Caregiver Accounts of Lucid Episodes in Persons with Advanced Dementia

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Abstract

Background and Objectives: Paradoxical lucidity is defined as an instance of unexpected lucid behavior in a person who is assumed to be noncommunicative due to a progressive and pathophysiologic dementing process. To inform studies of the prevalence, characteristics, and impact of these behaviors, this interview study examined caregivers’ experiences of witnessing paradoxical lucidity.

Research Design and Methods: Participants were family caregivers of persons living with advanced dementia caused by a neurodegenerative disease producing significant impairments in communication. Semi-structured interviews elicited the caregivers’ experiences of plausible lucid episodes. Data analysis used a thematic analysis approach.

Results: Most caregivers reported at least one episode of lucidity. Episodes were typically brief. Most involved utterances, but nonverbal behaviors were also common. The mental capacities associated with these behaviors included recognition, awareness of surroundings, recognizing others’ emotions, and goal-directed behavior. Most caregivers’ reactions were positive. Episodes did not lead to changes in major medical decisions but instead to efforts to either modify or reinforce daily caregiving efforts.

Discussion and Implications: Episodes of lucidity were common, a finding seen in other studies. If prevalence studies confirm this, the qualifier “paradoxical” should be eliminated. The caregivers’ familiarity with the person living with dementia allowed them to attribute meaning to subtle behaviors that might not otherwise be detected or considered lucid. Clinicians who care for persons with advanced stage dementia should routinely ask caregivers about episodes of lucid communication and their emotional reactions.

Keywords: paradoxical lucidity, mind perception, mental capacity, Alzheimer’s disease caregiving
For many years, clinicians and families have reported that persons with severe-stage dementia experience periods of unusual clarity (Nahm et al., 2012; Nahm & Greyson, 2009; Norberg et al., 1986; Normann et al., 2005), also known as episodes of “paradoxical lucidity.” A 2019 National Institute on Aging (NIA) working group defined 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 (Mashour et al., 2019).” The predicate “paradoxical” signifies that reports of lucidity defy the paradigm of severe-stage dementia, which holds that affected persons are not lucid and cannot regain lucidity.

Survey and interview studies of family and professional caregivers have largely examined quantifiable attributes of lucid episodes (e.g., frequency, duration, proximity to death) and how these episodes affect caregivers’ emotions and views of the person living with dementia (Batthyány & Greyson, 2021; Gilmore-Bykovskyi et al., 2023; Griffin et al., 2022; Normann et al., 1998). This work suggests that lucid episodes occur in most persons with severe-stage dementia (Batthyány & Greyson, 2021; Gilmore-Bykovskyi et al., 2023; Griffin et al., 2022). Given the apparent pervasiveness of these episodes, research is needed to further characterize their features and understand their clinical implications.

Better characterizing episodes of lucidity could achieve several benefits, among them an improved understanding of the neurobiology of dementia and a more nuanced conception of the minds of persons living with dementia, especially persons with severe-stage dementia. Dementia is widely regarded as a disorder of the mind—that is, an impairment in a person’s ability to formulate thoughts and intentions and integrate them with experiences of the world. Understanding the mental capacities of persons living with dementia can help patients and caregivers cope, explain what to expect in the future and, perhaps, critically appraise common cultural conceptions about how dementia affects the mind (Ney et al., 2021).
Here, we report findings from an in-depth interview study with family caregivers of persons with severe-stage dementia. Our results add a detailed characterization of the features of lucid episodes to inform refinement of the term “paradoxical lucidity,” its definition, and the development of approaches to measure and characterize lucidity in severe-stage dementia.

Methods

Study Design and Research Team

Given that paradoxical lucidity is currently a poorly characterized phenomenon, this study was designed to probe the boundaries of what a lucid episode is. Accordingly, to avoid artificially shaping or confining our interviewees’ responses, interview prompts and participant-facing study materials refrained from using conceptually loaded terms from the academic literature like “paradoxical,” “lucidity,” and “mind.” To examine our interview data, we chose to use thematic analysis because of its flexibility and lack of alignment with a specific epistemological framework that might narrow our focus to particular elements of lucid events (Braun & Clarke, 2006).

The topic of lucidity in dementia pulls together threads from many disciplines. The study team was designed to unite expertise to help ensure the collection of rich data and enrich our explanations of it by diversifying the bodies of knowledge from which we could draw. The team combines expertise in dementia care (JK), philosophy of mind (AP), bioethics (AP, JK, JC, EL), linguistic and medical anthropology (JC), clinical psychology (SS), and qualitative methods (all authors).

Sampling and Recruitment

We used a purposive sampling approach. Interviewees were adult, English-speaking, non-professional caregivers of persons with severe-stage dementia caused by a neurodegenerative disease who were alive or who had died within the past 2 years. We stratified our sample to achieve balance across basic characteristics of caregiving, including caregiver-person living with dementia relationship (spousal
vs. non-spousal), person living with dementia residence (home vs. long-term care), and person living with dementia status (living or deceased).

To recruit participants, we first generated a list of potentially eligible caregivers from the Penn Memory Center (PMC; Philadelphia, PA) Integrated Neurodegenerative Disease Database (INDD), a registry of PMC patients and their caregivers who have consented to being queried about research studies. The presence of a neurodegenerative disease in the patient was determined from the PMC INDD “primary diagnosis” field, and severe-stage dementia was determined using several clinical indicators. (See Online Supplementary Material for a full description of how we defined severe-stage dementia.) If a patient has died, the PMC INDD includes their date of death.

