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A Prospective Observational Study of Lucid Episodes in Advanced Dementia

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Abstract

Background and Objectives: Recent studies have provided new insights into lucid episodes (LEs) in people living with advanced dementia, but direct observational data documenting LEs are lacking. This prospective observational aimed to detect, characterize, and validate potential LEs.

Research Design and Methods: Data from longitudinal audiovisual observations of participants living with advanced dementia (N=20) were coded to generate measures of verbal output/expressions and nonverbal communicative actions (e.g., coherence, eye gaze). Potential LEs underwent structured multi-informant review for validation. We applied generalized estimating equations to compare features of validated LEs to a random 20% sample of participant data used to estimate baseline functioning. Data were fit to a homogeneous Poisson point process to estimate the number of observations needed to accurately estimate prevalence of LEs.

Results: Across 539 observations, nine validated LEs were evidenced by three participants (range 2–4). Shared significant differences across LEs included an increased rate of meaningful vocalizations, although heterogeneity in features of LE was observed.

Discussion and Implications: These findings represent the first prospectively documented and directly observed cases of LEs in advanced dementia. Features of LEs vary across individuals, but marked recovery of verbal communication abilities was a defining feature across all

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Conflict of Interest

We have no conflict of interest to declare.

events. LEs occur infrequently, but these findings suggest they may not be as rare as initially hypothesized. Larger samples and more diverse cohorts are needed to inform robust estimates of incidence and prevalence. Measurement advances to detect and characterize these events are critical to elucidating underlying mechanisms driving these events and advancing supportive interventions.

Keywords

Lucid Episodes; Transient Recovery of Function in Dementia; Paradoxical Lucidity; Terminal Lucidity; Lucidity in Dementia

Background

Progressive neurodegeneration associated with Alzheimer's disease and Alzheimer's disease related dementias is understood to result in irreversible losses in cognition and functioning (Alzheimer's Association, 2023). Lucid episodes (LEs) challenge this conventional understanding, presenting as a seemingly implausible transient recovery of function, such as coherent communication, after those abilities were considered irretrievably lost (Batthyány & Greyson, 2021; Eldadah et al., 2019; Mashour et al., 2019; Peterson et al., 2022). Distinct from cognitive fluctuations, LEs are reported by witnesses as highly salient events that present outside the spectrum of an individual's routine variation in abilities and are recognized as spontaneous and unexpected occurrences (Batthyány & Greyson, 2021; Eldadah et al., 2019; Gilmore-Bykovskyi, Griffin et al., 2023; Mashour et al., 2019; Peterson et al., 2022). A prior concept analysis (Morris & Bulman, 2020), has proposed the presence of meta-awareness, or a person's awareness of their dementia condition, as a core feature of LEs that potentially distinguish them from cognitive fluctuations, however evidence from more recent studies does not support meta-awareness as a defining feature of LEs, especially in advanced dementia (Gilmore-Bykovskyi, 2021; Gilmore-Bykovskyi, Block et al., 2023; Griffin et al., 2022; Peterson et al., 2022; Teresi et al., 2023).

Until recently, evidence on LEs was largely limited to retrospective case reports (Normann et al., 1998; Normann et al., 2005; Normann et al., 2006; Normann et al., 2002). A series of studies funded through a National Institutes on Aging initiative (2019) yields new evidence regarding LEs, finding that LEs span the late-stage disease continuum and may be more common than initially hypothesized (Gilmore-Bykovskyi, Block et al., 2023; Griffin et al., 2022; Griffin et al., 2024; Karlawish et al., 2024; Ramirez et al., 2024; Teresi et al., 2023). These studies further demonstrate that LEs can have a profound impact on witnesses (Benson et al., 2023; Gilmore-Bykovskyi, Block et al., 2023; Karlawish et al., 2024). Family caregivers in particular report strong emotional responses to LEs, with one study suggesting that up to 12% adjust care plans after witnessing an LE (Griffin et al., 2022).

Direct data documenting the occurrence of LEs are lacking, yet are essential to establishing an empiric understanding of the presentation of LEs. These data are also essential to establishing the context in which LEs occur or are elicited, and to quantitatively characterize specific features of LEs compared to an individual's unique routine variation in abilities or functional baseline. To address this gap, we conducted a multifaceted prospective

observational study with the objectives of detecting, characterizing, and validating LEs among a cohort of individuals living with advanced dementia in hospice care (Gilmore-Bykovskyi et al., 2024). In this report we detail the nature of validated LEs, and present analyses comparing specific features of validated LEs to participant baseline functioning. We also leverage these data to estimate sample size requirements for accurate estimation of LE prevalence in future research.

