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Terminal lucidity: A review and a case collection

Michael Nahm^a, Bruce Greyson^{a,*}, Emily Williams Kelly^a, Erlendur Haraldsson^b

^a Division of Perceptual Studies, Department of Psychiatry & Neurobehavioral Sciences, University of Virginia Health System, 210 10th Street NE, Suite 100, Charlottesville, VA 22902-4754, USA

^b Department of Psychology, University of Iceland, 101 Reykjavik, Iceland

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ABSTRACT

The unexpected return of mental clarity and memory shortly before death in patients suffering from severe psychiatric and neurologic disorders, which we have called “terminal lucidity”, has been reported in the medical literature over the past 250 years, but has received little attention. We review a range of terminal lucidity cases in order to encourage investigation of the mechanisms involved and possible insights into both the neuroscience of memory and cognition at the end of life and treatment of terminal illness. These examples include case reports of patients suffering from brain abscesses, tumors, strokes, meningitis, dementia or Alzheimer's disease, schizophrenia, and affective disorders. Several of these accounts suggest that during terminal lucidity, memory and cognitive abilities may function by neurologic processes different from those of the normal brain. We expect that significant contributions to better understanding the processes involved in memory and cognition processing might be gained through in-depth studies of terminal lucidity. Studying terminal lucidity might also facilitate the development of novel therapies. In addition, increased awareness of unusual end-of-life experiences could help physicians, caregivers, and bereaved family members be prepared for encountering such experiences, and help those individuals cope with them.

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1. Introduction

In a previous report we described the unexpected return of mental clarity and memory shortly before the death of patients suffering from severe mental disorders (Nahm and Greyson, 2009). This return of mental clarity often occurs in the last minutes, hours, or days before the patient's death. Observations of this phenomenon have so far not received much attention among psychiatrists and other physicians. We referred to this unexpected symptom remission at the end of life as “terminal lucidity”. In our previous report we presented the results of a literature survey of published case reports of terminal lucidity during the last 250 years, and included case reports of terminally ill patients suffering from Alzheimer's disease and from chronic schizophrenia. By drawing attention to terminal lucidity, we hope to stimulate future research into the psychopathology and neuropathology of mentally ill patients who suffer from an additional somatic disease. Such studies could facilitate the development of new therapies, and could contribute to an enhanced understanding of the factors governing the interplay between body and mind, as well as cognition and memory processing.

In the current article, we present further results from our literature survey and also include new case reports. We show that terminal lucidity is not limited to patients suffering from Alzheimer's disease and schizophrenia, but is also reported from patients with brain abscesses, tumors, meningitis, strokes, and affective disorders.

2. Prevalence of terminal lucidity

At present, we have identified 83 cases of terminal lucidity mentioned in the literature of the last 250 years and have collected comparable unpublished contemporary accounts. The published cases were reported by 55 different authors, mostly by professionals working in the medical setting. Of the cases that contained a description of the course of the illness, 22 patients were female and 32 were male. In addition to those particular case references and descriptions, we identified 18 general claims of physicians or caregivers who stated that they had witnessed terminal lucidity in mental disorders but gave no details of their observations.

In our literature survey, we were able to find only two sources that estimated the frequency of terminal lucidity in patients with mental disorders. The first is included in a book published in 1844 by Julius, who updated statistics performed previously by Thurnam on the patients of a British asylum (Julius, 1844). In one table of the book, Julius presented mental status changes at the

* Corresponding author. Tel.: +1 434 924 2281; fax: +1 434 924 1712.
E-mail address: cbg4d@virginia.edu (B. Greyson).

end of life in all 139 patients who died in the asylum from 1796 to 1841. In 13% of the cases, the mental state was considerably improved at the time the patients died. The greatest frequency of symptom remission at the end of life was displayed by patients diagnosed with mania (16%) and melancholia (17%). Julius mentioned that in a few cases of terminal lucidity the patients died of a sudden death such as stroke, but he included no case descriptions in his book. In only 2% of the patients the terminal mental condition was considerably changed for the worse, in 63% it remained unchanged, and in 22% it changed in quality, e.g., from mania to melancholia (Julius, 1844).

The second publication containing quantitative information on the prevalence of terminal lucidity was a recent investigation of end-of-life experiences. In that study, seven out of ten caregivers in a nursing home reported that they had observed patients with dementia and confusion becoming lucid a few days before death during the past five years (Brayne et al., 2008).