A research coordinator sent email or postal mail recruitment letters to potentially eligible caregivers and, among those who did not reply to the letter, followed up with up to three telephone calls. Individuals who expressed interest in participation underwent a telephone screening to collect demographic information and ensure they were the patient’s caregiver (see Online Supplementary Material for a description of how we defined caregiver). Demographic questions asked during the telephone call included the gender, race, ethnicity, level of education, employment status, and marital status of the caregiver and person living with dementia, as well as the relationship between the caregiver and person living with dementia, the length of time caregiving, whether the participant was the person living with dementia’s primary caregiver, and the living situation of the person living with dementia. These items were all reported by the participant for both the participant and the person living with dementia.

Reporting race, ethnicity, age, and gender in this study was mandated by the US National Institutes of Health consistent with the Inclusion of Women, Minorities, and Children policy. Race and ethnicity categories were defined by investigators based on the US Office of Management and Budget’s Revisions to the Standards for the Classification of Federal Data on
Race and Ethnicity (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White). Participants also had the option to select “Other” and specify any other self-reported race outside of the provided categories. Ethnicity categories included Hispanic or Latino and Not Hispanic or Latino. Gender categories were Male, Female, and Non-Binary. Participants also had the option to select “Other” and to specify any other self-reported gender outside of the provided categories.

**Data Collection**

MK (a research coordinator with an undergraduate background in anthropology and experience conducting qualitative studies on health-related topics) conducted semi-structured telephonic interviews between November 2021 and February 2022. The interview guide (see Online Supplementary Material) was piloted with 4 caregivers, and minor revisions were made.

Interviews focused on either the past four months (if the person living with dementia was alive) or the last four months of the person’s life, with slight phrasing modifications depending on whether the person living with dementia was alive or deceased. The interview consisted of five sections of open-ended questions and pre-written and spontaneous follow-up probes. The first three sections established details of the caregiver-person living with dementia relationship, the caregiver’s perceptions of the person living with dementia pre-dementia, the person living with dementia’s baseline level of cognitive and functional impairment and social capacities—all of which were important for understanding the nature and significance of any lucid episodes subsequently discussed.

Section four assessed whether the caregiver witnessed the person living with dementia having any unusually lucid moments. Participants were first broadly asked whether, during the four months in question, they had noticed any unusual behavior. If the answer was no, the
interviewer followed up with probes about instances of unexpected verbal communication, unexpected nonverbal communication, and any instances in which person living with dementia seemed “more connected,” “more aware,” “like [his/her] old self,” “back to baseline,” “having unusual clarity,” or “still in there.” We based these probes on the components of the provisional NIA definition (Mashour et al., 2019) If a caregiver answered any of these questions affirmatively, follow-up questions inquired about details of the episode, what might have caused it, their emotional and behavioral responses and whether the episode changed the participant’s perception of the person living with dementia’s experiences, thoughts, or capacities. The final section asked participants to broadly reflect on the nature of mind in dementia given the previous discussion.

Data Analysis

Audio recordings were professionally transcribed. We used NVivo qualitative analysis software (QSR International Pty Ltd., 2020) to manage coding. We began analysis while data collection was still underway, allowing us to determine theoretical saturation—i.e., the point at which the addition of new data did not alter the explanation being developed (Glaser & Strauss, 2009). As we did not find during analysis that there were additional attributes of PMC caregivers that could be identified during screening and were clearly associated with differences in how they conceived of caregiving or lucidity in dementia, we did not alter our purposive sampling approach during analysis.

Analysis was guided by the approach set out in Braun and Clarke’s (2006) original guide to thematic analysis. We selected this approach because its flexible orientation aligned with our desire to both describe and quantify basic characteristics of lucid episodes—given that much remains unknown about these episodes—as well as to interpret caregivers’ experiences of them their implications for how lucidity is conceptualized. A subset of authors (AP, JK, JC, KH, MK, CC) each independently reviewed a subset of 4 transcripts to identify codes, then met to discuss these codes and formalize them into a
codebook. In line with the thematic analysis approach, codes were inspired both by the discourse of interviewees and by the theoretical concerns of our research team. Two authors (MK, CC) independently coded a new subset of 9 transcripts and met regularly during this double-coding process to compare their coding, discuss discrepancies, and refine the codebook to address ambiguities and redundancy and increase comprehensiveness. Having developed a refined codebook and agreement on its use, MK and CC then single-coded the remaining transcripts. Once coding was complete, CC and MK identified those codes most pertinent to our research questions, condensed some codes into broader themes and broke others down into more specific themes as necessary, and posited relationships between these themes. For example, numerous specific descriptive codes on what interviewees found unusual about lucid episodes and the capacities they inferred from them were condensed into the high-level interpretive schemas of lucid episode types and associated mental capacities presented below.

Each interview was considerably long, and interviewees’ responses from the first half of the interview were potentially relevant for interpreting their subsequent descriptions and interpretations of lucid episodes. We therefore supplemented the cross-sectional approach of coding with memoing. This analytic method facilitates drawing connections between different parts of an interview. Each member of the core team independently wrote an interpretive memo about each interview transcript and an overarching memo in which they documented high-level trends or hypotheses emerging from the accumulation of individual memos. In a series of weekly full-team meetings, these memos were brought into dialogue with the thematic analysis in order to refine the themes and our conceptions of how they related.

