

Spontaneous Remission of Dementia Before Death: Results From a Study on Paradoxical Lucidity

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The aim of this research was to study paradoxical lucidity—the unexpected return of cognition and communication in patients with diagnosed dementia—systematically in a contemporary sample. We conducted a survey of caregivers who had witnessed at least one case of paradoxical lucidity in the year prior to survey completion. We assessed diagnosis and degree of preexisting cognitive impairment, cognitive state during the lucid episode, and temporal proximity of the lucid episode to death. Detailed case reports of 124 dementia patients who experienced an episode of paradoxical lucidity were received. In more than 80% of these cases, complete remission with return of memory, orientation, and responsive verbal ability was reported by observers of the lucid episode. The majority of patients died within hours to days after the episode. Further prospective study is warranted, as paradoxical lucidity suggests that there may exist a reversible and functional aspect of pathophysiology in severe dementia.

Keywords: paradoxical lucidity, terminal lucidity, dementia, end-of-life care, remission

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Those who care for patients with dementia occasionally report incidents in which their patients spontaneously and—given their diagnosis and disease severity—unexpectedly speak or behave in ways that appear to suggest lucid awareness of their environment, including re-

turn of memory and verbal function (Normann, Asplund, & Norberg, 1998; Normann, Asplund, Karlsson, Sandman, & Norberg, 2006).

Spontaneous remissions of severe cognitive impairment appear not to be limited to patients suffering from the dementias, but also have been reported in patients with brain tumors, strokes, brain abscesses, and meningitis, as well as mental disorders such as chronic schizophrenia (Nahm, 2012; Nahm, Greyson, Kelly, & Haraldsson, 2012). Such lucid episodes are frequently reported to occur in patients whose medical diagnoses make the possibility of spontaneous, albeit brief, remissions unlikely, either because the underlying disorder itself is generally held to rule out spontaneous remissions, or because due to the progression of the underlying disorder, the functional impairment is considered to be irreversible.

Much of what we currently know about this phenomenon is based on anecdotal reports. One prominent source of case histories is the older medical literature, especially of the 19th century, when individual case studies were a more

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common element of medical writing. Thereafter, interest in the phenomenon faded and few reports or discussions on the subject have been published (e.g., Turetskaia & Romanenko, 1975; Witzel, 1975). For example, Witzel (1975) followed 250 patients during the weeks prior to death, and reported that a number of patients showed increased vitality and general improvement shortly before death. He pointed out that “Immediately before death the need for analgesic medication decreased and many patients exhibited a short increase of vitality, appreciated food again, and appeared to be generally improved” (p. 82). However, Witzel did not provide any further details or statistical information on these cases.

In recent years, a number of studies (e.g., Fenwick, Lovelace, & Brayne, 2010; MacLeod, 2009; Nahm & Greyson, 2009) have prompted growing interest in the phenomenon that has been referred to as “lightening up before death” (MacLeod, 2009), “terminal lucidity” (Nahm & Greyson, 2009), or “premortem surge” (Schreiber & Bennett, 2014). The death-related designation refers to the fact that the majority of case reports suggest that these lucid episodes directly precede the precipitous clinical decline and death of the patient, echoing Witzel’s and the 19th-century physicians’ observations (Nahm & Greyson, 2009; Witzel, 1975).

In their historical review, Nahm et al. (2012) presented 83 case reports collected from the literature of the past 250 years. These case reports differed widely from each other in their thoroughness: some contained relatively detailed information on the patient’s diagnosis, the duration of the episode, and the degree of the patient’s improvement, yet others only briefly mentioned that some patients experienced a brief and surprising remission and then died. A few focused on the question of the mechanisms responsible for the brief remission before death. Most of these case histories were derived from an era in which the diagnosis of psychiatric and neurological disorders was less well described than today and different medical nosologies were applied. Furthermore, only a fraction of these reports had been documented with the intention to further the systematic study of the phenomenon.

