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RESEARCH ARTICLE

Developing and describing a typology of lucid episodes among people with Alzheimer's disease and related dementias

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Abstract

INTRODUCTION: This study examined lucid episodes among people living with late-stage Alzheimer's disease and related dementias (PLWD) and then developed a typology of these episodes to help characterize them.

METHODS: Family caregivers of PLWD provided information about witnessed episodes, including proximity to death, cognitive status, duration, communication quality, and circumstances prior to lucid episodes on up to two episodes (caregiver $N = 151$; episode $N = 279$). Latent class analysis was used to classify and characterize empirically distinct clusters of lucid episodes.

RESULTS: Four lucid episode types were identified. The most common type occurred during visits with family and among PLWD who lived > 6 months after the episode. The least common type coincided with family visits and occurred within 7 days of the PLWD's death.

DISCUSSION: Findings suggest that multiple types of lucid episodes exist; not all signal impending death; and some, but not all, are precipitated by external stimuli.

KEYWORDS
Alzheimer's disease and related dementias, family caregivers, lucidity, paradoxical lucidity

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1 | BACKGROUND

Some people with late-stage Alzheimer's disease and related dementias (ADRD) have been reported, largely by way of anecdote and case studies,[1,2] to exhibit unexpected episodes of spontaneous, meaningful, and relevant communication or behavior. These lucid episodes (LEs), sometimes referred to as paradoxical lucidity because of their inconsistency with current models of the pathophysiology of ADRD[3] and lack of scientific explanation, are characterized by periods of mental clarity in persons living with ADRD (PLWD) who are assumed to have lost coherent cognitive capacity. LEs in PLWD have frequently been overlooked and have received relatively little research or clinical attention,[2,3] but case reports have provided useful initial insights into their dimensions, especially those that occur at the end of life.[4,5] To date, there is little agreement on precise definitions of what an LE is and is not.[6–8] Characterizing these episodes could help specify definitions by distinguishing inclusion and exclusion criteria, which in turn could help identify gaps in the dominant models of ADRD pathophysiology that do not adequately explain temporary reversals of cognitive ability. Further conceptualization could also help properly educate care providers and family caregivers about their potential occurrence and support family caregivers.[9]

Gilmore-Bykovskyi et al.[10] have proposed a set of conceptual questions to harmonize and frame characterizations of LEs and guide investigations toward a robust and precise definition. Considering the early state of evidence, these questions are intended to frame areas of inquiry without making premature presumptions about definition criteria. For example, one guiding question asks if LEs exist along a continuum that extends throughout the disease trajectory. Although end-of-life LEs, often called terminal lucidity, are well documented in near-death studies among those with and without neurodegenerative conditions,[1,2] it is possible that LEs also occur at times other than impending death. Early characterizations of LEs in ADRD, therefore, should ideally include a set of episodes from PLWD at diverse stages of ADRD and in different settings and contexts.

In this study, we surveyed bereaved family caregivers of PLWD to elicit information about dimensions of LEs and then evaluated data to develop a typology of LEs. A typology approach (e.g., latent class analysis) groups cases or participants into types based on their common characteristics, identifying certain "combinations" of multiple characteristics that are empirically observed in a sample. Our aim was to determine whether distinct patterns or types of LEs exist that, in turn, could be used to refine conceptualizations and definitions of LEs. Developing a typology is an ideal first step for characterizing LEs because it allows for their heterogeneous and episodic nature that cannot be captured by separate dimensions alone or in isolation (e.g., duration, type of behavior, and context). It allows for heterogeneity of components that have been previously reported (e.g., duration, antecedent events, and communication quality) as well as other characteristics of those experiencing the episode (e.g., dementia stage or proximity to death) and those witnessing the episode (e.g., caregiving contexts and caregiver reactions). Creating a typology can also provide a starting point for developing an underlying theoretical explanation for LEs to be tested in future research.

RESEARCH IN CONTEXT

1. **Systematic review**: The authors reviewed the literature using traditional (e.g., PubMed) sources. Research on lucid episodes (LEs) among people with late-stage Alzheimer's disease and related dementias (PLWD) is in the earliest stages and has relied on case reports and cross-sectional study designs. Recent publications describe scientific and methodological challenges in studying LEs. Relevant citations are appropriately cited.
2. **Interpretation**: This is the first study to identify multiple types of LEs. Contrary to previous research, the most common type of LE is preceded by visits with family and occurs among PLWD who continued to live > 6 months after the episode. The least common type occurs within 7 days of death and coincides with family visits.
3. **Future directions**: These findings challenge the clinical assumption of a linear cognitive and behavioral decline for PLWD. They provide novel insights into a spectrum of LEs. Future research is needed to confirm these types of LEs, determine whether their neurological patterns differ, and if certain types can be induced or extended.