Human Subjects Protections

This study was deemed exempt by the University of Pennsylvania Institutional Review Board (protocol # 844515). Interviewees gave verbal consent and received $25 per 30 minutes of interview time.
Results

Among the 59 caregivers recruited, 33 (56%) agreed, 11 declined, 14 could not be reached, and 1 was determined to be ineligible. Of the 33 who initially agreed, one declined at a later point, one could not be reached to schedule the interview, and one ended the interview before completion. A final sample of 30 family caregivers for 29 persons living with dementia completed the study (two participants who shared caregiving responsibilities for one person living with dementia completed the interview together). Most caregivers (n=26, 87%) and persons living with dementia (n=25, 86%) were White. Three caregivers (10%) and 3 persons living with dementia (10%) were Black or African American, and the race of one participant (3%) and one person living with dementia (3%) were reported as “Other.” More than half of caregivers (n=17, 57%) and two thirds of persons living with dementia (n=21, 69%) were female. All others were male, with no caregivers or persons living with dementia reported as non-binary or another gender. Interviews averaged 2 hours in length.

Characteristics of Interviewees and Persons Living with Dementia

Nearly all interviewees identified themselves as a “primary caregiver” (see Table 1). The majority were spouses who had been caring for the person living with dementia for 5 or more years. Half the persons cared for lived in the community, and the remainder were in residential long-term care or deceased (see Table 2). Interviewees described the emotional experience of caregiving as a complex blend of love, gratification, obligation, burden, frustration, and grief.

All caregivers described their relative as having dementia caused by a neurodegenerative disease. Their functional impairments were consistent with severe-stage dementia and typically included needing assistance with most basic activities of daily living. Common descriptions
included “needing help with everything” or that the person living with dementia only had the capacity to “sit and sleep.”

Caregivers described severe impairments in communication. For example, one participant described her husband as unable to “understand anything…it’s all blank to him” (interviewee 5), while others referred to communication as “garble” or “gibberish.” Some persons living with dementia were seen as able to communicate, but the communication was usually described as passive, non-conversational, and limited to “yes” or “no” responses. Participants described their relatives’ recognition as severely impaired, typically unable to recall names or relationships and only sometimes able to understand others as important in their lives. Most persons living with dementia were described as unable to make plans or choices, and those who were able to select among options were perceived by caregivers as possessing only rudimentary preferences such as about what to eat, whether to take a walk, or what clothes to wear.

**Frequency and Manner in Which Lucid Episode Descriptions Emerged**

Lucid episodes were described in 25 interviews; seven interviews included descriptions of 2 episodes and one included descriptions of 3 episodes, making for a total of 34 reported lucid episodes. Ten of the episodes were described as types of behavior that occurred more than once. For example, a caregiver said that his wife had in multiple instances rubbed his back while walking past him, and in each instance he found this out of step with her other behavioral tendencies. Caregivers were not able to precisely specify how many times these repeated episodes happened; we have counted each as one episode here.

Our interview guide was structured to prompt descriptions of lucidity after questions about the caregiving relationship and the person living with dementia’s level of impairment; however, some reports of lucidity emerged without prompting. In 12 instances, when responding
to open-ended questions about lucidity in the final sections of the interview, the caregiver(s) brought up an episode that they had also described *before* this section of the interview. In 13 other instances, in response to our open-ended prompts about lucidity, the caregiver(s) brought up an episode that they had *not* previously described. Finally, in 9 instances, the caregiver(s) said no or expressed uncertainty in response to our open-ended prompts about lucidity; the interviewer then queried them about an episode they had described *earlier in the interview*, and the participant(s) affirmed that it fit the kind of episodes the interviewer was now asking about.

In 4 interviews, the caregiver reported episodes we did not classify as ‘lucid episodes’ because the caregivers did not judge the episode as out of the ordinary or unexpected, although further research may suggest that they should be classified as such. For example, one caregiver (interviewee 30) said his wife was sometimes “more connected” in social settings and other times seemed to comprehend what was happening in TV shows. Yet, he stated that “it’s not like a light switch” and characterized his wife’s cognition as “a constant.” Another caregiver (interviewee 62), after being asked whether her mother had moments of “unusual clarity,” responded, “Just those times where she’ll answer a full sentence and we’ll look at each other like, ‘She just said a whole sentence.’” This caregiver described these moments as frequent, characterizing her mother’s overall behavior as “consistent.”

**Reported Duration of Lucid Episodes**

Participants who reported lucid episodes were asked to estimate their duration. Twenty-one of 34 episodes were reported to last only seconds. These episodes tended to consist of single utterances of a word or phrase, gestures, facial expressions, or combinations thereof. Caregivers used terms like “quick,” “flash,” “flick,” “blip,” “blurb,” “spurt,” “glimmer,” and “glimpse” to describe these moments. The other 13 reported episodes were estimated to last a few minutes or


more and to consist of a conversation, series of utterances, or a perceived period of increased
alertness or engagement. The longest reported episode continued for an estimated 45 minutes. In
this case, the caregiver (interviewee 53) described the person living with dementia asking for and
consuming a cigarette and beer, singing songs with the caregiver and friends, and conversing
with them before going to bed; the next morning, he died.

**Reported Proximity of Lucid Episodes to Death**

Eight interviews were with caregivers of deceased persons living with dementia. All 8
reported lucid episodes. It was difficult for these participants to specify the episodes’ proximity
to death. In 4 of these interviews, caregivers described episodes that occurred at least several
months prior to death. In the other 4, the lucid episodes reportedly occurred closer to death: the
episodes were described, respectively, as occurring the night before the person living with
dementia died, within a few days of death, about two weeks prior to death, and about a month
before death.