Methods

Participants

Participants living with advanced dementia were recruited from a 12-bed dementia care hospice unit. The hospice setting was chosen due to prior case reports indicating an increased prevalence of LEs proximal to death (Batthyány & Greyson, 2021; Nahm & Greyson, 2009; Nahm et al., 2012), which could maximize opportunities to capture LEs. Eligibility criteria included: a medical diagnosis of any form of dementia as confirmed via medical record review, a score of ≥7 (severe) on the Dementia Severity Rating Scale (Clark & Ewbank, 1996), and documentation of decisional incapacity and presence of a legally authorized representative (LAR) to provide informed consent. Detailed information about the study design was published (Gilmore-Bykovskyi et al., 2024), and the protocol was reviewed and approved by the University of Wisconsin-Madison Institutional Review Board. Written informed consent was obtained from the LAR of potential participants with advanced dementia prior to participation in audiovisual observations. The study team monitored for signs of assent/dissent from participants with dementia throughout data collection procedures.

Data Collection

Audiovisual Data Collection: Data collection procedures were developed in partnership with clinical staff and with input from family caregivers before initiating the study (Coulson et al., 2024; Gilmore-Bykovskyi, Block et al., 2023; Gilmore-Bykovskyi et al., 2024). Audiovisual observations excluded personal cares such as bathing and dressing. Observation timing was limited by the availability of the research team who, per protocol, were present throughout observations between 8:00 a.m. and 6:00 p.m. Duration of participation was determined by LAR and participant preferences and typically continued until participants neared end of life. GoPro Hero cameras and Panasonic HC-W580 compact camcorders were unobtrusively placed in the environment and narrowly focused on participants. Auxiliary Sony audio recorders were affixed near participants to maximize audio data quality, when necessary.

Audiovisual Coding and Data Processing Procedures

Coding Procedures: Audiovisual data were classified by participant activity and social context to create standardized data segments, which were then coded to generate variables informing distinct verbal and nonverbal features of LEs. Data segments were transcribed using Codes for Human Analysis of Transcripts format (MacWhinney, 1992) and coded using the Computerized Language Analysis program to generate verbal output scores (i.e., counts, values, proportions) in domains including speech fluency, lexical diversity, and

semantic content (MacWhinney & Wagner, 2010). Noldus Observer XT (Zimmerman et al., 2009) was used to apply timed-event codes throughout each data segment with variable-specific onset/offset, yielding dimensions of frequency and duration to generate variables of verbal expressions (e.g., laughing, crying) and nonverbal communicative actions (e.g., eye tracking, waving, pointing; Cohen-Mansfield et al., 2009; Gilmore-Bykovskyi, 2015; Hubbard et al., 2002; Perugia et al., 2018). Variable duration and frequency were rounded to tenths of seconds and computed using the Generalized Sequential Querier (Bakeman & Quera, 2011). Variable-specific mean interrater reliability values across all computational linguistic scores and timed-event codes used in this study were previously established (80–90%, averaging 89.5% across all variables; Coulson et al., 2024; Mueller, Koscik et al., 2018). All generated variables are in Supplementary Table S1.

Codable Data and Representation of Baseline Functioning: Given the considerable resource-intensive nature of data cleaning, processing, and coding procedures, we prioritized "codable" data segments (i.e., participant was demonstrating behaviors that were measurable using the coding scheme). To generate an estimate of the participant's baseline functioning, a random 20% selection of their codable data from each observation day was coded.

Identification and Validation of LEs

Two pathways identified potential LEs: (1) caregivers, clinicians, or research staff who witnessed and reported the event to the study team during observation, and (2) systematic review of all video data by research staff. Systematic data review included screening for events demonstrating a noticeable, significant deviation from a participant's normal range of verbal and nonverbal communication. We reviewed and validated potential LEs via a structured case review process with multiple informants including family/friend caregivers and/or study site clinicians which has been detailed previously (Coulson et al., 2024; Gilmore-Bykovskyi et al., 2024).

Analysis

Outcome of Interest: A total of 71 coding variables were initially applied across standardized data segments. We removed redundant variables (i.e., could be expressed as a function of other variables). After removing redundant variables, several variables were still highly correlated within a participant. Therefore, we removed additional variables, until no two pairs of variables had a within-person correlation greater than .95. Variables were also excluded if they were undefined or 0. For example, laughter duration being zero seconds does not offer a meaningful contribution beyond what is already captured in a count-based variable representing laughter frequency. In each removal step, the variable to be removed was determined by considering which variables are most salient in estimating communication performance in dementia according to established theories or models in the field (Gilmore-Bykovskyi, 2015; Gilmore-Bykovskyi et al., 2015; Mueller, Hermann et al., 2018; Mueller, Koscik et al., 2018). Due to the individualized nature of dementia progression and unique routine variation in abilities (also referred to as baseline), we measured variable correlation separately for each participant. Consequently, different

variables were retained for different participants, ranging from 34 to 47 variables depending on the participant's individual profile.

