EDITORIAL
Intended Audience: Clinicians, General

Terminal Lucidity and the Need to Precisely Conceptualize End of Life Experiences

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The first person I ever watched die was a dear family friend diagnosed with metastatic lung cancer. She had a seizure while traveling in Spain in late October and was out of this world before Christmas the same year.

I was not, at the time, a researcher in the area of dying and death, so I didn’t know what to expect. But all of us working in four-hour shifts around the clock to keep her company through her final weeks noticed the change that happened one day. The cancer had spread to her brain by the time it was caught, and she had notable cognitive deficits based on where the lesions lay. Her speech was halting; she couldn’t find words. You had to listen with attentive patience.

Then, suddenly, she regained a complete flair for crisp and incisive conversation. I remember having dinner with her and her family one night, and it was if she’d never been ill. She offered witty opinions about the subjects at hand, with energy and insight. We all thought that the whole-brain radiation she had undergone had quite obviously shrunk the tumors that had been blanketing her brain.

Two days later, she was dead. The oncologist got the final MRI results of her brain lesions back a week or so later and relayed what he saw to her husband. The tumors had not shrunk in the least after the radiation effort. They had grown.

How to account for her mental vibrancy on the verge of death, then?
Can consciousness flow through and around the damaged architecture of the dying brain the way that water finds its way through a grate, or pebbled soil? Conventional medical wisdom holds that people with advanced Alzheimer’s or brain cancer or stroke cannot recover their cognitive function before they die. Their intelligence can only dim, like a wick rolled down in a lamp.

But the concept of “terminal lucidity” puts forth a different perspective, based on observations by doctors and families dating back centuries. Consider the statement of American physician Benjamin Rush who noted in 1812 that, “most of mad people discover a greater or less degree of reason in the last days or hours of their lives.” German biologist Michael Nahm reviewed the literature from Hippocrates to present times and introduced the term “terminal lucidity” a decade ago, defining it as “The (re-)emergence of normal or unusually enhanced mental abilities in dull, unconscious, or mentally ill patients shortly before death” (Nahm, 2009, p. 89).

One of the most remarkable accounts of terminal lucidity that Nahm found in his research comes from Fredrich Happich, the director of a German asylum known as Hephata, in the 1920s. There was a woman in his care with such severe mental disabilities that she had never learned to walk or to feed herself. Now in her twenties, and dying of tuberculosis, she had been in the institution, uttering no more than groans or growls, since toddlerhood.

On the evening of her death, the psychiatrist who was attending to her went to fetch Happich because he was so amazed by what he and a nurse were observing. This patient, who had never acquired spoken language, was now singing a hymn, over and over, about being ready to die. ‘Where does the soul find its home, its peace? Peace, peace, heavenly peace!’ According to Nahm (2009), “For half an hour she sang. Then, she quietly died. Her face, up to then so stultified, was transfigured and spiritualized” (p. 97).

This case, of Anna Katharina Ehmer (Nahm & Greyson, 2013-2014), along with another at Hephata, formed the basis of Happich’s appeal to Hitler not to euthanize the disabled as a “degenerate” class of no worth to his society. (To no avail.) He’d grown convinced there was a “hidden inner life” within the damaged brains and bodies of his patients.

Interestingly, in 2015, German medical researchers published a report of a woman diagnosed with “dissociative identity disorder,” who produced different electrophysiological brain activity patterns depending upon which “personality” was present. When a blind personality was at the foreground,
for instance, the neural activity associated with sight was absent (Strasburger & Waldvogel, 2015). There is much that remains a mystery about consciousness and the physical brain.

Cases of “terminal lucidity” have popped up sporadically in the scholarly literature, while families continue to experience and describe it without being aware there’s now a term for it. Scientific American contributor Jesse Bering, Associate Professor of Science Communication at the University of Otago in New Zealand, for example, wrote in 2014 of communing for five minutes with his previously comatose mother the evening before she died. “I didn’t quite see the experience as ‘supernatural’ when it happened,” he wrote. “And I’m not sure I do today either. But I also didn’t have a name for the experience then. In fact, one didn’t even exist.”

In many ways, that’s the most important point about these mysterious end-of-life experiences that can heighten our connection to the dying: we can’t fully discuss them until we name them and do so with common agreement.

It’s not dissimilar to how 19th century psychiatrists like Emil Kraepelin realized that they had to advance a more precise set of categories and terms for mental illnesses—that had long been observed but called everything from “moon madness” to “masturbatory insanity” (Ebert & Bär, 2010). It doesn’t matter that we still can’t agree on what causes psychosis, or that there may be many distinct causes; what’s critical is that we don’t spend our time questioning or denying that it even exists. We have been able to move the conversation forward.

As Nahm has written, “a wider knowledge about the phenomenon, and an awareness of its possible occurrence, would give those who attend patients the opportunity to optimally relate to a dying person who has been in a non-responsive condition for an extended period, sometimes years. As it is, this unexpected return of mental clarity and memory often comes as a complete surprise” (2017).

References


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