**Types of Behavior in Reported Lucid Episodes**

A range of behaviors occurred during reported lucid episodes, and a single episode could
involve multiple behaviors (see Table 3). Twenty-four episodes involved utterances. Most
commonly—in 15 of these episodes—these utterances were deemed unusual because of their
appropriateness to context. In 6 such instances, a person living with dementia accurately used a
proper name of a relative, friend, or pet when they had not done so for a considerable time. The
person or pet was either physically co-present or visualized in a photograph during the episode.
For instance, one participant (6) recounted that her niece walked into the room where the person
living with dementia was sitting. The person living with dementia said, “Oh, hi [nickname].
What are you doing here today?” This was unexpected, as the person living with dementia had
not accurately used a proper name for a long time, and the niece was not usually present. The other 8 contextually appropriate utterances described by caregivers were felicitous to the person living with dementia’s surroundings. A participant (interviewee 7), for example, described repeated instances in which he walked near the edge of an elevated platform or leaned over a banister; his father, normally nonreactive to such things, would warn him to “be careful.” Another caregiver (interviewee 14) took her mother to see a family friend whose toddler ran around while they talked; her mother interacted with the toddler, speaking in an animated, age-appropriate manner that surprised her daughter.

In 4 of the episodes involving utterances, interviewees described persons living with dementia producing language that was unusually sophisticated relative to their level of impairment. For example, a caregiver (interviewee 25) and his wife were participating in a group art project in which persons living with dementia made masks. The man was taken aback when his wife began to describe the features of her mask and their artistic significance. Though he found her speech unusually grammatically and lexically sophisticated, her ability to connect sentences logically remained impaired: she spoke “eloquently without making sense.”

In 3 episodes involving utterances, caregivers described persons living with dementia who were nonverbal or nearly nonverbal unexpectedly uttering words or gibberish. One participant (interviewee 40) noticed that when his wife visited with a particular friend, she would have “pseudo-conversations” in which she engaged in conversational turn-taking. Though he found her utterances nonsensical, he nevertheless thought this behavior was unusual given that she otherwise rarely spoke. Finally, 2 instances of unexpected utterances involved persons living with dementia singing songs, including apparently attending to pitch and rhythm. In one case (interviewee 14), the person living with dementia sang along to the radio, while another person
living with dementia sang along with family and friends with no accompanying music (interviewee 53).

Thirteen lucid episodes involved nonverbal behaviors reported as unusual. In 5 cases, the caregiver observed a facial expression—e.g., a smile or a soundless movement of the lips that resembled talking—that they found unusual because the persons living with dementia were described as otherwise doing almost nothing but sitting or sleeping. In 5 episodes, interviewees described unusual eye contact. In these instances, caregivers often struggled to articulate why they found the eye contact unusual. For example, an interviewee (interviewee 39) who cared for his wife said, “[S]ometimes I get eye contact. There just seems to be a glimpse. Maybe that—a glimpse of [person living with dementia name] just by looking in her eyes a little bit. And it might just be my perception…” Two episodes involved unexpected physical gestures like clapping to music. Finally, in one episode (interviewee 34), the person living with dementia unexpectedly danced with his wife when a piano was played at his nursing home.

**Mental Capacities Associated with Reported Episodes**

Participants interpreted the above-described behaviors as evidence of a range of mental capacities the person living with dementia either retained or temporarily regained during the lucid episode (see Table 4). Behaviors observed within a single episode could be associated with multiple different capacities.

In 12 episodes, interviewees believed persons living with dementia could temporarily recognize specific people or animals, typically by the accurate usage of proper names. In a couple episodes, usage of a name was accompanied by eye contact that, for caregivers, affirmed recognition. For instance, a caregiver’s (interviewee 18) mother unexpectedly uttered her nickname when she otherwise “had no clue who [the caregiver] was.” The caregiver added: “For
that second, for that moment that we shared in our eyes, you know, we’re looking at each other and it just came to her, and she knew who it was, but it left quick.” In one recurring episode described by a caregiver (interviewee 61), he inferred recognition from nonverbal gestures: he interpreted his wife rubbing his back as her “realiz[ing] that I’m her husband, she’s my wife, and, you know, we’re together.”

In 11 cases, a person living with dementia’s unusual behavior in a social situation evinced to caregivers a heightened capacity to understand the emotions and intentions of others. Typically, these episodes involved utterances of unexpected contextual appropriateness. A caregiver (interviewee 43) recounted taking his wife to a family party, where she asked their daughter, “How have you been?” This otherwise mundane interaction was interpreted by the participant as demonstrating an unusual level of social sensitivity given that his wife had been, in his words, a “stoic robot” since developing advanced dementia. Another caregiver (interviewee 63) described mumbling to himself about financial concerns when his wife, sitting nearby, said, “Don’t worry, you’re smart. You’ll figure it out.” This reassurance was “what I needed in the moment,” he said, a brief instance of his wife “getting through the fog” and attuning to his emotional state.

In 7 cases, unusual behaviors were interpreted by caregivers as evidence of temporarily elevated awareness of surroundings. These instances tended to occur with persons living with dementia who were notably impaired in communication and function, and they involved subtle movements such as facial expressions. For example, one caregiver (interviewee 22) described his wife as rarely reacting to anything in her environment and often keeping her eyes closed. Yet, he recalled seeing her move her lips when he sang her a folksong from their childhood. Another
caregiver (interviewee 31) described how his wife's smile made her seem “more alert than typical” when a priest visited their home to perform a blessing as she was “actively dying.”

In 5 instances, caregivers described unusual episodes that suggested to them the person living with dementia was able to form and purposively pursue a goal. For instance, in an above-mentioned episode that lasted approximately 45 minutes (interviewee 53), the person living with dementia asked his wife for a cigarette and beer. In that moment, “[h]e knew what he wanted,” she said, as if he were “normal” again. Another interviewee (32) recollected telling her husband, who was near the end of his life, “It’s okay. Let go.” To her surprise, given that she was uncertain of his awareness, he made eye contact, shook his head, and said, “No”—a response that she interpreted as an expression of his desire to keep living.

