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## Reports About Paradoxical Lucidity from Health Care Professionals: A Pilot Study

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### Abstract

Although clinicians caring for persons at the end-of-life recognize the phenomenon of paradoxical/terminal lucidity, systematic evidence is scant. This pilot study aimed to develop a structured interview instrument (referred to as measure below) for health care professionals to report lucidity. A questionnaire measuring lucidity length, degree, content, coinciding circumstances, and time from episode to death was expanded to include time of day, expressive and receptive communication, and speech during the month prior to and during the event. Thirty-three interviews were conducted; 73% reported ever witnessing paradoxical lucidity. Among 29 events reported, 31% lasted several days, 20.7%, 1 day, 24.1% less than 1 day. In 78.6%, the person engaged in unexpected activity; 22.2% died within 3 days and 14.8% within 3 months of the event. The phenomenological complexity of lucidity presents a challenge to elicit reports in a systematic fashion; however, staff respondents were able to report lucidity events and detailed descriptions of person-specific characteristics.

### Keywords

lucidity; end-of-life; measurement; dementia; neurological disease

There have been reports of lucidity in dementia, particularly in the late stages. This phenomenon has been referred to as *terminal* or *paradoxical lucidity* (PL) and defined as “the (re-) emergence of normal or unusually enhanced mental abilities in dull, unconscious or mentally ill patients shortly before death” (Nahm, 2009). There are few studies of the clinical phenomenon of PL. Geriatricians, nursing professionals and other clinicians caring for these patients immediately recognize the phenomenon when it is explained, but there is scant systematic evidence on this topic.

The formal literature on PL addresses nurses and caregivers’ personal knowledge of end-of-life experiences in dying people and lucidity in people with dementia. Information on terminal lucidity from a historical perspective relates to case studies of patients with mental disorders (Chiriboga-Oleszczak, 2017; Macleod, 2009; Nahm, 2009, 2011; Nahm & Greyson, 2009; Nahm et al., 2012). Chiriboga-Oleszczak (2017) identified *terminal lucidity* as a “well-known phenomenon for 19th century physicians” (p.35) but suggested that description of this phenomenon had almost disappeared in the 20<sup>th</sup> century. Nahm (2009) found 80 mentions of terminal lucidity by 50 different authors (physicians and psychiatrists), written in German or English dating from the 19<sup>th</sup> century. Noteworthy is that the term lucidity has been defined to include decision-making capacity with respect to discharge planning, resuscitation, financial planning, selecting a power of attorney, etc. (Lim et al., 2014). Another definition is return to consciousness among individuals without dementia.

Several recent studies have identified terminal lucidity as one aspect of end-of-life experiences reported by nurses/caregivers (Brayne et al., 2008; Claxton-Oldfield & Dunnett, 2016; Fenwick et al., 2010; Lim et al., 2018). In a study of older people living in a nursing home, Brayne et al. (2008) reported on end-of-life experiences discussed by 10 staff, such as older people having dreams that helped them prepare for death. Lim et al. (2018) conducted a 12-month retrospective medical records review of 338 deaths; three levels of consciousness among terminally ill patients were identified as occurring within 28 days of death: alert, unconscious, or sedated. Of the 151 patients who died in the wards, six patients (4%) experienced terminal lucidity, all dying within nine days of the event. Macleod (2009) attended 100 deaths in a hospice and observed six episodes of what he called ‘lightening-up’ in the last two days of life. The periods of lucidity lasted less than twelve hours. None of the patients had dementia but were in various stages of unconsciousness before the lucidity occurred.

Lucidity in people with dementia has been studied by asking nurses if they had observed events in which persons with dementia ‘appeared unexpectedly clear’ (Brayne et al., 2008; Fenwick et al, 2010; Normann et al, 1998). In a study of older people living in a nursing home, seven of the ten staff interviewed reported that older people who were unconscious or confused became unexpectedly lucid before they died and were able to interact with carers (Brayne et al. 2008). Fenwick et al. (2010) interviewed 38 carers for a 5-year retrospective study and 30 of the same carers were interviewed in a 1-year prospective study on end-of-life experiences. The one item relevant to terminal lucidity was “A patient, who has been in a deep coma, suddenly becomes alert enough to coherently say goodbye to loved ones at the bedside”. About one third (31%) of carers in the five-year study and 79% in the one-year study, responded positively to the item.

