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## The Impact of Episodes of Lucidity on People Living with Dementia and Their Caregivers: A Case Report

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### Abstract

People living with dementia (PLWD) may experience episodes of lucidity (ELs), defined as a sudden return of abilities presumed to have been lost and presenting as meaningful communication and connection. Early research on ELs in advanced disease stages suggests these are predominantly positive events. This case report draws from one outlier case from a descriptive qualitative study on caregivers of PLWDs' experiences with ELs. The caregiver reported events perceived as an EL being accompanied with unexpected self-awareness, leading to a negative emotional reaction and feelings of loss. This case report contributes insights to current understandings of ELs as exclusively relevant in advanced stages of dementia, as similar events may present in earlier disease stages; and may be associated with negative emotional experiences among PLWD. Future research is needed to consider ethical implications surrounding ELs and to support caregivers in anticipating and responding to ELs.

### Keywords

Dementia; Lucidity; Self-awareness; Neuroethics

### Background and Methods

The cognitive and functional losses associated with Alzheimer's disease and related dementias are generally thought to be progressive and irreversible. While there is no universal definition for the phenomena, episodes of lucidity (ELs) have been described by an interdisciplinary workgroup of researchers convened by the National Institute on Aging (NIA) as spontaneous and transient returns to prior levels of functional or communicative abilities have been reported, although their underlying mechanisms, course, and presentation remain poorly understood.<sup>1–5</sup> Recent studies focused on appraising caregiver experiences with ELs have found that while caregivers largely view ELs as positive moments, some

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reported mixed feelings or greater stress following ELs.<sup>6,7</sup> As research on ELs is in very early stages, reports elucidating the full range of potential impacts of ELs on people living with dementia (PLWD) are lacking despite being essential to preparing caregivers to respond to ELs and anticipate potential consequences of interventions that may attempt to stimulate ELs.

The present case report draws from one outlier case event that arose from a descriptive qualitative study examining caregivers' experiences with- and perceptions on ELs.<sup>6</sup> The caregiver in this case did not meet inclusion criteria for the primary study as their care recipient did not meet the conservative cut-off of a Clinical Dementia Rating (CDR) scale score of 2–3 indicating moderate to advanced impairment while the primary study investigated more advanced stages.<sup>8</sup> The care recipient had specific retained strengths in the domains of Memory, Community Affairs, Homes and Hobbies, Personal Care and moderate severe deficits in domains of Judgement/Problem Solving and Orientation (Table 1) leading to a more conservative global score of 1 (mild impairment). While this caregiver's data was excluded from analysis for the primary study, the caregiver expressed strongly that they had a relevant story to share regarding an EL and were still interviewed. Per caregiver report, the PLWD experienced increased insight into the degree of their impairment during ELs resulting in a negative emotional reaction for both the caregiver and PLWD; a distinct feature only mentioned once in the larger study including people with CDR scores indicating moderate-severe dementia.<sup>6</sup> This case expands on current evidence, suggesting that ELs may present along a continuum as individuals progress toward more advanced dementia – potentially presenting earlier – and that some ELs may result in a broader range of reactions for both PLWD and their caregivers.

## Case Report

This study reports the case of Berenice (pseudonym), a 72-year-old woman, and Arthur (pseudonym), a 72-year-old man living with mild Frontotemporal Dementia, Primary Progressive Aphasia, and Capgras syndrome. Berenice is wife to Arthur and has been his primary caregiver for three years. Arthur's CDR interview revealed substantial difficulty with orientating himself to time and place as well as handling problems and social judgement, and mild impairments in memory, community involvement, housework, and personal care (Table 1).

Data for this case report comes from an interview with the caregiver and primary study investigators. During the time of the interview, Berenice was made clear that there is currently no uniform definition for ELs, using a standardized prompt: "Though there is no one definition for episodes of lucidity, they are generally understood as a transient return of abilities seen as a shift in awareness, clarity or communication abilities experienced by someone living with dementia after they appear to have lost such abilities." In response to this prompt, Berenice described Arthur as a fluent communicator, but had difficulty remembering who people are or who he is:

"He actually 80% of the time speaks very fluently. So it's not going from being mute to talking. But what it is, is what he's talking about. Does he understand

daytime place? Does he know who I am? Does he know who the neighbors are? And usually he doesn't."

Arthur was described as needing frequent orientations to remember daily tasks:

"Every day is like Groundhog's Day, having to orient him. In fact, even OT [occupational therapy] said do three orientation things with him every day, and so we do. And, you know, and then 10 minutes later, he'll say, okay, what are we doing today? And I said, well, it's written on the wall. We just talked about it."

Berenice contrasted Arthur's typical fluctuations in comprehension and orientation with times where Arthur accurately recognizes communication partners and generally increased cognitive awareness. While the study team did not clarify with Berenice if Arthur's Capgras syndrome resolved during these times of increased ability to recognize others, Arthur was able to correctly identify people without mention of an imposter:

"But then every now and then he'll go, oh, yeah, that's [Neighbor's Name], you know, lady next door. But it's real... a little more clarity."

In contrast to these fluctuations in cognition, Berenice additionally described moments where Arthur's periods of greater clarity and awareness were significant and extended to introspection of himself. These moments were emotionally charged, particularly as Arthur became aware of and acknowledged the degree of his cognitive impairment. Berenice told the interviewer that during these periods of heightened awareness, Arthur frequently states that he "*would like to die*" and noted that he "*gets sad*" after episodes of increased awareness:

"When he will be very insightful... he said, I really only want to live another five or 10 months, this isn't worth it. And even prior to that, like maybe a month or two, maybe two months ago, I even videotaped him, because he kept saying over and over, I really I would like to die and nobody gets in trouble for it. So he is insightful, he knows. And he'll say this, "my brain doesn't work." You know, and then so why should I continue on?"