2 | METHODS

2.1 | Participants and survey procedures

Participants were recruited in February 2021 from UsAgainstAlzheimer's (usagainstalzheimers.org), a non-profit group that aims to improve early detection, diagnosis, and interventions for ADRD and mobilize participation in research on effective treatments and care quality. UsAgainstAlzheimer's administers the A-LIST, a unique online community interested in participating in research on ADRD. At the time of the study, the A-LIST had 8223 participants, of whom 3577 (43.5%) had either identified as a current or former caregiver in previous A-LIST queries or had not specified their role or interest in ADRD. UsAgainstAlzheimer's sent an e-mail invitation that described the study's purpose and included a hyperlink to an electronic survey. Non-responders were e-mailed reminders 4 and 15 days after the original mailing.

The survey included a general description of an LE based on definitions used in the literature[7] to help orient caregivers who were potentially unfamiliar with the phenomenon: "We are defining a lucid experience as unexpected, spontaneous, meaningful and relevant communication from a person who is assumed to have permanently lost the capacity for coherent interactions, either verbally or through gestures and actions." Questions on the characteristics and context of the episode were informed by previous surveys conducted by Batthyány and Greyson[4] and pilot tested on a small sample of ADRD caregivers. Respondents were asked if they had ever witnessed an LE in a relative, friend, or neighbor who has ADRD, and then given the option to report characteristics and details of up to two of the most memorable LEs witnessed.

UsAgainstAlzheimer's institutional review board (IRB) approved the study, and all participants provided informed consent prior to participating in the online survey.

2.2 | Measures

To develop distinct typologies, five dimensions of LEs were included: (1) proximity to death (e.g., within 24 hours of PLWD death; 2–3 days before PLWD death; 4–7 days before PLWD death; 1 week–6 months before PLWD death; PLWD lived > 6 months; PLWD is still alive), (2) cognitive status (e.g., mostly asleep/unconscious; mostly awake, but not responding or reacting; extreme difficulty with memory, attention, or focus; moderate difficulty with memory, attention, or focus; minor difficulty with memory, attention, or focus; fully aware, no impairments), (3) duration of LE (e.g., under 10 minutes; 11–30 minutes; 31–60 minutes; 1–4 hours; 4–24 hours; 2–7 days; > 7 days), (4) communication quality (e.g., aware, communication made complete sense; aware, communication made some sense; aware, but communication made no sense; aware, but only non-verbal communication; talked coherently while sleeping), and (5) circumstances prior to LE (e.g., visits from family or change in medication; multiple responses are possible).

We further compared caregiving contexts and caregiver reactions by the derived LE typology. We considered demographic characteristics of caregivers (e.g., sex, work status) and PLWD (e.g., dementia type, living in the same household) and their relationship (e.g., spouse or child caregiver) for caregiving contexts. For caregiver reactions to the episode, we assessed emotional reactions (e.g., how positive and stressful it was) and behavioral reactions (e.g., changes in care patterns or decisions).

2.3 | Typology analysis

Because previous reports have considered proximity to death a potentially important dimension of LE,[4,5] we limited our analysis to bereaved caregivers (i.e., the PLWD had died prior to the survey) who witnessed at least one LE and reported demographic and relationship characteristics. Each caregiver provided detailed information on up to two of the most memorable LEs (i.e., LEs nested within caregivers). Using a latent class analysis (LCA),[11,12] we classified empirically distinct clusters of LE experience by combining five characteristics of the LE (i.e., proximity to death, cognitive status, duration of LE, communication quality, and circumstances prior to the LE). The LCA, as a case-centered approach (vs. variable centered), is useful for capturing heterogeneous patterns of "naturally occurring" LEs, given that existing literature has not operationalized LEs specifically. Thus, it is critical to examine how caregivers' experience with LEs (e.g., duration, mode, and content) was combined with different stages of dementia (e.g., late and end of life), environmental context (e.g., place, time, and presence of other people), and conditions (e.g., medical and cognitive status).

We selected the best model for latent classes of LEs based on model fit statistics, including the Akaike information criterion (AIC), the Bayesian information criterion (BIC), sample-size–adjusted BIC (A-BIC), and entropy.[8,9] To compare caregiving contexts and caregiver reactions by the derived LE typologies, we used the "most likely" class variable, which was constructed via the latent class posterior distribution.

3 | RESULTS

3.1 | Sample characteristics and survey responses

Of the 3577 A-LIST members sent e-mails, 538 participated in the survey (see Figure 1). Of the 480 respondents who identified as current and former caregivers, 294 (61.3%) reported witnessing an LE at any time. Of those reporting LEs, 259 (88%) reported information about at least one episode, and 233 reported their own and PLWD demographic characteristics and information about LEs. Because proximity to death is not relevant for caregivers whose care recipients are alive, we further restricted our analytic sample to 151 bereaved caregivers (episode $N = 279$; 15% reported one episode, 85% reported two episodes).

Demographic characteristics of the PLWD and the caregiver who experienced LEs are found in Table 1. Most survey respondents were women (72%), children of the PLWD (75%), between the ages of 61 and 70 (44%), non-Hispanic White (87%), and married (53%). Of the PLWD who were reported to have a LE, 61% were women, 31% lived in the same household as the survey respondent, and 75% were reported to have Alzheimer's disease as opposed to other dementias.

