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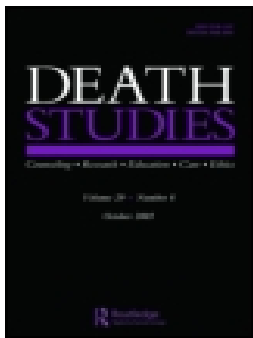


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Terminal lucidity in the teaching hospital setting

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ABSTRACT

Terminal lucidity is an unpredictable end-of-life experience that has invaluable implications in preparation for death. We retrospectively evaluated terminal lucidity at a university teaching hospital. Of 338 deaths that occurred during the study period (187 in the ICU and 151 in general wards), terminal lucidity was identified in 6 cases in general wards. Periods of lucidity ranged from several hours to 4 days. After experiencing terminal lucidity, half of the patients died within a week, and the remainder died within 9 days. More attention should be directed toward understanding terminal lucidity to improve end-of-life care in a meaningful way.

KEYWORDS

terminal lucidity; end-of-life experiences; dying; death; teaching hospital

Patients in a terminal state show a gradual decrease in cognitive and physical functioning, and eventually die. However, the dying process of patients is not always a one-way phenomenon. When inevitable death is predicted within several days or weeks, a few cases show marked improvement in cognition and general condition. The phenomenon of an extraordinary clearing of the mental state before death was observed in ancient times (Nahm & Greyson, 2009). Anecdotal accounts of visions and supernatural phenomena before death have been noted since at least the 15th century (Fenwick, Lovelace, & Brayne, 2007). Even though these phenomena received considerable interest and were well-described by 19th-century physicians, attention waned until Raymond Moody's 1975 publication, which again elicited interest in near-death experiences (Nahm & Greyson, 2009). Witzel's (1975) study is also considered an important reference regarding characteristics of dying patients (Macleod, 2009; Witzel, 1975). Although quantitative information was not presented, he studied 250 patients during the weeks prior to death, and insisted that many patients showed a brief increase in vitality and seemed to generally improve shortly before death.

There are several terminologies for describing the unexpected and unpredictable experiences occurring near the end of life. End-of-life experiences (ELEs) encompass a wide range of phenomena that develop in the days before, or at the time of, death (Fenwick et al., 2007). These include terminal lucidity, deathbed visions, enhanced physical ability to perform movements or skills before death, and the power to foresee the future (Fenwick & Brayne, 2011). Discussing all the above experiences is beyond the scope of this paper; therefore, the focus will be narrowed to primarily terminal lucidity. The term "terminal lucidity" was first introduced in 2009 as a specific phenomenon among the various ELEs (Nahm & Greyson, 2009). It was defined as "the (re-) emergence of normal or unusually enhanced mental abilities in dull, unconscious, or mentally ill patients shortly before death" (Nahm & Greyson, 2009; Nahm, Greyson, Kelly, & Haraldsson, 2012). Although it is a straightforward definition, it is necessary to consider the duration and severity of the dull, unconscious, or mentally ill states before the reemergence of alertness. Moreover, it seems that terminal lucidity is often accompanied by deathbed visions. These visions have been described

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in many cultures and include visions of deceased relatives or friends, religious figures, and a visionary language pertaining to travel (Fenwick & Brayne, 2011; Mazzarino-Willett, 2010).

There have been various efforts to explain the mechanisms underlying terminal lucidity (Chiriboga-Oleszczak, 2017; Nahm & Greyson, 2009). The Doctrine of Dissolution and the Doctrine of Concomitance were concepts used to explain the phenomenon (Macleod, 2009). According to these doctrines, illness eventually destroys the higher centers and leads to reestablishment of order against the disorder of disease, i.e. a new biological dynamic and homeostasis. However, the period during which adaptive functioning is regained is short and results in subsequent rapid decline and death. Chawla, Akst, Junker, Jacobs, and Seneff (2009) examined electroencephalogram activity at the time of death in seven patients with systemic critical illness and identified sudden surges. They speculated that the surges might be related to near-death experiences. Further studies are necessary to determine whether there is similar unusual electroencephalogram activity related to terminal lucidity or other ELEs. However, to date, terminal lucidity cannot be explained entirely as a consequence of physiological processes in the brain. To overcome the current materialistic paradigm of neuropsychiatry, “brain-free” consciousness has been proposed as a working hypothesis to explain the phenomenon; terminal lucidity should be interpreted, along with other end-of-life experiences, as potentially paranormal phenomena (Nahm & Greyson, 2009).