As to more recent case reports, Brayne, Lovelace, and Fenwick (2008) reported that about 70% of caregivers in a nursing home

stated that they had witnessed terminal lucidity in dying patients with dementia, severe cognitive impairment, and confusion within the preceding five years. In a follow-up study, Fenwick and Brayne (2011) report that in 45 accounts of end-of-life experiences, terminal lucidity was reported in 14% of the cases. Yet again, no further detailed or statistical information was given on these cases.

Lim et al. (2020) retrospectively searched medical records at a Korean university teaching hospital for cases of terminal lucidity. Of 338 deaths that occurred during the study period, terminal lucidity was identified in the medical records of six cases. The lucid episodes ranged from several hours to 4 days; all patients died within 9 days, with half of the patients dying within a week.

In the only prospective study published to date, Macleod (2009) observed 100 consecutive deaths in a hospice in New Zealand and found six cases of unexpected, spontaneous return of cognitive functions and verbal ability within 48 hr before the death of the patient. Macleod provided brief information about the age, gender, diagnosis, and medications of these six patients and the characteristics of their lucid episode (e.g., telephone conversation with sister, bidding farewell to family).

It should be noted that most of the studies reviewed here investigated the occurrence of lucid episodes in confused patients with a wide variety of diagnoses. It is precisely the range of disorders in which terminal lucidity seems to occur that may hinder a better understanding of the phenomenon, insofar as it is not clear yet whether we are dealing with a uniform phenomenon across diagnoses or with several diagnosis-specific phenomena with similar phenomenology. In view of the fact that lucid episodes are frequently reported to precede the death of the patient, it cannot be ruled out that unidentified disease-specific or treatment-specific factors may be involved in the occurrence of such lucid episodes. If this were the case, the merging of cases with a wide variety of diagnoses might lead us erroneously to define as a single phenomenon with possibly a single explanation what actually are quite different phenomena.

Thus, in view of the relatively meager data, it is not yet entirely clear to what extent paradoxical lucidity and terminal lucidity are related. In their whitepaper on paradoxical lucidity, Mash-

our et al. (2019) suggested a narrow definition of paradoxical lucidity as an episode of “unexpected, spontaneous, meaningful, and relevant communication or connectedness in a patient who is assumed to have permanently lost the capacity for coherent verbal or behavioral interaction due to a progressive and pathophysiologic dementing process” (p. 1107). The last criterion, that is, the occurrence of lucid episodes at a time when the capacity of such cognitive lucidity is believed to have been permanently lost cannot be assumed in many of the more recent case studies reported above. Although, for example, both Macleod (2009) and Lim et al. (2020) reported isolated cases where neurological disease was the primary diagnosis, we do not have sufficient information on the extent of cognitive impairment associated with the disease, nor do we know whether the patient was “assumed to have permanently lost the capacity for coherent verbal or behavioral interaction.”

Against this background, the objective of the present study was to elucidate further the phenomenology and structure of paradoxical lucid episodes in a contemporary convenience sample of patients with dementia. This study presents new data, with enhanced information on the extent of cognitive impairment, from a larger sample than were reported by MacLeod (2009) and Lim et al. (2020).

Method

Survey of Paradoxical Lucidity in Dementia Patients

Based on pilot testing with a group of 20 formal caregivers (i.e., nursing staff and medical personnel) and 20 informal caregivers (i.e., relatives and friends of patients), we designed a questionnaire that was administered through the Internet utilizing software developed by Survey Monkey (<http://www.surveymonkey.com/>). Data were collected in two periods: (a) between June 1, 2013, and June 1, 2015, and (b) between May 1, 2017, and August 15, 2019.

A brief opening statement and the survey itself were posted online. Listings published in several directories of palliative care units, neurological clinics, hospices, and dementia care locations in Europe (Germany, Austria, Switzerland, Liechtenstein, United Kingdom, Neth-

erlands, France, Belgium, Luxemburg) and the United States were then used to identify health care units with significant clinical exposure to terminally ill patients with a diagnosis of dementia. Additional participants were recruited via posts on registered membership online forums for (a) hospice workers and nurses and (b) family members and other informal caregivers of patients with Alzheimer’s, other dementias, or other chronic neurological disorders. No remuneration was provided for completing the online survey.