Descriptive statistics of LE dimensions used for typology are presented in Table 2. In total, 17.9% reported that the LE occurred within 7 days of death (5.6% within 24 hours, 4.0% within 2–3 days, 8.3% within 4–7 days of death). More than one third (34.1%) died 1 week to 6 months after the LE. The majority of PLWD lived > 6 months after the LE (48.0%). Most respondents (72.3%) reported that the PLWD cognitive status was in the late stages of dementia (i.e., unconscious to extreme difficulty). LEs were relatively short, with 77.3% reporting them lasting < 30 minutes. During the LE, 51.1% respondents reported that the PLWD was aware and their communication made complete sense. Another 31.9% reported that the PLWD was aware and that communication made some sense, and 9.4% reported that they were aware but only non-verbal communication was used. No respondents reported the PLWD talked coherently while sleeping. Visits from family or friends, music playing, valued rituals or behaviors, or reminiscing preceded 69.2% of LEs; however, 30.8% reported no special circumstances preceding the LE.

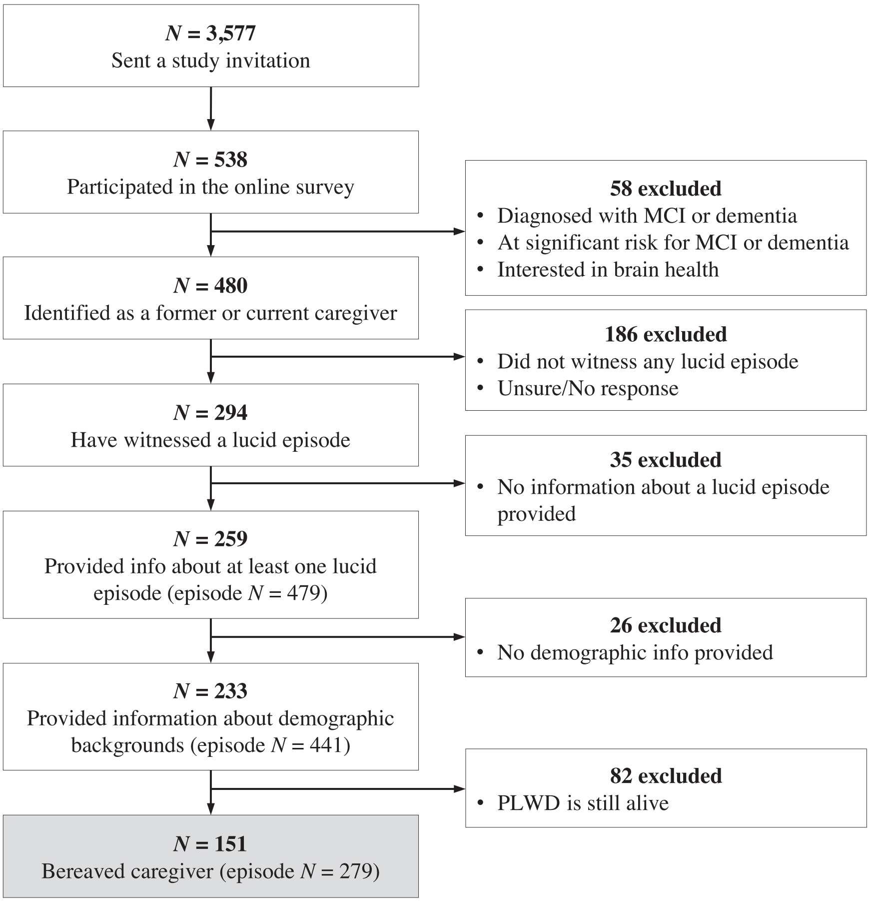


FIGURE 1 Flowchart of the sample selection. MCI, mild cognitive impairment; PLWD, person living with Alzheimer's disease and other dementias.

3.2 | Typology results

Model fit indices, including AIC, BIC, A-BIC, and entropy, were compared among different class solutions (see Table S1 in supporting information). The four-class model shows the lowest AIC and A-BIC, whereas BIC continues to increase as the number of classes increases. Item response probabilities of the four latent class model are shown in Table 2 and Figures 2 and 3. Table 3 presents comparisons of caregiving contexts and caregiver reactions by the derived LE typology.

Thirty-three percent of LEs were categorized as Type 1 (see Figure 2). This type of LE occurred in people with moderate to extreme cognitive difficulties who continued to live at least 6 months after the LE. Their episodes were relatively short (< 10 minutes), the communication made complete or some sense, and the LEs were associated with visits from family or friends. These episodes were more commonly witnessed by children who did not live in the same household and compared to the other types, had the least frequency of contact with the PLWD.

Thirty-one percent of LEs were categorized as Type 2 (see Figure 2). These LEs occurred among people with extreme cognitive difficulties who lived for at least 1 week, but often > 6 months after the LE. Communication during the LE made complete sense, but there were no special circumstances or stimuli noted that preceded the LE. These episodes were more likely witnessed by the spouse of the PLWD who lived in the same household. These LEs had the lowest positive appraisal and the highest stressful appraisal. Caregivers were less likely to make or change care decisions based on the LE.