Few studies have estimated the frequency of terminal lucidity. Most instances were reported before the 20th century. Nahm et al. (2012) identified 83 cases in the literature of the last 250 years and insisted that the prevalence of terminal lucidity in patients with mental illness was identified in only two sources. The first reference is included in a book published in 1844; 13% of 139 patients who died in a British asylum from 1796 to 1841 showed a considerable improvement in mental state near the end of life. The second was a recent (2008) paper, in which 70% of caregivers in a Gloucestershire nursing home answered that they had observed terminal lucidity in patients with dementia and confusion during the past five years (Brayne, Lovelace, & Fenwick, 2008). There are several other documented instances of terminal lucidity. Fenwick et al. received 300 reports from witnesses who observed end-of-life experiences (Fenwick & Brayne, 2011). Of these, 45 were rated as providing appropriate data, and terminal lucidity was observed

in 14%. To broaden the discussion, “lightening (up)” is a term used historically to describe terminal lucidity. William Munk was a famous Victorian physician who cared for the dying for more than 40 years. In his 1887 book, he described the phenomenon as the cessation of delirium and an extraordinary clearing of the mind before death and referred to it as “lightening up before death” (Hughes & Clark, 2004). In 2009, Macleod published a remarkable paper in which he described personal observations of the phenomenon (Macleod, 2009). He recounted six definite cases of “lightening up” in the last 48 hours of life of 100 patients at a hospice. Hitherto, terminal lucidity has been evaluated by literature review and a survey of healthcare workers in various institutions such as nursing homes or hospice centers (Brayne, Lovelace, & Fenwick, 2008; Nahm & Greyson, 2009) in Western countries. There is a similar term to refer to terminal lucidity in Asian countries, including Korea, called “回光返照 (Huí guāng Fǎnzhào),” which means sudden recovery of energy when close to death. However, this phenomenon has not been thoroughly studied scientifically in Asian countries. Based on the literature, we were able to identify a case of terminal lucidity in Korea (Kim, 2006). There was a custom to entomb individuals with a memorial stone in Korea during the Goryeo and Joseon Dynasty (918–1910 A.D.). Meaningful descriptions related to what happened during the deceased’s end-of-life period are presented on some memorial stones. To date, one of these descriptions is the only record that details terminal lucidity during that period.

Terminal lucidity has been considered as meaningful for the dying individual and that it makes the passage to death easier (Barbato, Blunden, Reid, Irwin, & Rodriguez, 1999; Brayne, Farnham, & Fenwick, 2006; Fenwick, Lovelace, & Brayne, 2007). Some health care professionals who have been taking care of terminally ill patients may agree that terminal lucidity exists and might have observed it more than once (Fenwick, Lovelace, & Brayne, 2010). However, most physicians and scientists have insisted that various end of life experiences, including terminal lucidity, are reactions to extreme stress. When encountering the phenomenon, such individuals are perplexed and have difficulty responding appropriately (Devery, Rawlings, Tieman, & Damarell, 2015; Workman, 2007). Thus, the phenomenon is dismissed as terminal restlessness, hallucinations, or delirium and does not receive careful consideration. Moreover, many critically ill patients get admitted to an intensive care unit (ICU) on a ventilator in a sedated state. Under these

conditions, it is impossible for such patients to experience terminal lucidity. As a result, the incidence and characteristics of terminal lucidity in general hospitals have yet to be thoroughly examined.