Statistical Analysis: For each participant and each variable, we used generalized estimating equations to estimate the mean and its 95% confidence interval of the variable, conditional on whether the segment was an LE or not, and, in the case of continuous variables, also conditional on the variable being positive. We assumed variables were clustered within days, with an independent working correlation structure. For count-based variables, we specified the link and variance functions as in a standard Poisson regression model with an offset term to account for varying segment durations. For continuous variables, we specified the variance function as in a Gamma regression model with a log link.

Given the small number of observation days for each variable and participant, we used the jackknife estimator, which is more robust with smaller sample sizes (Li & Redden, 2015), to obtain standard errors. We then used these estimates to construct 95% confidence intervals and perform Wald's t-test comparing means for LEs versus baseline. For the t-tests, we assumed k_1-2 degrees of freedom, where for integer variables k_1 is the number of days audiovisual observations were collected and otherwise k_2 is the number of days with non-zero entries since that is how observations were grouped (Paik, 1988). Some means could not be estimated because LEs were either perfectly separated from baseline episodes, or we lacked observations in either the LE group or the baseline group. We did not control for multiple comparisons due to the exploratory nature of the analysis, to avoid Type II errors and missing important variables. Thus, p values should be considered nominal, with results prioritized by lower p values.

Power and Sample Size Analysis: To inform future study design, we estimated the sample size necessary for accurate estimation of LE prevalence. Due to the small sample size and possibility of a person having multiple LEs, we fit a homogeneous Poisson point process to estimate the mean rate per day of LEs and perform a power and sample size analysis based on all 20 participants. We assume the number of LEs in any disjoint and bounded sets of observations are independent, and that the observed days are a representative sample of all days. Using this approach, we estimated the number of observation days required for a 95% confidence interval to be within given tolerances (NIST/SEMATECH, 2024).

Results

Participants and Audiovisual Data Collected

Twenty participants living with advanced dementia were enrolled between December 2021 and April 2024, with an 84% enrollment rate. Demographic characteristics are found in Table 1. Across all participants, we collected 1,433 hours of audiovisual data over 539 observations. One participant passed away before initiating audiovisual observation. For the remaining 19 participants, the number of observations ranged from 2–127, with a mean of 28, and a median of 20; and observation durations ranged from 0.2–7.5 hours, with a mean of 2.5 hours and a median of 2.4 hours.

Case Reviews and Validated LEs

A total of 16 potential LEs, evidenced across six (30%) of the 20 participants, were brought to case review. We conducted 42 case reviews, engaging 10 family/friend caregivers and eight study site clinicians, with some informants participating in multiple case reviews. Of the 16 potential LEs, nine (56%) were validated across three (15%) of the 20 participants (Table 2).

Participant A Findings

For Participant A, multiple linguistic measures of verbal output were significantly different between LE and baseline measures. During each validated LE, the overall number of meaningful vocalizations increased, as did the rate of words per minute, while the percentage of verbs decreased in the LE as compared to baseline. The variables with the smallest *p* values are displayed in Figure 1. The strongest significant effect ratios were the decreases in percentage of adjectives (0.19[0.06,0.60]), the increases in meaningful vocalizations rate (14.05[5.11,38.61]) and duration (4.90[2.72,8.83]), and laugh rate (4.35[2.35,8.08]) and duration (4.51[1.85,10.98]). A summary of Participant A's data is found in Supplementary Table S2.

Participant B Findings

For Participant B, measures of gestures changed more during LEs compared to baseline than for other participants. The variables with the smallest *p values* are displayed in Figure 2. The strongest effect ratios were the increases in percentage of past tense verbs (5.25[4.74,5.81]) and percentage of auxiliaries (3.33[2.49,4.45]). A summary of Participant B's data is found in Supplementary Table S3.

Participant C Findings

For Participant C, there were significant changes in eye gaze and a shift in vocal communication complexity. The variables with the smallest *p* values are displayed in Figure 3. The strongest significant effect ratios are the increases in joint visual engagement rate (11.31[1.07,120.18]), eyes oriented to person(s) duration (2.49[1.14,5.48]), the decreases in affectionate touch duration (0.12[0.04,0.33]), and percentage of modals (0.35[0.25,0.49]). A summary of Participant C's data is found in Supplementary Table S4.

Findings Across Validated Lucid Episodes

All participants with validated LEs displayed an increased rate of meaningful vocalizations, though the rate ratio for Participant A was much larger than those of the other participants. Participants A and C both had an accompanying increase in meaningful vocalizations duration, which was not considered for Participant B due to its high correlation with their meaningful vocalizations rate. For Participant A, no non-verbal communicative actions were very different between baseline and LEs, while for Participants B and C, there were increases in the duration and frequency of eyes oriented towards person(s). Additionally, Participant B displayed increased duration and frequency of symbolic gestures, and Participant C had a decrease in the duration of affectionate touch. This demonstrates the breadth of possible non-verbal changes during LEs.