Twenty-four percent of LEs were categorized as Type 3 (see Figure 3). These episodes occurred in people with extreme cognitive difficulties and were the least likely to have had the cognitive impairment diagnosed. These LEs coincided with a range of circumstances that engaged the PLWD (e.g., music, reminiscing, or valued rituals) or with a change in health-care or living situations (e.g., a new room or facility). In this type, PLWD continued to live at least 1 week, but often > 6 months after the LE. These episodes were more commonly witnessed by children of the PLWD who lived in the same household; and the LE led caregivers to make or change care decisions.

Twelve percent of LEs were categorized as Type 4 (see Figure 3). This type was consistent with previous definitions of terminal paradoxical lucidity, occurring close to death among PLWD at very late stages of life, with communication making complete sense, and coinciding with visits from family or friends. This type coincided with visits from family, had the highest positive appraisals, and the LE led to changes in care decisions.

4 | DISCUSSION

We found four typologies based on five dimensions of LEs. Type 1 episodes, the most common type of LEs in our sample, occurred with

TABLE 1 Characteristics of caregiver participants and their PLWD.

Variable	Caregiver	PLWD
Relation to PLWD		
Spouse/partner	19%	–
Child	75%	–
Other relative	5%	–
Friend/neighbor	1%	–
Female	72%	61%
Age		
Under 50	5%	–
51–60	18%	–
61–70	44%	–
Over 70	33%	–
Education		
Less than high school	0%	10%
High school	11%	45%
More than high school	89%	45%
Marital status		
Married	53%	–
Cohabiting	4%	–
Divorced/separated	11%	–
Widowed	17%	–
Never married	14%	–
Employed (full or part time)	30%	–
Non-Hispanic White	87%	–
Lived in the same household	31%	–
Contact frequency[a]	6.01 (1.56)	–
Dementia type (*multiple responses*)		
Alzheimer's disease	–	75%
Vascular	–	10%
Frontotemporal	–	7%
Lewy body	–	8%
Parkinson	–	3%
Never diagnosed	–	5%

Note: $N = 151$.

Abbreviations: PLWD, person living with Alzheimer's disease and other dementias; SD, standard deviation.

[a] *M* (*SD*); rated from 1 (once a year or less) to 7 (every day or living in the same household).

PLWD who lived > 6 months after the LE. These types of LEs coincided with visits from family, more frequently reported by children who did not co-reside with the PLWD and had the lowest frequency of contact. Unlike the other types, however, Type 1 LEs often only made some sense or made no sense at all. This type of LE draws attention to a specific challenge to studying LEs, one that requires careful consideration with future research. This combination of characteristics and conditions could suggest that unhabitual or rare visits may trigger a lucid response from the PLWD, or it is possible that family or friends unaccustomed to the routine and daily cognitive fluctuations of the PLWD either draw meaning from these fluctuations or are primed to pay closer attention to cognition or behavior that routine visitors overlook. Witnesses to LEs may introduce bias by interpreting episodes that others may not see that way, but conversely, they may also provide context that others may not have to determine whether something seems incoherent or if indeed, the communication is logical and coherent.[13] LEs, much like behavioral symptoms of dementia, can have different meanings depending on the context. However, unlike behavioral symptoms of dementia, no conceptual frameworks exist to identify causes, meanings, or effective caregiver responses to LEs.[14] This is a critical direction for future research on LEs.

Type 2 LEs were short in duration, and did not include any unique antecedents or special circumstances. Contrary to the literature reporting that LEs were typically prompted or triggered,[15] this type of LE was reported to happen randomly without any observable prompt or external stimuli. Although the degree of change or fluctuation in lucidity was not a unique characteristic of this type of LEs, it is possible that spouses who live in the same household as a PLWD may witness smaller fluctuations in mental clarity or coherent communication[9] that either would not be perceived, or without context, understood as a temporary return of lucidity. This type of LE, therefore, could be more prevalent in studies of community-dwelling PLWD, and less frequent in long-term care settings where staff may not be consistently present or attuned to small changes. Future research should consider these potential biases when examining these smaller, less "remarkable" lucid moments and on novel approaches to measure these more granular LEs. Methodological approaches including passive technology or digital biomarkers may detect more minute changes in cognition or behavior and capture more subtle LEs.[16]

Type 3 LEs occurred among people with extreme cognitive difficulties and were, in part, preceded by music meaningful to the PLWD, reminiscing, valued rituals, or changes in setting. Type 1 LEs occurred in PLWD who lived at least 1 week, but more often ≥ 6 months after the episode, possibly indicating that other LEs may occur throughout the later stages of ADRD. These LEs align with previous research highlighting the importance of meaningful activities (e.g., activities that are significant or reflect past interests, routines, habits, and roles)[17] and the cognitive, emotional, and functional benefits of engaging in meaningful activities for PLWD.[18] Interventions using music, for example, have shown reductions in agitation among PLWD.[19] Anecdotes and case studies in the literature and popular media often include emotionally laden antecedents for LEs.[7] That preceding or co-occurring pleasant activities are present, especially in a familiar setting with family, may indicate that this LE type is more easily observable by family and non-family because of seemingly obvious stimuli. Researchers should consider studying how activating areas in the cerebral cortex with pleasant activities, such as music, in a familiar setting, may lead to observable LEs; if the communication quality or context of this LE type is different than other types of LEs; and if the LEs can be extended with these types of intervention.