Death has now become medicalized and institutionalized, and it is addressed in a mechanical way, rather than as a spiritual journey (Howarth, 2000). According to a recent report by the Korea National Health Insurance Service, seven out of ten people (71.5%) die in hospitals, while only 17% die in their own home. This is similar to other developed countries (Fenwick & Brayne, 2011; Houttekier, Cohen, Pepersack, & Deliens, 2014; Mayor, 2007). To die alone in a hospital would certainly be solitary and dismal. Moreover, hospitals appear ill equipped to address death and provide care during the process of dying due to a lack of compassion and budgetary issues (Fenwick & Brayne, 2011; Mayor, 2007). This is unsurprising, given that the main purpose of a modern hospital is to treat disease, not to provide care during the process of dying. Considering that current societal changes have led to an increasing number of deaths in hospitals or institutions, it is clearly of value to describe the implications of terminal lucidity for terminally ill patients and evaluate its incidence and characteristics in a teaching hospital setting.

Method

Study population

We performed a retrospective study involving a total of 395 deaths reported at Dongguk University Hospital during the study period between March 2015 and February 2016. Of these deaths, 57 were excluded because the patients died within 24 hours of admission or a record of the level of consciousness 28 days prior to death was missing. A request to waive informed consent was approved by the appropriate ethics review board at Dongguk University Hospital (approval number: 2016-72).

Measurements and outcomes

We analyzed the level of consciousness of patients for 28 days before death. Consciousness was checked at least twice per day in general wards and at least once every two hours in the ICU. The level of consciousness was categorized as alert, drowsy, stupor, semi-coma, or coma in the medical records. In this paper, the level of consciousness was simply categorized as alert, unconscious, or sedated. Alertness was defined as a state of arousal in which a patient is attentive

and can answer any questions properly. The primary aim was to determine which patients who died during the study period demonstrated terminal lucidity. Only cases showing reemergence of alertness from dull or unconsciousness states were considered to be incidences of terminal lucidity (Nahm & Greyson, 2009).

Statistical analyses

All statistical tests were two-sided, and the level of significance was set at 0.05. Continuous variables are described using means and standard deviations, and categorical variables as the number and percentage. Descriptive statistics for demographic and clinical characteristics are provided. Summary statistics are presented based on the experience of terminal lucidity. We performed Student's *t*-test or Wilcoxon's rank-sum test to assess mean differences between groups defined by whether the patients experienced terminal lucidity or not. All categorical data were analyzed using Pearson's chi-square test or Fisher's exact test to compare groups. All analyses used SPSS (version 20.0; SPSS, Inc., Chicago, IL).

Results

Demographic and clinical characteristics of deaths in the hospital

Of the 338 deaths (191 men and 147 women) that occurred in the present study (Table 1), the mean age at the time of death was 71.29 years (SD = 14.48). The main causes of admission were malignant cancer (32.25%), respiratory disease (26.33%), cardiovascular disease (11.54%), gastrointestinal (GI) disease (10.36%), neurologic disease (8.28%), sepsis (2.96%), and other problems (8.28%). A total of 186 patients (57.06%) were alert when admitted to the hospital. More than 80% of them specified that they should not be resuscitated (do not resuscitate; DNR) and refused life-sustaining treatment. The main causes of death were malignancy (101 cases, 29.88%), respiratory disease (101 cases, 29.88%), sepsis (36 cases, 10.65%), cardiovascular disease (35 cases, 10.36%), neurologic disease (29 cases, 8.58%), and other causes (13 cases, 3.85%).

There were 187 deaths in the ICU; the mean age at the time of death was 72.50 years (SD = 14.05; Table 2). The main causes of ICU admission were respiratory disease (56 cases, 30.11%), cardiovascular disease (38 cases, 20.43%), sepsis (33 cases, 17.74%), neurologic disease (27 cases, 14.5%), GI disease (19 cases, 10.22%), and others (13 cases, 6.99%). At the time of admission to

Table 1. Demographic and clinical characteristics of the deceased in the hospital.