Power and Sample Size Analysis

A total of 20 participants were observed for a combined total of 556 days, 10 of which included an LE. This leads to a maximum likelihood estimate of the mean rate per day of .018, and a mean number of days between LEs of 55.6 (95% CI:[35.3,115.9]). If we assume the true average number of days between LEs is 60, we need at least 3,742 observations to achieve a 95% confidence interval width of at most 30 days. This is more than five times our current number of observations (556), reinforcing the need for more data on this rare phenomenon.

Discussion

This is the first prospective study integrating direct observation, audiovisual recording, and structured informant assessment to monitor for and validate LEs in individuals living with advanced dementia near end of life. We found that of 20 participants, three (15%) exhibited an LE that was validated by multiple informants, with all LEs demonstrating significant increase in the rate and/or complexity of verbal output as compared to their respective participant baselines. Features of nonverbal communication that support attentional and regulatory aspects of social communication, including eye gaze, were also significantly greater during LEs, although the specific variables and degree of significance varied across participants. As the data that were randomly selected to generate estimates of participant baseline only include data that met coding criteria (32.7%–49.0% of all data for participants demonstrating LEs), our findings very likely represent an underestimation of the true degree of difference in communicative recovery evidenced during an LE. Most LEs were under 1 hour, although one participant exhibited LEs reported by clinicians and family caregivers to last one day and two days, with the latter occurring in the last 10 days of life after a precipitous decline in awareness and functioning, potentially indicative of terminal lucidity (Nahm, 2022a; Peterson et al., 2022). The variability in individual participant baseline profiles of verbal and nonverbal communication highlights the complexity of detecting and characterizing LEs at a population level.

Although the specific profile of discrete LEs as compared to individual participant baseline communication varied, common features across all validated LEs include higher verbal output quality, quantity, and/or complexity compared to respective participant baselines. This finding aligns with reported LEs in retrospective and qualitative studies (Batthyány & Greyson, 2021; Eldadah et al., 2019; Gilmore-Bykovskyi, Block et al., 2023; Mashour et al., 2019; Peterson et al., 2022). We also found nonverbal communicative actions (i.e., eye gaze, symbolic gestures, and affectionate touch) to be LE features for some participants. As standard definitional criteria for LEs remain under development, validation of observed events necessarily relies on informant appraisal (Gilmore-Bykovskyi, Griffin et al., 2023; Peterson et al., 2022). Not all observed significant shifts were validated by informants as meeting provisional criteria for an LE (56% of potential LEs were validated by informants in this study). Bias and subjective variability related to personal meaningfulness or perceived significance of the degree of recovery in abilities evidenced during an LE may influence interpretation of the event and ultimately event validation. LEs were validated by either family caregivers or clinicians, who may vary significantly in conceptualization and

interpretation of LEs. For example, family caregivers may be more likely to validate an LE if there was an indication of the person living with dementia "returning to their old self". Hospice clinicians, on the other hand, are much less likely to know the person prior to the onset of dementia. Event interpretation may also be influenced by its context; for example, for some events family members were present anticipating end of life following a notable clinical deterioration–whereas for other events only clinical staff were present and family later viewed the video data.

Recent research also suggests that LEs may represent a broad phenomenon with multiple typologies of events (Griffin et al., 2024) and a low degree of clinical expert consensus on what constitutes an LE (Bangerter et al., 2024). As operational definitions and standard measures of LEs and LE types are in very early developmental stages, it is challenging to assess sources of respondent bias and disambiguate the influence of biases on event interpretation. The use of structured coding of video data to measure verbal expressions and nonverbal communicative actions helps mitigate these risks by enabling quantitative assessment of discrete actions during these events, enabling triangulation of these data with informant case reviews. Statistical analyses demonstrate a significant recovery and improvement in both verbal expressions and nonverbal communicative actions during LEs, supporting informant interpretation of events. Future research is needed to investigate and differentiate between events brought to case review that were validated as an LE and those that were not validated, and to determine differences in effect ratios between non-validated and validated LEs–shedding light on the potential influence of informant bias. Additional research focused specifically on data from case reviews can support efforts to identify which features are most consistently relied upon for interpretation and validation decisions.