In associating episodes of lucidity with mental capacities, caregivers sometimes reflected that persons living with dementia displayed qualities that reminded them of who they were prior to developing dementia. Such interpretations involved caregivers recognizing mental capacities that resembled qualities of the persons living with dementia before advanced dementia. This kind of observation was made in 12 instances, typically when caregivers attributed lucid episodes to the ability to recognize others or understand their emotions or intentions. For example, one caregiver (interviewee 3) recalled entering the room to find her mother in animated conversation with the caregiver’s boyfriend. The participant joked, “Mom, are you flirting with my boyfriend?” Her mother immediately shot back, “You mean my boyfriend?” This exchange reminded the caregiver of her mother’s past proclivity for wit: “That, to me, was my mom.”

Unusual behaviors did not, however, have to be this socially sophisticated to be evocative of past tendencies, however. The daughter and wife of a person living with dementia (interviewees 51/56) described recurring instances in which he wordlessly kissed his wife on the head. His
daughter saw this as “that little spark, that underlying, you know, part of him in there,” while his wife described it as evidence of his “true nature.”

**Perceived Causation of Lucid Episodes**

Despite considering various potential triggers, caregivers typically emphasized their uncertainty about lucid episodes’ causal mechanisms. Many concluded the episodes they witnessed were random. One caregiver (interviewee 3), who had done auditing work in her career, said of monitoring her mother’s behavior, “I analyze everything. […] That’s what I do. And so when it comes to her, I do the same thing.” Nevertheless, she was unable to describe a cause: “What had she been doing? Did she have her medicine? Didn’t she have it? Like, trying to analyze it and come up with something was—you know, I didn’t come up with anything.”

Of the participants who expressed greater certainty about the cause, several posited that the lucid episode was triggered by social situations with familiar people. A woman (interviewee 52) whose husband seemed to unexpectedly recognize her and her daughter said, “And so just maybe, you know, seeing his girls. Like, he said, ‘Oh, there’s my girls,’ you know? Maybe that gave him a happy feeling. I don’t know.” Others believed there was an association between the lucid episode and the time of day, the amount of exercise the persons living with dementia had gotten that day, how restful their sleep was the night before, or a recent change in medication. Finally, a few caregivers attributed episodes to spontaneous brain activity, as in the following woman’s explanation of her mother’s lucid episode:

Something obviously was going on in that head of hers. […] There was no obvious change in the immediate environment. […] [I]t’s something happening in her brain, that maybe there are certain connections that had pretty much cut off, and then all of a sudden
they got reconnected again? It’s like when you have a faulty lightbulb or something, it flickers on for a time, and then it dies. (interviewee 13)

Responses to Lucid Episodes

Caregivers’ reactions to lucid episodes fit one of four categories. Most expressed positive responses, using words like “happiness,” “moved,” “positive,” and “joy” or expressions such as “a moment of grace,” “thrilled to death,” and “warmed the heart.” Two caregivers reported negative responses: one of jealousy that the caregiver was not part of the moment when his wife was lucid (interviewee 40), and the other of sadness (interviewee 21) because she thought her husband was trying yet failing to make conversation. In one interview, a daughter (interviewee 3) described mixed emotions. She found her mother’s unexpected joke “super funny” but also “very sad” since the communication was fleeting. Finally, a few caregivers used terms with an indeterminate emotional valence, including “flabbergasted,” “interesting,” and “bizarre.” These terms highlighted their surprise with the unexpected nature of the episode.

Witnessing a lucid episode generally did not cause caregivers to execute changes in the person living with dementia’s medical care. It also did not change their expectations about the person living with dementia’s prognosis. Several caregivers of persons living with dementia who were still alive remarked that they expected these episodes to become less frequent over time. Ten participants said they brought up a lucid episode with the person living with dementia’s dementia care physician. Of those who recalled these conversations, most said that the physician emphasized episodes’ “short-lived” nature and the lack of relation to overall prognosis. “That’s what they say,” said one caregiver (interviewee 5): “You have some good days, some bad days. Eventually, it’s gonna be all bad days.” Most caregivers did not discuss lucid episodes with a physician because they were not sure what to say or doubted the relevance to clinical care.

Observations of lucidity did inspire changes to practices of daily care. Many caregivers described experimenting with ways to induce further lucid episodes: for example, stimulating the person living with
dementia by bringing them into more social situations, playing music, altering their diet, or increasing their amount of sleep. None of these attempts were reported as successful, even though some caregivers expended substantial effort. As one caregiver (interviewee 53) said, “I always tried things twice. Do you know what I mean? Like, whatever worked, I’d try again. And then, like, I’d get a completely different reaction from him.” A daughter of a person living with dementia (interviewee 6) remarked that she devoted “half [her] life” to figuring out how to cause her mother to experience more lucid moments.

**Discussion**

In this study, most caregivers of persons with severe-stage dementia reported at least one episode of behaviors that could reasonably meet the NIA expert panel’s provisional definition of paradoxical lucidity (Mashour et al., 2019). These episodes were typically brief and included utterances, gestures, movements, facial expressions, eye contact, or a combination of these behaviors. Caregivers associated several mental capacities, most often recognition and social awareness, with these behaviors. Below, we develop these findings and their implications for the definition and measurement of lucidity.