Although there are few quantitative estimates of the prevalence or degree of terminal lucidity, a recent survey of nursing home staff reported that “interviewees from all units reported first-hand accounts of previously confused residents suddenly becoming lucid enough in the last days of life to recognize and say farewell to relatives and carers” (Fenwick et al., 2010).

3. Causes and diagnoses of the mental disorders

In the case reports of the 19th century, the psychiatric diagnoses of the patients were usually antiquated, inadequate, or absent. The most frequent diagnoses were mania and melancholia. Similarly, diagnoses of the cases reported throughout the 20th century were often absent or inadequate. Nevertheless, there are several cases containing distinct diagnoses among the descriptions we retrieved. Among them are cases involving brain abscesses, tumors, strokes, Alzheimer's disease or other dementias, meningitis, schizophrenia, and probable affective disorders. With regard to dementia or Alzheimer's disease, we have additionally collected eight general statements of physicians and caregivers who claimed that they have observed incidents of terminal lucidity but provided no further details. With regard to schizophrenia, similar statements were advanced by three physicians.

In the following section, we describe case reports of terminal lucidity that pertain to the different diagnostic categories, although for some of these cases, particularly the earlier ones, diagnoses must be regarded as provisional. We acknowledge that some of these cases, particularly those reported outside the medical setting, might contain retrospective embellishments, or that in some cases the improvement in mental state might have coincided only accidentally with the approach of death. Nevertheless, this was not the opinion of those who reported the cases. It seems very likely that terminal lucidity does in fact occur under a variety of circumstances and that the published reports warrant attention.

4. Case reports of terminal lucidity

4.1. Brain abscesses

In a case published in 1822, a boy at the age of 6 had fallen on a nail that penetrated his forehead. He slowly developed increasing headaches and mental disturbances. At the age of 17, he was in constant pain, extremely melancholic, and starting to lose his memory. He fantasized, blinked continuously, and looked for hours at particular objects. When he additionally started to throw up frequently, he was admitted to a hospital. He was not able to sit or get out of bed. He remained in the hospital in this state for 18 days. On the morning of the 19th day, he suddenly left his bed and

appeared very bright, claiming he was free of all pain and feelings of sickness. He intended to leave the hospital the next day. A quarter of an hour after the attending physician left him, he fell unconscious and died within a few minutes. The front part of his brain contained two pus-filled tissue bags the size of a hen's egg (Pfeuffer, 1822).

In another case published in 1820, a nun moved to her sister's home when her monastery was closed. After she seemed to recover from scarlet fever, she fell into a delirium, went “raving mad,” and was admitted to an asylum. She was obsessed with the conviction that the monastery still existed, and violently insisted on returning to it. All treatments to improve her condition were unsuccessful. She lived under the care of a personal nurse in a single room specifically equipped for her, and was regularly visited by her sister. After three years, she developed a chronic fever caused by a large abscess. The more her physical strength declined, the calmer she became. Three weeks before her death, all traces of her former madness had completely vanished. When her sister visited her, she was intensely thankful for all that her sister had done for her. She remembered all details of her insanity, and was regretful. She received the sacrament of the dying in devotion and prayed until she died peacefully in the arms of her brother-in-law. When her cranium was removed for autopsy, the brain tissue swelled forcibly forth. The blood vessels were engorged with blood, and the brain tissue itself was unusually soft. It was not possible to close the skull again because of the large amount of swollen brain tissue. The dura mater was joined together with the inner surface of the skull bone (Vering, 1820).

4.2. Brain tumors

Morse and Perry (1990) reported the case of a 5-year-old boy who had been in a coma for three weeks dying from a malignant brain tumor, during which time he was almost constantly surrounded by various family members. Finally, on the advice of their minister, the family told the comatose child that they would miss him but he had their permission to die. Suddenly and unexpectedly, the boy regained consciousness, thanked the family for letting him go, and told them he would be dying soon. He did in fact die the next day.

Haig (2007) reported the case of a young man dying of lung cancer that had spread to his brain. Toward the end of his life, a brain scan showed little brain tissue left, the metastasized tumors having not simply pushed aside normal brain tissue but actually destroyed and replaced it. In the days before his death, he lost all ability to speak or move. According to a nurse and his wife, however, an hour before he died, he woke up and said good-bye to his family, speaking with them for about five minutes before losing consciousness again and dying.