It is possible that features of discourse coherence, or the informativeness, clarity, understandability, and connectedness of a speaker's communication (Olness & Ulatowska, 2011), might be influential in event interpretation. While "coherence" is typically considered in the context of words, phrases, and sentences, it also comprises more subtle aspects of pragmatic language, such as gesture, nodding, and other conversational devices used to maintain a topic with another speaker. For example, Participants A and C showed significant decreases in linguistic measures (such as verbs, nouns, and other words) in the LEs as compared to baseline, but both showed increases in laughing and meaningful vocalizations such as filler words ('um,' 'uh huh'), indicating potential awareness of the listener. In both cases, the quality of verbal output, rather than quantity, was a key element of the LE. Participant A showed decreases in total words, sentence length, and complexity but increases in words per minute; the LE involved accurately, and efficiently, labeling names of family members upon request. These shifts in pragmatic language use and semantic memory are measured by the individual's response to and interaction with their environment, are context dependent, and demonstrate that LEs may represent shifts (versus quantitative increases) in communication toward meaningfulness, informativeness, and connectedness.

This study highlights important methodological questions about the role of different data sources in defining and measuring LEs. Of particular importance is how the boundary of an LE is defined temporally and when to determine whether a series of event sequences constitutes one or multiple LEs. Another temporal boundary of interest is proximity to

end of life, as terminal lucidity is another related yet distinct phenomenon from LEs, defined as "the unexpected return of mental clarity shortly before death" (Nahm & Greyson, 2009, p. 942). Differentiating LEs from cognitive terminal lucidity is an ongoing area of research given the lack of evidence to indicate if there are physiological or biological differences between these phenomena (Benson et al., 2023, Gilmore-Bykovskyi, Griffin et al., 2023; Peterson et al., 2022). In this study, there was a wide range of time before death between LEs (between 9 days to 20 months), providing some further evidence that LEs do not necessarily imply terminal lucidity (Nahm, 2022b). As this study detected some events that extended beyond the hours of our audiovisual observation timeframes and were multi-day, we relied on both informant report and direct data to specify event boundaries. Given the limited volume of direct data documenting these events to date, additional primary data are needed to inform optimal strategies for specifying event boundaries and informing a broader evaluation of the tradeoffs of different criteria that could be applied to measure event features. Additional opportunities for future research include integration of physiologic markers into data collection to provide insights into potential biological or neurophysiological changes that may correlate with LEs.

Our findings also provide useful insights into sample limitations and requirements for future research, with accuracy estimates indicating that for robust confidence intervals roughly five times the number of observations would be needed. This highlights the critical need for methodological advances in approaches to event surveillance/detection and measurement tools to characterize salient features of events across individuals considering the time and resource intensive nature of in-person facilitated observation and gold-standard measurement which currently relies on manual coding. Augmenting these protocols with computer vision and automatic speech recognition models may substantially accelerate efficiency in quantifying verbal and nonverbal measures, making more rapid processing of larger volumes of audiovisual data feasible. The goal of larger volumes of data likely needs to be carefully balanced with participant preferences and priorities surrounding video observation, as our prior work suggests that close partnership and ongoing interactions between research staff, clinical staff at the study site, and participants and their families are critical to achieving high sustainability and retention (Coulson et al., 2024; Gilmore-Bykovskyi, Block et al., 2023).

This study has important limitations. Our sample of participants living with advanced dementia represents a limited range of racial, ethnic, and socioeconomic backgrounds. Although we have a significant depth of longitudinal observational data within each participant, our overall sample size is limited, leading to a very wide confidence interval for prevalence estimation, and is subject to multiple sources of selection bias. First, participants are recruited from a single hospice unit and observations take place at irregular dates/times. Additionally, the total amount of data varies by participant based on multiple factors including time to death or disenrollment. At least two participants were multi-lingual, and we were unable to code their verbal output in non-English language due to limitations of bilingual expertise on the transcription team. While the total duration of time exhibited speaking a language other than English was minimal, this potentially impacts the accuracy of coded data for these participants–one of whom demonstrated an LE. It is likely that as automatic speech recognition algorithms continue to improve,

automated multilingual transcription and analysis will address this limitation in the future. This study also has several important strengths including integration of direct observation, systematic measurement of verbal and nonverbal communication, and systematic integration of informant appraisal of potential LEs. Subsequent efforts will make these data resources available to the broader scientific community to support replication and further investigation into LEs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability

Audiovisual data and deidentified audiovisual coding data and interview data can be made available through IRB-approved procedures and data sharing agreements to protect participant privacy. For further information on data availability, please contact Dr. A. Gilmore-Bykovskyi. This research was not preregistered.