First, because we did not preface our study with the topic of lucidity or ask about lucidity using a single overarching prompt as done in prior empirical studies, caregivers’ reports emerged organically during the interviews. Often, interviewees brought up the episodes prior to being asked, for example when discussing aspects of their relationship with the person living with dementia or the person living with dementia’s impairments. Among those who brought up episodes in response to our lucidity-related questions, some did so when asked about unusual interactions, others when we asked about connectedness, moments of the “old self,” clarity, or awareness.

These findings suggest that assessments to capture the full spectrum of lucid behaviors should be sensitive to question wording and use multiple prompts and follow-up probes. We based our lucidity prompts on the components of the provisional NIA definition (Mashour et al., 2019), but as more empirical work is published, researchers can develop more precise approaches for detecting lucidity. For
example, the taxonomy of lucid behaviors (Table 3) and mental capacities (Table 4) identified in this study could be used to design novel questionnaires or be adapted into existing assessment interviews (Teresi et al., 2023).

Second, although our study was not designed to assess the prevalence of lucid episodes, our results suggest they are infrequent within individual persons with severe-stage dementia but common across this population. This is consistent with other empirical work, which has elicited reports of lucid episodes in 61% to 100% of caregiver respondents (Gilmore-Bykovskyi et al., 2023; Griffin et al., 2022; Normann et al., 2006). Collectively, these results should lead us to question the “paradoxical” in “paradoxical lucidity.” Here, “paradoxical” denotes an observation that is inconsistent with a disease theory. The disease theory for Alzheimer’s disease and related diseases that cause dementia is that impairments caused by neurodegeneration are irreversible. If prevalence studies establish the emerging finding that lucid episodes happen in most persons with severe-stage dementia, this suggests the need to drop the term “paradoxical” and modify the theory of disease.

Third, our results have implications for how researchers conceive of “lucidity.” Our interviewees described a wide range of unusual verbal and nonverbal behaviors, from lengthy utterances to subtle facial expressions. Other studies have also found that lucid episodes can manifest as nonverbal behaviors (Batthyány & Greyson, 2021; Normann et al., 1998). This suggests that the concept of lucidity should be adequately broad to capture its multifaceted nature. Definitions that require utterances—for example, Morris and Bulman’s notion of episodes “during which the person is aware of their own coherency and can express that awareness to others” (Morris & Bulman, 2020)—would in our view prematurely exclude behaviors that should presumptively be regarded as instances of lucidity.

Our findings further suggest that conceptions of lucidity should take a broad view of language. In a prior conceptual paper (Peterson et al., 2022), we suggested that lucid episodes involving utterances could be usefully unpacked by examining their semantic and pragmatic aspects. The former term describes an utterance’s internal morphological and syntactic qualities, while the latter describes how it
presupposes and affects changes to the social context. The present study supports the utility of this model for characterizing lucid episodes. The majority of unexpected verbal behaviors reported by caregivers were identified as such for pragmatic reasons, namely their unexpected appropriateness to context. Only a few were noted as lucid because the language was unusually structurally sophisticated.

This emphasis on linguistic pragmatics could be an artifact of study design. Our interviewees were caregivers who were highly familiar with the person living with dementia, and the episodes they reported often occurred when they were themselves interacting with the person living with dementia. These factors may have made interviewees more attentive to social context. Further, we agree with Gilmore-Bykovskyi et al. (Gilmore-Bykovskyi et al., 2022) that independent measurement of speech, abstracted from context, is capable of revealing important deviations from a person living with dementia’s typical capabilities solely on the basis of unusual semantic sophistication. Nevertheless, we are concerned that the greater ease of independently measuring the structural aspects of language will cause studies of lucidity to devote disproportionately little attention to pragmatics. As was repeatedly evident in this study, unusual sensitivity to social context is often not evident in the semantics of the person living with dementia’s utterances. For example, the verbal content of the person living with dementia who joked that the daughter’s boyfriend was in fact her boyfriend was a few simple words. What was remarkable about this episode was the sophisticated set of inferences that the person living with dementia had to make about the social situation to successfully produce a humorous turn of conversation.

Fourth, this study adds nuance to descriptions of how witnessing lucid episodes affects caregivers and the practice of caregiving. When we inquired about the emotional valence attached to specific episodes, we found the responses were typically positive, a finding that concurs with other studies (Gilmore-Bykovskyi et al., 2023; Griffin et al., 2022). However, in the long run, many recounted unsuccessful efforts to recreate the behaviors, and for some, the continuous decline of their relative’s condition made them conclude that the lucid episode was a generally pleasant “blip” amidst a “long
downhill slide.” We therefore suggest that, over the long term, a lucid episode often contributes to a complex tangle of emotions including jubilation, motivation, frustration, and resignation.

Caregivers uniformly reported that witnessing a lucid episode did not influence decisions about medical care. This finding resonates with other studies: Gilmore-Bykovskyi et al. found that only 2 interviewed caregivers said that lucidity presented an “opportunity to engage with the person living with dementia on critical decisions” (Gilmore-Bykovskyi et al., 2023), while in Griffin et al.’s survey of caregivers, only 12% of respondents said they had “changed decision[s] after lucid experiences,” including decisions about medical care, living arrangements, finances, end-of-life planning, personal and social needs, and how to provide better care (Griffin et al., 2022). While these findings collectively give a sense that lucid episodes have a limited impact on caregiver behavior, we caution that framing this impact in terms of “decisions” might explain the paucity of affirmative responses. We found that lucid episodes affected approaches to daily care, shaping, for example, how often they brought the person living with dementia into social situations, diet, and sleep schedules. Such changes are substantive and important but are not framed by caregivers as critical decisions. They are alterations in what might be called the “ordinary ethics” (Das, 2012) of caregiving, evincing shifted understandings of what constitutes good care.