	<i>n</i> (%)
Gender	
Male	191 (56.51)
Female	147 (43.49)
Age: Mean (SD) in years	71.29(14.48)
Main causes of admission	
Neurologic disease	28 (8.28)
Sepsis	10 (2.96)
Malignancy	109 (32.25)
Respiratory disease	89 (26.33)
Cardiovascular disease	39 (11.54)
Gastrointestinal disease	35 (10.36)
Others	28 (8.28)
Total admission period (days)	
≤1	1 (0.3)
2–7	107 (31.75)
8–14	48 (14.24)
15–28	78 (23.15)
>28	103 (30.57)
Mental status at admission	
Alert	186 (57.06)
Unconscious	141 (39.57)
Sedated	11 (3.37)
Number of Admission for 1 year before death: Mean (SD)	1.8 (2.8)
Duration of Admission for 1 year before death: Mean (SD) in days	39.94 (61.27)
Life-sustaining treatments	
Refuse	293 (86.69)
Place of death	
ICU	187 (55.33)
Ward	151 (44.67)
Main causes of death	
Neurologic disease	29 (8.58)
Sepsis	36 (10.65)
Malignancy	101 (29.88)
Respiratory disease	101 (29.88)
Cardiovascular disease	35 (10.36)
Gastrointestinal disease	23 (6.8)
Others	13 (3.85)

ICU: intensive care unit.

the ICU, alert consciousness was present in 81 patients (45.51%). During ICU admission, most patients received ventilator care (84.86%) and vasopressors (98.73%).

A total of 151 patients died in general wards, of whom 91 (60.62%) were male and 60 (39.74%) were female (Table 3). Their mean age was 69.79 years (SD = 14.89). The main causes of admission were malignant cancer (99 cases, 65.56%), respiratory disease (26 cases, 17.22%), cardiovascular disease (9 cases, 5.96%), sepsis (2 cases, 1.32%), neurologic disease (2 cases, 1.32%), and others (5 cases, 3.31%). Most patients (70.95%) were alert at the time of admission. Almost all refused life-sustaining treatments (98.01%).

Comparison based on terminal lucidity and characteristics of terminal lucidity

Among the 151 patients who died in general wards, six patients (3.98%) experienced terminal lucidity; four were male and two were female. There was no significant difference between the two groups in terms

Table 2. Demographic and clinical characteristics of patients who died in the ICU.

	<i>n</i> (%)
Gender	
Male	100 (53.48)
Female	87 (46.52)
Age: Mean (SD) in years	72.5 (14.05)
Main causes of admission	
Neurologic disease	26 (13.9)
Sepsis	8 (4.28)
Malignancy	10 (5.35)
Respiratory disease	63 (33.69)
Cardiovascular disease	30 (16.04)
Gastrointestinal disease	27 (14.44)
Others	23 (12.3)
Mental status at admission	
Alert	81 (45.51)
Unconscious	87 (48.88)
Sedated	10 (5.62)
Number of Admissions for 1 year before death: Mean (SD)	1 ± 1.77
Duration of Admission for 1 year before death: Mean (SD) in days	29.87 ± 59.78
Life-maintaining treatments	
Refuse	145 (77.54)
Main causes of ICU admission	
Neurologic disease	27 (14.52)
Sepsis	33 (17.74)
Respiratory disease	56 (30.11)
Cardiovascular disease	38 (20.43)
Gastrointestinal disease	19 (10.22)
Others	13 (6.99)
Total period of ICU care (days)	
≤1	16 (8.65)
2–7	84 (45.41)
8–14	40 (21.62)
15–28	21 (11.35)
>28	24 (12.97)
Life-sustaining treatments	
Ventilator care	157 (84.86)
Duration of ventilator care: Mean (SD) in days	12.84 (19.4)
Vasoactive drugs	157 (98.73)
Dialysis	55 (34.59)
Main causes of death	
Neurologic disease	27 (14.44)
Sepsis	29 (15.51)
Malignancy	7 (3.74)
Respiratory disease	67 (35.83)
Cardiovascular disease	26 (13.9)
Gastrointestinal disease	19 (10.16)
Others	12 (6.42)

ICU: intensive care unit.

of whether patients experienced terminal lucidity or not (Table 4). Among the patients with terminal lucidity, at the time of admission, three were alert, while the remaining three were drowsy. All six patients refused life-sustaining treatments and ICU care.

The periods of lucidity varied from several hours up to four days. Prior to terminal lucidity, three patients were in a drowsy state, two showed signs of stupor, and one was in a coma (Table 5). The unconscious state before terminal lucidity lasted for periods ranging from one to nine days. After experiencing terminal lucidity, one patient expired a day later (16.7%), two passed away five days later (33.3%), one died

Table 3. Demographic and clinical characteristics of patients who died in general wards.