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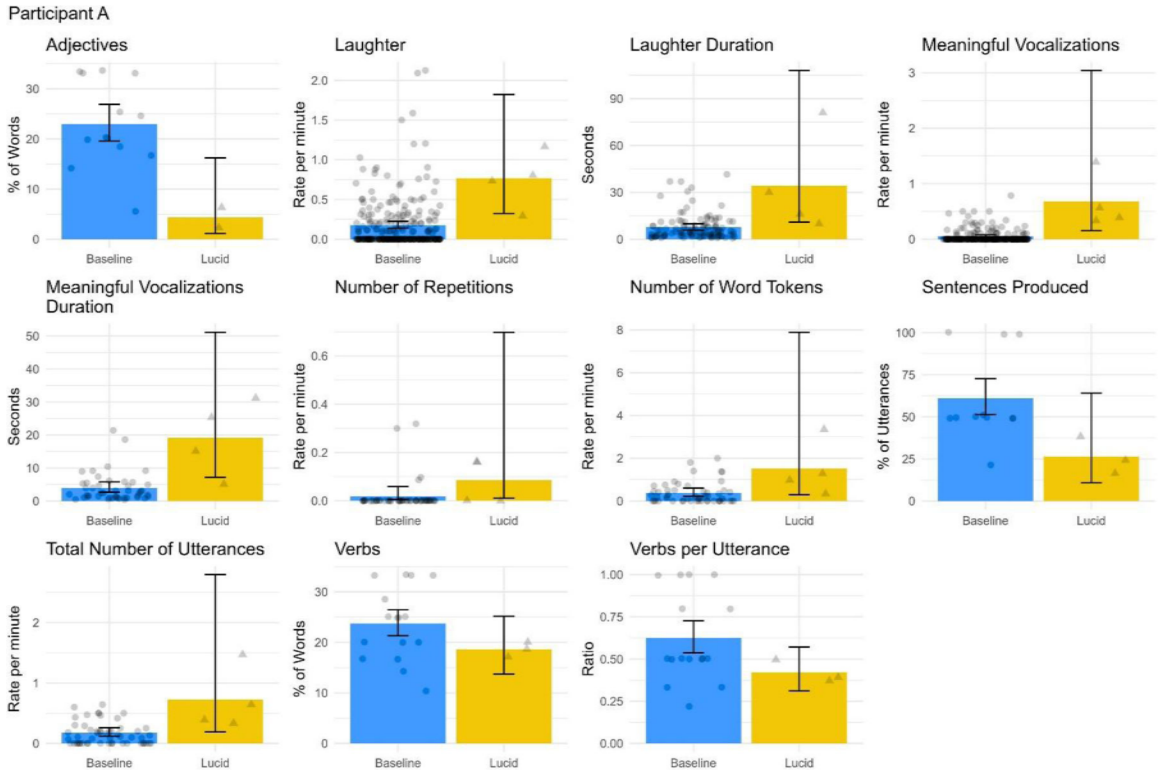

Figure 1.

Participant A Verbal and Non-verbal Variables During Baseline vs Lucid Episodes. Bar graphs of the mean values for the most statistically significant variables for Participant A during baseline and lucid episodes with 95% confidence intervals overlayed with the raw data. Percentage (%) values must be 0–100; ratios, rates and durations must be non-negative.