TABLE 2 Item response frequency of lucid episode dimensions and item response probabilities of the 4-latent class model.

Variable	Total sample	Type 1 (33%)	Type 2 (31%)	Type 3 (24%)	Type 4 (12%)
Proximity to death					
Within 24 hours of PLWD death	5.6%	0.05	0.03	0.00	0.26
2–3 days before PLWD death	4.0%	0.00	0.03	0.00	0.27
4–7 days before PLWD death	8.3%	0.01	0.07	0.04	0.42
1 week–6 months before PLWD death	34.1%	0.32	0.40	0.46	0.00
PLWD lived more than 6 months	48.0%	0.61	0.48	0.50	0.04
Cognitive status					
Mostly asleep/unconscious	11.8%	0.00	0.17	0.08	0.38
Mostly awake, but not responding or reacting	16.1%	0.25	0.12	0.04	0.28
Extreme difficulty with memory, attention, or focus	44.4%	0.39	0.44	0.60	0.29
Moderate difficulty with memory, attention, or focus	20.8%	0.29	0.20	0.22	0.00
Minor difficulty with memory, attention, or focus	3.6%	0.08	0.04	0.00	0.00
Fully aware, no impairments	3.2%	0.00	0.04	0.06	0.05
Duration					
Under 10 minutes	52.7%	0.51	0.53	0.51	0.60
11–30 minutes	24.6%	0.23	0.24	0.34	0.13
31–60 minutes	9.5%	0.16	0.11	0.02	0.03
1–4 hours	6.8%	0.10	0.05	0.01	0.15
4–24 hours	3.4%	0.00	0.06	0.05	0.03
2–7 days	1.1%	0.00	0.01	0.00	0.06
More than 7 days	1.9%	0.00	0.00	0.08	0.00
Communication quality					
Aware, communication made complete sense	51.1%	0.34	0.45	0.68	0.84
Aware, communication made some sense	31.9%	0.48	0.29	0.25	0.07
Aware, but communication made no sense	7.6%	0.13	0.11	0.00	0.00
Aware, but only non-vernal communication	9.4%	0.06	0.15	0.08	0.09
Circumstances prior to LE (*multiple responses*)					
Visits from family/friends	37.6%	0.78	0.00	0.12	0.74
Change in medication	2.9%	0.02	0.00	0.03	0.12
Change in health-care setting	9.3%	0.09	0.00	0.19	0.15
Music playing that was meaningful to PLWD	13.6%	0.20	0.00	0.26	0.06
Reminiscing (e.g., looking at pictures)	7.5%	0.04	0.00	0.18	0.17
Valued ritual or behaviors	5.4%	0.00	0.00	0.20	0.04
No special circumstances	30.8%	0.00	1.00	0.00	0.00

Note: Caregiver $N = 151$; Episode $N = 279$.
Abbreviations: LE, lucid episode; PLWD, person living with Alzheimer's disease and other dementias.

Type 4 was relatively consistent with other descriptions of "terminal paradoxical lucidity" in the literature,[1–3] with an important indicator being the PLWD dying soon after the episode, but only 12% of all episodes in our sample were categorized as Type 4. Family visitation was also an indicator, but given the cross-sectional design of our study, it is not clear if family presence close to death acts as a catalyst for LEs or if imminent death brings family awareness to fluctuations in cognition. While longitudinal research is needed to better understand this constellation of indicators, these findings also suggest that Type 4 LEs may happen less frequently than other types, and efforts to understand LEs only at the end of life may provide a limited scope of the phenomenon.

One key strength of our study is that we have captured a broad set of factors potentially associated with LEs. Confirmation of these typologies is being tested in a longitudinal study with current caregivers, which will help further validate LE types, establish their prevalence estimates, and possibly allow for refinements of LE assessments. Narrowing the items for assessment may reduce respondent burden in