	<i>n</i> (%)
Gender	
Male	91 (60.26)
Female	60 (39.74)
Age: Mean (SD) in years	69.79 (14.89)
Main causes of admission	
Neurologic disease	2 (1.32)
Sepsis	2 (1.32)
Malignancy	99 (65.56)
Respiratory disease	26 (17.22)
Cardiovascular disease	9 (5.96)
Gastrointestinal disease	8 (5.3)
Others	5 (3.31)
Mental status at admission	
Alert	105 (70.95)
Unconscious	42 (28.38)
Sedated	1 (0.68)
Number of Admissions for 1 year before death: Mean (SD)	2.76 (3.44)
Duration of Admission for 1 year before death: Mean (SD) in days	50.34 (61.3)
Life-sustaining treatments	
Refuse	148 (98.01)
Reason not to receive ICU care	
DNR	148 (98.01)
Sudden death	2 (1.32)
Unknown	1 (0.66)
Main causes of death	
Neurologic disease	2 (1.32)
Sepsis	7 (4.64)
Malignancy	94 (62.25)
Respiratory disease	34 (22.52)
Cardiovascular disease	9 (5.96)
Gastrointestinal disease	4 (2.65)
Others	1 (0.66)

DNR: do not resuscitate; ICU: intensive care unit.

eight days later (16.7%), and two succumbed nine days later (33.3%). The phenomenon was not predictable based on patient characteristics. The most common underlying disease was malignant cancer and end-stage renal disease (ESRD). All patients with ESRD received hemodialysis. The primary causes of death were various infections and cancer-related complications. Morphine was administered for pain control to those individuals with pancreatic and breast cancer. Dosages did not exceed the acceptable clinical range.

Discussion

Terminal lucidity has long been considered to signify poor prognosis (Chiriboga-Oleszczak, 2017). Nahm and Greyson (2009) reported that 43% of individuals who experienced terminal lucidity died within 1 day, 41% within 2–7 days, 10% within 8–30 days, and 6% more than 30 days later. According to the results of our study, half of the patients who experienced terminal lucidity died within a week, and the other half died within nine days. It appears unusual for patients to live more than two weeks after experiencing

periods of terminal lucidity. Thus, the experience of terminal lucidity can surprise and embarrass family and acquaintances, as well as health care professionals, if they are not prepared for it. It can provoke confusion when death or serious difficulties follow soon after someone experiences terminal lucidity. However, increased awareness of terminal lucidity and the provision of appropriate information may help affected individuals to address the phenomenon appropriately; it may help patients to meet death calmly, and the bereaved to overcome feelings of loss (Greyson, 1992). Although terminal lucidity seems to be a meaningful event in the dying process, with spiritual implications regarding preparation for death (Brayne et al., 2006), medical practitioners have not been interested in the effect of terminal lucidity on caregivers or how the phenomenon influences their work (Brayne et al., 2006). Even though patients would prefer talking to nurses rather than physicians about their experience, nurses are sometimes reluctant to respond to dying patients (Margareta, Berggren, Kasén, Wärnå-Furu, & Söderlund, 2015). End-of-life care is not a problem only for nurses and physicians, so palliative care teams should be educated regarding how to communicate appropriately with patients and be trained to address the various issues associated with terminal lucidity (Brayne et al., 2006; Cipolletta & Oprandi, 2014; Ferrell, Malloy, & Virani, 2015). In our study, all cases of terminal lucidity occurred in the general ward; none was reported in the ICU. It is very important to thoroughly discuss the necessity of ICU care with a patient or surrogate in a more thoughtful way, based on the patient's condition and prognosis (Jo, Yoo, Knafle, Van Riper, Beeber, & Song, 2017).

This study has several limitations. First, health care professionals in the hospital were not aware of, nor vigilant regarding, the development of the phenomenon. Therefore, there exists the possibility that some cases were not discovered and that the actual prevalence is higher. Increased awareness of terminal lucidity could help health care professionals be well prepared for observing and encountering the phenomenon. Second, this is a retrospective study that depended entirely on medical records of deceased patients. Although the verbalizations and behaviors of alert patients were coherent and meaningful, according to our definition of alertness, the medical records provided limited information. The format of the records and attitudes of health care professionals made it difficult to describe terminal lucidity thoroughly. It was nearly impossible to

Table 4. Comparison of clinical characteristics based on terminal lucidity.