Normann et al. (2002, 2005) published a case study of one woman with dementia, with whom they met for 20 hours over two weeks. These authors concluded that lucidity was “prompted by the conversational parties carefully focusing on topics initiated by the woman” (p. 895). Additionally, Normann et al. (2006) examined the frequency of occurrence and characteristics of people with severe dementia who, as described by caregivers, exhibit lucidity episodes. The Multi-Dimensional Assessment Scale with additional questions on lucidity episodes was used by staff to assess 3,804 nursing home residents. Ninety-two of these residents evidenced severe dementia and verbal communication issues, and fifty-two were reported to experience lucidity episodes. These residents evidenced higher “orientation” scores, were classified as more “emotional”, and took more outdoor walks with their carers than did those without lucidity episodes. An internet survey of paradoxical lucidity was conducted in Austria, Germany, and Switzerland in two time periods (between June 1, 2013 and June 1, 2015, and between May 1, 2017 and August 15, 2019) among 900 nursing and medical staff in palliative care units, neurological clinics, hospices, and dementia institutions (Battyány & Greyson, 2021). The question posed was: “In the past 12 months did you ever observe an unexpected return to clarity and cognitive function in your Alzheimer’s disease or dementia patients?” According to reports from 187 respondents, 124 persons with dementia experienced an episode of paradoxical lucidity. Data suggested that a proportion of dementia patients seem to experience full lucidity events close to the end of life. Among the patients with dementia and PL, 97% experienced the event 7 days or less before death.

Finally, a workshop convened by the National Institute on Aging in June, 2018 described the scant empirical evidence, and the challenges in researching this topic (Mashour et al., 2019). Stronger evidence is needed to establish the existence and understand the phenomenon of lucidity. The pilot study described here represents a preliminary step in this process.

## Aims

The aim of this pilot project was to develop a measure to assess the phenomenon of PL, also described as lucidity events, as reported by health care professionals specializing in dementia and neurological impairment. The goal was to determine the feasibility of obtaining systematic descriptions from formal staff caregivers of their experiences with unexpected lucidity by conducting individual interviews using a standard set of questions. This paper presents the first stages in the development of the lucidity measure and describes the findings of the pilot project.

## Method

### Definition

Although researchers use the term paradoxical lucidity, it is not understood readily by many front-line workers; thus, in our pilot work, the terms ‘lucidity event’ or ‘lucidity’ were used. Based on a review of the definitions extant for paradoxical lucidity (see Eldadah et al., 2019; Mashour et al., 2019; Peterson et al., 2021), the following definition was developed for use in this study: “unexpected episodes of spontaneous mental clarity such as the ability to

communicate in persons who had seemingly lost such abilities. This could include return to a higher level of communication, even if for a brief period”.

## Measure

The purpose of the development of the Lucidity in Dementia and Neurological Impairment measure was to construct an item set that could be administered by a researcher to front-line staff about lucidity events observed among their current and past patients. The targeted staff included certified nursing assistants, nurses, social workers, occupational and physical therapists. The domains of interest, in addition to the description of the event, were expressive and receptive communication, speech, and behaviors exhibited prior, during and after the event.

Because no such measure existed, it was necessary to construct a pool of items that could be modified for the intended purpose. The method was to review the literature and identify item sets that had been used in previous research, and to use expert review to suggest modifications to these items for use with front-line staff. The project’s measurement team identified domains from the literature and focused on obtaining granular information about lucid events. All iterations and modification were adjudicated by consensus of the research team.