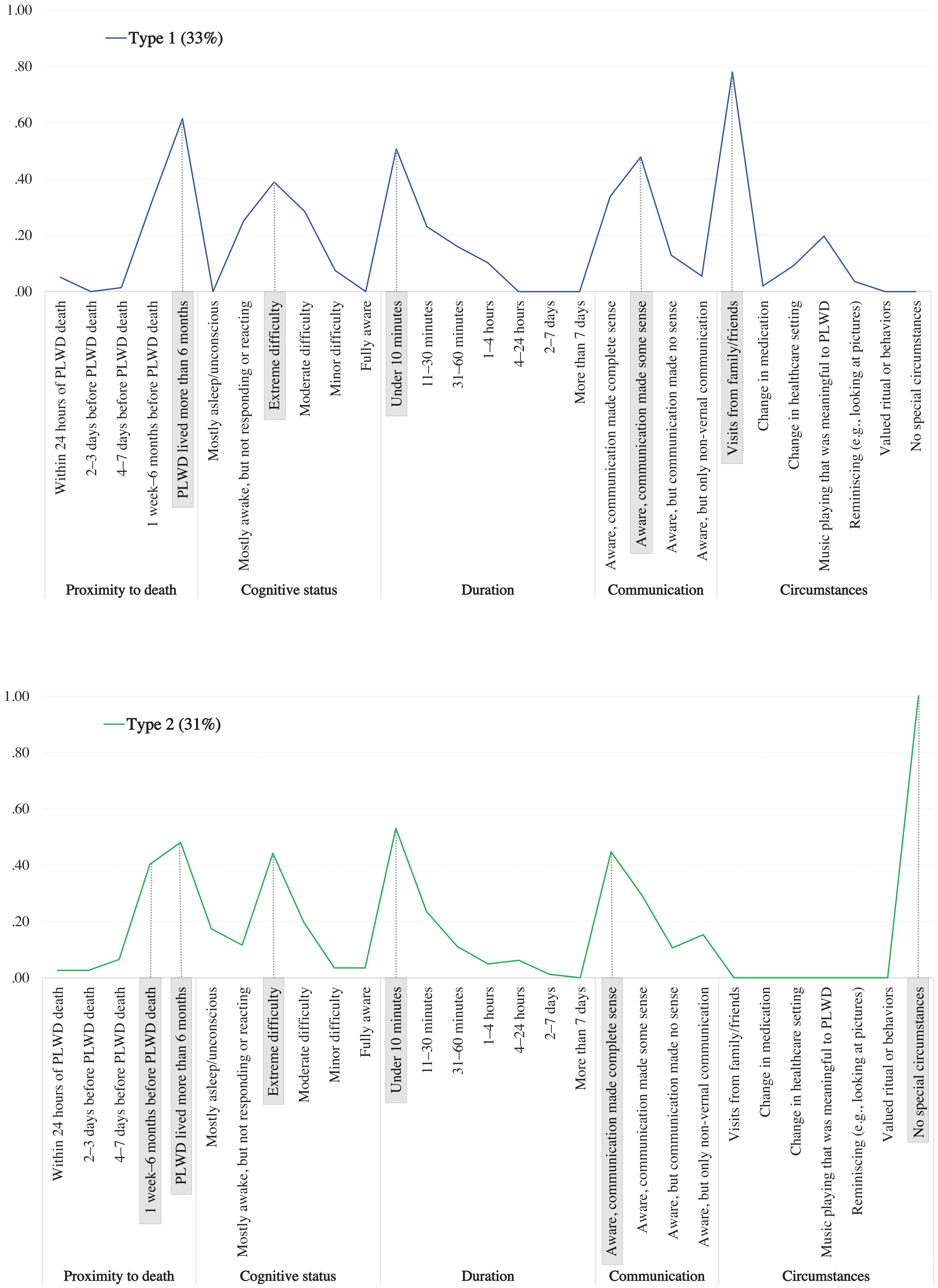
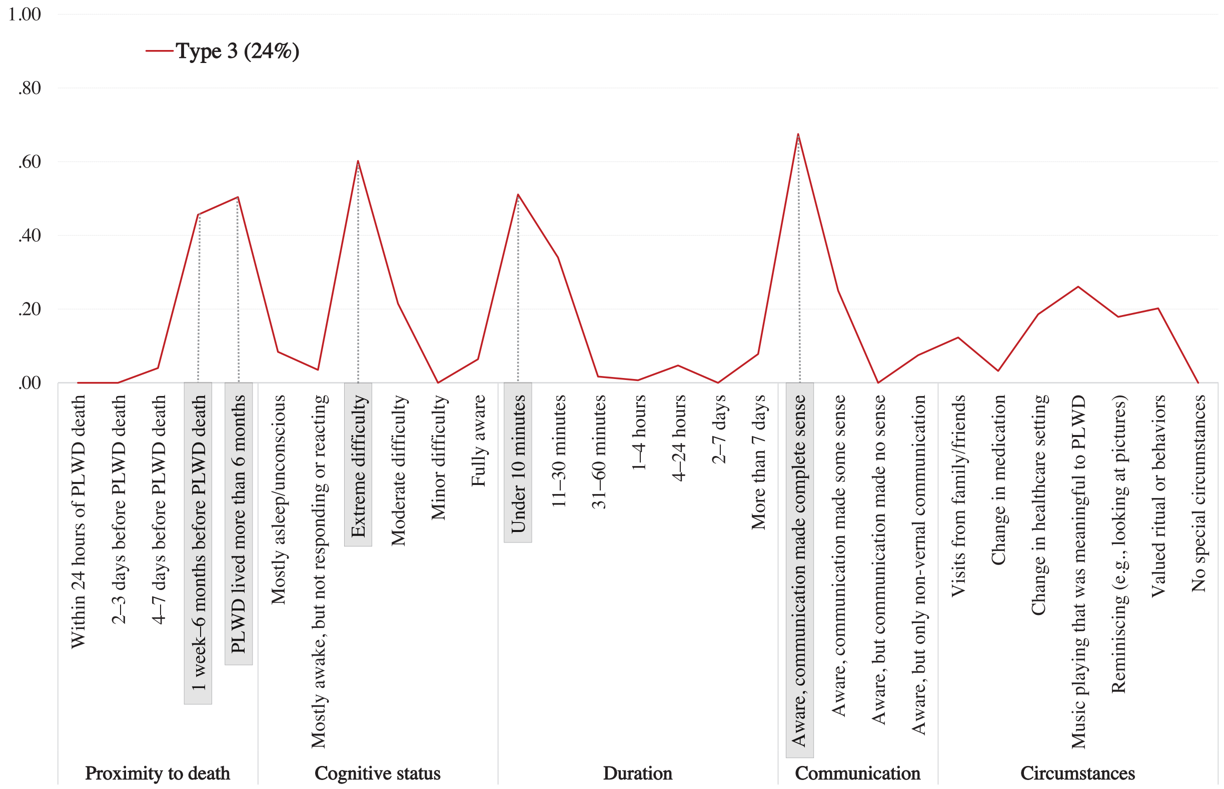