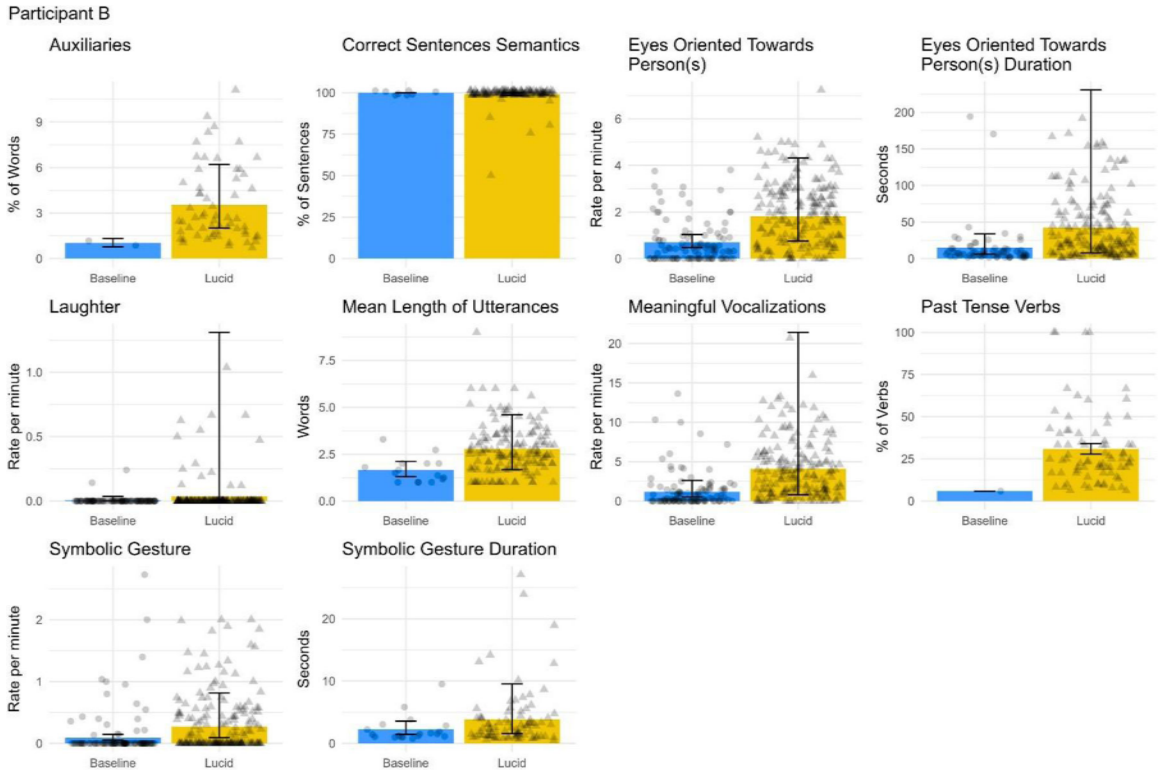

Figure 2.

Participant B Verbal and Non-verbal Variables During Baseline vs Lucid Episodes. Bar graphs of the mean values for the most statistically significant variables for Participant B during baseline and lucid episodes with 95% confidence intervals overlayed with the raw data. Percentage (%) values must be 0–100; lengths, rates and durations must be non-negative.

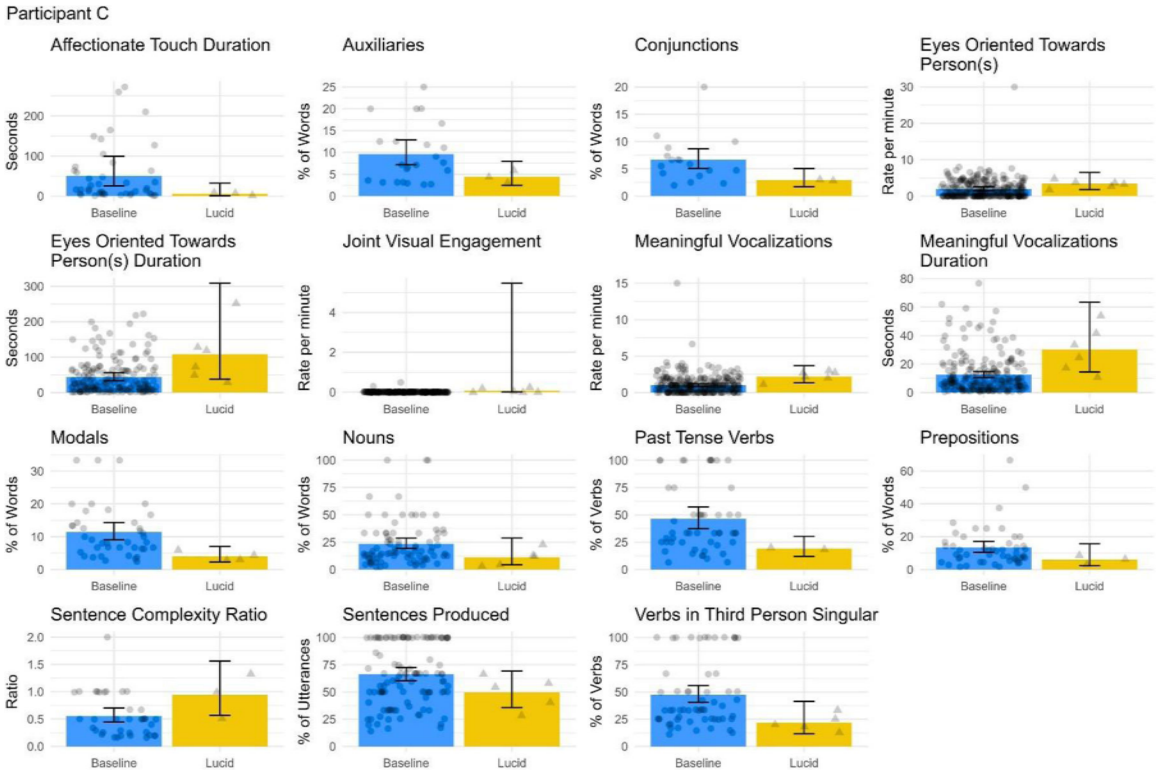

Figure 3.

Participant C Verbal and Non-verbal Variables During Baseline vs Lucid Episodes. Bar graphs of the mean values for the most statistically significant variables for Participant C during baseline and lucid episodes with 95% confidence intervals overlayed with the raw data. Percentage (%) values must be 0–100; ratios, rates and durations must be non-negative.

Table 1.