Thus, in preparation for the pilot work, the 6-item questionnaire developed by Batthyány (Batthyány & Greyson, 2021) was translated from German into English by a native German speaker who is fluent in English. Modifications were made to the first six items relating to diagnosis, length of observed lucidity, degree of lucidity, content of spoken communication, coinciding circumstances, and length of time from the lucid episode to death. Several iterations were developed prior to testing. The first version contained 14 items, with one open-ended item to describe the event, including what was said and done during the event. There was a list of potential circumstances that may have occurred near the time of the event (e.g., visitor, medical event). Subsequent iterations contained reformatted items such that individual events were described in sequence from most to least recent. Space was added to record information about the 2<sup>nd</sup> and 3<sup>rd</sup> occurrences of lucidity observed by the care provider, either in the same or different individuals for whom s/he provided care. Additional items related to the lucidity event include identification by the observer of the time of day that the event began, and if any other unexpected activity, e.g., singing or playing an instrument, occurred during the event. Fifteen binary items related to expressive and receptive communication, and speech in the month prior to and during the lucid event were added to ascertain the specific functions impacted during the lucid event. Nine items to assess capability in the areas of mental clarity, ability to respond to stimuli, and communicate in the month prior to and during the event were added. The items were rated on a scale from 1 – 5 where 1 is *complete lack of ability*, 3 is *moderate ability*, and 5 is *complete ability*. Examples of items indicating more severe dysfunction include, “Make needs known”, and “React to family member’s presence”.

Five patient-level (gender, age, race, ethnicity, education) and nine informant-level demographic items (e.g., age, race, ethnicity, profession) were added to the questionnaire. These items were obtained from the informant or if not known by the informant by review of

the medical record. The measure contains approximately 200 closed-ended items, and takes about 20 minutes if no events are recorded. If one or more events are reported, the interview could take one hour or longer.

### Procedures and Sample

A registered nurse who was also a doctoral student, supervised by a geriatric nurse researcher, conducted 33 interviews with two physicians, a nurse practitioner, 17 registered nurses (RNs), five licensed practical nurses (LPNs), two certified nurses aides (CNAs), a social worker, and five physical therapists working at hospitals (5), private offices (1), nursing homes (24) and assisted living facilities (3). See Table 1. Interviews were conducted in-person between August and November, 2019.

### Analyses

Because of the small sample size for this pilot study, only means, standard deviations, and percents were provided.

## Results

### Characteristics of the Informant Sample

Shown in Table 1 are the characteristics of the staff informants who reported on the lucidity events experienced by the patients for whom they were providing care. Years of staff experience in health care ranged from 3 to 32 ( $M = 11.6$ ,  $SD = 8.3$ ). The majority reported that they were Asian (51.5%) or Black (30.3%). Nearly half the sample (46.3%) was over age 45 (range 25–74 years). The mean hours worked per week was 40.

### Characteristics of the Patient Sample

The persons experiencing an event tended to be female (53.6%), White (64.3%), non-Hispanic (77.8%), with an approximate mean age of 75 years (Table 2). About 63% of the persons experiencing an event were still living at the time of the interview, about 22.2% died within 3 days of the event, and 14.8% died approximately 1 week to 3 months after the event. Most ( $n = 12$ ) were reported to have Alzheimer's disease while the rest were reported to have vascular dementia ( $n = 5$ ) or "other dementia" ( $n = 7$ ). Another thirty-six percent ( $n = 10$ ) reported patients with other neurological impairments (e.g., stroke, traumatic brain injury; Table 2).

### Characteristics of the Lucidity Event

Most respondents ( $n = 24$ ) reported that they could recall at least one of their patients with dementia or neurological disorder experiencing a lucidity event. While most respondents indicated one person with this experience, one health care professional reported five persons and one reported "25–30%" of those for whom they have provided care. This surprisingly high number (73%) was because respondents were asked to report on any such experiences without reference to a timeframe and the likelihood that not all reports would be adjudicated as cases. This resulted in reports of 28 unique patients with lucidity events; staff reported one patient with two events (29 total events).

Among 29 lucidity events reported, in almost half (48.3%), the person returned to full lucidity (Table 3). Thirty-one percent ( $n = 9$ ) of the events lasted for several days followed by 24.1% that lasted 31 minutes to 1 hour, and 20.7% that lasted for one day. Most of the events (44.8%) occurred in the morning while 34.5% did so in the afternoon. The person spoke in all events and in 78.6% ( $n = 22$ ) of events the person engaged in unusual and unexpected activity such as singing or playing an instrument.