As the focus of interviews were on understanding the lucid event, the study team did not confirm with Berenice if Arthur experienced suicidal ideation in the absence of self-awareness, although Arthur's suicidal ideation appeared to predominately occur with statements on his perceived declining cognitive abilities. When asked if anything precipitates Arthur's self-awareness, Berenice indicated internal factors, such as being calm and less stimulated may increase the likelihood of these periods of increased self-awareness.

## Discussion

This case sheds light on negative emotional reactions that may be associated with ELs when a defining feature is a spontaneous recovery of insight, which may have implications for efforts to understand potential consequences of interventions to stimulate lucidity. While routine cognitive fluctuations are a well-documented feature of dementia, ambiguity remains regarding when more remarkable recovery of abilities inconsistent with one's range of routine fluctuations, such as in this case, are interpreted as distinct events or hold specific

ethical implications associated with the magnitude of shift in abilities experienced by the PLWD.<sup>9</sup>

With disease progression, PLWD exhibit anosognosia wherein they lose insight regarding their condition and associated changes in their memory.<sup>10</sup> Insight, or self-awareness represents knowledge of aspects of the self, including current functioning or the changes that have occurred to the self over a period.<sup>10</sup> Prior research suggests changes to self-awareness occur independent from deficits in other cognitive and functional abilities, and that higher self-awareness of cognitive impairment in PLWD may be associated with lower optimism, self-efficacy, and self-esteem.<sup>11</sup> Collectively, these findings suggest that caution is merited in determining appropriateness of efforts to further elicit ELs for different individuals and situations, with attention to the risk for distress to the PLWD. Interestingly, meta-awareness, defined as: “insight into one’s own condition,” has been proposed to be a defining characteristic of ELs.<sup>2</sup> Meta-awareness may be a defining characteristic of lucidity in earlier stages of dementia when the PLWD still has retained functional and communication skills. It is important to note, however, that individuals in later stages of dementia may or may not experience similar increases in meta-awareness but demonstrate difficulties in communicating these experiences.

This case report may contribute valuable insights into ongoing work defining and conceptualizing lucidity, suggesting that ELs may not present uniformly in PLWD but, consistent with cognitive changes, may emerge along the continuum of worsening decline. As there is currently no universally accepted definition for ELs, there is ongoing discussion about the defining characteristics that constitute an EL.<sup>5</sup> Multiple definitions have been presented in published literature, and the distinction between paradoxical and/or terminal lucid episodes in particular is an active area of discussion.<sup>12</sup> A widely circulated definition from the NIA Workshop on Lucidity in Dementia highlights paradoxical lucidity as “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.”<sup>1</sup> Peterson and colleagues critically analyzed this definition’s criterion of *spontaneity, meaningful and relevant, and communication and connectedness*, arguing that these various criterion require further study and clarification.<sup>4</sup> More recently, attention has been paid to the importance of clarifying the meaning and definition of lucid episodes that are paradoxical, which implies the presence of an irreversible neurodegenerative brain condition that is inconsistent with observed mental lucidity.<sup>12</sup> Additionally, a preliminary research framework for investigating lucidity in dementia broadly states that restricting inquiry into lucidity to “remarkable” and “spontaneous” events in advanced dementia may prematurely narrow the definitional scope of what is and what is not an EL.<sup>5</sup> A more general definition for EL was provided by Norman and colleagues, who define an EL as an episode where the person appears to be more aware of their situation and function more adequately than usual, which is surprising to observers.<sup>3</sup> It is possible that a broader definition for lucidity as a phenomenon with various presentations (paradoxical, terminal, and other) may be more appropriate in these early stages of investigating lucidity, as the findings from this case report suggest that the specific ways that ELs are manifested may be diverse, and may

present differently in people living with mild dementia compared to people living with severe dementia.

As a potential first step towards enhancing definitional clarity of ELs, future research may look to differentiate ELs from cognitive fluctuations. Cognitive fluctuations are described as “alternating periods of cognitive impairment and normal or near-normal performance and pronounced variations in attention and alertness.”<sup>13</sup> Cognitive fluctuations have been more rigorously studied and documented than ELs, specifically described as a core feature of dementia with Lewy Bodies.<sup>13</sup> Perhaps attributable to lack of clear definitions and measures for ELs, there is currently no clear conceptual boundary between cognitive fluctuations and ELs and it remains unclear if there are physiological or biological differences between the two phenomena. The lack of a clear definition for ELs raises important methodological considerations as broader definitional boundaries may make it increasingly challenging to disambiguate ELs from cognitive fluctuation, yet a narrow and specific definition for ELs risks excluding related experiences at this preliminary stage in research.<sup>5</sup> It is clear from this case report that moments perceived as ELs are significant to both the PLWD and their caregivers. As the most proximal to ELs and experts in their own experiences, PLWD and their caregivers are critical informants to appraise ELs, and their perception of ELs should be taken into serious consideration when defining what constitutes an EL.

This report provides insight into situations where lucidity in dementia may be viewed as having a negative impact on PLWD and their caregivers. Clinicians and researchers should anticipate that responses to ELs may be varied. Further research is needed to understand how clinicians and researchers can support and prepare caregivers in the event they experience an EL.

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**Table 1.**

Arthur's Clinical Dementia Rating (CDR) Scores

<b>CDR Domain</b>	<b>Score</b>
<i>Memory</i>	1
<i>Orientation</i>	2
<i>Judgement and Problem Solving</i>	2
<i>Community Affairs</i>	0.5
<i>Homes and Hobbies</i>	1
<i>Personal Care</i>	1
<b>Total Score</b>	1

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