Fifth and finally, as another study has also shown (Griffin et al., 2022), caregivers usually did not discuss lucidity with medical professionals because they did not know what the clinician could do with the information. This finding is notable. Lucid episodes were common and of substantial emotional salience to caregivers. For many caregivers, episodes informed their day-to-day approach and justified their ongoing efforts. Clinicians should therefore not dismiss lucid moments as unusual and clinically unimportant events. Instead, they ought to develop skills to solicit whether these events have occurred and, if they have, probe caregivers’ reactions to them. Research to develop the topics to solicit and how to inquire about them should build on our findings describing the types of behaviors reported in lucid episodes and the mental capacities inferred from them.
This study has important limitations. First, a considerable portion (44%) of caregivers who were contacted for recruitment declined or were unreachable. It is possible that these caregivers would report different experiences with lucid episodes. Second, we interviewed a limited number of caregivers of deceased individuals, so we are not well positioned to comment on terminal lucidity—the presumption that lucidity is mechanically associated with the dying process (Nahm et al., 2012; Nahm & Greyson, 2009). Our contribution to discussions of terminal lucidity is simply to note that our findings, in combination with those of other empirical studies (Gilmore-Bykovskyi et al., 2023; Griffin et al., 2022), suggest that lucid episodes commonly happen in circumstances not proximal to death. Third, the demographic variation in our sample was limited: caregivers and persons living with dementia were predominantly white and well educated, and their relations were mainly spousal. This limited variation likely limits the generalizability of our study, though its precise effects on our findings are difficult to specify given the lack of extant work on how race/ethnicity, educational background, and relationship type shape the experience of lucidity. Finally, accounts of lucid episodes come from caregiver self-report. This allowed us to elicit detailed narratives of lucid behavior, as well as to draw on relationship and caregiving history that would not be apparent to an unacquainted observer. Methods that yield direct observations of lucid episodes will offer an important alternative perspective on the phenomenon.

Notably, caregivers did not simply interpret lucid episodes as generally unusual; they ascribed specific, complex mental capacities to these episodes, such as recognition, awareness of surroundings, understanding of others’ emotions and intentions, and goal-directed behavior. This suggests they perceive mind in persons with severe-stage dementia—a perception with substantial importance. “Dementia” draws from Latin roots to signify a loss of mind, an association that is reiterated in contemporary culture such as in the titles of reports and popular books (Congress of the U.S., Washington D.C. Office of Technology Assessment, 1987; DeBaggio, 2002). How observations of lucidity impact caregivers’ perceptions of the mind of persons living with severe-stage dementia is an important question for future research.
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CONFLICT OF INTEREST:

None.

DATA AVAILABILITY:

In compliance with institutional requirements and in order to safeguard the confidentiality of study participants, the full data set is not available to other researchers. The study reported in the manuscript was not preregistered.

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QSR International Pty Ltd. (2020). *NVivo, (released in March 2020).*

https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home
Teresi, J. A., Ramirez, M., Ellis, J., Tan, A., Capezuti, E., Silver, S., Boratgis, G., Eimicke, J. P.,
Paradoxical Lucidity from Health Care Professionals: A Pilot Study. *Journal of
Gerontological Nursing, 49*(1), 18–26. https://doi.org/10.3928/00989134-20221206-03
### Tables

**Table 1.**  
_Caregiver Characteristics (n=30)_

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13 (43.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>17 (56.7%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>White</td>
<td>26 (86.7%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Non-Hispanic or Latino</td>
<td>30 (100%)</td>
</tr>
<tr>
<td><strong>Age Range</strong> (mean=69.7; SD=8.91; range=50-86)</td>
<td></td>
</tr>
<tr>
<td>&lt; 65</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>65-74</td>
<td>11 (36.7%)</td>
</tr>
<tr>
<td>≥ 75</td>
<td>10 (33.3%)</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Some College or Associate’s Degree</td>
<td>10 (33.3%)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td>Post Graduate Education</td>
<td>11 (36.7%)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Retired</td>
<td>18 (60%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>15 (50%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td>Single</td>
<td>5 (16.7%)</td>
</tr>
<tr>
<td><strong>Relationship to Person Living with Dementia</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse or significant other</td>
<td>21 (70%)</td>
</tr>
<tr>
<td>Child</td>
<td>8 (26.7%)</td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Length of Time Caregiving for Person Living with Dementia</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>5-9 years</td>
<td>18 (60%)</td>
</tr>
<tr>
<td>10+ years</td>
<td>6 (20%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Caregiver for Person Living with Dementia</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25 (83.3%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (16.7%)</td>
</tr>
</tbody>
</table>

*Note*: SD = standard deviation.
Table 2.

*Person Living with Dementia Characteristics (n=29)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (31%)</td>
</tr>
<tr>
<td>Female</td>
<td>20 (69%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>3 (10.4%)</td>
</tr>
<tr>
<td>White</td>
<td>25 (86.2%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (3.4%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>1 (3.4%)</td>
</tr>
<tr>
<td>Non-Hispanic or Latino</td>
<td>28 (96.6%)</td>
</tr>
<tr>
<td><strong>Age Range</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td>(mean=76.1; SD=7.2; range=62-92)</td>
</tr>
<tr>
<td>&lt; 65</td>
<td>1 (3.4%)</td>
</tr>
<tr>
<td>65-74</td>
<td>12 (41.4%)</td>
</tr>
<tr>
<td>≥ 75</td>
<td>16 (55.2%)</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>10 (34.5%)</td>
</tr>
<tr>
<td>Some College or Associate’s Degree</td>
<td>4 (13.8%)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>8 (27.6%)</td>
</tr>
<tr>
<td>Post Graduate Education</td>
<td>7 (24.1%)</td>
</tr>
<tr>
<td><strong>Marital Status</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>20 (69%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>1 (3.4%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>6 (20.8%)</td>
</tr>
<tr>
<td>Single</td>
<td>2 (6.8%)</td>
</tr>
<tr>
<td><strong>Living Situation</strong></td>
<td></td>
</tr>
<tr>
<td>At Home (With Caregiver)</td>
<td>14 (48.3%)</td>
</tr>
<tr>
<td>Long-Term Care Facility</td>
<td>7 (24.1%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>8 (27.6%)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Person living with dementia age and marital status refer to age and marital status at time of death for the 8 persons living with dementia who were deceased at the time of the caregiver interview.
Table 3.