### **Expressive Communication and Speech**

As shown in Table 4, in the month prior to the event, most persons were reported to demonstrate considerable impairments in expressive communication. For example, 55.2% were reported as exhibiting unclear speech and were understood only with difficulty; 58.6% repeatedly struggled to find the right word to use or used the wrong word; 13.8% used only gestures, grunts, or primitive symbols to communicate; 51.7% did not convey their needs; 17.2% said nothing or only moaned; and 20.7% repeated one or two words. In contrast, during the event, few were reported to experience any problems; for example, 0% were reported to have unclear speech and were understood only with difficulty, 0% did not convey their needs, 0% said nothing or only moaned, and 3.4% repeated one or two words.

### **Receptive Communication**

Similarly, in the month prior to the event, many were reported to demonstrate receptive communication impairments, but few demonstrated problems during the event. For example, 65.5% were reported to have difficulty understanding people when they spoke and 17.2% did not understand any type of communication in the month prior to the event compared with 20.7% and 3.4% respectively during the event (Table 4).

### **General Abilities to Respond to Family and Staff and Make Needs Known**

The person's general abilities were often reported as impaired in the month prior to the event while these abilities were not impaired during the event. While items were rated on a scale from 1–5, responses 1 and 2 were collapsed into *lack of ability* and 3 – 5 into *ability*. Examples include 65.5% versus 0% were reported to lack mental clarity, 62% versus 0% could not talk in complete sentences, 67.9% versus 9.7% could not make needs known, and 44.8% versus 17.2% could not respond to staff requests in the month prior versus during the event, respectively (Table 4).

### **Examples of Lucidity Events**

The informant was a physical therapist describing an event within the past month of the interview. The person had a diagnosis of mixed Alzheimer's disease and Cerebrovascular Accident with severe cognitive impairment. The lucidity episode was observed by the therapist and family and lasted 1–3 minutes. The person was reported to have been noncommunicative with restricted or no speech and could not convey her needs. Her limited verbal responses were completely off-point. During a visit by family, the person was suddenly able to communicate and respond appropriately. She talked about significant people, places, and life events that family remembered, both positive and negative. There

was an increase in clarity of thought and the person suddenly remembered how to play an instrument. The person died one week later.

A second example was a nursing home resident with a reported diagnosis of vascular dementia who was nonverbal. The LPN informant (in a nursing home) and another staff member observed a period of lucidity lasting several days. The resident suddenly became verbal, asking for water. During the event the 95-year-old woman returned to a more lucid state and was able to speak. Prior to the event she was reported to have no speech. She died within three months.

The last example was reported by an RN describing a 55-year-old woman with traumatic brain injury living in a nursing home. The incident was observed by the RN, other staff and family. The person was non-verbal and did not respond to anyone; she was described as 'comatose'. However, one rainy day, the RN told the woman that her husband was not coming due to the rain. Suddenly she began speaking and talked about her husband clearly. She started participating in her own care and even laughed. She went from complete lack of ability to fully communicative. The episode lasted several days. The woman was still living at the time of the interview.

## Discussion

The present study expands existing work describing the construct of lucidity by providing a pilot study of the feasibility of assessing paradoxical lucidity systematically using a standardized interview methodology with formal caregivers. The data demonstrated the feasibility of using an informant-reported measure of lucidity events. The participation of a range of different types of health professionals working in various long-term care settings provided the opportunity for a broad perspective with respect to witnessing and describing lucidity events, thus informing the pilot measure development. In this study 57.6% had 10 years or more of experience caring for persons with dementia, enhancing their ability to provide information about lucidity events. Consistent elements from the description of lucidity events emerged from these interviews, including characteristics of those experiencing the events, the length and time of occurrence, and behaviors observed.

The majority of respondents reported ever witnessing at least one incident of a person experiencing paradoxical lucidity, corroborating the notion that it is a recognized phenomenon by caregivers (Mashour, 2019; Normann et al., 1998). Similar to prior findings (Macleod, 2009; Nahm et al., 2012), reports by respondents suggested that some persons experiencing lucidity were close to the end of life (37% died 3 months or less after the event). Because over half (63%) of those experiencing an event were still living at the time of report, findings also suggest the possibility that some individuals could show lucidity at different points across the continuum of dementia (Lee et al., 2012, 2014; Normann et al., 2006). Noteworthy are salient features of the events reported, i.e., the person spoke in all events, and the majority (79%) engaged in an unexpected activity, consistent with examples in the literature (Batthyány & Greyson, 2021; Kheirbek, 2019; Nahm et al., 2012; Normann et al., 2002; Peterson et al., 2021). Findings also highlighted the phenomenological complexity of paradoxical lucidity with regard to the variety of