Participant Characteristics (n=20)

Characteristic	Participants, N (%)
Age (y)	
Range	71–89
Mean	82
Number of participants ≥90	3
Gender	
Male	8 (40)
Female	12 (60)
Race/ethnicity	
White	19 (95)
More than one[a]	1 (5)
Marital status	
Married	9 (45)
Widowed or divorced	11 (55)
Education	
High school diploma or equivalent	2 (10)
Tech school, vocational training	2 (10)
Some college	2 (10)
4-year college	6 (30)
Post-college	8 (40)
DSRS[c] score	
Mean	48
Range	(37–54)
ASHA-FACS[c] overall qualitative dimension mean score	
Mean	1.69
Range	(1–3.8)
Years living with dementia	
0–5	7 (35)
6–10	5 (25)
>10	6 (30)
Not reported	2 (10)

Note. ASHA-FACS = American Speech-Language-Hearing Association Functional Assessment of Communication Skills for adults; DSRS = Dementia Severity Rating Scale

[a]One participant identified as Native Hawaiian or Pacific Islander, White, and Other.

Table 2.

Validated Lucid Episodes

Event description by participant	Estimated duration	Proximity to death	Informants[a]
Participant A			
Baseline[b]: Minimally verbal, occasional one-word answers, does not remember family members			
Diagnosis[c]: Alzheimer's disease and vascular dementia, 2 years prior to LE A1			
LE A1[d]: Verbalizes names of several family members while looking at various photographs.	5 minutes	20 months	1 caregiver, 2 clinicians
LE A2[e]: Remembers name given to stuffed animal and jokes about it with family and staff.	7.5 minutes	19 months	2 caregivers
LE A [e]: Responds verbally to several questions about personal and family history, answering accurately.	30.5 minutes	18 months	2 caregivers
Exemplar quotes from proxy-informant case review (LE A1): "I'm glad she still knows who us kids are, but, but those are older pictures too so I wonder if that has anything to do with it, the fact that they're older pictures and they're not what we look like now… She probably hasn't called me by my name for, probably [5–6 months prior] the last time she used my name, so yeah uh, just amazed at the interaction." – *caregiver* "Many times, I have to ask her some, I ask her something and I have to wait for a very long time. And, and sometimes get no response at all. That was just like you were having a conversation with anybody. Wow." – *clinician*			
Participant B			
Baseline[b]: Variation in verbal output and interactions, minimally coherent, frequent use of a few short phrases			
Diagnosis[c]: Alzheimer's disease, 10 years prior to LE B1			
LE B1[f]: Speaks in full sentences, initiates conversation, asks questions, lists names of family members, recalls social security number, physically active and ambulates.	1 day	52 days	4 clinicians[g]
LE B2 [f]: Following 2-week period of decline interpreted by clinicians as nearing end of life: Walks and eats/drinks, speaks in full sentences, asks questions, initiates conversation, talks about parents, accurately identifies family members, expresses contentment, states "I'm leaving soon."	2 days	9–10 days	4 clinicians[g]
Exemplar quote from proxy-informant case review (LE B2): "It's awesome to be able to watch this and witness it because we had so much time with him where it was just silly, meaningless little words and the littles games we would play with him which were also enjoyable, but it's just so nice to see a glimpse of who he was, you know, before we knew him." – *clinician*			
Participant C			
Baseline[b]: Verbal output seldom consisting of recognizable words, infrequent one-word answers			
Diagnosis[c]: Alzheimer's disease, 7 years prior to LE C1			
LE C1[e]: Verbalizes clear statements to clinician during mealtime.	10 minutes	4 months	1 caregiver, 1 clinician
LE C2[e]: Clear verbal responses to questions, verbally requests significant other to walk nearer.	4 minutes	3 months	1 caregiver, 1 clinician
LE C3[e]: Verbalizes clear answers to questions, verbalizes clear statements and needs, asks questions.	61 minutes	3 months	2 caregivers, 3 clinicians
LE C4[e]: Verbalizes a clear full-sentence question and responds to question with a full sentence.	1 minute	2 months	1 caregiver, 1 clinician
Exemplar quote from proxy-informant case review (LE C3): "And it sure sounded from a depth, you know. So, it's [participant C], it may well be that [participant C]'s soul is back, or that we just didn't…. There's something going on inside of her and she's now become, it seems, becoming aware of it." – *caregiver*			

[a] All informants who participated in case review, providing unanimous validation of the LE.

[b] Baseline functioning descriptors apply to the time period in which LEs occurred and were determined via collaboration between research staff and study site clinicians.

[c] Diagnoses informed via systematic medical record review.

[d] Initially identified as potential LE by research staff who witnessed the event.

[e] Initially identified as potential LE by research staff via structured review and screening of data.

[f] Initially identified as potential LE by family caregivers and clinicians who witnessed the event.

[g] Family caregivers' statements to research staff and captured in audiovisual data of LEs indicate they interpreted the event as unexpected/shocking, and the patient's communication as coherent, meaningful, and demonstrating a recovery of abilities including memory. Caregivers were unable to participate in the case review process.

[h] Abbreviations: LE, lucid episode.