Types and Frequencies of Behaviors Reported in Lucid Episodes

<table>
<thead>
<tr>
<th>Unusual behavior</th>
<th>Frequency (# of episodes in which the behavior was reported)</th>
<th>Description of behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Utterance</strong></td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Utterance:</td>
<td>15</td>
<td>A person living with dementia produces an utterance that is unusually appropriate to various features of the surroundings (e.g., accurate usage of a proper name, attention to one’s physical location)</td>
</tr>
<tr>
<td>production of</td>
<td>4</td>
<td>A person living with dementia produces language that is unusually complex relative to their current level of communication impairment (e.g., produces multiple complete sentences as opposed to single words or phrases)</td>
</tr>
<tr>
<td>sophisticated</td>
<td>3</td>
<td>A person living with dementia who is usually nonverbal or nearly nonverbal utters words or gibberish</td>
</tr>
<tr>
<td>language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singing</td>
<td>2</td>
<td>A person living with dementia with substantial linguistic impairment sings along to music or along with family/friends</td>
</tr>
<tr>
<td><strong>Non-verbal behavior</strong></td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td>5</td>
<td>A person living with dementia produces an unusual facial expression (e.g., a smile, or a soundless movement of the lips)</td>
</tr>
<tr>
<td>Eye contact</td>
<td>5</td>
<td>A person living with dementia makes eye contact with others which caregivers interpret as unusually meaningful</td>
</tr>
<tr>
<td>Gesture</td>
<td>2</td>
<td>A person living with dementia makes surprising physical gestures (e.g., clapping or pointing)</td>
</tr>
<tr>
<td>Dancing</td>
<td>1</td>
<td>A person living with dementia unexpectedly dances along to music</td>
</tr>
</tbody>
</table>
### Table 4.

**Mental Capacities Inferred from Reported Episodes**

<table>
<thead>
<tr>
<th>Mental capacity</th>
<th>Example</th>
<th>Caregiver interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition of specific people/animals</td>
<td>Participant 6: A person living with dementia encounters her niece who is typically out of the house working odd hours. The person living with dementia unexpectedly says, “Oh, hi, [nickname]. What are you doing here today?”</td>
<td>According to the caregiver, the person living with dementia briefly recognized her niece. “Because the fact that she said, ‘What are you doing here today?’ She's not normally there. […] and also just calling her [nickname]. Very few people call her [nickname]. That was just what my mom called her. In fact, nobody else calls her [nickname] except Mom. So those are just shades of her old self […]. I would've thought that that was her many years ago.”</td>
</tr>
<tr>
<td>Increased awareness of surroundings</td>
<td>Participant 7: When his son is leaning over a stair banister or edge of an elevated platform, a person living with dementia reacts by warning him to &quot;be careful.&quot; Once the caregiver is out of harm’s way, the person living with dementia ceases to engage in any sort of conversation and reverts into passivity.</td>
<td>According to the caregiver, the person living with dementia’s awareness of the surrounding environment returned when the caregiver was in dangerous situations, a phenomenon he found “bizarre.” “That type of [situation], you know, where harm will come to me, it just comes back. And I don't know where it comes from, but it comes back, and he starts engaging right away. Then if I'm away from it, then it subsides, doesn't...He won't continue on with the conversation after that.”</td>
</tr>
<tr>
<td>Increased capacity to understand others’ emotions or intentions</td>
<td>Participant 63: A person living with dementia hears her husband mumbling to himself about his frustration over a financial problem he is facing and says to</td>
<td>According to the caregiver, the person living with dementia suddenly showed sensitivity to her husband’s visible stress. Caregiver compared this to when the person living with dementia sees her</td>
</tr>
</tbody>
</table>
him, “Don’t worry, you’re smart, you’ll figure it out.”

daughter on FaceTime asks how her pregnancy is going, “…in those moments, there’s empathy. And there’s concern.”

“I appreciated the fullness that she made a connection that she somehow was outside of herself and was thinking about someone else, that it was me, which was nice…for that moment, her world just got a little larger, it didn’t get smaller.”

Ability to form and pursue a goal

Participant 25: As part of a group art project, a person living with dementia creates an abstract watercolor painting. While other group members continue embellishing their paintings, the person living with dementia states that her painting is finished and explains the painting’s meaning to the group.

According to the caregiver, the person living with dementia suddenly seemed “wise” in this moment. The person living with dementia, he believed, demonstrated unusual insight into her creation and strong intentions for how it should look and what it should represent.

“Other people were then embellishing their [paintings], doing all kinds of things that really kind of destroyed the purity of that central idea. The rest of the project, she refused to do it. She refused to mess with it. She took the first thing, put the paint, the pigment in the water, the image, and she would not touch it, change it. And everybody else was piling on glitter and gooey things. And she leaned over to me and she said, "Mine's better."”