elements that must be captured and documented in order to conceptualize, define, identify, and describe behavioral correlates of lucidity (see Gilmore-Bykovskiy et al., 2021). This complexity presents a challenge in terms of eliciting reports in a systematic fashion from a variety of informants, including front-line staff. This pilot study demonstrated that the construct of lucidity may encompass more than verbal communication, including non-verbal communication, participation in activities, such as playing an instrument, and ability for self-care and mobility.

A more accurate assessment and representation of lucidity is necessary to lead to insights into the neuroprocessing underlying this phenomenon (see Morris & Bulman, 2020). Long-term goals that could emerge from future studies of lucidity include educating families about PL, and the development of staff training interventions to enhance lucidity recognition and reporting. By studying the circumstances of such occurrences, it may be possible to determine situations that could trigger these incidents. As potential precursors and circumstances associated with lucidity are better understood and documented, they could prove existentially meaningful for both the person and caregivers. Staff and family caregivers can be involved as witnesses and thus, lucidity events might provide the opportunity for a mutually comforting interaction between the person and the caregiver, offering an invaluable sense of reassurance and support for closure at the end of life.

Study limitations include the use of a convenience sample. Thus, the findings may be only locally generalizable; however, there were a range of reporters from different disciplines and settings, which added to the strength of the findings. The project coordinator recruited all professional health practitioners; thus, there is the potential for selection bias. Additionally, these participants probably witnessed a cross-section of lucidity events, and their report may be based on a limited sample of older adults with cognitive impairment determined by their respective professional specialties. However, the average patient panel size per informant was about 400; thus, representing a relatively large number of individuals. These data do not permit definitive conclusions regarding quantitative aspects (e.g., incidence, prevalence, frequency of occurrence) or qualitative features (e.g., time of occurrence, preceding factors) of paradoxical lucidity. However, the study provides pilot evidence of the feasibility of obtaining staff reports of lucidity and informs the further development of a measure. Although about half of the events occurred within 12 months of the interview, it is acknowledged that the recall of communication, speech, and behavior as well as the circumstances of the event could be less accurate for events reported in the more remote past. However, it was demonstrated that staff were able to report having witnessed the phenomenon, providing detailed descriptions of its characteristics, and of those who experienced it. This early research may lead to better understanding and measurement of lucidity events. As highlighted by Batthyány and Greyson (2021), the promotion of systematic studies about paradoxical lucidity will facilitate the identification and examination of the physiological and/or psychological mechanisms operating in the recovery of cognitive functions among those cognitively impaired persons who experience such events at the end of life. Such an understanding may result in the development of evidence-based clinical and therapeutic interventions that may benefit individuals suffering from dementia and/or neurological conditions and their caregivers.



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**Table 1**

## Demographics of Unique Staff Members (N = 33)

	<i>n</i>	%
Profession		
Physician	2	6.1
Nurse Practitioner	1	3.0
Registered Nurse (RN)	17	51.5
Licensed Practical Nurse (LPN)	5	15.2
Certified Nurse's Aide/ Home Health Aide	2	6.1
Social Worker	1	3.0
Physical Therapist	5	15.2
Primary Appointment Location		
Hospital	5	15.2
Private office	1	3.0
Nursing home	24	72.7
Assisted living facility	3	9.1
Hours spend in clinical practice (work) per week [mean, (SD)] (min=35; max=60)	33	40.03 (5.90)
Approximate number of patients in panel/ practice/ facility [mean, (SD)] (min=4; max=520)	32	382.44 (216.41) <sup>a</sup>
Approximate number of years of clinical experience [mean, (SD)] (min=3; max=32)	33	11.56 (8.35)
Gender		
Male	11	33.3
Female	22	66.7
Age Group		
25–34	12	36.4
35–44	6	18.2
45–54	9	27.3
55–64	4	12.1
65–74	1	3.0
Refusal	1	3.0
Race/Ethnicity		
Asian	17	51.5
Black	10	30.3
White	3	9.1
Other/More than one race	3	9.1
Hispanic or Latino descent		
Yes	3	9.1
No	30	90.9

<sup>a</sup>The large number reflects the larger patient panels of certain providers, e.g., physicians and social workers.