The survey opened with a brief statement informing participants that they were taking part in a research study on lucid moments in patients diagnosed with dementia. Participants were then asked whether, in the past 12 months, they had first-hand experience with unexpected episodes of lucidity in patients with severe cognitive impairment, and if so, with how many. Those participants who replied that they had not witnessed unexpected return of mental faculties in at least one patient during the past 12 months were thanked and invited to provide their contact details for further information on the outcomes of our study.

Those participants who reported having directly witnessed unexpected return of mental lucidity in at least one of the patients in their personal care during the past 12 months were asked to provide further details about each individual case they witnessed. The majority of questions were in multiple-choice format, but questions that addressed quantitative data required the writing in of these numbers, and a number of questions allowed for additional free responses and comments. The survey was designed to assess information in the following domains: (a) age and gender of the patient; (b) diagnosis or cause of the patient’s cognitive impairment (open text field for free response); (c) degree of cognitive impairment on a typical day before the patient’s return to lucidity and clarity, with responses available in multiple choice format (1 = *normal cognitive status*; 2 = *minor difficulties in memory, attention, and focus*; 3 = *medium to marked difficulties in memory, attention, and focus*; 4 = *extreme difficulties in memory, attention, and focus*; 5 = *most or much of the time awake, but unresponsive*; 6 = *most or much of the time unconscious*; 7 = *other* [open text field for free responses]); (d) patient’s cognitive state during the episode (1 =

clear, coherent, and “just about normal” verbal communication; 2 = clear and lucid, but informant was not totally sure about coherence of verbal communications; 3 = clear and lucid, but largely incoherent in verbal communications; 4 = clear and apparently lucid, but non-verbal communication [gestures, gaze, etc.]; 5 = other [open text field for free responses or elaborations of rating]; (e) length of the lucid episode (1 = less than 10 min, 2 = between 10 and 30 min, 3 = between 30 and 60 min, 4 = several hours, 5 = approximately 1 day, 6 = several days); (f) temporal relationship of the lucid episode to death (1 = unknown; 2 = the patient did not die within 28 days of the lucid episode; 3 = the episode took place between 7 and 28 days before the person’s death; 4 = the episode took place between 4 and 7 days before the person’s death; 5 = the episode took place between 2 and 3 days before the person’s death; 6 = the episode took place between 2 and 24 hr before the person’s death; 7 = the episode took place less than 2 hr before the person’s death; 8 = other [open text field]) (See [online supplementary material](#) for the full survey).

To corroborate the data collected through the questionnaires, participants were asked to submit further confirmatory information where possible. In 17 cases, we received further information about the patient’s medical history and/or supplementary testimonies from additional witnesses of the lucid episode.

Descriptive statistics were applied to evaluate the obtained data using percentages based on the total number of replies within a category. Associations among variables were assessed with *t* tests, analyses of variance, and chi-square tests using SPSS Version 26.

Ethical Approval

Ethical approval was obtained from the Research Ethics Committee of the Viktor Frankl Chair of Philosophy and Psychology at the International Academy of Philosophy in the Principality of Liechtenstein. The study was carried out in compliance with the Helsinki Declaration of 1975, as revised in 2008. Participants provided informed consent online prior to completing the survey.

Data Availability Statement

All individual deidentified participant data, the study protocol, the study questionnaire, and the statistical analysis plan of this study can be obtained by a qualified investigator by contacting the corresponding author.

Results

Sample

In total, 221 respondents accessed the survey, of whom 187 completed it. Of those, 177 respondents reported having witnessed only one instance of terminal lucidity within the past 12 months, and an additional 10 reported having witnessed more than one instance. Some of these participants answered surveys for more than one case, resulting in detailed reports for a total of 197 cases.