	Terminal lucidity <i>n</i> (%)		<i>p</i> -value
	(+)	(-)	
Gender			
Male	4 (2.65)	87 (57.62)	1.0000
Female	2 (1.32)	58 (38.41)	
Age: Mean (SD) in years	76.33 (11.55)	69.52 (14.98)	.2488
Main causes of admission			
Neurologic disease	0 (0)	2 (1.32)	.4076
Sepsis	0 (0)	2 (1.32)	
Malignancy	4 (2.65)	95 (62.91)	
Respiratory disease	0 (0)	26 (17.22)	
Cardiovascular disease	1 (0.66)	8 (5.3)	
Gastrointestinal disease	0 (0)	8 (5.3)	
Others	1 (0.66)	4 (2.65)	
Total admission period: Mean (SD) in days	3.67 (1.03)	3.95 (1.24)	.5034
Mental status at admission			
Alert	3 (2.03)	102 (68.92)	.4821
Unconscious	3 (2.03)	39 (26.35)	
Sedated	0 (0)	1 (0.68)	
Life-sustaining treatments			
Refuse	6 (3.97)	142 (94.04)	1.0000
Reason why they did not receive ICU care			
DNR	6 (3.97)	142 (94.04)	.9386
Sudden death	0 (0)	2 (1.32)	
unknown	0 (0)	1 (0.66)	
Main causes of death			
Neurologic disease	0 (0)	2 (1.32)	.7261
Sepsis	3 (0.5)	7 (4.64)	
Malignancy	2 (0.33)	89 (58.94)	
Respiratory disease	0 (0)	34 (22.52)	
Cardiovascular disease	1 (0.16)	8 (5.3)	
Gastrointestinal disease	0 (0)	4 (2.65)	
Others	0 (0)	1 (0.66)	

DNR: do not resuscitate; ICU: intensive care unit.

Table 5. Clinical characteristics of patients experiencing terminal lucidity.

Age	Gender	Underlying diseases	Main causes of death	Mental status before TL	TL (days)	Interval from TL to death (days)	Specific findings
72	F	ESRD on HD, MM, HTN, DM	Multiple infection	Stupor (2)	<1	8	Called mother several times and then became calm and peaceful
83	M	dementia, pancreatic cancer	Pancreatic cancer	Stupor (9)	3	9	
85	F	colon cancer, HTN	Colon obstruction, bleeding	Coma (1)	<1	1	
75	M	ESRD on HD, HTN, DM, Arrhythmia	Acute pyelonephritis	Drowsy (8)	4	5	
56	F	breast cancer	Catheter related infection	Drowsy (7)	4	5	
87	M	ESRD on HD	Cardiogenic shock	Drowsy (8)	<1	9	

DM: diabetes mellitus; ESRD: end stage renal disease; HD: hemodialysis; HTN: hypertension; MM: multiple myeloma; TL: terminal lucidity.

obtain a detailed description of the conversations and behaviors of a patient experiencing terminal lucidity. Nevertheless, we found a meaningful description of a patient with dementia and pancreatic cancer during terminal lucidity. According to the description, he had been in pain and exhibited violent behavior. His consciousness gradually decreased, and he went into stupor. However, he regained alertness after being in stupor nine days later and called for his mother several times, then became calm and peaceful. Additionally, the analyses comparing those with and without terminal

lucidity would be under powered because of the small number of patients with terminal lucidity.

Cases of terminal lucidity were identified for the first time in a university teaching hospital. The implications of terminal lucidity in palliative care for terminally ill patients could contribute to a significant improvement of the quality of end-of-life care. Current medical knowledge and technology are extremely limited regarding understanding and predicting terminal lucidity. Although studying the dying is very difficult and has ethical concerns, further studies are necessary in order to evaluate the phenomenon

in clinical settings and identify a predicting factor through not only subjective but also objective and qualitative research methods in a prospective way.

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