In a case recently reported to us, a 42-year-old investment manager had a grand mal seizure “out of the blue” one night. Although his EEG showed generalized slowing, repeated MRIs appeared normal. Two months later, however, a repeat MRI showed a plum-sized glioblastoma multiforme. By the time he had surgery two weeks later, the tumor had doubled in size and a second had formed in his speech center. Following two surgical excisions, gamma knife radiation, intrathecal chemotherapy, and steroids, he was able to go back to work part-time. However, the tumor soon recurred, and after a failed trial of an experimental oral chemotherapy agent, he declined further treatment and enrolled in hospice care in his home.

He quickly became bedridden, blind in one eye, incontinent, and increasingly incoherent in his speech and bizarre in his behavior. He appeared to be unable to make sense of his surroundings, and when his family touched him, he would slap as if at an insect. He eventually stopped sleeping, talking deliriously through the night.

After several weeks of that, he suddenly one night appeared calm and started speaking coherently, and then slept peacefully. The following morning he remained coherent and conversed with his wife, discussing his imminent death with her for the first time. However, he stopped speaking later that day, and lay immobile in his bed, not eating or drinking for two more weeks, after which he expired after several hours of status epilepticus.

4.3. Strokes

Noyes (1952) described a 91-year-old woman who had suffered two strokes. The first stroke paralyzed her left side and deprived her of clear speech. After a few months, the second stroke rendered her entirely paralyzed and speechless. A daughter cared for her. On one occasion, an exclamation from the woman caught the daughter's attention, and she saw the old woman smiling brightly, although her facial expression had been frozen since her second stroke. The woman turned her head and sat up in bed with no apparent effort. She then raised her arms and exclaimed in a clear, joyous tone the name of her husband. Her arms dropped again, and she sank back and died. She may have experienced a death-bed vision of her deceased husband (Osis, 1961; Osis and Haraldsson, 1977), but unquestionably regained her ability to use her body and speech during that experience.

Another instance of terminal lucidity involving strokes had been reported in the 19th century (Daumer, 1865). After a man suffered his first stroke, he was almost entirely paralyzed for 11 years. He had also lost his ability to read or speak. After three years he had learned to recognize certain persons and speech again, but his mental faculties did not develop any further. Seven days before his death he suffered the second stroke. After this stroke, he regained almost full consciousness. He was able to speak in full sentences and understood lengthy passages of speech. Although he was an atheist for all his life, he now asked to see a minister and died in peace.

4.4. Alzheimer's disease and other dementias

In our previous publication (Nahm and Greyson, 2009), we gave examples of terminal lucidity in patients with Alzheimer's disease that were reported by Brayne et al. (2008) and Grosso (2004). The latter author described a second case of a demented patient who became mentally clear, recognized family members, and spoke coherently again shortly before she died. Osis (1961) mentioned another demented patient who regained normal mentality prior to dying.

Several terminal lucidity accounts involving dementia were included in the older literature. Marshall (1815) reported a case of a mad and furiously violent patient who suffered from memory loss to the degree that he did not even remember his own first name. When he fell seriously ill after more than ten years in the asylum, he grew calmer. On the day before he died, he became rational and asked to see a clergyman. He seemed to listen attentively to the minister and expressed his hope that God would have mercy on his soul. Although Marshall (1815) did not describe the mental state of the patient in more detail, his report suggests that the man had access to memories of his life again.

Recently, three personal accounts of terminal lucidity cases involving Alzheimer's disease were related to us. The first case concerned an elderly woman who suffered from the illness for 15 years and was cared for by her daughter. The woman was unresponsive for years and showed no sign of recognizing her daughter or anybody else. However, a few minutes before she died, she started a normal conversation with her daughter, an experience for which the daughter was unprepared and which left her utterly confused.

The second Alzheimer's case was remarkably similar. In this case it was a woman's grandmother who had neither talked nor reacted to family members for a number of years until the week before she died, when she suddenly started chatting with the granddaughter, asking about the status of various family members and giving her granddaughter advice. Her granddaughter reported that "it was like talking to Rip Van Winkle".

The third Alzheimer's case involved an 81-year-old woman who had been demented for a long time and was living in a retirement home in Iceland. Her family took turns visiting her, even though she had neither recognized any of them nor spoken to them for a year. On one occasion, her son Lydur was sitting at her bedside working on a crossword puzzle. Suddenly she sat up, looked him directly in the face, and said, "My Lydur, I am going to recite a verse to you". She then recited clearly and loudly the following verse, thought by her son to be quite relevant to her situation (translated into unrhymed English by E.H.):

Oh, father of light, be adored.
Life and health you gave to me,
My father and my mother.
Now I sit up, for the sun is shining.
You send your light in to me.
Oh, God, how good you are.