Of the 197 cases of lucidity reported, 124 (72%) occurred in patients diagnosed with dementia. The diagnoses of the remaining 73 cases included cancer with cognitive impairment, traumatic brain injury, chronic obstructive pulmonary disease, heart failure, renal failure, liver failure, pneumonia, pulmonary embolism, mitochondrial myopathy, bipolar disorder, and cardiac arrest. We report here the findings among only the 124 cases in patients diagnosed with dementia. We will report findings among of the nondementia cases elsewhere.

Demographic Data

The sample included 72 women (58%) and 52 men (42%). The mean age of patients was 80.4 years (*SD* = 11.1; range = 33–100).

Clinical Data

The most common diagnosis among the 124 patients was dementia, not otherwise unspecified (45%), followed by Alzheimer’s disease (25%). The eight dementia diagnoses represented in this sample are listed in [Table 1](#) in order of frequency.

Assessment of the patients’ cognitive state on a typical day before the lucid episode was available for all 124 reports. Almost two thirds of the patients had been unresponsive (39%) or unconscious (27%) most of the time. The six catego-

Table 1
Clinical Characteristics of Cases (N = 124)

Clinical characteristics	n (%)
Diagnosis	
Dementia not otherwise specified	56 (45%)
Alzheimer's dementia	31 (25%)
Poststroke dementia	12 (10%)
Vascular dementia	9 (7%)
Parkinson's dementia	6 (5%)
Frontotemporal dementia	6 (5%)
Lewy body dementia	2 (2%)
AIDS-related dementia	2 (2%)
Cognitive status prior to lucid episode	
Normal cognitive status	0 (0%)
Minor difficulties in memory, attention, and focus	1 (1%)
Medium to marked difficulties in memory, attention, and focus	7 (6%)
Extreme difficulties in memory, attention, and focus	35 (28%)
Most or much of the time awake, but unresponsive	48 (39%)
Most of the time unconscious	33 (27%)
Cognitive status during lucid episode	
Clear, coherent, and "just about normal" verbal communication	98 (79%)
Clear and lucid, but respondent not entirely sure about coherence	16 (13%)
Clear and apparently lucid, but nonverbal communication only (e.g., apparently meaningful gestures, gaze)	9 (7%)
Clear and lucid, but largely incoherent verbal communications	1 (1%)
Length of lucid episode	
<10 min	20 (16%)
10–30 min	26 (21%)
30–60 min	19 (15%)
Several hours	33 (27%)
~1 day	13 (10%)
Several days	13 (10%)
Proximity to death	
Died more than a month after lucid episode	4 (3%)
Died within 8–28 days	4 (3%)
Died within 4–7 days	18 (15%)
Died within 2–3 days	28 (23%)
Died within 2–24 hr	51 (41%)
Died within <2 hr	18 (15%)
Missing information	1 (1%)

ries of cognitive state prior to the lucid episode are listed in Table 1 in order of severity of impairment.

Assessment of the patients' cognitive state during the lucid episode was also available for all 124 reports. Almost 80% of the patients were rated as "clear, coherent, and just about normal verbal communication" during the lucid episode. The four categories of cognitive state during the lucid episode are listed in Table 1 in order of severity of impairment. In terms of the duration of the lucid episode, the median value was between 30 and 60 min. The six categories of duration of the lucid episode are listed in Table 1 in order of length.

Information on the proximity of the lucid episode to the patient's death was missing for one patient with a diagnosis of frontotemporal dementia. For the remaining 123 reports, the median survival after the lucid episode was between 2 and 24 hr. The six categories of duration of survival after the lucid episode are listed in Table 1 in order of duration.

Associations Among Variables

Neither age nor gender of the patients was significantly associated with any of the clinical variables, with the single exception that the two patients diagnosed with AIDS-related dementia

were significantly younger (38.5 years, $SD = 7.8$) than those with any other diagnoses (81.1 years, $SD = 9.8$; $F = 5.80$; $df = 7, 116$; $p < .001$).

