive state that may affect our emotions and behavior and involves vagueness, not knowing, and an inability to determine meaning or predict an outcome (Verduzco-Aguirre et al, 2021); Mishel, 1988.)

For some, the notion of uncertainty is “rooted in a paradox:” When we don’t have enough knowledge, the *problem* is that the future is different from the past whereas a *solution*, “depends on the future being like the past.” In other words, says early 20th-century philosopher William James, “We live forward, we understand backward” (as quoted in Rizzo and Dold, 2021). Further, uncertainty is seen along a continuum so that “many of our real-world problems must be seen as mixed cases of risk and uncertainty” (Rizzo and Dold).

“The boundary between risk (i.e., statistical probability) and true uncertainty is not sharp and is a matter of degree:” probability, which is calculable, is simply “a degree of belief” (Faulkner et al, 2021.) Uncertainty is qualitative and involves situations where “people are unable or reluctant to assign numerically defined probabilities” (Faulkner et al.)



"Anxiety," by artist Bhargov Buragohain, 2021. Uncertainty can lead to considerable anxiety in patients and caretakers.

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"The physician's verdict," by Belgian painter Emile Carolus Leclercq, 1857.

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In the context of illness, uncertainty likely develops when symptoms are inconsistent in intensity, frequency, location, or duration, such as those that occur in diseases with remissions and recurrences (Mishel, 1988.)

Uncertainty can involve ambiguity about the state of an illness, complexity about its treatment, lack of information about a diagnosis, and unpredictability in its course (Mishel, 1988).

Though "pervasive" (Guan et al, 2021) in patients with life-threatening illness, uncertainty remains "under-re-

searched" (Etkind et al, 2017). In the limited research conducted, though, it has been associated with being a self-perceived burden to caretakers (Saji et al, 2023) and considerable psychological stress in patients (Guan et al.)



Those living with illness uncertainty have described it as "certainty within uncertainty," "cyclical uncertainty," or even "psychological whiplash" (Langmuir et al, 2023.) Others have emphasized a "deeply unsettled" lack of control, a "loss of future plans," and a "much less defined future" (Shilling et al, 2017.)

Some patients and their caregivers have a higher tolerance for uncertainty than others. Researchers, though, explain that there remain "imprecision and variation" in measuring and conceptualizing *uncertainty tolerance* (Strout et al, 2018). It may reflect a balance between negative responses (e.g., anxiety, distress, and avoidance) and positive ones (e.g. hope and information-seeking) (Verduzco-Aguirre et al; Strout et al).

Some patients may want to maintain uncertainty "since it facilitates hope" (Mishel, 1988.) But when the level of uncertainty expands, it can reach a "critical threshold" and create instability and a "lost sense of coherence" (Mishel 1990.)

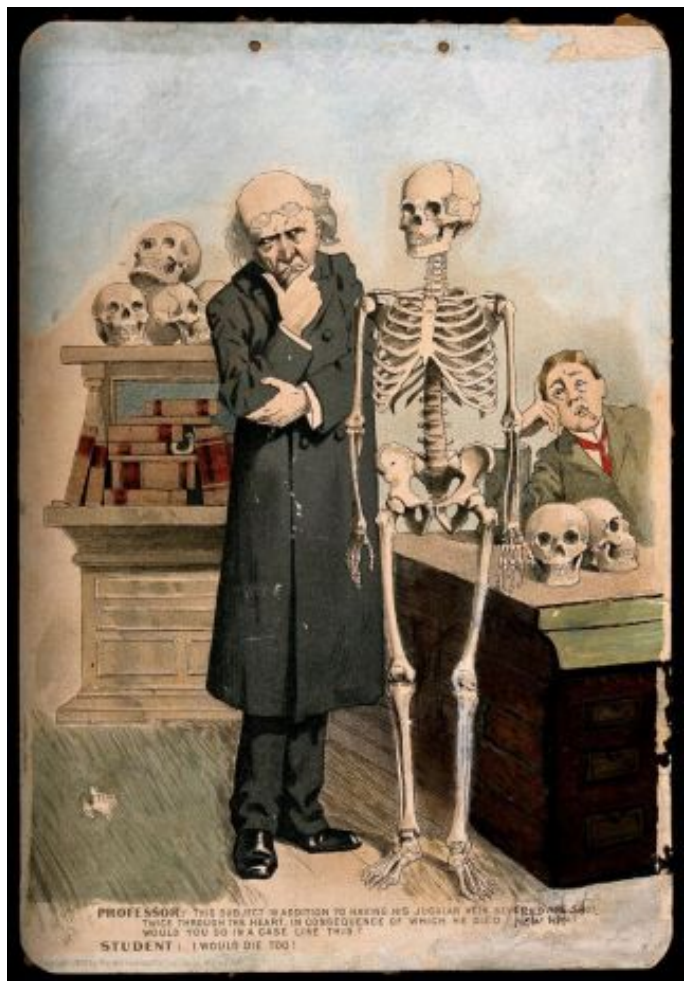


"The Dance of Death," German, 15th century. St. Mary's Church, Lübeck.

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uncertainty and a means of reassuring a patient and coping with uncertainty (Christakis.)

Physicians are often reluctant to make a prognosis because of fear of creating a self-fulfilling prophecy and because there is more uncertainty in predicting the future than



A professor asking a medical student his prognosis for a particular case, 1900. Many physicians avoid making a prognosis and offer statistics, or "prognosis by the numbers."

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One area in which uncertainty can figure prominently is in issuing a prognosis, i.e., a prediction. Prognosis "gives diagnosis and therapy their affective components" for physicians and patients. It is essentially "the future of the present illness" (Christakis, 1999.) Even fifth-century B.C. Greek physician Hippocrates wrote a treatise on its importance in medicine. Prognosis can create a sense of meaning about the illness, but it may be *both* a source of

in evaluating the present condition. Objectively, making a prognosis is difficult and potentially fraught with error that can have substantial consequences for a patient's care and a physician's reputation (Christakis). As a result, physicians may blur the distinction between an *inability* and an *unwillingness* to offer one.

They may also indulge in what Christakis refers to as "discrepant communication," i.e., communicating one prognosis to the patient and a different one to caregivers.

Further, physicians may see a "tension" between "population-based probability statistics" and their application to an individual patient (Christakis).

Nevertheless, physicians will fall back on statistics, which Christakis refers to as "offering prognosis by the numbers."

The use of artificial intelligence (A.I.) in diagnosing, treating, and even offering a prognosis for an illness is increasing. Based on "big data," A.I. can extract hidden patterns and gather relevant information missed by a clinician (Liao et al, 2023.) Kahneman has described that algorithms are often superior to experts. For example, he reported a study that found major inconsistency among experienced radiologists, who contradicted themselves 20 percent of the time when they were shown the same X-ray at different times (2011.)



'Meditation,' by Czech artist Bohumil Kubista, 1915. Narodni Galerie, Prague.

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A.I., at least to date, though, has its challenges and limitations, including "disordered data" due to a lack of standards in the data used to build some models. Further, training sample sizes used to establish A.I. models are often small (Liao et al.) Eventually, though, A.I. may improve clinical judgment and patient care and may play a role in lessening medical uncertainty.

For a related topic, see my post, ["Neither Sick Nor Healthy: Patients-in-Waiting."](#)

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