She then lay back on her pillow and was again nonresponsive, and remained so until she died about a month later. Her son immediately wrote down the verse, thinking it was his mother's poetry; but he later learned it was the first stanza from a psalm by an Icelandic poet.

4.5. Meningitis

Osis and Haraldsson (1977) reported the case of a woman in her 30s suffering from meningitis, who was severely disoriented, drowsy, and talking incoherently almost to the end. A few minutes before she died she came to herself. She cleared up, answered questions, smiled, and was slightly elated.

Besides other pathological findings on the psychological and brain anatomical level, the following case from the 19th century also included chronic meningitis. A widow and mother of five children lived in severe poverty. In time, she developed suicidal tendencies and increasing signs of mental disorder. After having often spent her days in an apathetic state, she suddenly became agitated, tearing her clothes and restlessly walking about the surrounding fields. Subsequently she was transferred to an asylum in November 1844. There she complained about strong feelings of vertigo. The memory of her past was gone, she talked incoherently, and she stated that she had never had children. From December on, she suffered severe attacks of vertigo that sometimes rendered her unconscious, cold, and stiff, with only marginal pulse. Even during intervals in which she was able to get out of bed, she never recognized where she was. In the summer of 1845, she suffered further attacks of bodily malfunction that left her increasingly unresponsive. The accompanying symptoms pointed to some kind of congestion in her brain. After her last seizure at the end of September, she was unresponsive for four months.

After that, her mental state began to improve as her body continued to weaken. Before she died in February 1846, memories of her entire life had been restored, she knew where she was, and she intimately thanked her caregivers for all they done for her. She died in full consciousness. The diagnostic findings included a sharp-edged piece of bone of one to two centimeters in diameter at the inner surface of the skull, and chronic meningitis. The blood

vessels were engorged with blood and the pia mater was swollen in a blister-like fashion. Blisters were also found in several other regions of the brain, as well as excessive fluid in the ventricles that resulted in a pathological increase of their normal volume (Leubuscher, 1846).

4.6. Schizophrenia

In our previous brief report (Nahm and Greyson, 2009), we summarized three cases of terminal lucidity in chronic schizophrenics (Turetskaia and Romanenko, 1975). The three patients were hospitalized continuously for 11, 20, and 27 years and displayed no lucid intervals for many years, the latter patient spending his last 17 years in a profoundly regressed catatonic state. Apart from specific idiosyncrasies, the three patients were almost normal shortly before they died.

Another case involving schizophrenia was mentioned by Osis (1961). This severe schizophrenic had been out of touch with reality for two years, but regained normal mentality shortly before death.

4.7. Possible affective disorders

In a case published in 1840, a woman of 30 years diagnosed with “wandering melancholy” (melancholia errabunda) was admitted to an asylum, and shortly thereafter, she became manic. For four years, she lived exclusively in a confused and incoherent state of mind. When she fell sick with a fever, she vehemently refused to take any medicine. Consequently, her health rapidly deteriorated. But the weaker her body became, the more her mental condition improved. Two days before her death, she became fully lucid. She talked with an intellect and clarity that seemed to exceed her former education. She inquired about the lives of her relatives, and in tears regretted her previous intractability toward taking medicine. She died soon thereafter (Butzke, 1840).

In 1832, a normal and seemingly happy family man fell sick with typhoid fever. He appeared to have recovered, but subsequently suffered more and more from abdominal distress. Eventually, he became increasingly melancholic and distrustful of his own family members, and he cried a lot and refused to eat. By the middle of 1834, his condition deteriorated and he was transferred into an asylum. He was completely apathetic, aboulie, and unresponsive, continuously standing or sitting on the same spot and staring at the ground if not moved by caregivers. No treatment changed his condition. After 8 months in the asylum, he began to suffer from an intestinal infection accompanied by severe dysentery, which led to his death. Despite extraordinary bodily suffering, his mental illness disappeared in every respect throughout his last week. His mental clarity had returned and stayed with him until he died. Organic abnormalities could not be detected in his brain on autopsy (Jacobi, 1837).