There were only two significant associations among the various clinical parameters assessed. First, those patients who had been unresponsive or unconscious prior to the lucid episode tended to have shorter lucid episodes than those patients who had been awake and responsive, despite cognitive impairments ($\chi^2 = 23.61$, $df = 10$; $p = .009$). Second, those whose lucid episodes lasted more than one day tended to live longer after the episode than those whose lucid episode lasted one day or less ($\chi^2 = 39.19$, $df = 5$, $p < .001$).

Discussion

Our goal in this study was to obtain a first approximate picture of paradoxical lucidity in dementia. There were several noteworthy findings in our study. Despite the fact that, prior to their lucid episode, more than 90% of the sample had been extremely impaired cognitively, almost 80% had lucid episodes that involved clear, coherent verbal communication that appeared “just about normal.” These expected lucid episodes usually lasted less than an hour, although 20% persisted for a full day or longer.

The finding that patients who had been unresponsive or unconscious prior to the lucid episodes tended to have shorter periods of lucidity is not unexpected, and may simply reflect those patients’ diminished cognitive reserve compared to patients who had been awake, despite extreme impairments in memory, attention, and focus.

Although earlier work assumed the temporal proximity of lucid episodes to death, fluctuations in cognitive function in the dementias that were unrelated to death have also been reported in the literature (e.g., Normann et al., 1998; Normann et al., 2006), although usually less pronounced and mostly in the early stages of dementia. It was therefore critical to investigate whether earlier reports of “terminal” lucidity did indeed capture a real phenomenon, rather than an epiphenomenon of case histories of transient lucidity that merely happened to have taken place close to the death of the patient. Our results suggest a strong association between unexpected lucidity and death. The temporal proximity to death was remarkably high in this study. More than two thirds of these pa-

tients died within two days of the lucid episode, and only 6% survived more than a week.

The finding that patients whose lucid episodes lasted more than one day tended to survive longer is not unexpected, and may reflect their increased vitality compared to patients with shorter lucid episodes. However, if that were true, then we might expect to find that patients with clearer cognitive states either before or during their lucid episode would survive longer, but that was not the case. The association between longer lucid episodes and longer survival may have a simpler explanation, bordering on tautological, namely, that patients who lived more than one day had more time to remain lucid than those who died within minutes or hours.

Cognitive fluctuations in the advanced dementias rarely, if ever, entail the often striking degree of return of cognitive function reported by our informants. More than 80% of the patients in this study appeared to have experienced a full, albeit brief, reversal of often profound cognitive impairment in advanced and end-stage dementia. Our data thus suggest the existence of a specific syndrome of death-related return of cognitive function and communication ability in patients whose diagnosis and disease stage renders such a return unlikely.

The association in this study between lucid episodes and imminent death should be interpreted cautiously, as 45 respondents (38%) found our questionnaire by learning about it in publications or lectures on “terminal” lucidity (all of whom reported one single case). However, the rate of cases of lucid episodes in temporal proximity to death did not differ significantly depending on the recruitment procedure of respondents: The rate of nonterminal paradoxical lucidity cases amounted to 2% in the sample of respondents recruited through information about “terminal” (rather than “paradoxical” lucidity), and 4% among the respondents recruited through other means. Our results thus suggest that paradoxical lucidity, broadly defined as unexpected lucid episodes in advanced dementia, shows some overlap with terminal lucidity, insofar as both appear to be death-related phenomena.

In their whitepaper on paradoxical lucidity, Mashour et al. (2019) point toward possible parallels between terminal lucidity and other unexpected arousal phenomena near death such as the near-death experience (NDEs). As several authors (Chiriboga-Oleszczak, 2017; MacLeod, 2009;

Mashour et al., 2019) point out, although the mechanisms of both NDEs and paradoxical lucidity are currently unknown, the two seem to share the phenomenon of unexpected cognitive arousal in the face of declining or compromised cortical function.