**Table 2**

## Demographics of Unique Persons with Lucid Events (N = 28)

	<i>n</i>	%
Age at time of incident [mean, (SD)]	28	74.86 (14.42)
Gender		
Male	13	46.4
Female	15	53.6
Race/Ethnicity		
White	18	64.3
Black	3	10.7
Asian	2	7.1
Other	5	17.9
Hispanic or Latino descent		
Yes	5	18.5
No	21	77.8
Unknown	1	3.7
Education		
High school/GED	4	14.3
BA/BS/Other Bachelor's	7	25.0
Doctorate (PhD, MD, JD, Other)	1	3.6
Other non-US degree	1	3.6
Don't know	15	53.6
Diagnoses <sup>a</sup>		
Alzheimer's disease	12	42.9
Other dementia	12	42.9
Parkinson's disease	2	7.1
Other	10	35.7

<sup>a</sup>Diagnoses are not mutually exclusive. Percents are for 'yes' (versus no)

**Table 3**

Degree of Lucidity, Length of Event, Time of Occurrence (N = 29 events)

Variable	n	%
Degree of lucidity during the lucidity event		
Return to full lucidity, no noticeable impairment	14	48.3
Return to lucidity but tired due to the illness or limited in a different way	9	31.0
Noticeably impaired in memory, rational thinking or communication skill, but significantly more lucid than before	6	20.7
Length of duration of observed lucidity event		
Under one minute	2	6.9
1–3 minutes	1	3.4
8–10 minutes	1	3.4
11–30 minutes	2	6.9
31 minutes to 1 hour	7	24.1
Several hours	1	3.4
One day	6	20.7
Several days	9	31.0
Time of day when event began		
Morning	13	44.8
Midday	2	6.9
Afternoon	10	34.5
Evening	3	10.3
Unknown	1	3.4

**Table 4**

Expressive, Receptive, and General Abilities of Persons Prior to and During Lucidity Events (N = 29 events)

Variables	1 Month prior to event	During the event
Expressive communication and speech	(n) %	(n) %
Unclear speech and were understood only with difficulty	(16) 55.2	0
Repeatedly struggled to find right word to use, or used wrong word	(17) 58.6	0
Used only gestures, grunts, or primitive symbols to communicate	(4) 13.8	(1) 3.4
Did not convey their needs	(15) 51.7	0
Had rapid speech that was difficult to follow	(2) 6.9	0
Had speech that contained very long pauses	(7) 24.1	(1) 3.4
Had speech restricted in quantity	(13) 44.8	(5) 17.2
Had speech that was rambling, incoherent or irrelevant	(10) 34.5	0
Had slurred speech	(4) 13.8	0
Said nothing or only moaned	(5) 17.2	0
Repeated one or two words	(6) 20.7	(1) 3.4
Receptive communication		
Difficulty understanding people when they spoke	(19) 65.5%	(6) 20.7%
Understood by depending on lip reading, written materials, or structured sign language	(2) 6.9%	0
Understood only primitive gestures, facial expressions, simple pictograms and/or recognized environmental cues	(3) 10.3%	(4) 13.8%
Did not understand any type of communication	(5) 17.2%	(1) 3.4%
General abilities <sup>a</sup>		
Lack mental clarity	(19) 65.5%	0
Lack of ability to communicate	(17) 58.6%	(1) 3.4%
Could not talk in complete sentences	(18) 62%	0
Could not speak in short phrases	(18) 62.1%	0
Could not make needs known	(20) 67.9%	(3) 9.7%
Could not point to objects	(15) 51.7%	(2) 6.9%
Could not react to family members presence	(8) 27.5%	(9) 31.1%
Could not respond to family	(11) 37.9%	(9) 31%
Could not respond to staff requests	(13) 44.8%	(5) 17.2%

<sup>a</sup>5-point value range dichotomized to *lack of ability* and *ability*