FIGURE 2 Item response probabilities of Type 1 and 2. PLWD, person living with Alzheimer's disease and other dementias.



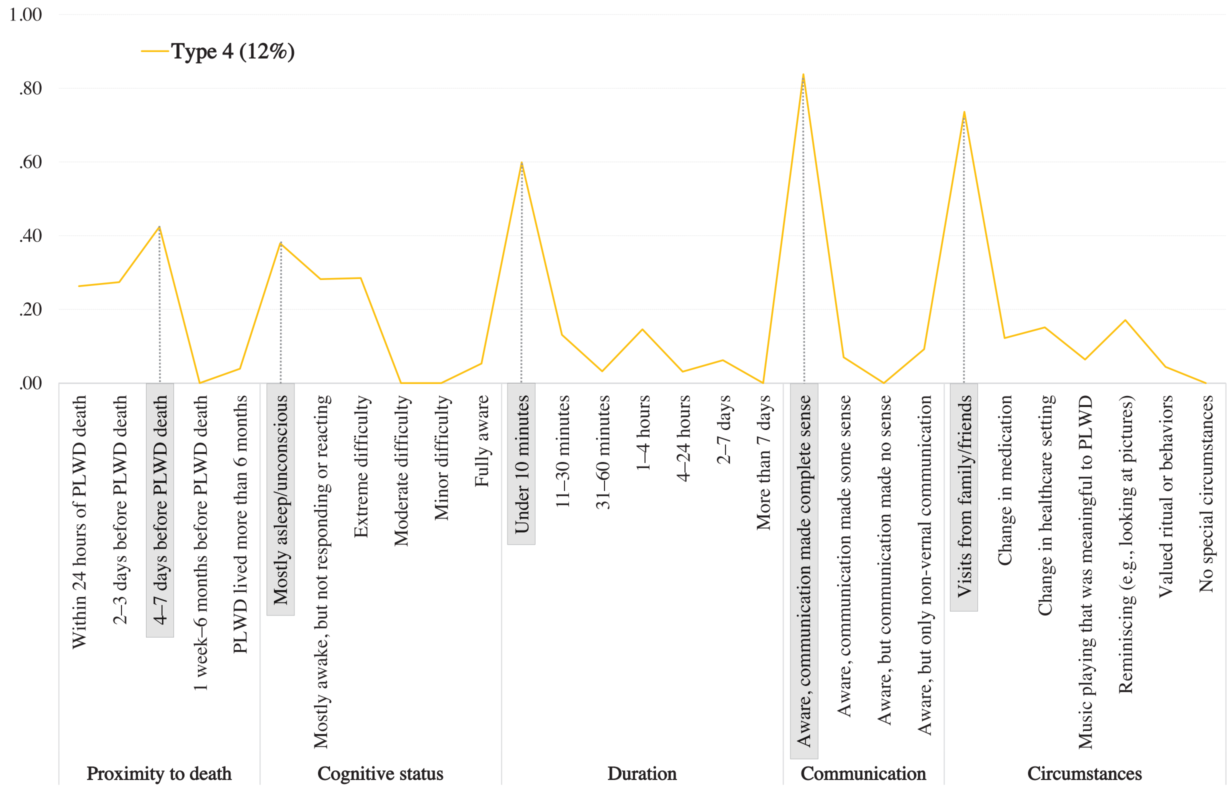


FIGURE 3 Item response probabilities of Type 3 and 4. PLWD, person living with Alzheimer's disease and other dementias.

TABLE 3 Comparisons of caregiving contexts and caregiver reactions by typology of lucid episodes.