For example, Batthyány (2015) analyzed 653 NDE reports of cardiac and/or respiratory arrest patients for unprompted, spontaneous references to quality of conscious mentation during an NDE. Replicating earlier findings (Kelly, Greyson, & Kelly, 2007), in a majority of NDEs, both figurative and abstract mentation were reported to be either preserved or markedly improved.

Only further studies will be able to elucidate whether and which physiological or psychological mechanisms during the dying process might be involved in cognitive remission in previously cognitively impaired patients, and, importantly, whether and how these mechanisms might be utilized or activated by new therapeutic strategies for the dementias and other neurological disorders.

Additionally, future research will need to address a further fundamental question: whether the current model of the dementias as irreversible pathological processes can be upheld in view of the fact that a certain proportion of patients might, toward the end of their lives, experience terminal lucidity.

This study has a number of limitations. Participants in this study included not only professional medical personnel, but also informal caregivers, including family members. It is possible that the latter in particular are more emotionally involved and may therefore, over time, develop a comforting and embellished narrative of the lucid episode and death of their relative, which could bias the report and mitigate credibility. However, if this were the case, one might expect to find differences between the case reports provided by family members and by those provided by professional health care personal. Yet we found that informal and professional caregivers provided similar answers to the questionnaires.

Additionally, we tried to minimize the influence of memory distortions, known to increase with passing time, by limiting the time window between witnessing the episode and answering the questionnaire to a maximum of 12 months. Although the possibility of memory distortions cannot be ruled out even for this relatively brief time window, further probing suggested that the influence of memory distortions appeared to be lim-

ited. The questionnaires of the better documented cases (i.e., those reports which were accompanied by further corroborating medical records and additional witness reports) contained similar accounts as the less well documented cases.

The latter finding also addresses another limitation: the potentially memory biasing impact of the specific question about the temporal relationship between lucid episodes and death. Here again, however, the fact that a direct temporal relationship between the lucid episode and the death of the patient was noted also in each of the detailed case descriptions provided by health care professional speaks against the possible criticism that merely asking this question might have induced memory distortions. It does not, however, solve the problem of selection bias.

Lastly, our scoring dimensions of the cognitive state before and during the lucid episode were fairly crude and simple. Based on our pilot testing, we tried to develop assessment criteria that were both understandable and evaluable for both professional and informal caregivers, and indeed again found no substantial differences in the assessment of cognitive status as a function of the professional training of the caregiver. Clearly, however, future research would benefit from stratified assessment instruments to measure the degree of unexpected lucid episodes of the cognitively impaired.

Notwithstanding its limitations and shortcomings, the results of this study converge with reports of historical (Nahm & Greyson, 2009) and smaller contemporary case collections (Macleod, 2009) to the extent that they suggest that an unknown number of dementia patients appear to experience full spontaneous remission of their cognitive function and verbal ability shortly before their death.

Further research may not only help elucidate a better understanding of cognition at the end of life in general, but might also facilitate the identification of endogenous recovery mechanisms and the development of new treatment options for cognitive impairment in the dementias, and possibly a large variety of other debilitating neurological disorders as well.

With regard to the question of the generalizability of our findings, we found evidence reported by nursing staff and caregivers, that supports earlier reports both of terminal lucidity and of paradoxical lucidity. Furthermore, we received responses both from Europe and the United States, which, in

liaison with the fact that similar contemporary reports have been published about cases in New Zealand (MacLeod, 2009), Korea (Lim et al., 2020) and Africa (Onuigbo, 1998) enhances generalizability.

Conclusion

To summarize, our data suggest that, in our sample, episodes of unexpected lucidity in the context of severe neurological compromise appear to be a primarily death-related phenomenon. Drawing attention to this phenomenon will hopefully stimulate further research on terminal lucidity, in terms of both its neurobiology and its potential to inform clinical and palliative care for cognitively impaired patients and their caregivers.

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