In another case (Bergmann, 1829), a young man for several years sat on a chair and stared continuously at the floor in front of him. He was very stiff and had great difficulties with even the slightest movements of his limbs. He could hardly walk, he never spoke a single word, and he never fed himself during these years. He finally fell ill with typhus. One day, he became lucid again and started to sing, including some clerical songs and the famous Freut euch des Lebens [Be glad to be alive]. The following day he died peacefully.

In another case from the 19th century, a man at age 22 was reportedly scared by a bear mask at a masked ball and subsequently became psychotic. For the next 52 years, he continuously imitated bear behavior by swinging his body and uttering bear-like growling sounds. He spoke no articulate words during these five decades. Then a few weeks before his death, as his terminal disease

progressed, he started to answer questions again. Though his mental capabilities were limited to a degree that he could answer only using “Yes” and “No,” he reacted in a precise and ordered manner that suggested he understood the questions addressed to him (Brierre de Boismont, 1862; Griesinger, 1876).

5. Discussion and conclusion

For physicians of the 19th century, terminal lucidity was well known. Nevertheless, discussions and case reports became fewer toward the end of that century and were almost absent in the medical literature of the 20th century. The publication of cases continued largely outside the medical setting. The only publications on terminal lucidity by medical professionals we could find from recent decades were the monograph on the three schizophrenics (Turetskaia and Romanenko, 1975) and a more recent brief mention of terminal lucidity in patients with dementia (Brayne et al., 2008). Given the intriguing phenomenology of some of the case reports, we consider further research into terminal lucidity an important task. Some of the cases presented, particularly those involving destruction of brain tissue caused by tumors, strokes, or Alzheimer’s disease, pose difficulties for currently prevailing explanatory models of brain physiology and mental functioning.

At present, we think that it is not possible to formulate definitive mechanisms for terminal lucidity. Indeed, terminal lucidity in differing mental disorders might result from different processes, depending on the etiology of the diseases. For example, cachexia in chronically ill patients might conceivably cause shrinking of brain tissue, relieving the pressure exerted by space-occupying intracranial lesions and permitting fleeting return of some brain function. As early as 1826, two distinct ways were described in which terminal lucidity can manifest (Burdach, 1826). First, the degree of mental derangement can decrease slowly in conjunction with the decline of bodily vitality. The cases of schizophrenia and other cases of the older literature belong to this category. Second, full mental clarity can emerge suddenly just before dying. The presented cases involving brain tumors and Alzheimer’s disease belong to this second category. These observations suggest that there may be no unitary mechanism behind terminal lucidity.

We hope that drawing attention to this phenomenon may stimulate research into the psychopathology and neuropathology involved in near-death states. Studying terminal lucidity could help elucidate the factors governing the peculiar relationship between mind and brain, particularly as the brain deteriorates (Fenwick et al., 2010); and it could facilitate the development of new therapies. In this regard, one historical example is represented by the research of Wagner-Jauregg (1887). After observing that symptoms of mental derangement sometimes decreased during high fever, he developed fever therapy for general paresis. In 1927, he received the Nobel Prize for Medicine for this achievement (Nahm and Greyson, 2009).

Within the past decade evidence has accumulated that the cognitive deficits in Alzheimer’s disease and related dementias may be due not solely to irreversible neuronal loss, but perhaps in part to potentially reversible functional impairments speculatively involving complex adjustments in molecules, signaling cascades, synaptic modifications, neuronal activities, or network interactions (Palop et al., 2006; Savioz et al., 2009). Although these reversible mechanisms may account for fluctuating cognitive functions in some patients in the early stages of Alzheimer’s disease (Gleichmann and Mattson, 2010), it is unclear whether they could explain the complete remission of cognitive deficits reported in terminal lucidity (Barton and Albright, 2008; Savioz et al., 2009). Likewise, some patients for whom life support has been withdrawn may manifest an

unexplained transient surge of electroencephalographic activity as blood pressure is lost immediately prior to death (Chawla et al., 2009). Although these patients have not been reported to show any clinical evidence of cognition, these findings suggest that the neuroscience of terminal states may be more complex than traditionally thought.

Research into terminal lucidity might lead to better understanding of the processes involved in memory and cognition. The unexpected return of mental faculties raises questions about cognitive processing at the end of life, especially in diseases that involve the degeneration of the brain regions usually responsible for complex cognition, and may suggest new neuroscientific models for memory and cognition in terminal illnesses. In addition, increased awareness of unusual end-of-life experiences on the part of physicians, caregivers, and bereaved family members could help them prepare for witnessing such phenomena, and thus better cope with them.

Conflict of interest

None.

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