Variable	Total Sample	Type 1 (33%)	Type 2 (31%)	Type 3 (24%)	Type 4 (12%)	F or χ^2
Caregiving contexts						
Relation to PLWD						
Spouse/partner	19.0%	16.5%	23.3%	17.6%	17.6%	1.51
Child	74.9%	76.9%	69.8%	79.4%	73.5%	2.17
Other relative	5.0%	5.5%	5.8%	2.9%	5.9%	0.83
Friend/neighbor	1.1%	1.1%	1.2%	0.0%	2.9%	1.86
Lived in the same household	31.5%	27.5%	36.0%	33.8%	26.5%	2.08
Contact frequency[a]	6.06 (1.53)	5.60 (1.85)	6.47 (0.89)	6.19 (1.45)	6.00 (1.72)	5.12**
Caregiver: female	71.3%	74.7%	67.4%	73.5%	67.6%	1.54
Caregiver: employed (full or part time)	30.5%	28.6%	38.4%	20.6%	35.3%	6.20
Caregiver: married or cohabiting	56.3%	59.3%	57.0%	50.0%	58.8%	1.54
Caregiver: more than high school	86.4%	82.4%	89.5%	89.7%	82.4%	3.05
Caregiver: non-Hispanic White	86.7%	80.2%	87.2%	88.2%	100.0%	8.71*
PLWD: female	61.3%	60.4%	62.8%	60.3%	61.8%	0.14
PLWD: diagnosed with Alzheimer's disease	75.6%	80.2%	70.9%	69.1%	88.2%	6.57†
PLWD: never diagnosed	4.3%	2.2%	4.7%	7.4%	2.9%	2.70
Caregiver reactions to lucid episodes						
Positive appraisal[b]	4.08 (1.23)	3.82 (1.26)	3.74 (1.39)	4.51 (0.97)	4.71 (0.58)	10.04***
Stressful appraisal[b]	2.03 (1.32)	1.99 (1.22)	2.24 (1.49)	1.91 (1.25)	1.79 (1.25)	1.33
Changed care decisions	8.6%	9.9%	4.7%	10.3%	11.8%	2.58
Searched for more information	19.0%	19.8%	16.3%	23.5%	14.7%	1.76

Note: Caregiver $N = 151$; episode $N = 279$. ANOVA for continuous variables and χ^2 tests for categorical variables were conducted to compare caregiving contexts and caregiver reactions between typologies.

Abbreviations: ANOVA, analysis of variance; LE, lucid episode PLWD, person living with Alzheimer's disease and other dementias; SD, standard deviation.

[a] *M* (*SD*); rated 1–7 (every day or living in the same household).

[b] *M* (*SD*); rated 1–5 (very).

† $P < 0.10$.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

future research and practice, but may also allow for optimal tailoring of educational materials to support caregivers and health-care providers who witness LEs.

Our study has several limitations. First, it should be noted that our survey was not designed to estimate the prevalence of LEs, but instead to examine types among those who reported witnessing them. Second, at the study's outset we attempted to provide caregivers a working definition to understand and contextualize the LE phenomenon, one that was also at a reasonable reading level. In doing so, we may have biased our sample toward a specific set of caregivers, such as those caring for people having lived or living with more extreme cognitive impairments. More than 70% of the sample reported caring for a person living with at least extreme cognitive difficulties prior to the LE. It is possible that interpretations of LEs based on this preliminary definition included episodes that eventually may not be considered LEs. Type 1, for example, may include a broader scope that includes "good day and bad days"[10] or this type may identify earlier points on the disease course continuum when these events occur. Third, self-reported data may have led to recall bias about dimensions of LEs and their reactions to them. Bereaved caregivers may have limited recall or recall specifics that are personally meaningful, but may have more difficulty recalling important, yet nuanced, dimensions. Capturing LE dimensions in real time or in close proximity to the LE may reduce these biases. Fourth, participants were drawn from an Alzheimer's disease advocacy group and do not represent all ADRD caregivers, and by association, all LEs. Those invested in ADRD advocacy may have closer family ties with the PLWD they care for or may participate to make meaning out of their caregiving experiences, both of which are useful for providing data on LEs, but may not be typical of all caregivers. Fifth, with the prevalence of ADRD estimated to be higher among Hispanics and non-Hispanic Blacks compared to non-Hispanic Whites,[20] our sample, which was predominately White (87%), may not be generalizable to other racial and ethnic groups or their caregivers. Especially given that the typology approach produces solutions "specific" to a sample, future study samples will need to be more diverse to understand if other types of LEs exist or if Types 1 through 4 are applicable. Finally, our derived typologies shared some characteristics across all LE types, yet some measured dimensions were not dominant in any LE type. For example, no one type of dementia was dominant in any typology. Because research on LEs is in a relatively nascent stage, our proposed typologies should be tested and refined in larger samples; research that is currently underway with a large, longitudinal sample of current caregivers would allow consideration of other characteristics and for subanalyses by type of dementia.

5 | CONCLUSIONS

Findings suggest that multiple types of LEs exist, that not all LEs are indicative of the end of life, and that some episodes are precipitated by external stimuli while others are not. Additional research is needed to confirm these types of LEs, and to determine whether they are valid in a more diverse sample of PLWD and their caregivers. Our findings also challenge the clinical assumption of a linear cognitive and behavioral decline for PLWD, suggesting that this decline can, at least temporarily, shift. A deeper understanding of temporary reversals of cognitive ability could lead to pathways to induce some types of LEs and extend the duration of others.

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CONFLICT OF INTEREST STATEMENT

Joan M. Griffin discloses a contract with Exact Sciences Corp. that is paid to her institution. No other authors report conflicts of interest. Author disclosures are available in the supporting information.

CONSENT STATEMENT

All participants in this study were consented per IRB guidance and regulations.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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